

## **Making Your Health Care Wishes Known Living Wills and Mandates**

### **Making your health care wishes known: Living Wills**

A growing number of people are asking questions about how they can be involved in decisions about their health care now and in the future. Living Wills are being discussed more and more often as one tool to help a person's doctor and family members to make the best decisions possible when they are no longer able to speak for themselves.

The Adult Clinical Ethics Committee has prepared this booklet to help you. **We want you to know that the most important thing that you can do is choose a spokesperson and then talk to them about what your wishes are.** This booklet helps you to understand the steps and there are two examples at the back for your use.

Each of us has the right to make decisions about our health care. Many people are afraid that if they become really sick their wishes will not be respected. The idea of a Living Will or Mandate was created as a tool so that you can describe the things in your life that are most important - your values and beliefs about health illness. Your spokesperson then uses your tools when you are no longer able to work with the doctor yourself because you are injured or very sick.

### **What you need to know about Quebec Law**

The law in Quebec is different than the law in the rest of Canada. In our province, we follow the Quebec Civil Code. The Civil Code tells us that we must protect the rights of each person to make their own decisions. It clearly says that each one of us has the right to consent to, refuse or withdraw from treatments.

Each of us has the responsibility to make decisions for our health. The Civil Code also says that you can choose who you want to make decisions for you if you cannot because you are injured or ill. This person is called a spokesperson or Mandatary. The Civil Code protects you by making sure that if you can't make your own decisions that someone who knows you well will make your decisions for you. If you have not chosen someone to speak for you the law has made a list of people who doctors will call.

The list in the Civil Code is as follows:

1. the person **you have chosen** as your spokesperson (**usually a family member**), or that the **court has chosen** - a curator or tutor

If you have not chosen someone specific then the doctor will contact ...

2. **your spouse (married, common law, same sex partner)**

If you have no spouse...

3. **a close relative (perhaps a parent, brother or child over 18)**

If none of the above exist then the doctor will speak to

4. **a person of special interest ( a close friend)**

The Civil Code tells your spokesperson how they must make decisions for you. Decisions must be made in your best interest and following your wishes as much as possible. This is where a Living Will is important. Once you are no longer able to speak for yourself, your spokesperson will use your Living Will as a tool to tell the doctors what is important to you. **Then your spokesperson and the doctor will work together to find the right treatments and care.**

It is important to remember that in Quebec, the Living Will itself has no legal weight. The legal power for decision-making is given to the person- you or your spokesperson. **For this reason it is important to choose your spokesperson wisely and be sure that they know your wishes by talking to them and then writing your wishes in a Living Will.**

### **What is the difference between a Living Will and a Mandate?**

#### **What is a mandate?**

A mandate is an official form in which you name a spokesperson. Most mandates have two parts -one for health care decisions, the other for money or business decisions. Some people wish to have the same person look after both types of decisions and others prefer to have two different persons.

In this pamphlet we are **only** talking about health care decisions. It is not necessary to have a notary or lawyer involved in the health care mandate however, for business decisions you will need to consult a notary or lawyer. For this reason many people prefer to use a notary in the preparation of both. Notaries and lawyers encourage you to choose a spokesperson but they cannot help you decide about treatments. So some people prefer to also write a Living Will to describe their wishes.

A mandate is used most often when you become permanently unable to make your own decisions. The final decision is made in court so that your rights will be protected and the right person will become your spokesperson.

#### **What is a Living Will?**

A living will is often written in the form of a letter or a checklist. It is informal and is used to describe the type of treatments you do or do not wish to receive. In a Living Will you are also encouraged to choose a spokesperson.

Anyone can write a Living Will but remember it is a tool and not a legal form so you should expect the doctor to ask you or your spokesperson how and why your decisions were made. It becomes a useful document when you are permanently or temporarily unable to make your own decisions.

**In both the mandate and the Living will, the most important point is to choose a spokesperson.** If you have a Mandate and you become unable to speak for yourself, your spokesperson will make him or herself known to the health care team and then with the help of a notary or lawyer your spokesperson will go to court to be officially recognized. This process takes time, as much as 6-8 weeks, but the doctors and nurses will make every effort to work with your spokesperson to follow your wishes while this process is taking place. The Living Will can assist your spokesperson at this time

#### **Who should have a Living Will or Mandate ?**

Any adult can express his/her wishes about health care by telling their doctor or by writing it in a Living Will. Some people may feel it is more important than others, for example: people who know they do not have long to live, people who have a long term illness that they know will get worse over time, people who are older, people getting ready for surgery, people who have family that live far away, who have no family or who have family that they do not get along with.

