

MY WILL AT THE END OF LIFE



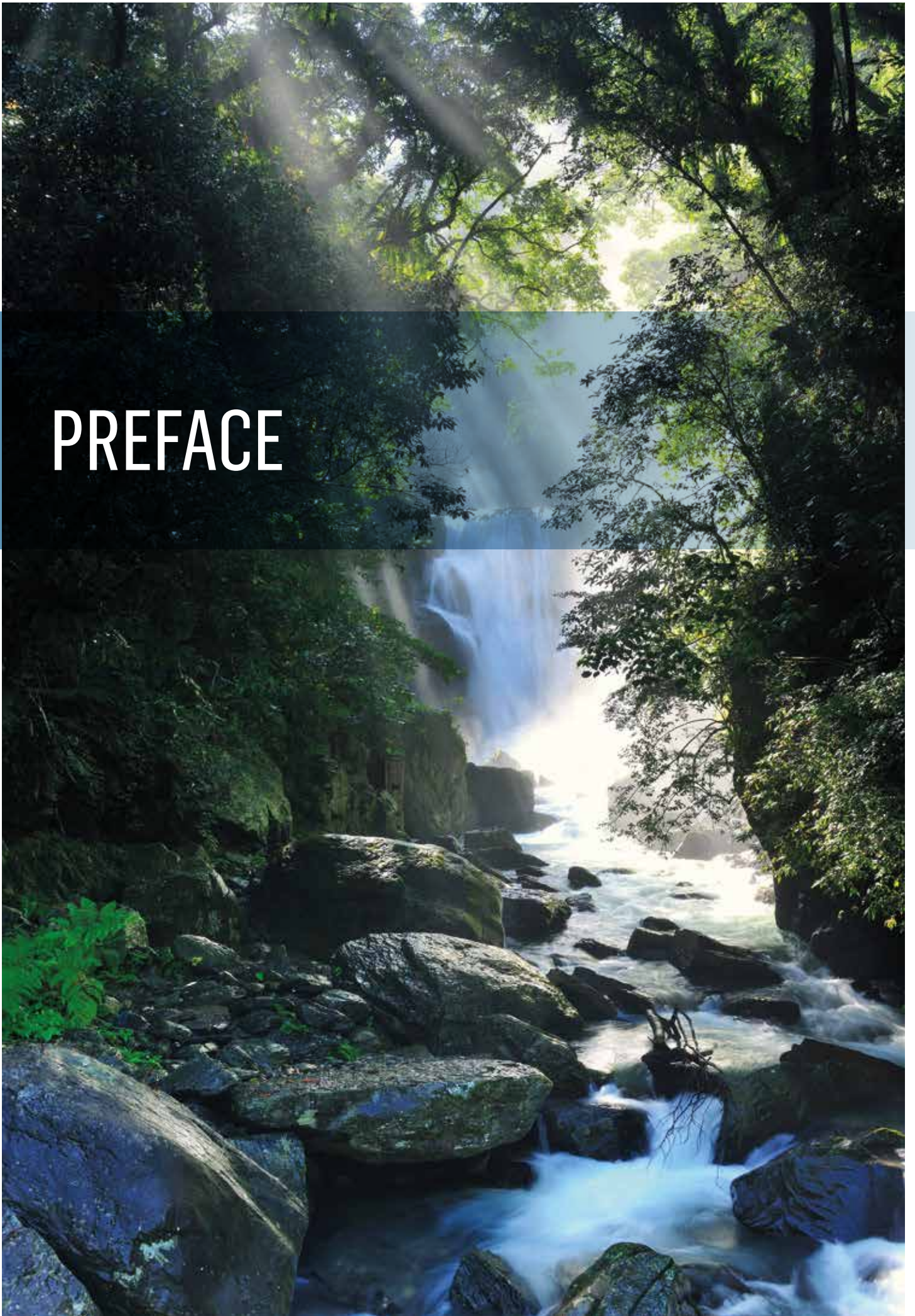
LE GOUVERNEMENT
DU GRAND-DUCHÉ DE LUXEMBOURG
Ministère de la Santé

Direction de la santé



LE GOUVERNEMENT
DU GRAND-DUCHÉ DE LUXEMBOURG
Ministère de la Famille, de l'Intégration
et à la Grande Région

PREFACE



THE END OF LIFE: WHAT IF WE TALKED ABOUT IT?

