



CHILDREN AND ADOLESCENTS COPING WITH A PARENT'S CANCER

GUIDE FOR FAMILIES
AND CARE PROVIDERS



Cancer J'écoute Psychosocial Support Service
Canadian Cancer Society
Quebec Division, 2016



**Société
canadienne
du cancer**

**Canadian
Cancer
Society**

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Parents, children, partners, friends, and grandparents, this *Guide* is dedicated to your courage.

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ILLUSTRATIONS BY LUC BEAUDOIN, ARTIST

Luc Beaudoin, painter and sculptor, divides his time between leading art expression workshops and working on his own creations. His artistry is strongly influenced by Oriental traditions that seek to harmonize the subject with its space. His paintings are imbued with a magic that is at once whimsical and sensitive yet powerfully presented in a cascade of colours gently nuanced by the play of light and the movement of the watercolour medium itself. These works are depicted in such a way as to leave interpretation open and accessible to all who encounter them.

Cover, *The Cellular Universe*, Luc Beaudoin
lucbeaudoin.ca

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Note : To facilitate reading, the term “child” will be used to refer to a youth under 18 years of age.



The Passage, Luc Beaudoin

PREFACE BY DR CHRISTIANE LABERGE

When I was asked to write this preface, I had to delve into my memories as a teenager. I had just found out that my 43-year-old mother had breast cancer. We visited her at the hospital after her extended radical mastectomy. That was in 1968. She was only supposed to have a cyst removed. At the time, breast cancer was a death sentence! My parents gritted their teeth, protected us, and carried on with their lives. They rejected the very idea of death. In fact, my mother died at the ripe old age of 81.

Have attitudes changed that much since then? We surely have given people permission to express themselves

according to their values. But do we really talk about it or not? We inform family members and colleagues about it, or we clam up. There are so many different reactions – and we hope they are well-adapted to each and everyone involved.

It is my belief that all aspects of care must be done respectfully, through a combination of active listening, consideration of the person's journey as well as the various limitations presented by the loved ones. To me, there is only one certainty: we come out of this adventure a different person. Why the word adventure? Many surprises arise during a journey, such as discoveries about oneself and others, the beginning of new friendships and the ending of old ones. We allow ourselves unsuspected reactions and forgive angry emotions because we understand. In the end, we learn a lot.

I hope that this work will help you along on your journey by presenting different ways of managing this period in life in as healthy a way as possible and by giving you a time of reflection in keeping with values that you and your loved ones cherish.

It is my hope that this guide will be beneficial!

MARIE-CLAUDE'S STORY

“NAVIGATING THROUGH ROUGH WATERS”

A disease as insidious as cancer starts gently but gradually takes over our lives for an extended period of time, dragging along those around us. There are our parents, my mother who spontaneously told me, “It should have happened to me, not to you... at 37, you’re too young... not you, not my daughter. Then, there is our lover, who doesn’t want to believe it, for whom the whole world stops for a moment, the one who wants to be reassuring, but is trembling inwardly - the one who loves us, but feels helpless.

Then, there are the children. I have three: Clara age 2, Antoine age 8, and Emma, age 12. For them, their world is turned upside down and they feel frightened, sad, and angry. My eldest daughter chooses to hold things inside. Sometimes, her feelings build up until they explode in a burst of emotions and an overflow of tears. At other times, she is soothed and escapes by reading novels. At Christmas, she made a heartfelt appeal to her grandmother: “You don’t know what it is like to live with a mother who has cancer. I can’t sleep. I’m scared.”

There is our son who asks tons of questions, who wants to understand and be reassured. Throughout this adventure, he is anxious every night before going to bed. I have to implement strategies to help him find sleep. For the first time in his life, he is aware that life is uncertain and can have an end. He once told me, “You know Mom, if you die from this cancer, you’ll be gone and you won’t think about it anymore, but I’ll be left with my pain and I’ll miss you. So, it’s more difficult for me.” At this moment, a mother’s

heart just crumbles. We want to tell him that life is beautiful, that everything will be okay, but inside, we also have this fear that overwhelms us and we feel very small in the face of all these emotions we have to deal with. There’s also my baby who doesn’t really understand much, who senses things, but can’t express them. Throughout the illness, she would ask me, “Your little booboo, is it gone, Mommy?” She lived this adventure with me - snuggling, affectionate - and even wanting to care for me when I came back from my chemotherapy sessions, feeling awful and exhausted. My children helped me stay afloat and find my inner reserves of strength when I thought they had sometimes dried up. They were involved in my battle right from the very beginning.

“Time will take care of everything.” Yes, at first this sentence bothers us. We don’t believe it. We are not there yet. But later, in hindsight, we end up believing it. We look back on the past year and positive images come to mind. These little moments that we usually consider trivial become wonderful. I remember my tall and beautiful Emma who returned from school, her eyes lit up, who would crawl into bed with me and tell me about her day. We were there, cuddling, talking and simply taking the time to be together. I also remember that Clara took care of me by bringing me my medication and thermometer. I remember all the moments in the countryside, where the children spent the day playing outside, inventing games and worlds where the disease no longer existed!

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WHAT YOU NEED TO KNOW AS A PARENT

MARIE-CLAUDE,
37 YEARS OLD,
MOTHER OF THREE

“I’m hurting and I feel bad for the others. I want to protect those I love. I want to show them that I’m strong, confident, and ready to fight. I try to make myself believe that I’m well despite everything, that I’m hopeful and nothing has changed. But in fact, I’m scared stiff. I’m facing the unknown and I don’t have the answers.”

The parent with cancer

Parents do not expect to be diagnosed with cancer. In the life cycle called parenting, parents have learned to take on new roles. They have also realigned their responsibilities as spouses and perhaps even redefined their sense of self in concordance to what being a parent means to them. In short, they have rearranged their lives and themselves in order to care for their children.

A cancer diagnosis creates a complex and paradoxical situation in which they may find themselves torn between



Alone in the world, Luc Beaudoin

the natural inclination to care for, groom and guide their children, and not having the energy or capacity to do so because their body has decided otherwise. Inevitably, the family unit will have to make adjustments that may either be sporadic, temporary, or long-term. Each family member will experience these changes differently.

As parents, you may show involuntary emotional or behavioural reactions to the illness, whether it be guilt, fear, anger, diminished availability for your child or spouse, irritability, intolerance, or impatience.

You may also go through increased episodes of stress or despair and even moments of panic.

It may help to call upon extended family members, friends and colleagues to help build a close social and family network to support you and your family through this journey. Do not hesitate to seek professional counselling for occasional advice or regular support.

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WHAT YOU NEED TO KNOW AS A PARENT

CHRISTIAN, LIVING WITH CANCER AND TALKING ABOUT HIS PARTNER

“There is another great injustice and it’s the role of a caregiver. In addition to being distressed and in shock, the caregiver does not receive the support offered to the sick person. Moreover, they are burdened with a large part of the daily responsibilities.”

The caregiver parent

The other parent or the primary caregiver also faces a precarious situation that may become overwhelming. They too may experience a wide variety of emotions such as worry, fear, anger or frustration, and helplessness. The multiplicity of changes that arise, as well as the interrupted life projects and increased responsibilities with regards to finances, parenting, household chores and the organization of the family schedule may affect caregivers physically and emotionally.

If the illness persists for several years or requires significant involvement, the spouse or caregiver should seek necessary support for themselves to prevent exhaustion, whether it be organizational or psychological.

Frequent discussions can help the caregiver and family members to open up about their personal limits and needs, to establish action plans together and to find solutions. Support from outside the immediate family should be sought as early as possible in order to maintain the family balance.

Moments in which love, affection and laughter are shared are crucial to sustain and nourish the family ties. These precious times bring hope, emotional healing, and contribute to the cultivation of stronger family dynamics.

The child

The child's perceptions

Regardless of their age, your children know you. They know your way of doing things and are familiar with your daily rituals. Your mood and attitudes, your daily comings and goings, your emotional reactions and the way you look after them – all of these things are a part of their lives. When something unusual occurs or when things are not quite what they usually are, children, more often than not, can feel it. They can consciously or unconsciously sense your anxiety, your worries, and even your fears. They can also notice a change in your behaviour, in your habits, and of course in your increasingly frequent absences from home. However, that does not mean that you should hide the truth or attempt to suppress your emotions. There are ways you may address what is happening with your children which will be covered in the following pages.

