

SUPPORT GUIDE FOR FAMILIES AND THEIR RELATIVES



CIUSSS DE L'ESTRIE – CHUS

Preparing Children for the Palliative Illness or Death of a Loved One

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Introduction

In the event of an illness, one of the main concerns of a parent or relative is protecting the children. Sometimes, the initial reaction is to avoid addressing the illness or death for fear of making the children sad or worried.

Questions that parents or relatives consider:

Do I have to talk to them about it?

Will I upset the child?

Will they understand?

How should I approach the subject?

When should we talk about it?

Etc.

It has been demonstrated that children need to be informed and involved when an illness affects one of their relatives, so it is essential to encourage communication.

In general, children are able to adapt to difficult situations and with proper support, this experience can equip them to manage the current situation as well as the future testing experiences they will encounter in their lifetime.

“Giving proper support to children requires teaching them to trust the adults around them.”

Josée Masson, Social Worker

This guide was designed to help you support children coping with a relative's illness in the palliative phase or death.

At any time, feel free to **share your questions and concerns** with a professional or member of the care team. Both the staff and this guide are here to help you.

Why is it important to talk to children about an illness in the palliative phase or the death of a loved one?

Regardless of age, children have the right and need to know. Even in attempts to conceal the situation, they will quickly pick up on the adults' concerns, perhaps hear them talk about the illness, and probably notice changes in their environment: changes in routine, altered behaviours of the parents or relatives, physical changes of the sick person, etc.

A lack of information will make them more uneasy than the truth, potentially leading the child's wandering imagination to the conclusion that they might even be responsible for the situation.

"Even if nothing is said, children still know."

Josée Masson, Social Worker

Children need to feel included in this family experience. They must be trusted, because they too are capable of coping with reality. Informing them is demonstrating how important they are.

"Death following an illness is the only type of grief that can be planned for, so someone's death should never be a surprise for the child."

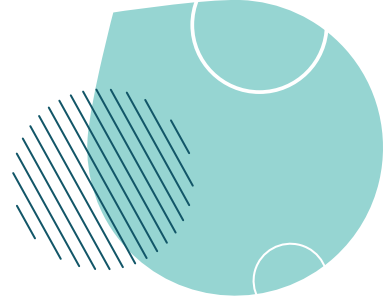
Josée Masson, Social Worker

Who should talk to the child?

Parents are always the best people to deliver this news. Since children trust their parents, it is easier for them to freely express themselves.

If the parents do not feel comfortable enough to approach the situation on their own, a significant adult for the child may be there to support them during this difficult but necessary moment. If needed, a professional can also provide support.





Where should we talk about it?

Ideally, it should be discussed in a place where the child will **feel comfortable to have a free, unrestrained response**. If the child is out, it would be better to have them return home to break the news. However, if the child could potentially hear about it from other people or through other means, going to them and telling them first is recommended.

The discussion is best made in person. However, if it has to be over the phone, make sure a significant adult is at the child's side to provide support.

When should it be talked about?

As soon as possible. Taking the initiative to talk to the child without delay rather than waiting for them to raise the issue is recommended.

The best time to discuss it is when parents observe that the child notices, hears, or feels something related to the end of life or death of the loved one.

In a family with several children, it is advisable to tell them all at the same time, regardless of their ages. The younger children will learn from the older children's behaviour and they will feel they are part of the family.

An illness in the palliative phase or the death of a loved one is part of a family's history.

How should we talk about it?

Stay composed

Even though the situation is emotional, it is important to remain calm throughout the discussion and during the child's reaction.

Express your emotions

Keep in mind that it is normal to be emotional, even for an adult, and that expressing your emotions is generally the right approach. For children, it is not seeing the adults cry that causes concern, but rather not knowing why they are crying. Moreover, as children learn predominantly by observing adults, they will see that it is normal to be affected by the situation, to feel emotions and share them.

Provide information bit by bit

The announcement may leave the child in shock. Their understanding may become limited and any information may be difficult to grasp. Therefore, it is advisable to avoid giving too much information at once, and rather space out details to allow the child to gradually process the information.