Our end of life is a special time. Death is, above all, a personal subject, and talking about it gives rise to all kinds of feelings: fear, uncertainty, sadness, anger, but also possibly relief. Talking openly about our end of our life has become increasingly common in modern society. The individuals concerned want to decide for themselves what their end of life will be, and many have a highly individual approach to their last moments.

The Government welcomes this development and wishes to allow every citizen to freely make the best arrangements for this inevitable moment. It is in this spirit of free choice that this booklet aims to provide citizens with impartial information about end-of-life legislation and the options available to them.

To ensure respect for a person's end-of-life will, even if they are no longer able to express themselves, part of the brochure consists of "advance directive" and "end of life" forms that can be used by citizens to document their choices. Any patient can complete both an advance directive and end-of-life provisions.

This booklet will be widely distributed, including to healthcare professionals and to residential and care institutions. It will also be available in electronic form on our Ministries' websites.



A handwritten signature in black ink, consisting of a stylized 'C' followed by a period.

Corinne CAHEN
Minister for Family Affairs and Integration
Minister for the Greater Region



A handwritten signature in black ink, consisting of a stylized 'E' followed by a horizontal line.

Étienne Schneider
Deputy Prime Minister
Minister of Health

A photograph of a dense, misty forest. A dirt path winds through the center, surrounded by lush green vegetation, including ferns and moss-covered ground. Large, gnarled tree branches frame the top and left sides of the image. The atmosphere is soft and ethereal due to the mist. A semi-transparent dark grey horizontal band is overlaid across the middle of the image, containing the word "INTRODUCTION" in white, bold, sans-serif capital letters.

INTRODUCTION

Everyone, at any age, sick or healthy, wonders about his/her end of life and wishes to retain the power to decide.

Luxembourg's legislative system gives you the opportunity to express your will by participating actively and in full awareness with your care. You have the chance to express, in writing, your wishes for the treatment you would like to receive by drafting an advance directive (concerning palliative care) and/or end-of-life provisions in the event that you are no longer able to communicate due to loss of consciousness as a result of illness, accident or dementia.

END OF LIFE LEGISLATION IS FRAMED BY THE FOLLOWING THREE LAWS:

- 1. The law of 16 March 2009 on palliative care, advance directives and end-of-life care**
- 2. The law of 16 March 2009 on euthanasia, assisted suicide and end-of-life provisions**
- 3. The law of 24 July 2014 on the rights and obligations of patients**

To understand the situations in which an advance directive or end-of-life provisions take effect, it is important to distinguish between two possible end-of-life scenarios:

1. If you are conscious, you can express your choices at that time. Your will overrides the advance directive or end-of-life provisions;
2. You are no longer able to express your will as you are unconscious or incapable (in a state of dementia): if there is an advance directive and/or end-of-life provisions in place, your wishes recorded therein must be respected according to the terms of the law.

Each of these laws involves a trusted person. This trusted person, designated by the patient, is the person who makes the decisions on behalf of the individual who is unable to do so. He/she must know the preferences, values and beliefs of the person for whom he/she is the spokesperson. He/she will have to make decisions based on the most recent wishes expressed by the individual at the time he/she was deemed fit to do so. The choice of this trusted person is hence extremely important, and the selected individual must naturally agree to take on the task.

IDEALLY, YOU WILL CHOOSE SOMEBODY WHO:

- is an adult (this is a legal obligation for end-of-life provisions);
- can be at your side if necessary;
- is prepared to discuss your future decisions, and who genuinely listens to your wishes;
- is prepared to speak on your behalf;
- is able to act according to your wishes;
- takes responsibility for such a task;
- knows you well and understands what is important to you;
- will be able, in due course, to manage any conflicts that may arise between family members, relatives and medical staff;
- will be a strong advocate of your will when faced with physicians and institutions.