MARIE, 4 YEARS OLD, AFTER HER MOTHER'S MASTECTOMY

“My mom only has one breast because the other one hasn’t grown yet.”

Talking about cancer with your child

Children understand, interpret, and express things differently from adults. This is why parents often tend to believe that if they don’t tell their child about the illness, they will not know what is happening and will be able to go on with their lives without being troubled by the harsh realities of life.

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WHAT YOU NEED TO KNOW AS A PARENT

The first instinct as parents is to protect and care for their children. That is why parents usually do not share adults issues with them. It simply does not concern them. However, when an illness such as cancer occurs in the family, it does concern them because it will affect their everyday lives and their way of looking at the world.

In reality, children with whom nothing is shared may experience more distress than those to whom situations are explained. Children are resilient, which means that they are flexible and possess a great adaptability. Health care professionals agree that children usually adapt to changes better when they know what is happening, are informed about new developments, and can take part in discussions as well as in some decision-making.

The child's reactions

The occurrence of a parent's illness may elicit different reactions in a child, regardless of whether or not the situation has been discussed with them. A child can sense changes without being consciously aware of what these changes actually are.

Children have their own unique way of reacting to things that are new to them or to situations that they do not understand. Depending on their developmental stage, they may not have learned how to recognize the various emotions that arise within themselves or how to express or deal with them. As parents, you can be instrumental in helping them do so.

Following the news of the diagnosis, children may adopt an attitude that does not match what they feel. They may, for

ANTOINE,
8 YEARS OLD

"You're going to have a metal breast?"
"Is it contagious?"



Gathering Dew, Luc Beaudoin

instance, seem insensitive, nonchalant or even cheerful. Such incongruent reactions may demonstrate confusion or fear and should not be interpreted as non-caring or indifference.

Know that if your child has difficulties that seem related to your illness, this does not mean that you have done something wrong or that you are a bad parent. Their reactions may be alarming or worrisome because parents work so hard to ensure that nothing undermines the child's well-being or interferes with the joy of childhood. The pain you feel when your child cries or is anxious could affect you to the point of making you feel powerless and helpless concerning their emotions. As a parent, your response is often to intervene, educate, resolve, and protect. Is it not the role of any parent? Obviously, these skills that you have as a parent are both essential for you and your child, but living with cancer is also about learning to let go. Without realizing it, wanting to control or overprotect your child hinders you from truly listening to your child and recognizing their actual emotions.

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WHAT YOU NEED TO KNOW AS A PARENT

A few examples of what might cause reactions in children:

- fear of no longer being loved and fear of being abandoned
- fear of a parent's death or of feeling responsible for the parent's illness
- anxiety regarding changes in life habits and daily routine and in the integrity of the family
- anxiety, worrying about not knowing what will happen

JOSÉE MASSON,
SOCIAL WORKER
SPECIALIZING IN CHILD'S
GRIEF

"It is important to understand and accept that children's reactions when faced with major life challenges, such as a parent's illness, are normal, unpredictable, and unique. This helps us to accept the fact that our children react."

Some reactions you may observe in your child

The purpose of this list is not to pinpoint your child's reactions, but to give you an idea of the wide variety of reactions they may present. Your child's reactions to illness in the family may vary in type, time, and intensity. Reactions are normal and learning how to appropriately express one's emotions takes time.

As a parent, you know your child best. Trust your intuition.

If an unusual behaviour persists over time or if you are concerned about your child's behaviour, you should seek professional help.

A health professional can help your child, but they can also help you to guide or support your child with what they are experiencing. In reaction to a parent's cancer, a child may:

- express anger or aggressiveness
- experience learning difficulties at school
- have trouble concentrating
- have trouble sleeping (unable to fall asleep, sleep more than usual)
- suffer from various somatic complaints (stomach ache, increased asthma attacks)
- appear sad
- become agitated, anxious, irritable, or nervous
- demonstrate emotional instability
- become more emotionally dependent toward the parent with cancer
- regress in their manners or conduct (acting like a baby, bed-wetting...)
- demonstrate behavioural problems (being aggressive, lying, being contrary)
- withdraw or isolate themselves (no longer want to sleep over at friends' houses)
- have difficulty in their relationships with friends
- develop nervous habits, such as nail-biting, sniffing repeatedly, throat clearing...

The importance of communication

Have you ever found yourself in front of a beautiful sunset or in the middle of a wonderful nature walk being unable to truly enjoy it? Although you may be physically present, your mind can be somewhere else and prevent you from connecting with the joy and beauty that surround you. If you pay attention, you may notice that you do the same in the presence of your loved ones that is natural and normal, simply because it is the nature of the mind to ponder, plan, organize and wander in the past or to the future. The mind is an amazing tool, yet it sometimes hinders you from

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WHAT YOU NEED TO KNOW AS A PARENT

ANTOINE,
9 YEARS OLD, WHEN JACK
LAYTON'S DEATH WAS
ANNOUNCED

"He didn't die of old age because 61 isn't old.
It's cancer, isn't it?!"

wholeheartedly cherishing life's most precious moments.

Even if you have much on your mind, try to find specific moments when you can give your child your undivided attention, body, mind, spirit and heart. This may mean that you may have to turn off your phone and avoid other possible distractions. Although these moments may be brief, being fully present during those occasions will improve the quality of your words, gestures and interactions, which will be beneficial to your child as well as yourself.

In all stages of development, children need to be supported and guided in what they are going through, even more so when something important happens in the family. Children are sensitive to words, to the tone of voice, as well as to body language. Because they are so perceptive, secrets, covert conversations and lack of information can create more confusion and insecurity than open communication. It is preferable to talk with your child if you or someone in your family is diagnosed with cancer rather than letting the child find out the news from a third party or delaying the discussion until the cancer has reached an advanced stage. It is important to ensure that children have access to emotional support to guide and to help them cope with the present situation as well as any eventuality. It may be useful to seek the help of a professional or a person significant to the child to encourage and facilitate communication. This external support can help bring to light certain things that the sick parent and the child may not have shared. The support of a significant figure can also be of help in situations when parents are incapable or unable to offer a space or time to share. It is important for the child to have a confidant with whom they can feel comfortable to talk or ask questions.



On the Journey Together, Luc Beaudoin

PART I

WHAT YOU NEED TO KNOW AS A PARENT

Modes of communication

Communication, as presented here, has been divided into two components: receptive and active dialogue.

Receptive dialogue is expressed as an open and non-judgmental quality of presence:

“I’m listening to you, I hear you.”

Offering an open and non-judgmental ear gives children a safe and trusted space where they can feel welcomed and loved by the adults around them. It gives them the opportunity to discover and feel what may be happening beneath the surface (fear, anxiety, doubts, etc.). By offering a non-judgmental presence, the receptive dialogue encourages children to communicate but it also teaches them that each emotion is useful and legitimate.

It is, however, important to let children open up at their own pace. Being authentic about their own feelings is the best way for parents to prompt a child to trust the flow of emotions within themselves and talk about what they feel and think.

Reaching out to your child, as understood here, isn’t just an action, but rather a state of attentiveness and openness. Validating their emotions and reactions and reassuring them that it is ok to feel what they feel is also a comforting gesture you can offer them. Supporting and guiding your child through the occurrence of the wide range of emotions they may encounter will contribute to a healthy emotional development. It will help them learn to allow themselves to feel, understand, manage and give a voice to their uncomfortable emotions rather than avoid or flee from them. Becoming more aware of your own emotions as a parent, and mindfully welcoming your child’s feelings can diminish your tendency to control or disregard your child’s feelings in an attempt to “protect” them from their own unpleasant experiences.

Being attentive will also allow you to notice early signs of distress in your child. Signs can manifest externally in their behaviour, temperament, or body-language or be as subtle as inattentiveness, isolation, tuning-out or shutting down.

Active dialogue: “Let’s talk about it.”

Active dialogue will help parents to identify their child’s feelings, not only those they can name, but also the ones related to their observations and interpretations of reality. It enables parents to better understand how children perceive what is going on. Therefore, through dialogue, children can learn to express their needs more easily and put into words what might be abstract or confusing. This is a valuable aid to help them find their way through the parent’s illness.

