Guide for the person and their loved ones

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## ADVANCE REQUEST FOR MEDICAL AID IN DYING



Québec

#### Produced by

The Direction des communications of the Ministère de la Santé et des Services sociaux

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You have been diagnosed with a serious and incurable illness that could make you unable to make decisions for yourself about your health. You may want to think about the care options that might be available to you. You may be thinking about care that would improve your quality of life, about palliative care and end of life care. It is essential to discuss these options with your doctor, specialized nurse practitioner or any other professional who is involved in your care.

You may be considering the possibility of making an advance request for medical aid in dying. This guide aims to support you and your loved ones as you think about making an advance request. It contains information on advance requests, the steps to follow to make a request, some details on the administration of medical aid in dying following an advance request and answers to frequently asked questions.

Do not hesitate to ask for help. It is normal that all this information seems hard to understand. Write down your questions and discuss them with your doctor or specialized nurse practitioner.

For more information, go to the <u>Advance request for medical aid in</u> <u>dying page</u> on the Québec.ca website.

#### Any other professional refers to any health or social services professional such as:

- Nurse
- Licensed practical nurse
- Psychologist
- Pharmacist
- Social worker
- Physiotherapist
- Occupational therapist, etc.

### INFORMATION ON ADVANCE REQUEST FOR MEDICAL AID IN DYING

After talking with your loved ones and your professionals, you may want to make an advance request for medical aid in dying.

Medical aid in dying is care that can be given to you, if you request it and are eligible for it, to relieve your suffering, by causing your death. An advance request is a request for medical aid in dying that is made in advance by a person who has a serious and incurable illness leading to the inability to consent to care, for example, Alzheimer's disease.

### HOW TO MAKE AN ADVANCE REQUEST FOR MEDICAL AID IN DYING

To make an advance request, you must absolutely be assisted by a doctor or a specialized nurse practitioner (SNP).

If you do not have a doctor or specialized nurse practitioner, another professional can help you find one and they are obliged to help you do so. As a last resort, if you cannot find a professional to help you, contact your health and social services institution or call the 811 service.

#### Meet with the doctor or specialized nurse practitioner

More than one meeting will probably be needed to make an advance request.

The doctor or specialized nurse practitioner will make sure that:

- you have all the information about the disease;
- you have a good understanding of the disease, its symptoms, its course, possible treatments and care to relieve suffering;
- you are making the advance request freely, with no coercion or pressure by your loved ones or anyone else.

This information will allow you to think about the clinical manifestations associated with the disease that could lead you to want to receive medical aid in dying.

It is important that you take the time to discuss your advance request with anyone you want to discuss it with.

#### Criteria to make an advance request

When you make an advance request, you must:

- 1. be of full age and capable of giving consent to care;
- 2. be insured within the meaning of the *Health Insurance Act* (valid health insurance card, with up to date information);
- 3. have a serious and incurable illness leading to incapacity.

### Describe the clinical manifestations associated with the disease

In your advance request, you will have to describe the clinical manifestations associated with the serious and incurable disease leading to the inability to consent to care that will have to be present and will be considered as your consent to receive medical aid in dying, when the time comes.

Take the time to think about the clinical manifestations and write them down so that you can discuss them with your doctor or specialized nurse practitioner. **Clinical manifestations** are the observable signs or symptoms of the disease.

You must describe them in detail in your own words in your advance request.

### TRUSTED THIRD PARTY

If you wish, you can designate someone close to you who will have certain responsibilities regarding your advance request when you are no longer able to consent to care. It is not mandatory to designate a trusted third party in order to make an advance request; however, it is strongly recommended that you do so.

The trusted third party will assist you when you make your advance request. This will allow them to fully understand your wishes.

The trusted third party will have to inform the professionals who are caring for you:

- of your advance request if you are no longer capable of consenting to care;
- if they observe the presence of the clinical manifestations you identified in your request;
- if they believe that you are experiencing persistent and unbearable suffering.

The professionals who are caring for you will also inform your trusted third party if they observe that you are no longer able to consent to care or any other change in your health.

For this reason, it is important to inform the professionals who are caring for you of any change in your trusted third party's contact information (address and telephone number).