#### **How should I choose a spokesperson?**

The person you choose should be someone who you feel will be able to speak clearly with the doctors and nurses. It is very important that your spokesperson is someone who will understand your wishes and be willing to carry them out. It could be your spouse, or another family member or a trusted friend or companion. **You must speak to the person and be sure that they feel they can fulfil their responsibility.**

**What do I need to think about before choosing a spokesperson and discussing my wishes with him/her?**

The first step is to be sure that you have a good understanding of your health status. Talk with your doctor and/or another health care professional (nurse, social worker) to find out what to expect and what types of treatment choices exist. Use this information to guide your decisions. *The most important part of making decisions is to think about your own beliefs and your feelings about health, life and death. Thinking about this and helping your spokesperson understand what is most important for you is even more important than trying to predict the type of treatment that you will need or want.* These are not easy topics and you may wish to speak to your minister or priest, your family doctor, a family member, close friend or health care professional.

There are several examples at the back of this pamphlet to help you choose the best model of Living Will for you. Some people prefer a checklist model (See the MUHC Living Will Checklist). Others prefer to use a letter format (See Writing a Living Will). Several organizations have models that can be used -

**It is important to remember that treatments and choices will be different for each person. The choices that you make should talk about your health and your values. It is also important to talk to a doctor so you understand what treatments are the best for you.**

**How do I ensure that my wishes are followed?**

For a Living Will - Once you have discussed your wishes with your spokesperson and written out your wishes, be sure you sign the form (or letter) and include the date. Two witnesses should sign the form. (The person who is a witness cannot be the same person that is named as your spokesperson - it could be a friend, a neighbour, your priest or pastor).

For a mandate - Once you have named your spokesperson, discussed your wishes with him/her and written out your wishes the form needs to be signed by you with the date and two witnesses. (See note above about who can be a witness). If a notary or lawyer is helping you, they will find witnesses for you

The most important part of this process is for you to take the time to talk to your spokesperson. Be sure they are clear about what it is that you want and why you have reached the decisions you have. This will help them to explain your wishes when the time comes. It is also very important for you and your spokesperson to understand that not every illness can be predicted. You or your spokesperson will need to be prepared to discuss treatment options so that they reflect your wishes. It is the doctor's responsibility to help you and your spokesperson to understand what treatments are the best for you considering your health, illness and wishes.

Once you have made your decisions and have talked to your spokesperson and family it is important to discuss your decisions with your doctor. If you are regularly followed in a clinic or by the CLSC, let them know who your spokesperson will be and what you have told them. **Be sure that your family doctor or specialists, your spokesperson and your family have a copy of your document.**

Be sure that you present your document any time that you are admitted to the hospital or Emergency Room and instruct your spokesperson and family to do the same. You may wish to

complete a wallet card similar to the one on the back of this pamphlet. It will tell the doctors and nurses the name and telephone number your spokesperson.

Remember that it will not be necessary for your spokesperson to use your Living Will to make decisions **UNLESS YOU ARE UNABLE TO SPEAK FOR YOURSELF. Until that time, it is your right and your responsibility to speak for yourself and make your wishes known.**

**What if my situation changes or I change my mind?**

People, their life and their families change from time to time. You should look at your Living will and be sure that the decisions you have made are still the right ones. It is also important to review it if your situation or your health changes

An example of such changes:

- If your spokesperson is unable to fulfil his/her role
- If your decisions have changed
- If your condition changes for better or worse
- If your family situation changes

If you change your spokesperson, or your Living Will, remember that you must provide new copies to all those who should know.

**Conclusions**

**PLEASE REMEMBER:**

**#1 Choose a spokesperson so you are prepared:** You need to identify someone you trust to speak on your behalf if you are not able to speak for yourself.

**#2 Help them to make decisions by making your wishes clear:** Making your health care wishes known will give you the knowledge that you have expressed your wishes in a clear, direct manner giving your doctor, and other caregivers guidelines for your care that fit your beliefs and feelings. Most importantly it will give your spokesperson and family clear directions so they can have peace of mind when working with your doctor to make the best decisions.

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**The last section of this booklet describes some treatments you and your spokesperson need to understand. It also provides two types of Living Wills that you might consider using.**

It is important to understand the medical terms and what they are used for. It is clear that people have different opinions about the use of machines and treatments to prolong one's life. Some people feel strongly that they wish treatments using machines to be continued even if long term, others insist that they be used only for a short period of time and others do not want these treatments no matter what. You need to decide based on your own values and beliefs about health, life and death.