The end of life is a point that we all, inevitably reach. Reflecting upon it makes it possible to ensure that your will is respected. Speaking about it to your relatives will spare them the additional suffering of having to make the choice when the time comes.

This brochure provides you with all the documents you need to steer your reflection and the expression of your wishes.

You remain free at all times to amend your wishes and to draft new documents.

A photograph of a birch forest with a dirt path, overlaid with a semi-transparent brown banner containing the text "ADVANCE DIRECTIVE". The forest is lush with green foliage, and the path is visible in the foreground. The text is centered on the banner in a white, sans-serif font.

ADVANCE DIRECTIVE

PREAMBLE

The law provides for what can be regulated by an advance directive. It includes:

- treatment conditions;
- the limitation of treatment;
- the discontinuation of treatment, including pain treatment;
- psychological and spiritual support.

Your advance directive is applicable if both of the following conditions are met:

- you are in the advanced or terminal phase of a serious and incurable condition, and
- you are no longer able to express your will.

As long as you can express yourself, it is your expressed will that counts.

Before filling out this document, it is recommended that you talk first with your trusted person, your family and your doctor.

According to the provisions of the law, you are entitled to:

- relief from physical and psychological suffering; e.g., pains, respiratory problems, psychological unrest, anguish, thirst, ...;
- respect for your wishes regarding possible psychological and spiritual support;
- assurance that the points raised by your trusted person be considered in any decisions to be taken.

ADVANCE DIRECTIVE FORM

SURNAME AND FIRST NAME:

ADDRESS:

ID NUMBER:

DATE AND PLACE OF BIRTH:

TEL/GSM:

E-MAIL:

In the event that I find myself in the advanced or terminal phase of a serious and incurable condition, whatever the cause, and that I am unable to express my will, I have drafted my advance directive, which, in application of the law, is to be taken into account by the attending physician.

I request that all decisions are taken on the basis of my advance directive and/or, where applicable, in consultation with my trusted person.

TRUSTED PERSON

I hereby authorize the person mentioned below:

- to express my will regarding decisions relating to care and treatment and
- to give consent on my behalf for the proposed measures.

SURNAME AND FIRST NAME:

DATE OF BIRTH:

ADDRESS:

TEL/GSM:

E-MAIL:

I hereby authorize the doctors and nursing staff to provide my trusted person with all information necessary to accomplish this.

- (1) Request that exams and treatments are stopped in the event that they do not bring about relief, improvement of my condition or hope of healing, and would only delay my death without being able to stop the course of the disease.

This includes the specific case of an irreversible coma; i.e., a circumstance in which my brain has sustained serious and lasting damage due to accident or disease, resulting in a loss of consciousness that would in all likelihood be irreversible;

yes no

- (2) In accordance with my decision under (1), I hereby request that my doctor does not perform the following treatments and measures if they do not bring about an improvement in my condition or my hope of healing and are only delaying my death.

The following treatments / measures are no longer to be carried out:

- artificial respiration / ventilation;
- artificial feeding;
- artificial hydration;
- administration of all drugs that no longer contribute to my quality of life;
- dialysis;
- hospital treatment;
- others

(3) Additional remarks:

.....

.....

(4) My wishes for end-of-life care and support are as follows:

a) Regarding the health care team, for my bodily care and well-being:
(e.g.: bed / chair position, massages, essential oils, music, favourite foods / drinks, etc.)

.....

.....

.....

b) Regarding support:
family / relatives, psychological support, spiritual / religious support, volunteers, other
(please provide precise information)

.....

.....

.....

A COPY OF THIS ADVANCE DIRECTIVE HAS BEEN SENT TO:

1. My trusted person

SURNAME AND FIRST NAME:

ADDRESS:

.....

TEL/GSM:

E-MAIL:

2. Attending doctor

SURNAME AND FIRST NAME:

ADDRESS:

.....

TEL/GSM:

E-MAIL:

3. Medical record (e.g.: Shared care record, CIPA, hospital, etc.)

.....

.....

4. Other person(s)

SURNAME AND FIRST NAME:

ADDRESS:

.....

TEL/GSM:

E-MAIL:

Following the drafting of my advance directive, I have also reflected on other points of importance to me.