Talking about the disease with children is also a way of showing them that you are concerned and trust that they are able to cope with the situation, like the other members of the family. An open and active dialogue will help your child learn to tolerate shortcomings and cope with the frustrations and uncertainties of daily life. They will also learn how to handle situations which are not always in line with their expectations, and perhaps find more acceptance in the events they find difficult or that make them feel uncomfortable.

Moments of loving and attentive communication contribute to reducing anxiety and fears, but also allow children to organize and make sense of emotions that surface and translate them into words, gestures or choices. Being receptive to the child’s experiences creates a physical and emotional closeness with the parent that diminishes the gap that often occurs between family members when things are kept silent.

Not telling your child what is going on gives way to their incredibly fertile imaginations, which may create much worse scenarios than what is occurring in reality.

Even though you may not always know yourself what to expect in the course of the illness, explaining the unpredictability of the situation teaches children to cope with uncertainty. It is a process for both parents and children to learn how to live one day at a time, and in due course to find help and the necessary resources to solve a given problem. It is okay to tell your children that they may hear all kinds of things from people in the hospital, in school, or in the neighbourhood. Inform them that what they might

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Quality Time, Luc Beaudoin

hear will not necessarily be true and if they hear anything different from what you have told them, it is important that they tell you about it. Let them know that you will keep them informed about changes. Encourage them to ask questions because each cancer experience is unique and the information that has been given to them might not apply in your case.

Other modes of expression

You can also invite your child, whether he is 3 or 17 years old, to communicate via different forms of expression. Games, stories, drawing, plasticine modelling (play dough), painting, poetry, music, dance, exercise, and sport may enable them to express their emotions, tensions, and mood. The more children are encouraged to experiment with these forms of expression, the easier it will be to find the one that suits them best in expressing themselves and release

the tensions that tend to build up in difficult times. Such activities may also allow them to find their own answers.

Communication through parent-child activities

Do not underestimate the benefits of a shared parent-child activity and the time spent together, even if it is brief.

Books are excellent teachers, especially during difficult times. Selected based on the age of the child, they explain, clarify, and enable the child to see things from a different angle. Books about cancer enable the child to understand the emotions and changes related to the disease. According to their developmental stage, books help children identify with the characters of the story in order to help them feel normal and less alone. For younger children, drawing, painting, making arts and crafts or role playing with the parent is an activity that is quite appreciated. It allows them to speak the same language during this time of sharing.

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WHAT YOU NEED TO KNOW AS A PARENT

LISA CORBEIL, PSYCHOLOGIST

“Children’s books are an excellent way to approach difficult subjects with children. Books enable us to find words and images to explain certain situations to children when we are at a loss. In addition, books help children identify with the stories and characters, allowing them to feel understood and less alone. Besides appealing to children’s inner resources, books have this marvellous capacity to move and inspire us, thereby creating wonderful moments of discussion and sharing. Of course, it is preferable that parents read the book first before reading it with their child.”

The parent has access to what is going on “inside” the child. Through such playful or artistic activities, children can express what they may not be able to express in words.

A few words to use when communicating emotions

- Sadness: pain, grief, sorrow, unhappiness, dejected, affected, discouraged, overwhelmed.
- Anger: angry, feeling down, annoyed, shocked, offended, hurt, outraged, frustrated, resentment.
- Insecurity: worried, scared, frightened, distrustful, anxious, lack of confidence, timidity.
- Guilt: responsible, at fault, mistake, clumsiness, foolishness, error, blame.

A few suggestions to facilitate communication

While talking to your child, use age-appropriate vocabulary:

- Share the news or new developments yourself and as soon as possible.
- Tell all of your children about the diagnosis at the same time.
- Choose a favourable time and place.
- Use a calm tone of voice.
- Be clear, frank, and honest.
- Talk about the facts in a brief and precise way.
- Use real words such as “sickness” and “cancer”.
- Be patient with children without expecting a particular reaction.
- Encourage them to share with you what they feel, at their own pace, without forcing them.
- Give children the time they need to assimilate what you have told them.
- Go over what was discussed at a later time and ask them what they think, how they feel about what you have shared with them.
- Reassure them while demonstrating your affection.
- Validate their understanding and answer their questions by sticking to the essentials.
- Avoid giving too much information at the same time.
- Tell the children, gradually, about changes and new developments affecting family activities and the daily routine. It is also important to inform them about the availability of the sick parent as well as the possible changes in their appearance.

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ANTOINE, 9 YEARS OLD

“Mommy, where will we meet in our dreams tonight? In Harry Potter’s castle? Far from cancer!”

Pitfalls to be avoided

The parent’s guilt

“Mommy isn’t able to take care of you this week, so to compensate you can have as much dessert as you want and go to bed whenever you wish.” This can create confusion with regard to established family rules.

Role reversal

The parent may sometimes have the tendency to approach the child with the unconscious intention of finding consolation. Turning the child into a confidant is an emotional responsibility that is too heavy and inappropriate for them.

Emotional blackmail

“If you want Mommy to feel better, you must help with the chores around the house. “If the parent doesn’t recover, children may end up believing that it is their fault because they did not do what they should have for the parent to get better. “You know that it saddens Daddy a lot if you don’t visit him at the hospital.” The child may not be ready to go to the hospital and feels pressured to do so. Some children, especially teenagers, may already feel torn between continuing to participate in their activities and caring for their ill parent.

Lies and distortions

“Daddy went on vacation to his sister’s for a few weeks.”, when in reality he’s gone for treatment. If the child asks questions about the aunt, this could be the beginning of a series of lies that can damage the trust in the relationship. “Mommy will get better, you’ll see.” It is better to tell the child the truth without making promises in the event that the situation worsens.

Bad choice of words

“Daddy has gone to a better world.” The child may develop the belief that this world is bad and ungrateful and doesn’t want to be a part of it any more or want to join Dad. “Grandma has gone to sleep.” The child may become afraid of falling asleep or anxious that the parent will fall asleep and never wake up again.

Anger, sadness or other emotions

You can tell your children that you are angry or sad or that you are frustrated, but do make sure you tell them you are not angry at them or sad because of them. “I find it difficult to have so little energy and always need to rest. That’s why I lose my patience more easily when it’s noisy in the house.”

Excessive indulgence

A child who suffers because their parent has cancer remains a child who needs limits, guidelines, and support. The parent who becomes permissive and more flexible doesn’t help the child to develop their ability to cope with difficult situations. “I know that I’m going to bed early and I won’t know at what time you will come back. But I think it’s important that you’re back by 11 p.m., even if your friends stay out later. Can you come back on your own or do we need to arrange transportation for you?”

PART I

WHAT YOU NEED TO KNOW AS A PARENT

Hospital visits

Several parents wonder if they should bring their child to the hospital to visit an ill parent. Knowing it can be disturbing even for an adult to see a person in a weakened physical or psychological condition, it is essential to discuss with the child and prepare them for the visit.

It is therefore important to talk to children about the situation at hand so they know what to expect. The appearance of the person could have changed (hair loss, weight loss...). The person could be too weak to speak or not be as attentive as usual.

If the child wants to go, the decision will depend on several factors:

- the age of your child
- the closeness or relationship of the child with the ill person
- the stage of the disease
- the child's capacity to remain calm or speak softly
- the duration of the visit

The visit could be cancelled at the last minute or postponed. Explain that it is not because the parent doesn't love them anymore or doesn't wish to see them, but rather because of the illness. You can suggest to the child to draw a picture or card or write a poem for the sick parent or relative. The following are simple examples of what the child could do to contribute to the parent's care, once at the hospital:

- Bring a glass of water.
- Hand a pillow or arrange the blankets.
- Change the water in the flower vase.
- Caress the parent's hand or back.
- Sing a song or tell a funny story learned at school.



Smaller than myself, Luc Beaudoin

If the child doesn't wish to visit the person in the hospital, ask questions and you might find out why the child is reacting this way and what you can do to better meet their needs. The child may:

- Express a fear of going to the hospital; try to find out more.
- Simply not feel like going or not want to miss out on an activity.
- Want to go, but may be afraid or uncomfortable for different reasons: the smell of the room or dislike of the person sharing the room or a negative past experience.

