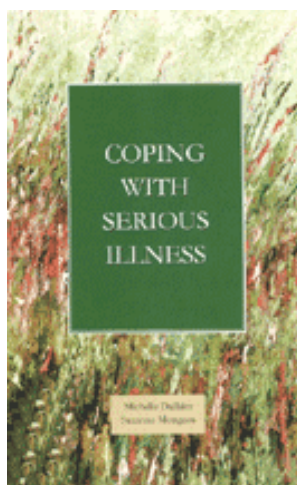




Serious illness

Coping with serious illness

Introduction



This brochure is for all those people who, for one reason or another, are affected by a serious disease. It contains the questions most often asked by those suffering from a critical illness.

Part One addresses questions such as : how to deal with the changes resulting from a serious disease, what are the appropriate decisions to make about treatment, and how to deal with pain.

Although many serious diseases can be cured, or at least controlled for extended periods of time, the time comes when each of us must face the last phase of life. Part Two of this brochure examines this issue and looks at a number of related questions: how to express one's last wishes, how to deal with children coping with the terminal illness of a loved one, and how to live the remainder of one's life.

These questions are difficult and often upsetting. It is important to remember that not everyone will be facing all the problems presented in this brochure. Each person is unique with one's education, values*, culture and life experiences. Each one deals with disease in a very personal way, using and even discovering his own resources as well as those of his environment and community.

This brochure does not read like a novel, so it is all right if you pick and choose what interests you. Read at your own pace. If what you read is upsetting or causes concern' don't hesitate to discuss it with a relative or a health-care worker you trust. Reading this brochure is no substitute for the richness of discussions between the seriously ill, their families, and the caregivers.

You will notice that some words are followed by an asterisk (*). These are keywords which are defined at the end of the brochure. The section entitled "Resources" indicates where you can get

the information, care, or services you may one day need.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. Coping with serious illness. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Confronting the changes

Serious* disease causes upheavals; life is no longer what it was. You may not always understand your reactions and the reactions of those close to you. You may be asking yourself how you are going to get through this difficult time. This section will provide some insight and help you handle these issues.

Yesterday, my doctor told me that I have a serious disease. I just can't believe it! He must have made a mistake. What's happening to me?

You are having a hard time accepting what is happening to you because you are in a state of shock. For the moment, you are unable to deal with your emotions and concerns. And that is normal. Take all the time you need. That is how you prepare, at your own speed, to confront the situation.

I often "replay" the scene in my mind when the doctor gave me his diagnosis*. How do I get this idea out of my head?

People who have experienced significant stress often "re-live" the moment in their minds. Talking about it may help. It is a way to:

- come to grips in your own time with what is happening to you;
- identify the emotions you are feeling;
- put some order in your reactions;
- gradually free yourself from the emotions you have experienced.

I've felt anxious and afraid ever since finding out about my condition. What can I do?

Other people in similar circumstances have found the following to be helpful in dealing with their fears.

- First of all, acknowledge that being afraid is a normal reaction.
- Try to identify your fears: Are you afraid of suffering? Of becoming dependent? Of losing control over your life? Of dying? It's easier to find ways of dealing with a specific fear than trying to cope with general anxiety.
- Talk with people you trust (family and friends, caregivers, volunteers*), because having someone supportive listen to you is often a relief.

- Talk with people who are going through the same experience. They can share with you what helped them deal with their fears. You can meet such people at the clinic, when you go for your treatments, or by joining a self-help group.
- Live one day at a time, maintaining a few activities that are really important to you.
- Remember that many serious diseases can be treated or cured.
- Gather information about your disease, treatments, and possible side effects.

Why do I occasionally express anger towards those I love?

You are probably frustrated by the changes in your life and unexpected situations brought on by the disease. You have less tolerance towards things that bothered you before you got ill. You may be venting your irritation on the people around you. In reality, chances are the situation-not your caregivers-is what is bothering you the most.

What can I do about my anger?

First of all, go easy on yourself because anger is not only normal but also useful in this situation.

Try to determine what's bothering you. Is it because you are in the hospital waiting for treatment? Because you can no longer do the things you like best? Because you can't work for the time being? Because you've lost part of your independence?

Discuss your anger with people you trust to see how you can use it in your fight against your disease.

Finally, when you have calmed down again, let your family and friends know they were not responsible for your bad mood (if, indeed, they were not).

Since I've been sick, I'm not the same person anymore. Sometimes I am discouraged and sad; other days, I feel hopeful. I can't tell whether I'm moving forward or losing ground. Is this normal?

People tend to react to difficult situations this way. Ups and downs are normal and you need to remember this because on hard days you will be able to keep up the hope that tomorrow is another day and may be better.

Should I tell the people close to me about my condition?