If you did not identify a trusted third party, the professionals who are caring for you have an obligation to take note of your advance request and inform the health care team of your wishes. The **trusted third party** must be a competent person of full age, whom you choose yourself. It can be a family member, a friend or any other trusted person.

Their responsibility is to ensure that the wishes you have expressed in your advance request are known, when you are no longer able to do so yourself.

You can designate a second trusted third party (substitute) in case the first one is no longer able to fulfil their responsibilities when the time comes.

### How do I prepare to make an advance request for medical aid in dying?

Here are some things you can do to prepare for the meeting with the doctor or specialized nurse practitioner:

- learn about the serious and incurable disease leading to incapacity;
- learn about how this type of disease progresses in general and the possible clinical manifestations associated with it;
- think about the clinical manifestations of the disease that seem intolerable to you and for which you would like to receive medical aid in dying when they are present;
- make a list of questions you want to ask the doctor or specialized nurse practitioner about the disease, its clinical manifestations, possible care options or any other subject;
- discuss your thoughts on the advance request with your loved ones and anyone else you want to discuss it with;
- if you want to designate one or two trusted third parties, talk to them to ask if they agree to take on this responsibility, and ask them to go with you to your appointment with the doctor or specialized nurse practitioner.

The following will also be helpful when you make your advance request:

- make sure that your health insurance card is valid;
- make sure that the address in your health insurance card file is up to date and make a change of address if necessary;
- note the date of diagnosis of the serious and incurable disease leading to incapacity;
- note the name of the doctor or specialized nurse practitioner who diagnosed the disease;
- consult a notary if you wish.

Once all your questions have been answered, the doctor or specialized nurse practitioner will ask you to write down the clinical manifestations of the disease that you wish to include in your advance request.

#### Fill out the advance request for medical aid in dying form

The doctor or specialized nurse practitioner will fill out the advance request on an electronic device (computer or tablet) in front of you.

- You will have to share the description of the clinical manifestations of the disease that you have identified.
- The doctor or specialized nurse practitioner will transcribe in your words the clinical manifestations you have identified.
- The doctor or specialized nurse practitioner will confirm that these manifestations may be associated with the disease.
- They will also enter information to describe the clinical manifestations in medical terms.
- They will explain to you that if you develop the clinical manifestations listed in your application, you will be able to receive medical aid in dying only if all the criteria set out in accordance with the law are met.

The form will be signed by the following people:

- yourself, as the requesting party;
- your trusted third party or both of your trusted third parties (if you have designated any);
- two witnesses (unless a notary is involved in the request);
- the doctor or specialized nurse practitioner who is helping you with your advance request.

#### Advance request made before witnesses

Witnesses are present only when the advance request is signed. The doctor or specialized nurse practitioner will be able to identify these people with you when the request is signed.

Witnesses may not be a trusted third party you have designated.

#### Advance request by notarial deed

If you choose to make a request by notarial deed, you must identify a notary. We suggest you contact the notary before making your advance request for medical aid in dying and discuss your intention to make an advance request with them.

The doctor or specialized nurse practitioner and the notary will give you more information about the procedure.

#### Advance requests register

Once your request has been completed and signed, the doctor or specialized nurse practitioner will enter your advance request in a secure register.

If you have chosen to make your advance request by notarial deed, the notary will make sure the request is entered in the register.

It is mandatory that your advance request be entered in the register to be valid and applicable, when the time comes.

#### When the disease has progressed

Doctors, specialized nurse practitioners and other professionals will monitor your condition regularly throughout the course of the disease.

If the disease has progressed and you are no longer able to consent to care, a professional will check the register to see if you have made an advance request for medical aid in dying.

Your trusted third party or any member of the health care team will have to say, when the time comes, that you appear to have the clinical manifestations listed in your advance request. They will also report that you appear to be experiencing enduring and unbearable suffering, if this is the case.

The doctor or specialized nurse practitioner will assess your health. They will check if you meet the criteria to receive medical aid in dying and will inform you and your trusted third party.

