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Annex

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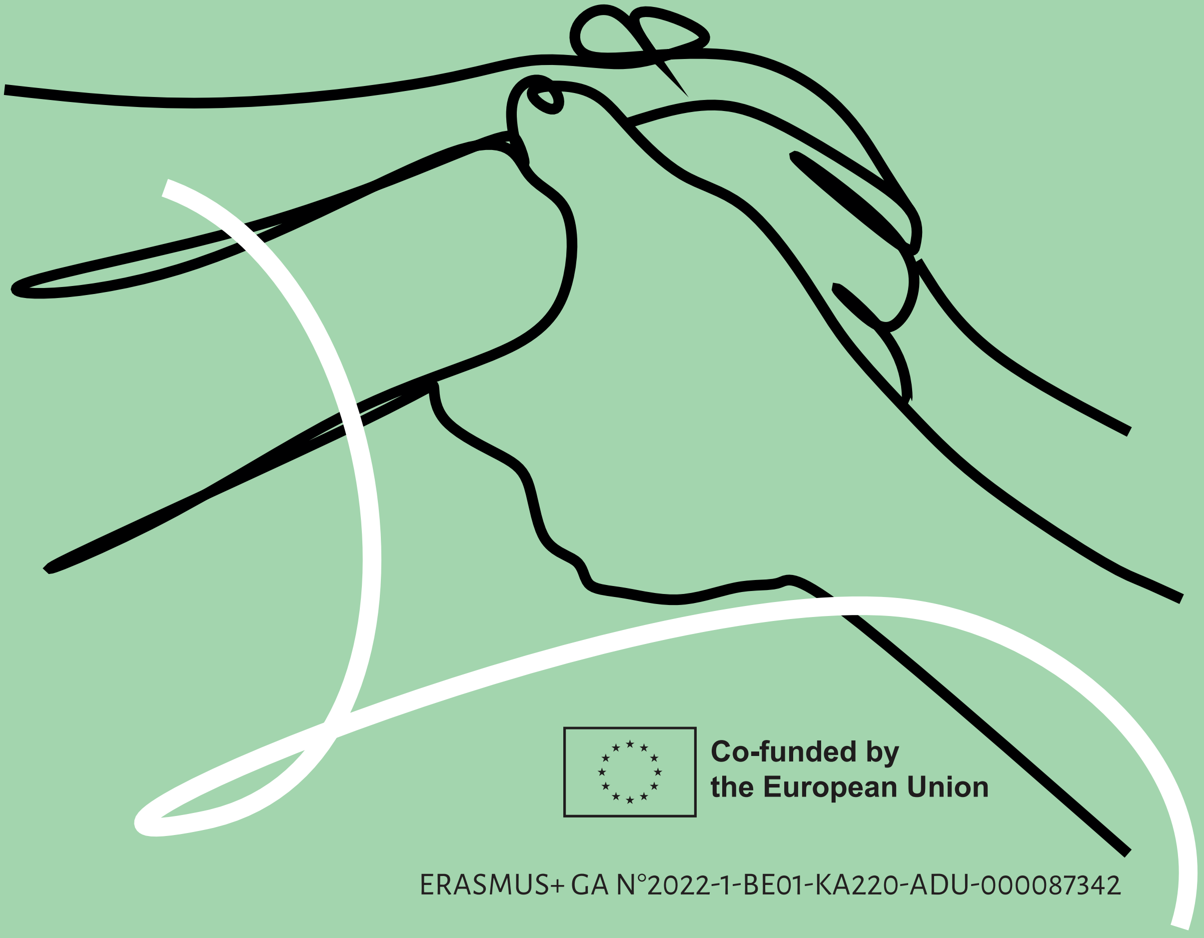
Hold My Hand

...at the end of life

A GUIDE TO CONSCIOUS ANTICIPATION OF THE END-OF-LIFE

LEGAL AND POLITICAL FRAMEWORKS



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I. Introduction

Anticipating end-of-life issues is a complex and delicate matter that raises many ethical, medical and legal concerns, and is surrounded by taboos.

In response to these concerns, many countries have developed legal frameworks to deal with end-of-life issues. This document aims to present the main laws and regulations in force in the four partner countries of the project: Belgium, Italy, Portugal and Sweden.