You may feel tempted to hide your illness from those closest to you to avoid upsetting them or for other reasons. If you do feel that way, you might want to consider to what extent you risk feeling even more isolated, depriving yourself of their support, and blocking communication with them. Tell yourself that those who know and love you probably sense that you're ill and are wondering what's going on because your illness changes the way you behave.

I live alone and no longer have any family. I'm wondering how I'm going to get through this crisis. Who can I turn for help?

It's not easy to face serious disease alone because, when you're ill, you need human warmth and comfort more than ever. Many people, however, develop friendships in self-help groups. Others find that volunteers and caregivers are good listeners. You may even feel less alone reading the accounts of people who have gone through the same experience as you have.

I've noticed an uneasiness in the people around me since they found out I am ill. It seems to me some people are avoiding me. What's the reason behind this change?

These people may be afraid of the disease and the emotions that it causes. They are avoiding you because they don't know what to say or how to act around you now that you're ill.

The impression that people are avoiding me hurts me deeply. What can I do?

If these people are important to you, you can share your feelings with them and express your needs. They may understand what is making them react in this way and change their behavior, if they can.

If your efforts don't result in a change, you should instead focus on people who are prepared to support you through this time. As all other major events in life, illness tends to draw some people closer to you and push others away.

Why has it become so difficult to communicate with my family and friends since I've become sick?

Serious* disease brings about many changes in your relationships with family and friends.

- You are more tired and so are they. Treatments and hospital trips take a lot out of you, which limits the energy you have for one another.
- You, your family and friends are having emotional reactions to your illness, and your reactions may be different from theirs. Let's say you are often in a bad mood, while your loved ones may feel very sad. Such differences in feelings may lead to misunderstandings.
- You may also be annoyed at changes in your activities at home, with your circle of friends, or at work. For example, your disease may prevent you from contributing financially to your household. You may feel uncomfortable for causing so many changes.

Communicating with loved ones may be more difficult because you are having a hard time adapting to all the changes. Generally, when you recognize these changes and can talk about them, your relationships with friends and family grow closer, despite problems related to your disease. Being together often gives much more meaning to life.

What can I do to help my family and friends get through this time?

You can help them by:

- sharing with them what you are experiencing and how you feel;
- explaining your needs;
- letting them take care of you. Indeed, they won't feel as powerless and useless if they can contribute to your well-being.

How can my family and friends support me?

They can help by:

- accepting the situation as it is. Comments such as "It's not serious; everything will be fine" provide no real relief;

- showing concern for what you are experiencing emotionally, not just when you hear the diagnosis* but throughout the course of your disease;
- giving basic practical assistance (preparing meals, picking the kids up at school, etc.);
- letting you make your own decisions;
- allowing you to continue being useful;
- sharing the bond between you through words and gestures;
- making you laugh like before, because life goes on even if the disease changes how you live.

I have to pay out a lot of money because of my disease. Can I get reimbursements for any of my expenses?

You may be eligible for compensation for some of your expenses. For more information, see the "Resources" section at the end of this brochure.

Some people claim that serious disease has actually made positive changes in their lives. How can this be?

The following personal account may shed some light on this:

When I found out that I was seriously ill, I was afraid of dying. It was at that point I realized how important living was to me. I look at things differently now. I don't take life for granted anymore, so I get the most out of it. I now have a much clearer sense of what is important to me. I used to rush everywhere ...now I take the time... to appreciate nature, to be with the people I care about. I never put off things till tomorrow. I've come to understand that life is both strong and fragile at the same time".

Overall, what can I do to help myself deal with these changes?

The following are suggestions from people who have gone through the same experiences and have shared them with us.

- Think back on how you faced difficult situations in the past and how you worked them through.
- Review your life, recalling the good and the bad things that happened to you. This may help you decide what changes you want to make in your life.
- Reflect on "unfinished business" in your relationships and on things left undone. You may have something special to say to one of your loved ones. You may want to get in touch with a family member from whom you have been estranged for a number of years.
- Try to understand your reactions and emotions by sharing them with someone you trust. You may feel less overwhelmed by events.
- Set reasonable goals for yourself, such as taking a short walk every day.
- Do things that you like for yourself or your loved ones.
- Take a look at what gives you the strength to keep up the fight (your children, work, friendships, plans, or religion).

- Identify the people you would like near you during this time.
- Encourage the participation of family and friends by letting them care for you and by sharing your thoughts and questions with them.
- Remain hopeful because most sick people can still appreciate life once they have adapted to these changes.

These suggestions can help you keep some control over your life and provide a certain amount of relief.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. Coping with serious illness. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Making the right decisions

Learning that you are critically ill can put you in a state of shock. During this time, it may be difficult to understand the information provided by your doctor or other health-care workers. But you still need to make decisions.

Having a serious disease often means a lot of tests and medical appointments. How do you get the information you need and come up with your own opinion?

These are some of the problems we look at in this section.