Use appropriate words

When discussing what is happening, it is important to be truthful and to explain the situation using factual words (illness, death, cancer, suicide, etc.).

Death must be briefly explained in simple, clear terms, for example:

- Dying is when someone stops living and their body does not work any more.
- The person has passed away forever and cannot ever come back.

Questions from children help to follow their progress in understanding and in grieving.



Situations to avoid

When explaining death to a child, it is important to avoid confusion and remember that children's imagination can run wild.

- Dying is not falling asleep: The child could become afraid of sleeping.
- Dying is not a journey: People who go on a journey return.
- Dying does not allow someone to continue seeing or hearing: The child may fear being continually observed or listened to.
- Dying is not living in the sky and having a home there: The child might feel abandoned.

We must share our beliefs with the child and explain that people around them might explain death in different ways because everyone has their own beliefs and death remains a mystery.

Validate the child's experience in the following days

It is recommended to question the child about their understanding of the situation in order to validate it. This feedback will also be used to fill in or correct details as needed and to answer their questions.

Stay attentive and be tolerant

The child needs time to understand what is happening and to assimilate the information. As a result, they may ask the same questions several times. They need to feel that the adults around them are available to provide answers. Even if you think you have already answered clearly and feel like repeating would be pointless, the child should not feel rushed or ridiculed. Keep in mind that their understanding will develop gradually and depends on their knowledge, experience, age, and the information received.

Possible responses from children

Since children often struggle to translate their emotions into words (pain, sadness, anger, fear), they tend to express them through their behaviour (irritability, isolation, regression, aggression, anxiety). They must be **monitored**, but **also accepted** for their response to this stressful situation.

Many parents wonder if they should be worried about their child when they notice changes. Remember that when it comes to your child, **you are the expert** and you know them better than anyone else. Trust your instincts and ask your child how they are doing.

Keep in mind that almost any kind of reaction is normal, for example:

- Increase or decrease in appetite;
- Physical discomforts;
- Regression or behavioural changes;
- Lack of focus;
- Social withdrawal;
- Trouble sleeping, etc.

When a child talks about suicide or shows signs of suicidal ideation, immediately consult a professional for an assessment.

Be aware of guilt!

The child may **feel responsible** for the illness or death of their relative. They may think it is their fault because they said something mean, misbehaved, or when they were upset, had wished death upon the relative. It is important to **pay close attention** to feelings of guilt, to **clearly identify** and **speak openly** about such feelings while **reassuring** the child that their behaviour or words did not cause the illness or death.

If the concern persists, there are three things to consider that might lead you to consulting a professional:

1. Significant behavioural changes that **persist over time**.
2. **Intensity** of behaviours that **remain or increase** over time.
3. Changes in behaviour that **affect the child's overall function** and limit them from performing their normal activities.

Help the child express their emotions

Encourage the child to express their emotions and ask them to show you how they feel, using the images that follow.



It is important to notify the day care or school of the serious illness, treatment, hospitalization, change in the person's living environment, or current and future grieving.

Visits to the hospital

It is important to give the child the opportunity to visit the sick person.

If the child refuses

Never force the child to visit the sick person. Listen to their needs and choices and provide support. While respecting their decision, try to be understanding of their refusal and reluctance. Sometimes, their decision is based on unwarranted fears.

If the child accepts

It is important to properly prepare the child before the visit.

Describe the patient's condition, the physical premises, and the environment

Seeing the sick person will not traumatize the child provided that they are informed of any significant changes (appearance, behaviour, etc.) beforehand.

Give them as much information as possible: floor, room number, presence of nursing staff, medical devices, etc. You can also take pictures of the person and location to show to the child prior to the visit.

Before entering the room, ask the nursing staff about the patient's condition and inform the child if necessary.

Validate the child's decision several times on the way to the room

If the child changes their mind once there, they must never be forced to go into the room. Their choice must be respected.