MY WISHES REGARDING MY BODY AFTER DEATH

Organ donation

- do not give authorization for any of my organs to be removed for the purposes of organ transplant
- I give authorization for any of my organs to be removed for the purposes of organ transplant, with the exception of the following organ(s):

.....
.....

After my death, I wish:

- to be buried
- to be cremated
- my ashes will be

Other wishes regarding my funeral:

.....
.....
.....
.....
.....
.....
.....

I hereby certify that this advance directive corresponds to the expression of my free and informed will, and that I have drafted this directive after careful consideration.

In original copies

....., on

Place / date

Signature

.....
Surname and first name

IF YOU ARE PHYSICALLY UNABLE TO WRITE / SIGN THIS DOCUMENT YOURSELF, YOU MAY NOMINATE TWO PEOPLE TO TRANSCRIBE THE WORDS THAT YOU DICTATE TO THEM, WITH BOTH SIGNING AS WITNESSES.

We, the undersigned, witnesses under Article 5 (2) of the Law of 16 March 2009 on palliative care, advance directives and end-of-life support, certify that this document is the expression of the free and informed will of:

MR/MS:

who is unable to write and sign his / her own advance directive.

SURNAME AND FIRST NAME:

POSITION:

ADDRESS:

.....

DATE AND SIGNATURE:

SURNAME AND FIRST NAME:

POSITION:

ADDRESS:

.....

Signature

.....
Date

SUPPLEMENTARY EXPLANATION

Having written, dated and signed your advance directive

- Keep the original at home in an easily accessible place
- give a copy
 - to your trusted person
 - to your attending doctor
 - to CIPA staff, hospital staff, etc. (if applicable)
 - to a third person
- if you wish, keep a copy in your shared care file

RENEWAL:

The period of validity of the advance directive is not fixed by law. It is therefore valid until such time as it is amended or repealed. Nevertheless, we recommend that you review the advance directive every 5 years and confirm or modify it according to your choices.

ADVANCE DIRECTIVE QUESTIONS AND ANSWERS

1. What is meant by "palliative care"?

Palliative care is active, continuous and coordinated care, practised by a multidisciplinary team in a way that respects the person being cared for. It covers all the physical, psychological, spiritual and social needs of the person being cared for, as well as providing support to friends and family. The process includes the treatment of pain and psychological suffering. Professionals from a range of disciplines including doctors, nurses and caregivers, physiotherapists, psychologists, social workers and others work together closely to achieve this goal. The will of the sick person is respected in all of the treatment decisions.

Palliative care provides comprehensive care for the sick person.

2. Where are palliative care services offered?

Palliative care is provided in the patient's home, at hospital, at Haus Omega - a palliative care centre - and in nursing homes.

3. Who has the right to palliative care?

Anyone in the advanced or terminal phases of a serious and incurable illness, whatever the cause, has a legal right to palliative care.

4. Who pays the costs of palliative care?

The costs of palliative care are paid by the National Health Fund (Caisse Nationale de Santé - CNS) at the request of the attending physician ("medical care records" for end-of-life patients).

5. End-of-life support leave

Did you know that according to the law you are entitled to "end-of-life support leave" to stay with a dying person from your immediate family?

You are entitled to 5 days (maximum 40 hours) per year and per person at the end of their life, which can be divided according to the needs of your relatives.

You can find the application forms for this leave at www.cns.lu, tel. 27 57 - 1.

For additional information, see the end of this document.

A photograph of a dense forest of tall evergreen trees, likely pines or firs, under a hazy, misty sky. The trees are silhouetted against the light, creating a dramatic and somewhat somber atmosphere. A semi-transparent blue banner is overlaid horizontally across the middle of the image, containing the text "END-OF-LIFE PROVISIONS" in white, bold, sans-serif capital letters.

END-OF-LIFE PROVISIONS

END-OF-LIFE PROVISIONS FOR AN ADULT PERSON CAPABLE OF DRAFTING, DATING AND SIGNING THE DOCUMENT

In accordance with the law of 16 March 2009 on euthanasia and assisted suicide

End-of-life provisions are an advance request for euthanasia made in the event that the patient should find himself/herself, at a later point in his/her life, in a situation of irreversible unconsciousness according to the current state of scientific knowledge, and be suffering from a serious and incurable accidental or pathological condition.