I have an appointment with a specialist in a few days. I have a number of major decisions to make and I'm very anxious. How can I get myself ready for this appointment?

Here are some tips to help you:

- Try to determine what is bothering you.
- Prepare in writing a list of questions for your doctor.
- Ask a family member or friend to accompany you. Choose someone reliable who will stay calm and be able to support you.
- Meet with your family doctor to prepare for your appointment with the specialist.

If you're still not ready to make a decision by the end of the appointment, ask for a little more time to think things over and make a second appointment for the near future to finalize things.

I've just had a number of X-rays and blood test. Who do I see to find out the results?

The exams and tests help determine the nature of your disease. They are part of what is called a diagnosis*. Your doctor is your first source of information about your disease and the treatment available for controlling it. Don't hesitate to ask him questions.

If you are consulting a number of specialists working from outpatient clinics, it's a good idea to have all the results sent to your family doctor. He can help you understand what is happening.

If you are in the hospital, you should find out who your attending physician is, because he has overall responsibility for your care.

My doctor explained the diagnosis to me, but I still have a lot of questions. Can other people help me better understand my disease?

If you are being treated at a hospital or CLSC, your nurse, social or other health-care worker, familiar with the disease, can be of assistance.

If you're not sure who to contact, call Info-Santé at your CLSC. A nurse is there 24 hours a day, seven days a week, to take your call.

You can also get in touch with one of the many associations dedicated to certain diseases. As well, you could join a self-help group, where you will meet people who have gone through crises similar to yours. Sharing with them can help you both understand what's happening to you and decide what's best for you. You will find more information on these resources on page 40.

What kind of information can I ask my doctor?

You can ask your doctor about:

- the nature of your disease;
- the course of the disease in the event you undergo a series of treatments and the course of the disease in the event you don't;
- which treatments would be best for you;
- the consequences or side effects of treatments.

Your doctor will answer your questions while taking into account your specific situation.

Does my doctor have to tell me the truth about my disease?

Your doctor will answer your questions honestly. He will be attentive to your requests and will follow your pace in providing answers in a caring manner. If you don't want to be informed, tell him so.

How can my nurse, social worker, psychologist, pastoral* assistant, or other caregiver help me make decisions?

All these people can answer a certain number of questions about your treatment, medication, or financial and family problems. They can listen to you and suggest sources of additional information. They can also let your doctor know that you would like to have more information. They can reassure and encourage you. This should help clarify things so you can make the appropriate decisions.

Does my doctor have all the answers about the chances of success in the treatment of my disease?

Your doctor has general information about your disease and possible treatments. There are statistics available on the success rates of the different treatments. The role of the physician is to be aware of this information and be able to explain it to you, so that you can then make your own decision.

On the other hand, it's often hard for a physician to predict how a specific person will respond to a given treatment because everyone is different. This is why the doctor's answers sometimes may appear vague.

As your treatment progresses, your doctor will probably be able to give you a clearer idea of the chances of success.

I started treatments a few weeks ago, but I want to stop. Cant I?

You have the right to change your mind during the course of a treatment. But before you decide, you need to:

- examine why you want to stop the treatment. Are the side effects too unpleasant? Is it a way of expressing your anger? Do you feel discouraged? etc.;
- share your feelings with your family and friends;
- discuss the treatments with your doctor and get all the information you need to determine the consequences of your decision.

Can I refuse a treatment suggested by the doctor?

Yes, you can refuse any treatment proposed by your doctor. He will have to respect your choice. The final decision rests with you since it is your body and your life.

Your doctor will probably insist that you reconsider. He will be even more insistent if he feels that the treatment could be effective. After all, it is only normal: his job is to care for the sick. In fact, your doctor must make sure that you fully understand the consequences of not receiving the treatment and give you the opportunity to change your mind. Maybe there is another type of treatment you could find more acceptable.

Can I get a second doctor's opinion?

Yes. You can ask for a second opinion at any time. Physicians themselves often ask a colleague for an opinion. Working as a team often allows for better care. Talk it over with your doctor or nurse.

Why should I ask so many questions about my disease and possible treatments?

Your understanding of your disease depends on asking questions. If you are well-informed, you will be equipped to make your own decisions. You will be able to commit completely to getting better and to getting on with life despite your disease.

Is it a good idea to know the truth about my disease?

Let's suppose that you are losing weight and always feel tired, but don't want to see your doctor because you are afraid of being seriously ill. What is going to happen to you in the long run? How will you fight against the disease?

Being afraid of getting bad news is normal. However, you will be better prepared to deal with the disease if you know what's going on.

Can I ask my doctor not to discuss my condition with my family and friends?

Yes. Any information concerning your disease belongs to you. Your doctor has no right to give any information to your family and friends without your permission. On the other hand, having the support of loved ones can be a great help when you're going through hard times. It's worth thinking about!