Some examples to use

- There are a lot of tubes and devices used to...
- There is a large bandage because...
- She is a little confused because...
- When he is sleeping, sometimes...
- When he breathes, it makes funny noises...



During visits

Follow the child's pace

Children live in the moment, so their emotions and reactions can change quickly. They can burst into laughter one moment and suddenly start crying the next. They may stay at the person's bedside for a few minutes and then want to move on or go play. Therefore, games, activities, and snacks should be available to keep them occupied during hospital visits or meetings with the doctor. It is also recommended to have another significant adult to take care of them if needed.

Provide for special moments between the child and the person at the end of life

During visits, make some time for special moments, i.e., make time for the child to be alone with their relative or to do a significant activity for them with the person at the end of life. These moments will become cherished memories of the loved one for the child.

Some ideas

If the child and relative share common interests, a time could be scheduled to allow them to enjoy an activity together again, for example, watching a movie, reading books, drawing, looking at photo albums, etc.

To create a symbolic memory, you could suggest that the child and person at the end of life copy their fingerprints onto a sheet using hand paint (available in bookshops and art supply stores). This work of art can then be laminated or framed.

Leave room for your imagination and your child's. During this time, the child should be allowed to make a gesture that they consider symbolic. This will help them make sense of their experience.



Saying goodbye (farewell) at the end of each visit

When death is imminent, it is recommended to help the child say their goodbyes after each visit. It is better for the child to do so several times rather than missing out on the opportunity. They should be encouraged to talk to the sick person or to touch them, even if the person is unconscious. The child may need to see you say farewell before they can say their own goodbyes.

Validate the child's experience following their visit

Back home, take time to talk with the child so that they can express their feelings and emotions about the visit. This is a good time to listen to what they have to say and to answer their questions.

Feel free to contact a team member if you would like support during these visits with the child.

The child's place at the hospital

Meetings with the medical team

During hospital visits, the child may ask the care team questions about their relative's situation. They should feel free to ask any questions they may have.

Participation in family care

The child can be asked to provide some care. For example, they can give medication with the nurse, bring a cold washcloth, get water or ice, etc. The child will then feel involved in caring for their relative's illness and thus feel useful.

Decor of the loved one's room

The child is allowed to bring one or more meaningful objects to the hospital (teddy, drawings, photos, etc.) and to leave them in the room.



Services offered to the hospitalized person and their loved ones

A team of social workers and professionals is available to support you in these difficult times. You can request such support by contacting the care team or by calling the secretariat of social services (extension 13333).

Specialized oncology services

Composed of social workers, psychologists, nurse navigators, sex therapists, and nutritionists, the oncology team is available to accompany and support sick people and their relatives throughout treatment. Individual, couple, or family meetings are possible to help you adapt to this new reality. If needed, the team can also help you intervene with your children.

Spiritual care

The spiritual care team is available to provide support to the hospitalized person or their relatives

in meeting their spiritual and religious needs. Please ask the care team or submit your request by calling Fleurimont Hospital (extension 14476) or Sherbrooke's Hotel-Dieu Hospital (extension 24460).

Family meetings

Since it is essential to continue family activities as normally as possible, if the condition of the hospitalized person permits, a room can be reserved for special events (family dinner, party, etc.). Ask the health care team to find out what is available on the premises.

The child's understanding of the concept of death

As children grow up, their concept of death develops. It is rare for children to have an accurate idea of death before the age of 9 or 10, depending on their experience, maturity, and the information they have received.

Babies and very young children

- Feel tension, anxiety, and distress;
- Struggle to understand separation;
- Experience death as simply a **temporary absence**.

Young children

- Think death is a **temporary, reversible phenomenon**;
- May ask the same questions over and over;
- Know death exists, but do not feel directly threatened;
- Do not understand what the body ceasing to function means;
- Feel tension and perceive changes;
- Do role-playing games when a death occurs.



The child's understanding of the concept of death

Children

- Begin to understand the finality of death, that it is **irreversible**;
- Become interested in the reasons for death and the functions of the body;
- Also play games that refer to death.