Learning about the legal and policy frameworks related to end-of-life issues will help a person anticipate their own wishes and make choices in full awareness. It will also help ensure that their end-of-life directives are legal and likely to stand scrutiny.

The anticipation of end-of-life choices, such as medical, inheritance or after-death issues, is not restricted to terminally ill patients. Everyone can at some point ask themselves questions and make appropriate decisions well in advance.

At the level of care planning, advance directives involve making decisions about the medical care individuals wish to receive at the end of their lives, or when they are longer able to make decisions independently.

By planning ahead, an individual can also designate a trusted person to make decisions on their behalf if they become incapable of doing so, thus ensuring that their wishes are respected and that medical care is directed to meet their physical, emotional and spiritual needs.

In terms of estate planning, individuals can plan for the transfer of their estate in the event of death. Often seen as a tedious task, such planning can actually provide peace of mind that a person's loved ones can be supported financially and emotionally after their own death. To achieve this, estate planning requires a thorough understanding of the current laws and regulations that govern inheritance and the passing of property.

As for funerals, individuals can anticipate what they want and express their final wishes for this farewell ritual. These decisions allow them to remain active participants in their life until its end, and, to a degree, even afterwards. It also helps to lighten the burden on loved ones at an emotionally charged time.

When decisions and preparations have already been made in advance, the family can focus on being present and supportive during the final moments, rather than having to deal with difficult decisions and logistical matters. In fact, planning for these various aspects of the end-of-life experience can even avoid conflict and disagreement between family members. When patients have clearly expressed their preferences, family members do not have to decide or disagree about what is best for them and what they would have wanted. This allows for a dignified passing.

In order to facilitate the flow of information and help everyone make informed and reasoned choices, this document addresses the following themes:

- End-of-life support: Advance directives, Euthanasia, Anticipation of care
- Advance directives after death: Organ donation, Donation of the body to science
- Representation: Companion, Reference person
- Funeral and Estate planning.

2. International and European Legal and Political Framework (historical perspective)

In the European Union, palliative care is regulated by a series of guidelines and recommendations, which seek to ensure the quality and accessibility of these services throughout the territory. Directive 2011/24/EU on "the exercise of patients' rights in cross-border healthcare" states that patients have the right to receive adequate and effective palliative care in any Member State of the European Union.

In addition, the Prague Declaration of 2013 reiterated the European Union's commitment to ensuring access to palliative care, and its availability across the continent. In terms of national legislation, several European countries have specific laws regulating palliative care. For example, in 2016 France passed a law that recognizes the right of all patients with advanced and incurable diseases to receive palliative care and support to alleviate suffering, regardless of their age, social, or financial status. In Spain, Law 39/2010 on Patient Autonomy establishes that patients have the right to receive clear and accurate information about their diagnosis and prognosis, as well as to receive adequate palliative care in case of serious and incurable diseases. In summary, palliative care is an important topic in the European Union, with guidelines and regulations aimed at ensuring the quality and accessibility of these services.

Each member country may have specific legislation, but in general the goal is to ensure that patients have access to adequate and effective palliative care, regardless of their condition or location.

In 2001, the European Health Committee prepared a set of guidelines according to which palliative care should integrate the psychological and spiritual aspects of patient care and that it should provide support to the grieving family.

In 2002, the World Health Organization developed a broad definition of the subject: *"Palliative care seeks to improve the quality of life of patients and their families in the face of the consequences of a potentially fatal disease, through the prevention and relief of suffering, identified early and accurately assessed, through the treatment of pain and other related physical aspects, related psychological and spiritual problems..."*.

The Assembly of the European Parliament, with Resolution 2249/2018, urged Member States of the Council of Europe to take measures to systematically provide psychological, emotional, and spiritual support to patients and families.

Within the specific scope of the items to be addressed in this document, there are several international conventions that recognize the right of people to a dignified and respectful funeral.

The European Convention on Human Rights, adopted in 1950, guarantees the right to private and family life and the right to freedom of thought, conscience, and religion. These rights are relevant to funeral practices, as they allow individuals and families to choose the ceremony that best suits their beliefs and traditions.

The International Covenant on Civil and Political Rights, adopted in 1966, recognizes the right to life, the right to freedom of thought, conscience and religion, and the right to protection from inhuman or degrading treatment. These rights are also relevant to funeral practices, as they ensure that individuals and families will not be subjected to practices that go against their beliefs.