How can I make the best decisions?

In summary, our suggestions for making appropriate decisions are:

- ask questions to get all the information you need;
- make sure you have a clear understanding of your disease;
- weigh the advantages and disadvantages of the treatments;
- take time to think things over;
- talk to a family member or a friend that you know well and trust; it could help you see things clearly and reassure you.

Each individual has a different background, different activities, relationships, hopes, and dreams. Each decision is unique. The right or appropriate decision is the one that suits you best.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. *Coping with serious illness*. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Relieving pain

Most people are afraid of suffering when they learn they have a serious disease. They are very apprehensive of physical pain and other upheavals the disease may cause. These upsets often result in worrying, which can increase pain and discomfort. This section provides information that will help reassure you about controlling physical pain.

Can all kinds of pain be relieved?

Nowadays, most kinds of pain can be relieved through the use of a range of medications. Doctors will recommend aspirin or other anti-inflammatory agents for some kinds of pain; for others, acetaminophen, amitriptyline, carbamazepine, and the like. In other cases, narcotics* (codeine, morphine, hydromorphone, etc.) may be prescribed.

The medication is selected according to the kind of pain. It is often necessary to combine medications in order to provide relief. Talk with your doctor if the medication is not making you comfortable.

Morphine gets mentioned quite a bit. What is it?

Morphine is a medication that has proven to be highly effective and widely used to relieve certain kinds of pain. It belongs to the large family of narcotics.

The effects of narcotics last about four hours. To prevent pain from recurring, they should be taken regularly every four hours, including during the night.

Once the dosage needed to relieve your pain is determined, your doctor may be able to prescribe a longer acting form that can be taken every 12 or 24 hours.

Is morphine lethal?

No. When properly administered, morphine provides relief from pain and allows patients to live more comfortably. Nevertheless, morphine must be prescribed carefully, just like medication for heart ailments, diabetes, and high blood pressure.

In the past, morphine was used only in the final phases of terminal disease, which led to the belief that morphine caused death. These ideas have persisted over the years among caregivers as well as among the sick and their families. Because of this belief, some patients refuse to take morphine and deny themselves adequate relief.

Can my doctor prescribe morphine or another narcotic without discussing it with me?

No. Your physician cannot prescribe morphine or any other medication without discussing it with you. The role of your physician is to provide the best possible relief and to explain the risks and advantages of the proposed medication. The decision rests with you. Remember also that you can review the decision with your doctor and make any necessary adjustments afterwards, which will also be carried out with your consent.

Should the use of morphine be held off as long as possible?

No. Morphine can be used as soon as it becomes evident that narcotics are appropriate for treating the pain and that a weaker narcotic would not be effective. It is often better to treat pain aggressively at the outset, since pain can be difficult to control if left too long without relief.

Is there a maximum dose for morphine?

No. The dosage is the quantity needed to control the pain. The dosage is adjusted gradually.

Does morphine have unpleasant effects?

Morphine, like all narcotics, usually causes constipation. Morphine and a laxative are usually prescribed together.

At the start of the treatment, morphine may cause drowsiness* and nausea. These symptoms soon subside. Narcotics are generally well tolerated.

Is morphine effective with all kinds of pain?

Morphine and other narcotics are not as effective with some kinds of pain, such as in the bones and nerves. In such cases, other medication is used, sometimes in combination with narcotics.

Why is relieving pain so important?

People are in a better mood when their pain is relieved. They can rest better and their appetite and activity level increase. They also find it easier to read, think, communicate with loved ones, and relax.

What can I do to get relief from pain?

Begin by observing your pains and describing each one of them to your doctor. Take the prescribed medication and don't hesitate to let your doctor know if the pain persists.

Worrying, as well as fear, anger and sadness, can increase the intensity of pain. Sharing your feelings with someone you trust can help relieve your pain.

There are also activities that may help: relaxation or meditation exercises, painting, writing, listening to music, taking a hot bath, getting a massage, and so on.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. *Coping with serious illness*. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Expressing your last wishes

You may be wondering what will happen if serious* disease renders you incapable of making your own decisions. You may be concerned about managing your affairs, organizing your day-to-day life, selecting between care alternatives depending on your condition, or making your will. This section deals mainly with the various ways of making known your last wishes about the care you want, even if you become incapable of deciding for yourself.

What happens if I am suddenly unable, for one reason or another, to give my consent for the care required by my condition?

Legislation provides for consent being given by your spouse or, if your spouse is unable or you are not married, by a closerelative or another person with close ties to you (see art.15, C.C.Q. Civil (Code of Quebec)).

How would my spouse, a close relative, or significant other know what I want?

The individual providing consent in your place will be aware of your wishes if you have shared them with him. If you have never expressed your feelings on such matters, he will have to decide based on what he believes is your best interest. Legislation requires him to ensure the care will be beneficial for you, even if risks are involved; that the care is appropriate under the circumstances; and that the risks are not greater than the anticipated benefits (See art.12, C.C.Q.).