These provisions must be sent to the following address:

**Commission Nationale de Contrôle
et d'Évaluation de la loi du 16 mars 2009
sur l'euthanasie et l'assistance au suicide
Ministère de la Santé
L-2935 Luxembourg**

End-of-life provisions must be registered under an official system for the systematic registration of end-of-life provisions with the *Commission Nationale de Contrôle et d'Évaluation* (National Commission for Control and Evaluation). These provisions may be reiterated, withdrawn or modified at any time. The *Commission Nationale de Contrôle et d'Évaluation* is required to seek confirmation of the will of the declarant once every five years from the date of the registration request. All changes must be registered with the *Commission Nationale de Contrôle et d'Évaluation*. However, euthanasia may not be performed if, as a result of the steps he/she is required to take, the doctor becomes aware of a demonstration of the patient's will, subsequent to the duly recorded end-of-life provisions, by which the patient withdraws his/her wish to undergo euthanasia.

END-OF-LIFE PROVISIONS FORM

SECTION I. MANDATORY DATA

My personal data are as follows:

SURNAME, FIRST NAME:

ADDRESS:

ID NUMBER:

DATE AND PLACE OF BIRTH:

TELEPHONE:

Optional data:

GSM :

EMAIL ADDRESS:

In the event that I can no longer demonstrate my will, I record in writing in these end-of-life provisions that I wish to undergo euthanasia, if my doctor states:

*that I am suffering from a serious and incurable accidental or pathological condition
that I am unconscious and
that this situation is irreversible according to existing scientific knowledge.*

Personal remarks regarding the circumstances and conditions in which I wish to undergo euthanasia:

.....
.....
.....
.....
.....
.....

This statement was made freely and consciously. My wish is that these end-of-life provisions are respected.

Date and signature of the applicant:

.....
Date

Applicant's signature

If you are physically unable to write and sign this document yourself, you can nominate a person of your choice to transcribe the words that you dictate to them, in the presence of two witnesses. The document is then signed by the witnesses and your trusted person. The reasons why you were unable to write and sign the provisions yourself must be set out in the document and certified by a doctor.

We, the undersigned, witnesses under Article 4 (2) of the Law of 16 March 2009 on euthanasia and assisted suicide, hereby certify that this document is the expression of the free and informed will of:

MR/MS :

who is unable to write and sign his/her end-of-life provisions for the following reasons:

SURNAME AND FIRST NAME:

POSITION:

ADDRESS:

DATE AND SIGNATURE:

SURNAME AND FIRST NAME:

POSITION:

ADDRESS:

DATE AND SIGNATURE:

SURNAME AND FIRST NAME:

POSITION:

ADDRESS:

DATE AND SIGNATURE:

SURNAME AND FIRST NAME OF THE TRUSTED PERSON:

Signature

.....
Date

SUPPLEMENTARY EXPLANATION

Having written, dated and signed your end-of-life provisions

- Validate them by registering them with the *Commission Nationale de Contrôle et d'Évaluation* (National Commission of Control and Evaluation).
- keep a copy of the end-of-life provisions and the registration letter to the *Commission Nationale de Contrôle et d'Évaluation* at your home.
- give a copy of the end-of-life provisions and the registration letter:
 - to your trusted person;
 - to your attending doctor;
 - to CIPA staff, hospital staff, etc. (if applicable);
 - to a third person.
- If you wish, keep a copy in your shared care file.

End-of-life provisions may be reiterated, withdrawn or modified at any time. All changes must be registered with the *Commission Nationale de Contrôle et d'Évaluation*. However, euthanasia may not be performed if, as a result of the steps he/she is required to take, the doctor becomes aware of a demonstration of the patient's will, subsequent to the duly recorded end-of-life provisions, by which the patient withdraws his/her wish to undergo euthanasia.