The Convention on the Rights of the Child, adopted in 1989, recognizes the right of the child to identity and nationality, as well as to family life. These rights are relevant to funeral practices as they ensure that children have the right to a funeral that respects their dignity and identity.

Regarding succession planning, there is no single international convention specifically regulating the subject. However, some international conventions can have an impact on estate planning, recognizing, for example, the right to property or the right to protection of private and family life. Some relevant international conventions are:

European Convention on Human Rights (ECHR) of 1950: this guarantees the right to protection of one's property and respect for private and family life.

1989 United Nations Convention on the Rights of the Child: this recognizes the right of children to preserve their identity, including their name, nationality, and family relationships.

The Hague Convention of 1 August 1989 on the Protection of Children and Cooperation in Respect of Intercountry Adoption: this aims to protect children from unlawful travel and placement and provides mechanisms for international cooperation in the field of adoption.

The Hague Convention of 5 October 1961 on the Abolition of the Requirement to Legalize Foreign Public Documents: this facilitates the Recognition of Wills and Other Legal Acts Related to Succession Planning between Signatory Countries.

These conventions have an indirect influence on estate planning, guaranteeing human rights and the protection of the interests of individuals and families.

3. Legal and Political Framework – Partner Countries:

The legal and political framework of a given theme differs according to the country in question and its cultural traits. As such, in each of the following areas, readers will be able to identify the various perspectives of each partner country of this project.

End-of-life support

As a disease progresses and individuals enters the final stages of life, it is important to be aware of the legal or juridical framework of their country, for example regarding Advance Directives of Will, euthanasia or the anticipation of care, so as to guarantee respect for their wishes in these matters.

Here are the legal and political frameworks of each partner country participating in this project.

Belgium

Legal context

In Belgium, three complementary laws came into force in 2002 to regulate end-of-life medical practices:

The law of 22/08/2002 on patients' rights

This law aims to protect the rights of the patient, specifying the characteristics of the relationship between the patient and the professional with a view to improving the quality of health services.

The main patient-rights covered by this law are:

To receive quality health services: Each patient receives the best possible care according to their needs, based on medical knowledge and available technology. Services are provided with respect for the dignity and autonomy of the patient, without any discrimination (e.g. social class, sexual orientation or beliefs). Care, in the sense of preventing, treating, and relieving physical and psychological pain, is an integral part of the patient's treatment

Free choice of a professional: The patient chooses the professional and can consult another at any time. On the other hand, any doctor may refuse to provide services to a patient for personal or professional reasons, except in case of emergency. However, if the caregiver withdraws from the provision of care, he or she must provide or ensure continuity of care

To be informed about their status: The physician provides the patient with all the necessary information about their condition and its probable evolution. The healthcare professional also indicates the behaviour to adopt accordingly (for example, when there are risks in case of pregnancy)

Free consent to care with prior information: Before starting a treatment, the doctor must obtain the patient's free and informed consent. This implies that the doctor clearly informs the person about the nature of the planned intervention. Timely disclosure shall include the following aspects of the procedure: its purpose, nature, urgency, duration and frequency; any contraindications, side effects or significant risks involved; the need for follow-up, financial implications and possible consequences of a refusal of consent; finally, any possible alternatives. In case of emergency, when it is impossible to discern the will of the patient or his representative, the professional performs all the necessary interventions and documents the situation in the patient's medical record

Updated medical records, which can be consulted and copies obtained: The doctor should keep in a safe place his records for each patient. This record contains data on the patient's identity and other information. The patient may ask the doctor to add certain documents to the file (for example, a scientific article on the patient's illness, a document appointing a trusted person or an attorney). If the patient changes health care provider, they can request the transfer of their data to ensure continuity of care

Respect for privacy and intimacy: Unless the patient agrees, only professionals who are needed may be present during care. Information related to the health of the person may not be disclosed to third parties unless there is a legal exemption and the need to protect public health or the rights and freedoms of others

To lodge a complaint with an ombudsman: If a person feels that one of their rights as a patient is being violated, they can lodge a complaint with the relevant ombudsman service

Pain management: The law also provides that the rights of individuals who can no longer exercise them may be exercised by their representative

The law of 28/02/2002, amended in 2014 and 2020, decriminalizes euthanasia.