It doesn't appear easy to decide in someone else's place. How can I help my loved ones deal with complications like this?

You can make their task easier by:

- deciding ahead of time what's important to you;
- keeping your loved ones informed about what's important to you;
- informing health-care workers, including your physician, about your last wishes. Your physician may record them in your medical file;
- appointing a mandatary* in anticipation of incapacity who will make decisions on your behalf once the mandate has been recognized by the court;
- writing down your last wishes (living will).

What questions should I ask myself in determining what my last wishes should be?

You can ask yourself questions such as:

- under what circumstances would I want to receive cardiac resuscitation?
- under what circumstances would I want to be connected to a respirator?
- if I were in a deep coma*, with no chance of recovery, would I still want to be fed artificially?
- if I were suffering from a serious disease, unable to communicate, and bedridden 24 hours a day, would I want to receive care to prolong my life or only to make me comfortable ?

How can one anticipate all the situations that may arise at the end of life?

There is no way to anticipate all the situations that may arise. Many diseases cause incapacity, so that the person can no longer make decisions for herself. Incapacity can develop slowly or occur suddenly. It may be slight or profound, short-lived or permanent. It may occur only in the last days of life.

Moreover, things that are important to you now may not be in a decade or two. Therefore, it's important for you to keep thinking about this throughout life and, more importantly, to talk about it with your family. This will make it easier for them to assess which care is in your best interest if ever you are unable to decide for yourself.

I've heard about a living will. What is it

A living will is a document describing the care and treatment you would like to receive under certain circumstances. It will be used to get a better idea of what you consider important should you become incapacitated. Basically, you write down and date the conclusions of your reflections concerning your last wishes.

I've heard that the law doesn't recognize living wills. Is this true?

There are no specific provisions in the Civil Code regarding living wills. On the other hand, legislation requires that a person's wishes-expressed either orally or in writing-be considered when decisions affecting care are made for this person. Make sure that your family has a copy of your living will. They will be able to convey the information to your doctor and other caregivers should you ever become incapacitated.

What is a mandate given in anticipation of incapacity*?

Generally, a mandate is a contract by which a person, the mandator, gives to another, the mandatary, the power to represent him or her in the performance of a juridical act (See art. 2130, C.C.Q.).

A mandate given in anticipation of incapacity can provide for acts to ensure the protection of the person, full or partial administration of her estate, and her overall moral and physical well-being (see art. 2131, C.C.Q.).

A mandate given in anticipation of incapacity can be quite simple: you could name your only daughter to make decisions for you regarding your care. Or it could be highly complex: you could appoint a number of administrators to manage your possessions, another group of people to ensure your care, and name your son to handle decisions relating to your health.

If your financial or personal situation is complex, you should call on the services of a specialist

(notary, lawyer, etc.).

Who should I choose as mandatory* in anticipation of incapacity?

You should choose someone you know well and trust completely. This person will convey your wishes, should you be unable to do so, and will make decisions in your best interest.

What are the advantages in naming a mandatory in anticipation of incapacity?

Here are a few advantages.

- It lets you choose the person or persons who will make decisions on your behalf should you become unable to do so.
- It can prevent disputes, especially among family members and friends who don't get along very well.
- It can avoid legal proceedings, such as a tutorship or curatorship, which would be more costly.
- It lets you maintain control over your life, even if you are incapacitated.
- It can be comforting should an accident or a serious disease result in incapacity.

Who can help me find and complete a living will or a mandate given in anticipation of incapacity?

You can get information from your CLSC or your residential or long-term care centre. Bookstores carry living will and mandate forms or literature on these topics. You can also contact the Communications Department of the Public Curator.


In summary, how can I best prepare myself for the eventuality of incapacity?

First of all, you have to reflect and decide what your last wishes are. Then, make sure that your spouse, children, family, friends, physician, and mandatory (if any) clearly understand your wishes. Keep them informed, throughout the years, of any changes in your last wishes.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. *Coping with serious illness*. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Dealing with your children

Adults struggling with serious* disease often worry about the children around them. What can they say to them? How can they ease their suffering? How can they help them? This section provides information on how to deal with children and teenagers.

Should my children be told about my disease?

Given the number of changes brought on by serious disease (moods, daily habits, physical changes, etc.), children soon realize that family life is different from what it was. If they aren't aware of your illness, they may imagine their own reasons for the changes, which may actually be more harmful to their development. For example, a child who doesn't know his mother is critically ill could think that his parents are sad because he fights too much with his little sister.

When excluded from the evolution of the disease, children often feel quite isolated and may have difficulty trusting adults around them in the future.

Who can give my children information about my disease?