The *Commission Nationale de Contrôle et d'Évaluation* is required to seek confirmation of the will of the declarant every 5 years from the date of the registration request.

If you express any other wishes outside of the end-of-life provisions contained in the form, these are not covered by the law of March 16, 2009 on euthanasia and assisted suicide. These wishes, while legal and valid, cannot therefore be registered with the Commission. Rather, they come under the advance directive or personal wishes. Therefore, we recommend that you inform your trusted persons and your relatives of the existence and the content of this document. We also recommend that you give a copy to your doctor and, if necessary, to the persons in charge of the institution taking care of you (e.g., a hospital or an integrated nursing home).

QUESTIONS AND ANSWERS ABOUT END-OF-LIFE PROVISIONS

1. What is meant by "euthanasia"?

Euthanasia is the act, carried out by a physician, that intentionally ends the life of a person at the express and voluntary request of that person.

The patient may request euthanasia or assisted suicide, and the doctor may act upon this request without being subject to criminal prosecution or civil claims for compensation, provided the substantive conditions of the law are met.

2. Is it advisable to draft an advance directive if I have registered my end-of-life provisions?

Yes. In the event that you are no longer able to express yourself, this allows you to resolve a multitude of situations and wishes that are not covered by the end-of-life provisions. As indicated above, if you express other wishes besides the anticipated request for euthanasia on the end-of-life provisions form, these will not be registered by the Commission of Control and Evaluation. To be sure that these are taken into account, it is better to write an advance directive and inform your trusted person, your doctor and, if necessary, CIPA staff, hospital staff, etc.

3. End-of-life support leave

Did you know that according to the law you are entitled to an "end-of-life support leave" to stay with a dying person from your immediate family?

You are entitled to 5 days (maximum 40 hours) per year and per person at the end of their life, which can be divided according to the needs of your relatives.

You can find the application forms for this leave at www.cns.lu, tel. 27 57 – 1.

For additional information, see the end of this document.

CONCLUSIONS

Your advance directive and your end-of-life provisions are documents whose purpose is to respect your will in the event that you are no longer able to express yourself. It is important to know that as long as you are conscious and able to express your desires, it is the expression of your will that takes precedence over your advance directive and your end-of-life provisions.

The advance directive is a document whose legal value is similar to that of a holographic will. For it to have legal value, it is sufficient that you write it and sign it. End-of-life provisions, however, must be registered with the *Commission de Contrôle et d'Évaluation* of the Law of 16 March 2009 on euthanasia and assisted suicide in order to have legal value.

END-OF-LIFE CONSULTATIONS

YOUR ATTENDING DOCTOR

Mäi Wëllen, Mäi Wee - association pour le droit de mourir dans la dignité Lëtzebuerg

www.mwmw.lu

secretaire@mwmw.lu - Tel.: 26 59 04 82

Consultation service: info@mwmw.lu - 621 306406

Omega 90

138, rue Adolphe Fischer

L-1521 Luxembourg

Tel.: 29 77 89 1

E-mail: info@omega90.lu

www.omega90.lu

Fondation Cancer

209, route d'Arlon

L-1150 Luxembourg

Tel.: 45 30 33 1

E-mail: fondation@cancer.lu

www.cancer.lu

INFORMATION

Commission Nationale de Contrôle et d'Évaluation de la loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide

Ministère de la Santé

Allée Marconi/Villa Louvigny

L-2120 Luxembourg

Mr. Raoul FRANCK (Secrétaire)

Tel.: 247-85626

E-mail: cnce.euthanasie@ms.etat.lu

Patienteverriedung

1b, rue Thomas Edison

L-1445 Strassen

Tel.: 49 14 57-1

Fax.: 49 14 58

www.patienteverriedung.lu

Service national d'information et de médiation dans le domaine de la santé

73, rue Adolphe Fischer (4th floor)

L-1520 Luxembourg

Tel.: 24 77 55 15

info@mediateursante.lu

www.mediateursante.lu

You can also consult the Palliative Care Guide (Guide des soins palliatifs) and the Guide to Euthanasia and Assisted Suicide (guide "L'Euthanasie et l'assistance au suicide") at www.sante.lu