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WHAT YOU NEED TO KNOW AS A PARENT

Existential questions

Following a cancer diagnosis, many people living with cancer or caregivers ask themselves myriads of existential or spiritual questions. Being a parent also requires having to respond to children's existential questions on fear, anger, sorrow, and the meaning of the disease, suffering, death, and life.

Adults may think children can't handle the situation, but the reality is that children actually cope better when they know the truth. When proper information is lacking, children naturally tend to create dramatic scenarios based on their apprehension or imagination in order to fill in the blanks. Talking about the disease with children helps make sense of something that is mysterious and painful. This also helps them deal with their worries, particularly when they have trouble discussing them.

Before talking to their children, some parents take the time to explore what these great life questions mean to them personally and what values they would like to transmit to their children. It can be very useful for parents to first discuss these topics with their partner or friends so that they can clarify and organise their ideas and put their thoughts and emotions into words.

Such discussions will allow the children to better cope with the changes and emotions triggered by the illness of their loved one. It will also guide them throughout their lives when dealing with doubts and fears, and will prove very useful during difficult experiences. Hence, children will naturally come to understand that opening up and discussing painful situations is beneficial as it allows them to seek and receive the necessary help and support to cope.

Existential questions, beliefs and lifestyle choices differ considerably from one individual to another. As a parent, you should trust your own core values concerning these great existential questions. While respecting and sharing your innermost beliefs with your child, you will perhaps notice that the answers you offer may evolve and even change throughout your life experiences.

Death: should we talk about it?

Medical science has made great strides and the higher survival rate today is much more a reality than 20 years ago. The information available is more detailed and several services have been created to help surmount the experience of cancer. Despite the progress made, being diagnosed with cancer, a recurrence, or even going for a routine follow-up after treatment can raise fears and doubts. Going through a cancer experience still reminds us of our mortality. The concept of death can be painful for us and for others to think about. Life expectancy and the end of life are legitimate concerns. But before tackling these subjects, the context should be considered. Is the prognosis favourable or not? Is it a concern for the child, parent, or family and friends? Is the parent living with cancer ready to address these questions?

Why talk about death?

Talking about death following a cancer diagnosis does not mean throwing in the towel or entertaining dark thoughts. Talking about death can help the parent, as well as the child become more aware of this important aspect of life.

A child whose parent has a serious illness may be worried about the parent's death, but may not express it. Insecurity, anticipation, and fear can be particularly painful for a child. Discussing death with your child may not be easy, but it is an important subject. It will allow them to make sense and perhaps find meaning in something that is mysterious and intangible. As has been mentioned earlier, shedding light on painful situations makes them more palatable.



PART I

WHAT YOU NEED TO KNOW AS A PARENT

How to talk about death?

Talking about it is important, but equally important is how it is done. As a parent, your own beliefs and perceptions about death and the way you address the subject will influence the legacy of values you pass on to your child. Opening up on such an uneasy subject will teach your child that life struggles can be more easily faced with sincerity and with the encouragement and support that can come from sharing.

When you find it appropriate to address the subject, prepare yourself for it. Talking about death with your child or with another family member is sensitive, especially if you have never done so before. As much as possible, this process should respect each person's own way and own time. However, your child might surprise you by asking about death even before you have considered it yourself. First, it is suggested that you validate what death means for your child and evaluate their concerns. You may ask them what they have been told by relatives, teachers or friends and what they have understood from it, in order to clarify perceptions about the situation as a whole.

Finding additional help and resources

If, for any reason parents are unable or unavailable to address these issues with their child, they should ask other family members, friends, or health care professionals for help. If possible, parents should decide how they wish to handle the situation and what important messages they wish to convey to their child.

It is important that children are informed about what is happening and know that they are being taken care of. They also need to know that their parent is in good hands. Depending on their age, you may also take the time to explain the roles of the various members of the health care team attending to their parent.

Several families choose to seek additional help in order to meet as best as possible the needs of each member. Social

workers, psychologists, therapists, community organizations, and doctors can support and guide parents and caregivers as well as children.

When one parent is ill, it is preferable to inform individuals in the child's circle who may be able to help: teachers, coaches, close friends and their parents. Informing them will widen your child's support system. People who care for your child will also better understand their reactions and behaviours should they change: sorrow, confusion, anger, and aggressiveness, isolation.

Establishing cooperation with principals, teachers, coaches/trainers, or psychoeducators can greatly contribute to supporting your child through this experience. Helpful resources, such as psychologists or social workers, are also available in hospitals, CLSCs or private organizations.

Resources

Few organizations offer specific resources for children and adolescents whose parent has a cancer diagnosis. Therefore, family members and the professionals involved should consider the whole range of resources available including health care, family and friends, medical, professional, spiritual community, and school networks.

Depending on the school, children can have access to the following services: psychologists, psychoeducators, social workers, and nurses. The teaching and administrative staffs are also important resources.

RESOURCES

On the following page



◀ Opposite image : *Sheltered*, Luc Beaudoin

Resources around you

Family	Social	Medical	Professional	For youths
Parents	Neighbours	Pivot nurses	Psychoeducators	Tel-Jeunes (Services provided in English)
Brothers	Friends	Psychiatrists	Psycho-oncologists	Kids Help Phone
Sisters	Colleagues at work	Paediatricians	Psychologists	Deuil-Jeunesse (Services provided in English only in Montreal and Quebec City)
Uncles and aunts	Religious leaders	Medical practitioners	Social workers	Première ressource, aide aux parents (Services provided in English)
Parents-in-law	Sports trainers/coaches		Psychotherapists	
Grandparents	Teachers			
Cousins				
Godparents				

THE CANADIAN CANCER SOCIETY CAN HELP YOU AT EVERY STAGE OF THE ILLNESS.*

Interdisciplinary teams of professionals and qualified volunteers are here to listen and support you.

1 888 939-3333 | cancer.ca

INFORMATION



Get answers to your questions on:

- All types of cancer, diagnostic tests, treatments, side effects, clinical trials and many other cancer-related topics.
- Publications.
- Cancer-related resources in your region (home care, transportation, accommodation, support groups, etc.).

SUPPORT



Help you to:

- Find ways to cope with the disease.
- Better communicate with your loved ones.
- Speak to someone who has already been there.



CancerConnection.ca

Our online community where people facing cancer and their loved ones can share experiences 24/7 and build relationships to help them through their cancer journey.

* Our services are free and confidential.

PART I

WHAT YOU NEED TO KNOW AS A PARENT

How to talk with your child

Brief reminder

- Take a moment to determine what you wish to communicate to your child. As a form of preparation, you can write down the important points or practise with your spouse or a significant person regarding what you want to tell your child.
- Remember that how you discuss the subject will vary according to your child's age. For instance, if you want to define what "cancer" means, use simple words that your child will understand.
- Choose a time that will be conducive to this discussion: a moment when you can talk for a long time or answer questions, if need be.
- Choose a quiet place where both parents and children will be comfortable to ask questions and express emotions authentically.
- Tell the truth and use the real terminology.
- You have the right to say that you don't know.
- Check with the child what they have understood from what has been explained.
- Give the child space and time for reactions, periods of silence, tears, and questions.
- Your child may not respond as you imagined. Be prepared for different reactions. Your child will feel more understood and welcomed if his thoughts and emotions are respected rather than dismissed.
- If your child does not demonstrate an external reaction or does not want to talk, let them know that you or another significant person will be available to listen when they are ready.
- The next day or a few days later, ask your child how they feel about what has been said in the last discussion or about the latest developments.



Looking ahead, Luc Beaudoin

PART II

CHILDREN UNDER 3 YEARS OF AGE

CLARA,
2 YEARS OLD

“Has your little booboo gone, Mommy?”