You can tell your children about your disease as can members of your immediate family who are close to them. You can also ask for help from health-care workers or other significant persons in dealing with this delicate task.

Should I let my children visit me at the hospital?

Hospital visits let children maintain contact with the person who is ill. They must, however, be adequately prepared beforehand. Someone should describe the hospital room and its equipment as well as the physical appearance of the sick person before the children actually visit. Their age must also be taken into account in determining how long the visit should last. Once the children are back home, it is a good idea to discuss with them their reactions and feelings.

If a child doesn't want to visit a sick person at the hospital, it is important to respect his choice and to explore with him why he made that decision. The child can then be helped in finding different ways to maintain the bond with the sick person. Alternatives may include writing a letter, drawing pictures, sending photos, or talking on the telephone. The child may change his mind in time.

Now I know there is no cure for my disease. Should I tell my children?

Learning of your condition will be painful for your children, but it will also help them prepare for what is coming. When they are ready to do so, they may also want to ask more questions about

the future.

My children have been asking questions about death and dying. What can I tell them?

Children need concrete explanations, such as: "When you die, your heart stops beating; you no longer breathe, move, or talk. You no longer eat, drink, or feel pain."

It's important not to confuse the actual cause of death with certain beliefs. For example, a little girl who is told that the angels took her grandmother away because she was so nice, might be afraid of them coming back to get her nice daddy, too. You can, however, use your beliefs to help your children work through their grief. For example, if you believe in an afterlife, you can tell them that people in heaven think of their loved ones.

It is a good idea for children to go to the funeral parlor or attend the funeral?

As with adults, going through a funeral* ritual can help children show their grief, say a last goodbye, and feel less alone. They do need to be told beforehand, however, that they will see people cry because they are very sad. As is the case with hospital visits, children will need to talk about these experiences again.

It is important to remember that children, like adults, need to grieve*.

What are the best ways to help children get through this difficult time?

Children need to:

- feel that the adults around them are receptive to their questions and emotions;
- get clear, honest and concrete explanations geared to their age and level of understanding. These explanations help them realize they are not responsible for the disease. Explanations must be given gently and can be given over time. This approach respects the rhythm and sensitivity of children;
- understand that everyone is taking good care of the ill person whom they love;
- be concretely reassured about the impact on their daily life. For example, they need to know who is going to pick them up after school, if their parent can no longer do so;
- participate in their own way in providing care to the ill person. For example, they can entertain her by making drawings for her, fluffing her pillows, and so on;
- express, through games, what they are experiencing as a result of this difficult situation. For example, don't be surprised if a little girl spends a lot of time taking care of a "sick" doll.

The school and daycare should be informed about the situation so they can provide additional support.

Rather than being overprotected, children need to be included when one of their loved ones is critically ill.

(*) [See keywords](#)

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Living the time that remains

A cure is not always possible and facing death is not easy. Would thinking about it now help when the time comes? Can one really prepare for death?

In this section, we will take a look at the questions most frequently asked by the terminally ill.

Ever since I learned that my treatment won't provide a cure, I often wake up during the night. I have nightmares and feel uneasy. What's happening to me?

Your fear of dying is possibly the cause. Death destroys life and all the bonds we have. Most people are afraid of the unknown. We often are afraid of dying in pain and of the passage from life to death.

I just can't believe that I'm going to die. I'm extremely upset and angry. So are my family and friends. How can I live through this?

Strong emotions are normal in this situation. It's never easy to come to grips with the fact that your life has come to an end. Your reaction and that of your family and friends demonstrate how much everyone holds onto life.

Since you are all completely distraught, share your feelings with a health-care worker or volunteer you trust; it may help. A pastoral* assistant can also assist you during this distressing time.

I've heard about palliative care. How can it help me?

When a cure is no longer an option, palliative care can be used to relieve pain and provide the best level of comfort possible to let you make the most of the time remaining.

Palliative care involves health-care workers from many disciplines (nurses, social workers, psychologists, physicians, pastoral* assistants, etc.) and volunteers*. These people have an interest, experience, and specific training for helping a patient discover his inner strengths by listening to him, supporting him and by providing relief.

Palliative care can be provided in a hospital, a hospice or at home.

My physician told me that I don't need to stay in the hospital and that I can go back home. I'm worried about that. What can I do to calm down my fears?

First of all, try to indentify your specific concerns. Are you worried your loved ones will wear themselves out? Or you won't receive enough care and won't be able to go back to the hospital?

Are you afraid of being alone? Are you afraid of dying at home? You can discuss your concerns with your physician, the nurses, the social and health-care workers. They surely can help you.

If you're going back home, they can provide information about available resources, including self-help groups and volunteers, and put you in touch with the CLSC in your community.

I've been told I can die at home. I'm not sure how I feel about this. What can help me make the decision?