In 2002, Belgium passed a law that decriminalizes euthanasia in certain situations. The law defines euthanasia as "a (medical) act, *performed by a third party (physician), that intentionally ends a person's life at his request*." A capable and fully-conscious patient can make a request for euthanasia; *this is a request made in the present for a present situation*. The application must be written and signed. It is carried out by a doctor in accordance with the conditions and procedures established by law; for a doctor not to respect these procedures is a punishable act. Equally, a doctor is free to decide whether or not to perform euthanasia.

For the current order, patients must, at the time of the request

- Be conscious and able to express their will
- Be in a desperate situation
- Be in constant and unbearable physical and/or psychological suffering, resulting from a serious accident or incurable illness.

This request should be made voluntarily, thoughtfully, repeatedly and without external pressures.

A prior declaration of euthanasia can be drawn up on an official form by a conscientious person who expresses their desire to be euthanized if they becomes irreversibly unconscious. *This is a request made in the present for a future situation.*

The doctor who performs euthanasia based on a prior declaration must, first of all, prove that the patient is irreversibly unconscious due to an incurable illness or the serious effects of an accident. The prior declaration of euthanasia remains in effect for an unlimited period, though is revocable at any time.

The law of 14/06/2002, amended in 2016, is related to palliative care

In 2002, the law on palliative care established the right of all patients to "*benefit from palliative care at the end of life.*" Palliative care is defined as "*all care provided to a patient suffering from a disease no longer responding to curative therapies and likely to lead to death.*"

This palliative care is provided on a physical, psychological, social, moral, existential and, where appropriate, spiritual level. It aims to ensure and optimize the quality of life of patients and their relatives and close caregivers for as long as possible.

The law has evolved so that palliative care is no longer limited to a few weeks at the end of a patient's life, but is extended to an advanced or terminal stage of a serious or progressive life-threatening illness, regardless of actual life expectancy.

Since the law was amended in 2016, palliative care can also cover patients who are still responding to curative therapies. If they are no longer identified as palliative on the basis of life expectancy, it is important to have other criteria based on the severity of their needs to make the diagnosis.

For this purpose, the PICT (Palliative Care Indicators Tool) was developed. It is a palliative scale for identification of the stage of disease and identifies three filters, in the way of questions, to determine by successive elimination whether or not a patient is deemed to be palliative:

- The "surprise question" for measuring life expectancy: “Would you be surprised if your patient died in the next 6 to 12 months?”

- A measure of the fragility of a patient
- An analysis of the incurability of the disease

If the first response is negative and the next two are positive, the patient is identified as palliative.

Policy framework

Under the Law of 22 August 2002 on the rights of the sick person, the Federal Public Health Service created the Federal Commission on the Rights of the Sick.

This committee collects information on issues relating to patients' rights, formulates opinions for the Minister, assesses the application of the law and the functioning of the Ombudsman's duties, and makes recommendations in this regard.

A patient who feels that one of their rights is not being respected by a professional (for example, lack of information about their state of health, difficulties in accessing their records, insufficient quality of care) can resort to the Federal Mediation Service's 'Patients' Rights', which will try to resolve the disagreement in conjunction with the patient and the doctor.

Article 5 of the Euthanasia Act of 28 May 2002 stipulates that the doctor who has performed euthanasia must complete a registration document. This document must be sent within four working days to the Federal Commission for the Supervision and Evaluation of Euthanasia, which handles the documents submitted.

The Commission is also responsible for preparing a biennial report for the House of Representatives.

On January 29, 2003, the Federal Unit for the Evaluation of Palliative Care was created within the scope of the Federal Public Health Service. The missions of this unit are:

- To regularly assess " *needs in the field of palliative care and the quality of the responses given*"
- To provide information about what still needs to be examined or developed and how best to do so
- To submit an evaluation report to the legislative chambers every two years

The Palliative Care Act also stipulates that ministers responsible for social affairs and public health must submit an annual progress report to the legislative chambers as an essential part of their political memorandum.

Italy

Legal context

In December 2017, Law 219/2017, ‘Provisions for informed consent and advance directives’, was approved in Italy.