Developmental stage and perceptions

Children under the age of three are quite attached to their mother and dependent on their parents (or caregivers). Their security comes from the love, playfulness, regular presence, and the daily care parents give them. The consistency of their daily routine (meals, baths, games, signs of comfort, love, and attention...) will anchor and contribute to developing their sense of security. Naturally, young children are entirely focused on their desires and needs without understanding the concept of time. They can notice changes within their daily routine or within their parents' behaviours, without knowing or understanding the cause. Their perceptions and reactions are mainly emotional. They have not yet learned to intellectualize information or decode the complexity of the spoken language. For a child of this age, the way something is said is as important as the choice of words. Even if they have not yet developed the capacity to grasp the importance or significance of a situation, they are still affected by it.



Contemplation, Luc Beaudoin

PART II

CHILDREN UNDER 3 YEARS OF AGE

Needs and reactions

Young children do not always know how to express their needs clearly, especially needs that arise from new and unknown situations. When a parent is ill or unable to care for their child, the reassuring presence and love of another significant person will console and comfort them. A familiar and caring presence does not replace the parent, but it contributes to the nurturing and security the child needs for a healthy development.

SOPHIE DAGENAIS, PSYCHOLOGIST

“No matter how young they are, it is essential to contribute to the development of their social, intellectual, and physical awareness. There is a wide variety of fun and playful ways by which you can nourish their growth and stimulate their learning. Games, social activities, and outings, can add to the development of their full potential.”

The emotional reactions of children under three years of age will manifest mostly through their body language, mood, and behaviour (smiling, crying, agitated, trouble sleeping, being more quiet or withdrawn, etc.). The changes in your child’s usual temperament and behaviours are a good indication that something is going on beneath the surface. Reactions will vary from one child to the next, and because you know your child so well, you will be able to identify if a specific mood or attitude is unlike them. Being able to do so, however, requires slowing down and turning off the “automatic pilot” to become present and attentive, to watch and listen. Being heartfully and mindfully present with your child will also allow you to feel more connected and understand them better.

Communicating with children under 3 years of age

MARIE, 3 1/2 YEARS OLD

“Why are you going to the hospital, Mommy?”
“Because there are lots of tiny dandelions in my breast and I must have them taken out with a special treatment.” “I have a great idea. I’m going to put lots of fertilizer on your breast and it’s going to be better really, really quick.”

Parent-child communication

At that age, the parent-child communication is built not only through language and sounds but also through physical contact and play in the course of the daily routine. Warm words and cuddles, songs and smiles, tickles and laughs are comforting and promote a sense of security. By making the daily moments (dressing up, changing diapers, meals, baths, etc.) a source of enjoyment, you reinforce the bond and establish the foundation of good communication with your little one.

PART II

CHILDREN UNDER 3 YEARS OF AGE

Illness-related communication

Children of this age have the capacity to understand more concepts than they can express. Therefore, a suggestion would be to explain the situation using few and simple words or using a picture book that deals with the subject.

Talking with children in a clear and simple manner about the upcoming changes in their lives and activities will make them feel more secure.

As children of this age experience life and events from an emotional perspective, using a language based on feelings will provide for a better understanding. For instance, *“Daddy loves to play with you”* or *“Mommy misses you a lot and can’t wait to come back home.”*

A few examples for communication

Talking about the illness

“The doctor told Daddy that he is sick. That’s why he is so tired and needs to rest.”

“Daddy is going to the hospital a lot because he is sick.”

“Mommy is sad because she is sick.”

Talking about treatments

“To help me get better, I need to go to the hospital to take medicine.”

“The medicine is very strong and Mommy’s hair will fall out, but it will grow back.”

Talking about the sick parent

Give them answers to their questions:

“Where is Daddy? Why isn’t he here? Who is taking care of him?”

Talking about changes in their routine

Give them answers as to who will pick them up at the daycare centre or will babysit them.

“Mommy is going to the hospital because she is sick. Grandma will stay with you today. Mommy will be back in time for the afternoon snack with you.”

Getting them involved

Small gestures, short activities, and brief parent-child interactions must not be underestimated. Children of this age are proud to participate in certain tasks through which they feel they are contributing to the well-being of the ill parent. The child can:

- Hand a pillow or arrange the blankets to improve the parent’s comfort.
- Snuggle with the parents in their bed with a book.
- Sing a song.
- Draw nice pictures to put up in their parent’s bedroom.
- Show a sign of affection.

In brief

Developmental stage

- They do not differentiate between themselves and their environment.
- They live in the present and barely understand the concept of time.
- They are comfortable and secure in a familiar environment with significant figures and may show signs of distress outside of these boundaries.

PART II

CHILDREN UNDER 3 YEARS OF AGE

Perceptions

- Their perception of life and others is mainly emotional.
- They usually understand facts better than explanations.
- They can sense that something is wrong or unusual even if they don't know the exact nature of the problem.

Reactions

- They have not yet developed the capacity to express their emotions verbally.
- Their reactions will be mainly manifested through a change in their behaviour.

A few suggestions for communication

- Offer your child lots of love and attention through affectionate physical contact. Take them in your arms, caress them, make them laugh. Children under three need encouraging, tender and loving words and physical contact, but also playfulness and laughter.
- Stick to the same routine in an environment that is familiar to them as much as possible.

If on the other hand, you have to leave them in the care of someone else, or if they accompany you to an unknown place or simply feel distressed, use familiar comforting objects from their daily life to soothe or reassure them. You may bring calming music that they like, or sing a song with them, bring their favourite toy or even a piece of your own clothing which is soft and cozy.

- Ask someone important to the child to take care of them when you can't.



Part of the artwork
Cellular Universe, Luc Beaudoin

PART III

COMMUNICATING WITH CHILDREN AGES 4 TO 7

Developmental stage and perceptions

Children ages 4 to 7 have a simple and concrete way of thinking. They are learning how to express themselves correctly and how to make themselves understood. At this stage of their development, they understand and make sense of what is said to them.

- They are familiar with the concepts of “today”, “yesterday” and a near future as in “tomorrow”, but may not yet have grasped the concept or the implications of a more distant “future”.

- They are learning to respect and follow the family values and rules.

- They can relate to the state of being sick or feeling ill.

- They can identify most body parts, but not necessarily all of their functions.



PART III

COMMUNICATING WITH CHILDREN AGES 4 TO 7

Children of this age range can grasp, to various degrees, the concept of a cause and effect relationship. Hence, they are able to understand that the illness can bring about uncomfortable or even undesirable changes. By discussing the situation with them, you will help them understand what is happening to their parent, to themselves and to the family as a whole. Keeping them informed on what is going on and how it will impact the family organization will help your child feel that they are not alone.

- They understand, to a certain extent, that the disease can be life-threatening.
- They understand that the medical staff and the treatments are helping to heal the ill family member.
- They understand the illness mostly through the concrete changes it causes.
- They conceive the disease and pain as something that will be of short duration.
- They may feel responsible for the parent's illness.

Needs and reactions

- They usually react more to changes affecting their life rather than the disease itself or the suffering of the parent.
- They may sometimes express their feelings verbally, but will mostly show emotional reactions in their attitude or behaviour.
- They may feel angry toward the situation as a whole and be more prone to become angry easily and suddenly in their interactions with others.
- They observe the adult's body language and attitudes in order to know how to react.

Communicating with children ages 4 to 7

Parent-child communication

In everyday situations, children from ages 4 to 7 are learning how to communicate and how to interact with others. They are constantly learning new concepts about life but also gaining more understanding about themselves and about their place in the family and in the community. Hence, the quality of presence you offer in both the receptive and active dialogue will serve to build a confident and emotionally intelligent inner structure for your child. By taking the time to answer their questions, to explain the situation and to listen to their concerns (and pay attention to what is lying underneath the emotional reactions), you are teaching them to recognize what their needs are, to trust their inner resources and to deal with life's struggles while respecting those around them.

Communication related to the disease

At this age, children understand clear and simple facts. If too much information or too many details are given, they become confused. They also need an emotion-based communication. This means that their emotions should be considered and taken care of not only by active listening, but also by choosing proper words, using a soft tone of voice and being patient and kind during the discussion.

This is a stage where they are particularly interested and inquisitive. If they ask you for more information and you are unsure how to answer them, be honest and tell them so. You can tell them that you will think about your answer or seek the answer, and you will let them know when you have found it.

A few examples for communication

Talking about the disease

"I'd like to tell to you what happened to Mommy because I want you to know what's going on."

"You know that Grandpa hasn't been feeling well for a while. The doctor told him today what is causing him to feel that way."