You can:

- look at whether it's important for you to die in familiar surroundings with your family and friends around you, or if you prefer a hospital setting with your caregivers in attendance;
- discuss the idea with your family and friends to find out their wishes and concerns, and share yours;
- get information on available in-home services.

I'm worried about my family and friends. What can I do to make the future easier for them?

You can talk about your concerns and look at how they will arrange things once you are gone. If your affairs are in order (will, debts, funeral arrangements, guardianship in case of incapacity, and the like), you may already be making their life easier.

I feel guilty and useless because I am so sick. I'm afraid that my family and friends are wearing themselves out visiting me at the hospital or taking care of me at home. How can this go on?

We tend to think that our lives are worthwhile only if we are healthy and active. It's so easy to forget that we are always important for our loved ones.

We build trusting relationships with family and friends throughout our lives. Even though they may be weary, your loved ones can feel the need to be close to you right up to the end. Put yourself in their shoes: wouldn't you want to be close to? So, make the most of their presence if it makes you feel good.

It's hard to see how there could be any pleasure in the last days of life. Could you give me some examples?

Seeing the grandchildren again, giving a gift to someone dear, enjoying nature, listening to your favorite music, having visitors, getting letters, having someone read to you, and many more. These are the kind of things that have brought joy and pleasure to people at the end of their life.

My doctor is proposing more treatments, but I've had enough. I've refused them. All I want is to be relieved of my pain. Will God forgive me for refusing treatment?

Some believers are worried about their reception in the afterlife if they refuse to suffer. But most major religions do not require believers to bear just any kind of pain and suffering. You should talk about your concerns with your pastoral assistant, rabbi, or spiritual advisor.

My body has changed so much since I fell ill. I've lost so much weight that I don't

recognize myself in the mirror. What can help me accept these changes?

It's normal to be distressed by the changes in your physical appearance. Accepting these changes is not easy. You're probably worried that your friends, family and caregivers will stop caring about you because of the changes. Remember that your worth* doesn't depend on appearance and that all those around you already know that.

Realizing that your intrinsic worth* has nothing to do with your appearance can help you both get through this difficult time and get more out of the time you have left.

We often hear the expression "dying with dignity*". What does it mean?

The media tend to use this expression quite a bit. Patients and families of patients define dignity in different ways.

For some, dignity means not depending on others, not being incontinent, not being confused, not having visible lesions, and so on. It's as if being ill and suffering was undignifying.

But what if preserving one's dignity till the very end meant that each individual maintains their full worth as a human being despite the losses caused by the disease, and that they deserve respect regardless of circumstances?

How much time do I have left?

Science cannot exactly predict how long a terminally ill patient will survive. Some physicians try to give an approximate figure when asked. Since no one really knows how much time there is left, it is wiser not to believe too strongly in such predictions.

Does dying hurt?

From all appearances, the moment when the heart stops beating and the last breath is drawn, is generally quite calm. The last moments of life are often more peaceful than is usually thought.

Is reconciliation with death possible?

Throughout the course of the disease, individuals are led to this final stage in life. The upheavals and difficulties encountered have gradually brought them to seeing life from a different perspective. Terminally ill patients feel that their bodies can go no further.

For some, feeling that they have accomplished what they wanted helps them reconcile themselves with death. Others are helped by their religious convictions. Some, however, don't reconcile themselves with the end of life.

In a general sense, what can help me make the most of the time I have left?

Let us share some experiences of people who have gone through the same trial:


- Allow yourself to feel your emotions, even those you would normally consider negative (anger, sadness, discouragement). These emotions can help you make your way through this last stage in your life.
- Try to identify exactly what fears you have related to death, care and the future of your family, and talk this over with people you trust.
- Find comfort through meditation, reflection or prayers, depending on your beliefs.

- Look for things that could make you happy.
- Recall good memories and share them with family and friends.
- Respect yourself when you feel your body can go no further.
- Remember that you keep your intrinsic worth*.

(*) [See keywords](#)

Source : Dallaire Michelle, Mongeau Suzanne. Coping with serious illness. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Conclusion

Worry and fear are normal feelings for those coping with a serious illness. This brochure is provided in the hope it will help those who are in this situation.

Source : Dallaire Michelle, Mongeau Suzanne. Coping with serious illness. Régie régionale de Montréal-Centre, Direction de santé publique, Direction de la programmation et coordination, avril 1998, 42 pages

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Keywords

Coma:

A state of prolonged unconsciousness, including a lack of response to stimuli and ability to communicate. Some patients recover from coma; others do not.

Diagnosis:

Determination of the nature of a disease. The physician determines the disease from which a patient is suffering based on the person's symptoms and other information she provides as well as by using the results of various analyses (blood tests, X-rays, etc.).

Dignity:

The respect each person deserves regardless of social status, illness, behavior or suffering.

Drowsiness:

A state of being half-asleep or being unable to keep from falling into a light sleep.