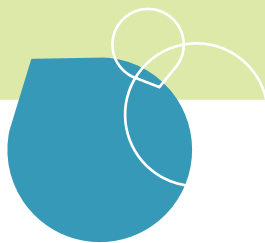
Preadolescents

- Understand that death is **universal** (everyone dies) and **irreversible**;
- Often keep their distress to themselves.

Adolescents

- Have a more realistic understanding of how vital organs can cease to function;
- Understand the concept of death and their own mortality;
- Ask about life after death and search for meaning.

Regardless of the child's age, it is important and necessary to talk to them about death. Their questions can help you understand how they are managing the concept of death. This is an opportunity to validate their understanding and answer any questions.





Needs of grieving children

Presence

The death of a relative generates feelings of emptiness and insecurity in children. They will need to feel like the people around them can partially fill this loss. They need to be able to rely on adults who are accessible and available.

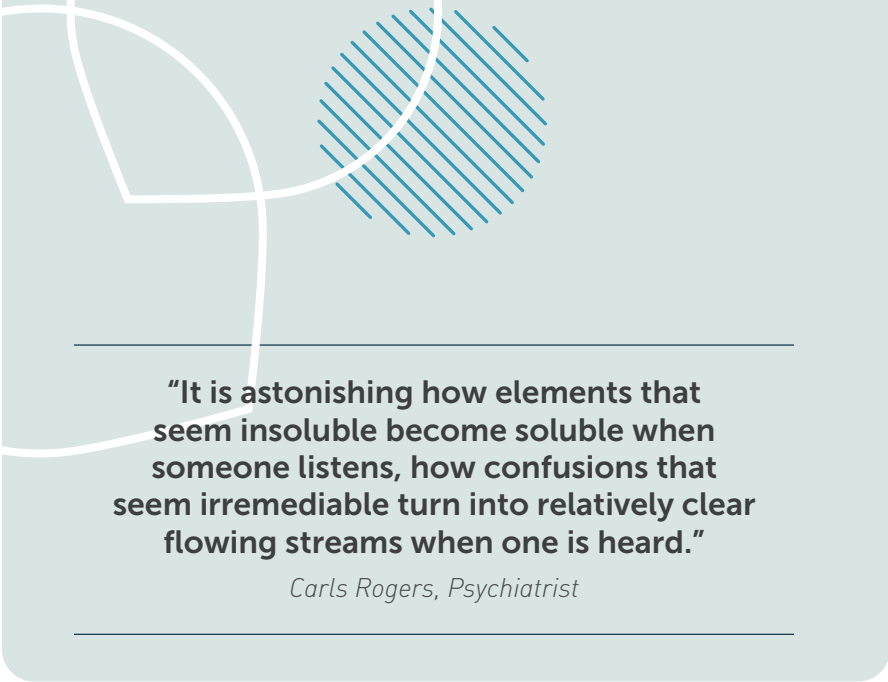
To talk and be listened to

It is important to allow the child to talk and cry, and to listen to them. It will make them feel that they are also allowed to experience grief.

Remaining available is essential to help the child better understand what is happening. Children won't ever talk much about their grieving process. Despite this, they should not be forced or coerced into talking. Be attentive to simplifying your verbal AND non-verbal language.

Stability

Children need to know that someone will take care of them. Ideally, the child's routine should remain essentially the same as before the death. Their bedroom, toys, home, day care, school, and after-school activities often provide reassurance.



"It is astonishing how elements that seem insoluble become soluble when someone listens, how confusions that seem irremediable turn into relatively clear flowing streams when one is heard."

Carls Rogers, Psychiatrist

Reassurance

Children need to be told that they are not in danger, that there are people to take care of them, and that their reactions and emotions are normal. They need to see that despite the grief and disruption to their lives, the adults around them are in control. They need to know what will happen to them and their family in the short term and also the future.

Recognition

Children need to be taken into consideration in this trying period. They need to be involved in the various approaches and discussions, which will demonstrate acknowledgement of their grief and connection with the deceased.