PART III

COMMUNICATING WITH CHILDREN AGES 4 TO 7

“I don’t really know how to tell you this, but I’m going to try to explain it to you as best as I can. Then, you can tell me if you understand.”

Check with the child to discover what they have understood: “What do you understand of this? Can you tell me what it means in your own words?”

Talking about cancer

Don’t be afraid of using the word “cancer”, using real words when explaining something to your child diminishes the possibility of confusion and misinterpretation. Children may have heard the word “cancer” already from someone else, on television, or even from you while you were talking to a relative or a friend on the phone.

“Have you ever heard about cancer before? There are many different types of cancer.”

“A few days ago, Daddy found out that he was sick and had cancer. He will be sick for a while, but we don’t know yet how long.”

“Every time the doctor tells us something new, we’ll let you know. We also want to know if you have any questions or if there are things you do not understand. Sometimes when someone we love is sick, it can make us sad, angry or afraid and that is ok.”

Talking about treatments and side effects

“The treatment to help me get better is very strong. My hair might fall out, but it will grow back.”

“We don’t know if the medicine is going to work. It could help Mommy get better, but we’re not sure.”

“To get better, I have to undergo treatments that are called chemotherapy and radiation therapy. Have you heard these words before?”

“Chemotherapy is a medicine that kills the bad cells inside Mommy’s body, which are responsible for cancer. They are like soldiers who are going to war and this requires a lot of energy from Mommy. She is going to feel sick and more tired after taking the medicine, but don’t worry, it’s normal.”

“Radiation therapy is a way to cure Daddy. Painless laser beams enter Daddy’s body to kill the bad cells. The nurses will make pencil marks on Daddy’s skin to know where to aim the beams.”

Talking about emotions

“When something new happens in our family, we can feel things in our body that we never felt before. That’s okay. It happens to adults too. Sometimes, we feel many emotions at once like joy and sadness and fear and that’s also normal. Talking about it with someone who loves us can be very helpful.”

“I am here to listen to you if you want to talk about how you are feeling. If you prefer talking to someone else about it, that’s okay too.”

“Even if I sometimes look sad, I want you to know that it’s not because of you. It’s because of the illness. Sometimes, it makes me angry and other times it makes me sad. I’m still capable of taking care of you. I just need to let my sadness come out.”

“Crying is a way to release the pain or the sadness that’s inside. Sometimes, it does a lot of good. So, if you feel like it, it’s okay to cry.”

Talking about the sick parent

“Doctors and nurses are giving medicine to Daddy to make him better. That’s why he cannot come back home right now. He has to stay in the hospital even if he would prefer to be here with you. He will come back home as soon as he can after his treatments.”

Talking about changes in children’s routine

When you have figured out the new logistics surrounding the family schedule, inform your child:

- Tell them who will take care of them while you are absent.
- Let them know who will drive them to the swimming lessons when Mommy cannot go.

PART III

COMMUNICATING WITH CHILDREN AGES 4 TO 7

Getting them involved

Children are proud to participate in activities through which they feel they are contributing to the well-being of the parent. At times, they may or may not feel like being involved, and it's important to respect that.

Children of this age may be very pleased and proud to contribute by:

- bringing a glass of water
- handing a pillow or fixing the covers if the parent is bedridden
- singing a song
- drawing pictures
- participating in the preparation of a meal or snack
- giving an affectionate gesture

In brief

Developmental stage

- They learn to communicate and interact with others.
- They gain more understanding about their place in the family and community.
- They learn to express their needs while respecting those of others.

Perceptions

- They can understand what is happening when simple words are used.
- They create their understanding of the disease in terms of the concrete changes caused by it.
- They need reassurance about what will be done to help and support them.

Reactions

- They are able to express their feelings verbally, but may also show emotional reactions in their attitudes or behaviours (i.e. regressive behaviours).

- They are more likely to react to changes affecting their lives rather than the disease itself or the suffering of the parent.

A few suggestions for communication

- Answer honestly as best as you can when questions arise.
- If you don't know what to say, let them know that you will look for the answer and get back to them.
- Try as much as possible to respect the usual daily routine and inform them about changes that may occur.



Offering the Moon, Luc Beaudoin

PART IV

COMMUNICATING WITH CHILDREN AGES 8 TO 11

Developmental stage and perceptions

Between the ages of 8 and 11, children are at a stage where they are interested in learning about their surroundings. They want to understand how things work, are very curious and ask many questions.

They are starting to think more abstractly even if they sometimes do not understand subtleties. Their way of perceiving the world is progressively oriented to facts. They understand the concepts of good or bad and are beginning to differentiate between what is socially acceptable or unacceptable.

They need to be lovingly supported by being listened to as well as being given clear explanations.

Relationships with friends and with people outside the immediate family gain importance.

In relation to the illness, children ages 8 to 11:

- Are old enough to worry about their own health.
- Mainly associate the disease with the symptoms they see.
- Will define the disease both in terms of the changes experienced in their daily lives as well as the effects they can observe in the ill parent.
- Understand that the disease can be life-threatening, but also that it can be cured.
- Understand that medical science and treatments can cure the person with the illness.



Balloons, Luc Beaudoin

PART IV

COMMUNICATING WITH CHILDREN AGES 8 TO 11

MÉLANIE, ADULT, REMEMBERS WHEN SHE WAS 9 YEARS OLD

“After the shock, life continued. We were extremely lucky because we lacked for nothing. The disease didn’t affect my comfort or my quality of life. On the other hand, I went to school, being physically in class but mentally with my father during his treatments. We had, two-week breaks between his treatments during which I made myself believe that our situation was normal because Dad went to work.”

Needs and reactions

- They ask for clear explanations.
- They turn mainly to the family to confide their feelings of sadness and worry.
- They may feel angry toward the situation as a whole and be more prone to express anger towards members of the family.
- They can blame themselves for the occurrence and persistence of the disease.

Communicating with children ages 8 to 11 years

Parent-child communication

They need clear and simple explanations. They ask many questions in order to understand what is happening, and make sense of what they feel and what they have been told. As parents, you must equip yourselves with patience and welcome them over and over again when they come to you asking for more information or clarification. Their

growing independence may fool us into thinking that they need less of our attention. Although they are becoming more mature and want to do things on their own, they still need our caring ear and affectionate attention. Taking the time to answer them, discussing certain issues with them and even participating in activities of their own choosing will ensure more open relations and guard against withdrawal because of feeling misunderstood or unwelcomed.

Communication about the disease

At this age, they will ask a lot of questions because they want to understand the whole process of the disease. In their logic, everything has a beginning and an end. Hence, their questions about the disease will follow the same pattern: Why and how did it appear? How will the disease progress and when will it end? When you have no answer, tell them so, and get back to them later on when you know. When your children ask you questions, you can see it as a puzzle they are trying to solve, seeking to build the evidence between the disease and the visible symptoms. Because of the importance of accurately naming and explaining the disease, understand that it is okay to use the word “cancer” when they are around. If they feel welcome to ask you questions, they will feel more equipped to deal with the illness. For this particular reason, it is better they hear the information from you rather than a third party. Moreover, maintaining ongoing and open communication will be reassuring and will help maintain and strengthen your child’s trust towards you. Children will also appreciate if parents can help them find ways to cope and figure out what to say to their friends and other people in their surroundings.

A few examples

Talking about the disease

“I’d like to talk to you about something important.”

“I’d like to explain what is happening to Mommy because I want you to understand what’s going on.”

PART IV

COMMUNICATING WITH CHILDREN AGES 8 TO 11

Talking about cancer

“What do you know about cancer? Do you know there are several types of cancer?”

If your prognosis is uncertain:

“Daddy has a disease called cancer. He’s going to be sick for a while. We don’t know for how long and we don’t know what his chances of getting better are.”

If your prognosis is unfavourable:

“My cancer is very advanced and doctors don’t think I’m going to be cured. The medical team will do everything in their power to slow down the disease, but we don’t think I have long to live.”

If your prognosis is favourable:

“Although some people die of cancer, the type of cancer I have is not very serious, so doctors say that I will be able to get better.”

“Every time the doctor tells us what’s going on, we’ll follow-up with you. We would also like you to let us know if you have any questions, if you feel sad, or afraid.”

