

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

A full-page background image of a waterfall in a dense forest. Sunlight filters through the trees, creating a bright, ethereal atmosphere. The waterfall flows over large, mossy rocks, and the surrounding vegetation is lush and green. The word "PREFACE" is overlaid in white, bold, sans-serif capital letters on the left side of the image.

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 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.



Corinne CAHEN

Minister for Family Affairs and Integration
Minister for the Greater Region



Étienne Schneider

Deputy Prime Minister
Minister of Health

A full-page background image of a dense, misty forest. A dirt path leads from the bottom center towards the middle ground, flanked by lush green ferns and other vegetation. Large, moss-covered tree trunks and branches frame the top and sides of the path. Sunlight filters through the dense canopy, creating a soft, ethereal glow. The word "INTRODUCTION" is overlaid in white, bold, sans-serif capital letters on a dark, semi-transparent horizontal band across the middle of the image.

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 dense forest of tall evergreen trees, likely pines or firs, with a thick layer of mist or fog hanging between the trees. The scene is captured from a low angle, looking up at the towering trees. A semi-transparent blue horizontal banner is overlaid 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

END-OF-LIFE PROVISIONS

SURNAME, FIRST NAME:

ADDRESS:

TELEPHONE:

POSSIBLE FAMILY RELATIONSHIP:

☐ yes ☐ no

B. (Optional) provisions regarding the manner of burial and the funeral ceremony

This image shows a full page of white paper with horizontal dotted lines. The lines are evenly spaced and run across the width of the page, providing a guide for handwriting or typing. There are no margins, text, or other markings on the page.

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:

.....
Date

Signature

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'Evaluation* (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'Evaluation* 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'Evaluation*. 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'Evaluation* 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