Love

More than ever, children need to be shown that they are loved, through both words and gestures.

Encouragement

Soft words of encouragement should be used so the child understands that their grieving will wane over time, and that they will not remain unhappy all their life. However, saying things that could make them feel rushed or misunderstood in their grieving **must be avoided**, such as:

“You’re strong, you will get over it.”

“You didn’t see them much, so it’s not so bad.”

“You’ll see, soon enough you won’t even remember.”

How to help children grieve

Participating in funeral arrangements

The child’s participation throughout the funeral process is very important (choice of photos, music, flowers, preparation of a drawing, crafts, etc.). Their participation will help them to, among other things, acknowledge everything that is happening, deepen their understanding of death, and begin their grieving process.

The parents or another person significant to the child should prepare them before the day of the funeral by providing as many details as possible:

- As applicable, describe the coffin or the urn;
- Describe the locations (funeral home, church, cemetery, etc.);
- Talk about the emotions they might feel during the day;
- Inform them about how adults may behave (people laughing, crying, telling stories about the deceased, being devastated, in disbelief or denial, etc.).

IMPORTANT

Keep in mind that the child lives in the present, so it is normal for them to want to play, keep moving, and even laugh. They cannot dwell in intense emotion for a long time. It does not mean they do not have grief or are unaware of the loss; it is simply children being children! Plan games and prepare snacks to pass the time.



Talking about the deceased person

To help the child grieve, it is important to talk to them about the deceased. The following are questions to encourage the child to communicate:

- What did you like doing most with this person?
- What did this person do to make you laugh?
- What do you miss most about this person since they passed away?
- If you could talk to them today, what would you tell them?
- What games did you like to play with this person?

Do an activity to honour the deceased

A parent or relative may suggest doing some kind of ritual or activity. It could simply be setting up a special place with photos and meaningful objects to honour the deceased. A parent or relative could also make a photo album, scrapbook, gift box, etc. in honour of the deceased. Then, explain to the child that they can go to it as often as they feel the need or when they miss the person.

You could also bring the child to a location that was special to them and the deceased person (park, arena, beach, restaurant, etc.) and encourage them to talk about their memories (why they liked to come to this place, what they liked about this activity, etc.).



Resources to help you

The CSSS in your area can provide support or referrals as needed. To find the CSSS nearest you: **sante.gouv.qc.ca/repertoire-ressources/**

Social workers, marriage or family therapists

- Social worker from the oncology team of the CIUSSS de l'Estrie – CHUS | 819-346-1110, ext. 13333

Private

- Psychologists | ordrepsy.qc.ca/english
- Social workers and therapists | otstcfq.org

Workers in the school environment

- Find out more at your child's school about accessing the services offered by such professionals.

Organizations providing support for bereavement

- Deuil jeunesse | 1-855-889-3666
- La Rose des vents de l'Estrie | 819-823-9996
- Coopérative funéraire de l'Estrie et Naissance Renaissance Estrie
"J'écoute ma toute petite voix" - Special support group for bereaved children 819 569-3119
- Consult your local CSSS for the support groups available near you.
quebec.ca/en/health/health-system-and-services/service-organization
- La Maison Monbourquette | 1-888 LE DEUIL (533-3845)



Web sites to consult for information on grieving

Talking about grieving with
children and teenagers
kidsgrief.ca

Canadian Cancer Society
cancer.ca

Fondation québécoise du cancer
fqc.qc.ca

Canadian Virtual Hospice
virtualhospice.ca

Maison Monbourquette
(Resources available in English)
maisonmonbourquette.com

La Gentiane
lagentiane.org

La Rose des vents de l'Estrie
rosedesvents.com

Corporation des
thanatologues du Québec
domainefuneraire.com

Reading suggestions

There are a multitude of books for bereaved children as well as tools in your bookstores and libraries. This could help you bring up the subject or better understand the child's experience.

Notes





Authors

E. Beaudin, C. Rossignol

Social workers from the Fleurimont Hospital oncology team

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Service des communications

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