Talking about treatments and side effects

“I must undergo treatments known as chemotherapy and radiation therapy. Normally, they should cure me, but we don’t know for sure yet. I must first start the medications and then the doctor will tell us if I’m going to recover or not.”

“Chemotherapy is a medication that fights the disease inside Mommy’s body. This treatment is strong and my hair could fall out, but it will grow back.”

“Radiation therapy is a way to cure Daddy. A machine will project a painless laser beam. This laser beam is aimed to kill the cancer cells. The nurses will make pencil marks on Daddy’s skin for guiding the beams.”

ANTOINE, 9 YEARS OLD, BEFORE HIS MOTHER'S CHEMOTHERAPY SESSIONS

“Are you also going to lose your nose hair? Because you know, they’re important to stop you from getting sick.”

Talking about emotions

“I would really like for us to chat about how you feel. It can be whenever you want and we can discuss anything that you wish.”

“I am here to listen if you want to talk to me about how you feel or what you think. If you prefer to confide in someone else, that’s okay as well. What’s important is that you can talk to someone about the things that bother you.”

“Even if I look sad sometimes, it’s not your fault. It’s the effects of the disease but I’m still capable of looking after you. I just need to let my sadness come out.”

“Crying is a way to release the pain or the sadness that’s inside. Sometimes, it does a lot of good. So, if you feel like crying, it’s okay to cry.”

Talking about the ill parent

Give the child as much information as you see fit and most importantly, inform them of the whereabouts (absence, return, and hospitalization) of the ill parent.

PART IV

COMMUNICATING WITH CHILDREN AGES 8 TO 11

Talking about changes in their routine

One day at a time, tell your children about the changes that are likely to take place in the family and their personal routine, especially those affecting their personal activities. Tell them about who will take care of them in what situation.

Getting them involved

At this age, children will be proud to participate, especially if you let them suggest what they would like to do to contribute to the family or the well-being of the ill parent. Invite them to get involved by taking reasonable and age-appropriate responsibilities that are adapted to their living environment (cleaning their room, making their lunch, etc.) and suggest tasks that will increase their self-esteem such as:

- finishing household “chores”
- helping with tasks the ill parent is no longer capable of doing
- being calm and quiet at home
- completing their homework

“You don’t listen to me!”

Has your child ever told you “You don’t listen to me!”? When being on “automatic pilot”, you may listen to what is being said without hearing the message implied. In those moments, attention is no longer on what is most important to you but rather on what you “have” to “do”. It takes much practice to remember how to “be” mindfully present. However, approaching the one-on-one moments with your children with a fresh and open mind will help you pay attention differently. Cultivating what is called a beginner’s mind in the world of mindfulness, means to avoid thinking you already know what your child is communicating. The beginner’s mind helps you attend to something with an attitude of gentle investigation, patience and acceptance. This in itself is a display of love and affection and is thus beneficial for both the parent and the child. Children easily pick up on their parents’ absent-minded moments, but they also recognize and tremendously appreciate when parents give them their undivided loving attention.



Slowing Down, Luc Beaudoin

PART IV

COMMUNICATING WITH CHILDREN AGES 8 TO 11

In brief

Developmental stage

- They need to understand how things work and ask plenty of questions.
- They better understand what is happening when simple words and clear explanations are used.
- They need to spend time with their parents, playing, talking, reading, making arts and crafts or other educational activities.

Perceptions

- They mainly associate the disease with symptoms they see and the concrete changes caused by it.
- They understand the imperceptible causes and effects of the disease when simple explanations are used.

Reactions

- They can understand what it feels like to be ill based on their own experience.
- They can express compassion toward the parent's situation.
- They can be affected by the changes in their daily routine and activities.
- They can be concerned about the parent's well-being.

A few suggestions for communication

- Check with children to discover what they have understood from your discussion: ask them to repeat, in their own words what you have said.
- Answer their questions as best as you can or let them know that you will as soon as you have the information.

- Stick to the daily routine as much as possible and tell them about changes that may take place, one day at a time.
- Encourage them to continue seeing their friends and attending outside activities.
- Give them tips on how to handle what is being said about their parent's disease.
- Respond as promptly as possible to their concerns about the disease so that they can develop their understanding.
- Help them find words or images explaining the new emotions and feelings they are experiencing.
- In order to help them express their feelings, you may engage in role-play with them, or share that you too sometimes feel angry, sad or confused.

Opposite image : *Growing Together*, Luc Beaudoin ▶



Les amoureux

PART V

HOW TO COMMUNICATE WITH ADOLESCENTS (12 YEARS OF AGE AND ABOVE)

Developmental stage and perceptions

The adolescent is in a physical and mental phase of development marking the transition from childhood to adulthood. This growth period, known as puberty, is characterized by the development of secondary sexual characteristics and important behavioural changes.

Even if they strive to become independent and free, teenagers still need emotional support and love from their families. This paradoxical situation leads them to question the family rules and values established since childhood as well as social norms in general. Parents must remain vigilant to be able to differentiate between adolescents' typical attitudes and reactions to those that are situational.

Teenagers are heavily influenced by their peers and group pressure, and attach considerable importance to friends and non-family relationships. However, home should still be the place where they can find security, comfort and a warm non-judgmental ear. In order to flourish to the fullest during this self-affirmation phase, teenagers need their parents' trust and encouragement to continue nourishing their self-confidence. In spite of their capacity to be independent, teenagers need guidance, along with limits and responsibilities.

CLAIRE FOCH, HUMAN RELATIONS AND FAMILY COACH

"The parent's disease makes adolescents fragile. They need affection, support, and to be listened to in a manner that will foster their inner strength to get through this ordeal. By guiding them to their own resources you will provide them with life-lasting tools."

In relation to illness, adolescents

- Are interested in understanding the body and the general function of its organs.
- Have probably already heard the word "cancer" and may know that there are several types.
- Understand the significance of a serious illness and some of its implications.
- Most likely know that death is a possible outcome of the disease.

Needs and reactions

- They may feel divided between their need for independence and their desire to stay close to the sick parent.
- They may be concerned about the pain and suffering of the sick parent.
- They may worry about the outcome of the disease, which could lead them to search for information.
- Their emotional reactions or mood swings may be directed spontaneously towards those present, without regard to the sick parent.
- Older teenagers are conscious and more understanding of the reality surrounding cancer and may fear having cancer themselves one day. Hence, they may feel the need to seek information and investigate with someone, the possibility of having the illness.

PART V

HOW TO COMMUNICATE WITH ADOLESCENTS (12 YEARS OF AGE AND ABOVE)

Talking with adolescents

Parent-adolescent communication

The type of communication you have built with your kids throughout their childhood will not change drastically during adolescence or in the face of a cancer diagnosis. You may find your child struggling with situations and emotions, but the trust, respect and acceptance you have established as a channel of communication remains. And if, on the contrary, communication has been strenuous, the occurrence of a cancer diagnosis in the family may be a good place to start readjusting the quality of communication you wish to establish with your children.

Although they are growing closer to being adults, adolescents need to be heard and seen for whom they are rather than for their temperamental behaviour, their mistakes, or their mood swings. It is important to remember that adolescents go through strong hormonal and emotional changes. Practising a presence of acceptance and non-judgment with your adolescents will enable you to stop, or at least slow down, and hear what is truly being said underneath the uncomfortable silence or intense emotional reaction.

Adolescents are bright, sharp, and mature enough to know their parent's fears and opinions as well as their personal ways of dealing with life struggles. Hence, they can consciously or unconsciously catch you trying to "act as parents", trying to have things your way, rather than listening authentically. They are old enough to disagree with you and confront your ideas and ways of doing things, but they are also able to see and be affected by your suffering. That is why it is to your benefit to hear them out and consider their point of view. It may confront you in very uncomfortable ways, and you may not necessarily agree, but remember that communication is a two-way street. If each person can be truly heard, then is it with more awareness that you can support each other and find solutions to meet everyone's needs, all the while respecting the family's fundamental values and rules.

Communication about the disease

Whether your teenagers easily express their emotions or have the tendency to avoid sensitive subjects, you as a parent or significant relative can compassionately initiate and encourage discussions. Inviting your children to open up will help them put words to their inner experiences and reorganize confused thoughts and ideas.