#### **Terms you need to understand before making your decisions**

**Dialysis**: Dialysis is a treatment which uses an artificial kidney machine. It is used when the kidneys no longer work. This machine takes the place of the kidney - balances water in body, takes away waste products, etc. Dialysis can be short-term or life-long.

**Irreversible coma**: Coma is a word used to describes an injury to the brain. The person is unconscious or semi-conscious and unable to recognize or communicate with family or surroundings. There are many types of coma. Sometimes if the injury to the brain is minor, caused by swelling or infection, the patient will recover. If the injury is caused by large amount of bleeding, or a severe blow to the head or lack of oxygen over a period of time the person is not able to recover (to interact with family, care for self, talk, etc.) and the coma is irreversible.

**Ventilation by machine**: If we are unable to breathe on our own, a special tube (endotracheal or ET tube) will be placed through the mouth and throat into our lungs. This process is called intubation. The tube is then attached to a ventilator (respirator or breathing machine) which automatically breathes for us and provides oxygen. Ventilation can be used on a short-term basis to assist us when we have a severe illness. Some people require long-term ventilation, particularly someone who is paralysed or who has a specific disease that makes them too weak to breathe.

**Artificial Nutrition (sometimes called tube feeding)**: When we are not able to eat by ourselves because of illness or coma artificial nutrition is a treatment to provide calories, fats or proteins to our bodies. A small tube (dobhoff) can be passed through the nose into the small bowel or a tube

(jejunostomy, gastrostomy) can be placed through the skin, by a small incision, into the stomach. Artificial nutrition is most often used to boost recovery during a period of illness. Sometimes it is considered for long term support. Similar to any other type of treatment there are risks as well as benefits. You need to understand both the risks and the benefits before deciding that this treatment is right for you.

**Intensive Care:** Sometimes patients become so ill that they must be transferred to an Intensive Care Unit. This is a unit where the patient will need special equipment to watch their heart rate and blood pressure. The doctors and nurses may need to do special tests and treatments and give drugs that cannot be given anywhere else in the hospital. The patient often is so sick that they cannot breathe on their own and need a machine to breathe. They often cannot talk because they are too sick, because they are in a coma or because they have been given drugs to keep them calm when they are so sick. The sickest patients in the hospital go to Intensive Care and leave the unit only when this special level of care is no longer needed.

**I.V. (Intravenous):** A small needle is passed through the skin into a vein. The needle is attached to clear tubing. This tubing is used to provide direct access for fluids, medicines. The needle may be placed in the hand or on the arm or leg and will need to be changed a couple of times per week.

### **Resuscitation**

Whenever an MUHC patient's heart or breathing stops unexpectedly, hospital staff act immediately to try to restart the heart and breathing. Since there are only minutes before someone dies when the heart or breathing has stopped, efforts to make the heart or breathing start again (resuscitate) are begun as fast as possible. This often will require mouth-to-mouth resuscitation or positioning a tube into the lungs via the mouth (so-called intubation) to allow air to be repeatedly pumped into the lungs. At the same time, the chest may be squeezed or compressed in an effort to restart the heart pumping or to keep blood pumping through the body until it can be restarted by medications. Sometimes there is a need to pass an electric shock through the chest to the heart. Resuscitation or starting the heart or breathing is always done, unless a patient has clearly said not to do it, or if resuscitation would be unsuccessful, futile, it would do nothing to prolong life, or it would leave the patient brain dead or irreversibly handicapped.

### **Do Not Resuscitate Orders**

Resuscitation is always started immediately by staff, unless it has been decided by the patient that she/he does not want to be resuscitated, or that there is no possibility whatsoever that resuscitation could be successful. Even when resuscitation is started, it is not always successful; sometimes the heart or breathing cannot be restarted; at other times, the patient is left permanently unconscious (i.e. in a coma or brain dead) or left with severe brain damage (i.e. memory or intelligence loss); sometimes, it can worsen other diseases, such as kidney, liver or heart disease. Hospital staff are very aware of these risks and harms, and want to avoid them whenever possible. So, they will discuss with each patient, and their family or decision-makers, whether resuscitation is likely or unlikely to be beneficial or make one's health much worse. If the patient does not want to be resuscitated, staff will be ordered to respect this decision, by a "do not resuscitate" order. This will not change any other care or treatment the patient needs.

Extract from **“Making Your Health Care Wishes Known, Living Wills and Mandates”**  
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