If all the criteria are met to administer medical aid in dying to you, the process will be initiated. Two doctors or specialized nurse practitioners will assess you. Both must consider that all the criteria are met to administer medical aid in dying to you.

At each stage of the assessment process, the doctor or specialized nurse practitioner will inform you, your trusted third party, your loved ones and the health care team of their findings.



It is important to understand that an advance request made in accordance with the law does not automatically guarantee that you will receive medical aid in dying. The act that governs medical aid in dying sets out strict criteria that professionals must respect.

So, in addition to the clinical manifestations that you have identified in your request, all the criteria set out in the law must be present for medical aid in dying to be administered to you, in particular, you must:

- be insured within the meaning of *the Health Insurance Act* (valid health insurance card, with up to date information);
- be suffering from a serious and incurable disease leading to incapacity and be unable to consent to care because of the disease;
- have the clinical manifestations associated with the disease described in your advance request;
- have a medical situation that gives the doctor or specialized nurse practitioner reason to believe that you are experiencing enduring, unbearable physical or mental suffering that cannot be relieved under conditions considered tolerable.



### FREQUENTLY ASKED QUESTIONS

### What is a serious and incurable disease leading to the inability to consent to care?

A serious and incurable disease is a disease that cannot be cured. The term "leading to incapacity" means that the disease may render the person incapable of making decisions, including decisions about their health care.

#### What does "be capable of giving consent to care" mean?

A person who is capable of consenting to care understands the information they are given about the disease and its course. They also know what each care option involves, including medical aid in dying, as well as the pros and cons of each choice. They are able to decide what they prefer and communicate their wishes clearly.

### Can a doctor or a specialized nurse practitioner refuse to help me make an advance request?

A doctor or a specialized nurse practitioner may refuse to or be unable to help you with your request. In this case, they have an obligation to transmit the information so that your request is taken care of by another professional.

### If I make an advance request, is it certain that I will receive medical aid in dying?

No, making an advance request does not assure you that medical aid in dying will be administered to you.

Two doctors or specialized nurse practitioners will have to assess you and confirm that all the criteria are met for you to be able to receive medical aid in dying.

For example, if the doctor or specialized nurse practitioner does not find enduring, unbearable physical or mental suffering that cannot be relieved under conditions considered tolerable, medical aid in dying cannot be administered to you, even if you have the clinical manifestations mentioned in your request.

#### Can I cancel my advance request if I change my mind?

Yes. If you are still able to consent to care (capable of consenting), you may withdraw your request at any time.

To withdraw a request, you must be assisted by a doctor or a specialized nurse practitioner. It does not have to be the same professional who helped you make your advance request.

The request to withdraw your advance request must be signed by you and the doctor or specialized nurse practitioner. It is also important to inform your trusted third party if you identified one in your request.

#### Can I modify my advance request?

Yes. If you wish to modify your advance request, you must make a new request, i.e., complete the whole advance request process again. Once it has been entered in the register, the new request will replace the old one.

### Do witnesses have to read the advance request before signing it?

No. The role of witnesses is, in particular, to verify the identity of the people who sign the advance request form.

You are not obliged to tell the witnesses what is in your request. It is up to you.

#### What if I don't have a trusted third party?

It is not mandatory to have designated a trusted third party.

The health or social services professionals who are caring for you will consider your request in in due course. They will make your wishes known.

# What happens if my trusted third party does not report the presence of the clinical manifestations described in my advance request?

The health or social services professionals who are caring for you will consider your request in due course. They will make your wishes known.



### What happens if I refuse to receive medical aid in dying when I am no longer able to consent to care?

The doctor or specialized nurse practitioner and the other professionals who are caring for you will assess your condition. They will talk with you and your loved ones. They will try to determine if your refusal is caused by the symptoms of the disease.

In any case, respecting your wishes will be a priority. We suggest you talk to your doctor or specialized nurse practitioner for more details.

#### Will the same doctor or specialized nurse practitioner who helped me make my request administer medical aid in dying to me when the time comes?

Not necessarily. If the doctor or specialized nurse practitioner who helped you when you wrote your request is still taking care of you when the time comes, they will be able to do so. Any other doctor or specialized nurse practitioner can also do so.