MELANIE'S STORY ADULT, WHO SUPPORTED HER FATHER WHILE STILL A TEENAGER

"Dad's illness lasted 5 years. The older I grew, the more I understood the risks that he was up against, and the angrier I was. I confronted my teachers! I was probably considered an opinionated teenager. It was my way of venting!

Very often, I preferred to withdraw from discussions focusing on the concerns of my classmates because back then I found that they made a mountain out of small things.

I knew that both my parents had to endure their respective emotions caused by this ordeal. I didn't want to add to it. So, I confided in one of my father's sisters. I found a willing ear over 1,200 km from our house. I feel forever indebted to her because she often crossed that distance, upon my request, when the situation was unbearable."

PART V

HOW TO COMMUNICATE WITH ADOLESCENTS (12 YEARS OF AGE AND ABOVE)

Teens may feel torn between their desire to spend time with the ill parent and going out with their friends. Reassure them that it is not only okay to spend time with their friends, but essential to their well-being. At this stage of their development, socializing with friends can temporarily help put their minds on something other than their parent's disease. Friends are a valuable part of a healthy support system and can greatly contribute to alleviate the cancer experience.

From their point of view, adolescents are capable of finding answers to their questions on their own. They may research to gain more information on the disease. What they find may be accurate or not, so ask them to share what they have learned with you. You will then be able to establish more accurately what applies to the ill parent's situation. By inviting them to share their ideas, participate in finding solutions or partake in decision making, you are contributing to diminishing the feeling of helplessness that many people feel in the face of an illness like cancer. You are also contributing to making them feel recognized, trusted, and gratified.

A few examples for communication

Announcing the diagnosis

"I have something important to tell you. The news is hard to break, but I want you to be aware of it and know what's happening."

"If you remember, I told you that I had to go for some tests at the hospital. I got the results and can give you more information about my health problems."

Talking about cancer

"Do you know what cancer is? Do you know that there are several types of cancer? We will do our best to explain it to you, but you can also do some research to have a general idea about what I've been diagnosed with. Afterwards, we can talk about it and see what applies to my specific condition."

"We will keep you informed on what is happening. We want you to know that we are available if you have any questions or concerns you wish to address. We will do our very best to help you, anytime."

If your prognosis is uncertain:

"At this stage of my cancer, doctors can't tell me what my chances of recovery are. I have to undergo other tests before they can comment any further on that matter."

If your prognosis is unfavourable:

"My cancer is at a very advanced stage and the chance of recovery isn't very good. My health care team and specialists will do all they can to slow down the disease, but we think I don't have much time remaining. Maybe a few months left to live."

If your prognosis is favourable:

"I've been diagnosed with cancer and the disease is at quite an early stage. The doctor says that it isn't very serious and with treatments, I should recover."

Talking about treatments and side effects

"To have the best chances of recovery, I must go for chemotherapy and radiation, which should both work well. Then, when treatments are over, I will undergo other tests and the doctor will tell us if they were effective or if more are needed."

"Chemotherapy and radiation can have several side effects. Some are visible, like the loss of my hair while others will require me to keep in touch with my health care team. They'll tell me what to do."

Talking about emotions

"How do you feel about what I just told you?"

"Each time you need to, I want you to feel free to come to me. I like it when you talk to me about how you feel, even if I become emotional. When you talk to me, it also helps me talk to you and does me a lot of good."

VALERIE'S STORY

ADULT WHO REMEMBERS WHEN SHE WAS 15-16 YEARS OLD

"My mother told me about her cancer diagnosis as if she were breaking the news to a responsible adult. I quickly realized that the situation was serious because a course of chemotherapy and radiation treatments had been planned. I felt that she trusted me by telling me this news. I was grateful to her for having acted in this way because I knew what we were facing.

I had a deep need to see my friends, with whom I talked about it. I knew that I could count on them. Sometimes, I also felt terribly guilty about going out to have fun with my friends while my mother was suffering physically, even if she often told me to carry on with my school and social activities.

I was happy and proud that my mother asked me to accompany her to her chemo sessions. I would sit down beside her and we would talk, tell stories, and chat with the other patients. In spite of the

circumstances, I think that my mother was overjoyed that I accompanied her to the hospital.

Before the onset of the disease, I was paid an allowance for doing weekly household chores: dusting, sweeping, etc. I started helping more with the daily routine when my mother started suffering from the side effects of her treatments. I wanted to support her as much as possible, as best as I could, but at times I found it difficult. Sometimes, I even had the impression that I was the parent. On the other hand, my mother thanked me often for helping her and every time, I felt I was contributing to making her daily life easier. That was important to me.

When my mother told me that the prognosis was disheartening, I screamed and cried a great deal in her arms. I could see on her face to what extent my reaction bewildered her. The next day, I pulled myself together and decided that I would make the best of my time left with her. That was the best decision of my young life!"

"I appreciate that we can talk about how we feel. But I also want to respect you when you don't feel like it or when you find that I ask too many questions. Feel free to let me know and we'll talk another time."

Talking about the sick parent

Give them the information that you have on the diagnosis, treatment, prognosis, and doctor's recommendations. Answer their questions about the absence, return, or hospitalization of the ill parent.

Keep them informed as you receive updates. Emphasize that taking it one step at a time or one day at a time is a relevant approach for both the sick parent and loved ones.

It may be helpful for your family to seek professional help in order to allow for a safe sharing space where everyone's

needs can be heard and understood. A family counsellor or psychologist can also offer ideas and advice regarding the reorganization of activities and responsibilities at home as they relate to the treatments and needs of the ill parent.

Talking about changes in their routine

Tell your adolescent of changes that are likely to take place in family routine, one day at a time.

When feeling torn between staying with their family and going out with friends, try to help them find what would be a good balance for them. You may take the time to help them better understand the underlying feelings. Being clear about your own needs and responsibilities versus theirs will contribute to clarify false impressions, and diminish fears or feelings of guilt.

PART V

HOW TO COMMUNICATE WITH ADOLESCENTS (12 YEARS OF AGE AND ABOVE)

Getting them involved

They like and feel proud to contribute to the well-being of their parent, particularly if they feel nothing is being imposed on them. They will find it very gratifying to be trusted, to be found responsible, and a part of family decision-making. This is also beneficial for the parents because it maintains communication and enables teens to find out more about the disease and share their concerns and emotions.

Be careful not to make them feel that the well-being or the health of the parent depends on what they do or do not do. For example, the well-being of the sick parent does not depend on whether they:

- complete domestic chores
- help with tasks that the parent is no longer capable of doing

In brief

Developmental stage

- They are at the stage of puberty, so it's crucial to remember that they are in the midst of important hormonal, emotional and behavioural changes.
- They need to be recognized for who they are rather than for their temperamental behaviour, their mistakes or their mood swings.
- They need your trust, listening, and encouragement as well as limits, responsibilities and security.

Perceptions

- They can understand the seriousness of the illness and its implications.
- They can see or feel your physical and emotional suffering.

Reactions

- They may feel confused in the midst of an emotional roller coaster.
- They may be torn between their need for independence and security and their desire to remain close to the sick parent.
- They may, out of concern, do their own research or seek external support.

A few suggestions for communication

- Be readily available and encourage discussion about the way you both feel.
- Keep them posted on the information you get as you go along.
- Answer their questions or let them know as soon as you have the information.
- Invite them to share and discuss with you what they have heard or read about the disease.
- Trust them and hear them out.
- Invite them to take part in family decisions.
- Give them the opportunity to continue participating in family chores.
- Encourage them to continue their activities outside the house and see their friends.

Opposite image : *Letting Go*, Luc Beaudoin ▶



Luc Beaudoin

BIBLIOGRAPHY

Kabat-Zinn, J. *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, And Illness*. 1990.

Kabat-Zinn, J. & Kabat-Zinn, M. *Everyday Blessings: The Inner Work of Mindful Parenting*. 1998.

Shapiro, S. & White, C. *Mindful discipline: A Loving Approach to Setting Limits and Raising an Emotionally Intelligent Child*. 2014. New Harbinger Publications Inc.

NOTES :

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