Funeral:

Ceremony (lying in state, burial, mass, cremation, wake, etc.) for a dead person. It helps loved ones accept the fact that the person is deceased.

Incapacity:

The inability to make decisions for one's self. Incapacity may be partial, full, temporary or permanent. Some diseases (such as Alzheimer's disease, tumors, serious brain infections, paralysis affecting the ability to communicate, and comas) can result in incapacity.

Grieve (to):

A painful process which helps the bereaved person accept their loss.

Mandatory in anticipation of incapacity:

Person designated to make decisions on behalf of an individual incapable of doing so. Remember that, when the time comes to fulfill his role, the mandatory must be recognized by the court in

order to assume his responsibilities.

Narcotics:

A family of medications inducing sleep and numbing the pain. They include: codeine, morphine, hydromorphone, and oxycodone. These medications can be taken orally, as suppositories, or injected into a muscle, vein, or under the skin. They can also be absorbed by the body from a skin patch. Sometimes, they are administered continuously through a pump injecting the medication under the skin.

Pastoral Assistant:

A person who has received training to respond to the spiritual or religious needs of the ill and their families.

Serious Disease:

Any disease that is life-threatening in the short or medium term: cancer, AIDS, amyotrophic lateral sclerosis, multiple sclerosis, severe cardiac, neurological, or respiratory disease, severe renal failure, diabetes with serious complications, and so on.

Value:

Something that has worth or importance. We can speak of values that guide the life of a person, an institution, or a society. One's values can conflict with the values of others.

Volunteer:

A person who gets involved willingly and without pay. Volunteers in the area of palliative care normally receive special training for supporting the terminally ill.

Worth:

The intrinsic worth of a person mainly means that all people are equal despite the changes brought on by illness, and that their rights are fully maintained.

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Resources

Information and Referrals

If you have a health problem and don't know where to turn, contact Info-Santé CLSC. This service is available day and night, every day of the week. To get the Info-Santé number for your CLSC, <http://www.msss.gouv.qc.ca/>

The Information and Referral Centre of Greater Montreal also provides telephone information and referral services about health and social security resources. You can reach it at (514) 527-1375. Web site : http://www.info-reference.qc.ca/index_a.html

Emergency

Urgence-Santé responds to emergency calls (24 hours a day, 7 days a week), offers ambulance services, and performs emergency medical interventions. Dial 911.

CLSC

The Local Community Service Centre (CLSC) is the gateway to our health-care system. Your CLSC provides medical care, nursing care, and emotional support. Each CLSC also offers home-care services to help the sick remain in their homes. The following home-care services are provided: nursing care, home-help services (hygiene, meals, housekeeping), support to family and friends, and rehabilitation services.

The CLSC can evaluate your needs with you and your family and refer you to more specialized resources, if required.

Hospital

Each hospital has an emergency room open day and night. The ER staff can assess whether you should be treated as an out-patient or hospitalized. Hospital stays are short. When you are released, you will continue to receive the care and services you need at home for as long as you need them. If your condition requires a longer stay, you will be referred to a residential and long-term care centre or a rehabilitation centre. Hospitals also have specialized outpatient clinics.

Residential and Long-Term Care Centres

Residential and long-term care centres offer, on a temporary or permanent basis, an alternative environment when a sick person can no longer stay at home, despite the support of family and friends, the CLSC, or other organizations.

Residential and long-term care requests must be made with the CLSC, if the sick person is still living at home. If she is in the hospital and can no longer live at home, the hospital will forward the request.

Associations, Self-Help Groups, Foundations, etc.

You can find out which associations, self-help groups and foundations work with specific illnesses by contacting the Information and Referral Centre of Greater Montreal at (514) 527-1375. Web site : http://www.info-reference.qc.ca/index_a.html

Financial Aid

You may be eligible for some kind of financial compensation. For more information, contact the following organizations:

- Employment Insurance: http://www.hrsdc.gc.ca/en/gateways/nav/top_nav/program/ei.shtml
- Régie des rentes du Québec : <http://www.rrq.gouv.qc.ca/en>
- Revenu Canada : <http://www.ccra-adrc.gc.ca/menu-e.html>
- Ministère du Revenu du Québec : <http://www.revenu.gouv.qc.ca/eng/ministere/index.asp>
- Régie de l'assurance-maladie : http://www.ramq.gouv.qc.ca/index_en.shtml

Your CLSC or hospital social worker can also provide additional information.

Public Curator

If you need more information about the mandate given in anti-cipation of incapacity, you can contact the Public Curator <http://www.curateur.gouv.qc.ca/cura/html/anglais/home.html>

Literature and Audiovisual Documents

Organizations dedicated to helping people with specific illnesses can suggest reading material (brochures, personal accounts, etc.) or audiovisual documents for you and your family.

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