Competent adults can now decide for themselves which medical treatments to accept or decline, both for the present and the future, so long as they have adequate information about the consequences of their choices.

Under this law a trusted person or ‘*fiduciary*’ can be appointed to act as an assistant and representative in dealings with doctors and health facilities.

Advanced directives may be established:

- by public deed or private public deed
- by private deed delivered personally to the civil registry where the individual resides

In cases where the physical condition of the patient does not allow it, directives can be expressed by video recording, or with devices that allow an incapacitated person to express their will.

These forms may also be used to renew, amend, and revoke a patient’s wishes at any time.

In cases where reasons of urgency or emergency prevent the revocation of an advanced directive with the relevant forms, it may be revoked by a verbal statement collected or filmed by a doctor, with the assistance of two witnesses.

In Italy, euthanasia remains a crime.

Article 580 of the Italian Penal Code (instigation or complicity in suicide) states that anyone who causes others to commit suicide (determinant) or encourages them to do so (instigator), or in any way facilitates a suicide (facilitator), shall be punished, in the event of death, by imprisonment of five to twelve years. If the suicide attempt results in serious bodily injury but no death, the term of imprisonment is one to five years.

In 2019, the Constitutional Court ruled that it is not always a crime to help someone in “intolerable suffering” kill themselves, subject to the following criteria:

- they are being kept alive by life support treatment
- they have an irreversible pathology, where the physical or psychological suffering is considered intolerable
- they are fully capable of making free and conscious decisions
- they intend to commit suicide, as expressed independently and freely

- this suicidal intent is as stipulated in articles 1 and 2 of Law No. 219/2017

these conditions and the intended manner of implementation have been verified by a body of the National Health Service, and the territorially competent ethics committee

In the event that all these conditions are met, the facilitation of suicide is not considered a crime.

Palliative Care is defined in Law 38 of 2018 as "*a set of therapeutic, diagnostic and care interventions directed towards the patient and their family, aiming for the complete care of patients whose underlying disease is progressive, has a poor prognosis, and no longer responds to specific treatments*". It must "*ensure respect for the dignity and autonomy of the person, their need for health, equity and quality of care, and its adequacy to specific needs*", according to three fundamental principles:

(a) the protection of the dignity and autonomy of the sick person without discrimination

(b) the protection and promotion of the quality of life until its completion

(c) adequate health and social care support for the sick person and the family

Policy framework

Italy's Law No. 38 of March 15, 2010, "Provisions for access to palliative care and pain therapy" represents an important milestone in the European healthcare landscape, ratifying a citizen's right not to suffer.

A report to the Assembly of the Republic on the application of this law for the years 2015-17 (https://www.salute.gov.it/imgs/C_17_pubblicazioni_2814_allegato.pdf) presented a document entitled 'A model for the development of local Palliative Care Networks', with recommendations in the following areas:

1. Early identification of patients
2. The implementation of Local Palliative Care Networks
3. Professionals: activities and skills
4. Evaluation of the care path

Portugal

Legal context

The Assembly of the Republic confirmed, on May 12, 2023, the new version of the law on medically assisted death. The law will only enter into force 30 days after the publication of the regulation (it must be approved by the Government within 90 days after publication in the Official Gazette).

The president of the Portuguese Republic, the conservative Marcelo Rebelo de Sousa, finally promulgated the law that decriminalizes euthanasia, approved by Parliament after an arduous legislative process.

This was the fifth time that deputies passed a decree on the decriminalization of medically assisted death. The decree states that medically assisted death can only occur through euthanasia if assisted suicide is impossible due to the patient's physical disability.

The request for euthanasia is made in writing by the patient and addressed to a guiding physician chosen by the applicant. This doctor oversees coordinating all the information and assistance to the patient, that is, he is the main interlocutor

Medically assisted death (not punishable) occurs by decision of the person himself, of legal age, of Portuguese nationality or legally residing in national territory. This person must be in a situation of suffering of great intensity, with definitive injury of extreme severity or serious and incurable disease. And you can practice it or be helped by health professionals.

The law clarifies these concepts:

- suffering of great intensity – that which results from a serious and incurable disease or from a definitive injury of extreme severity (with great intensity, persistent, continuous or permanent and considered intolerable by the person himself);
- definitive injury of extreme severity – it is a serious, definitive and widely disabling injury that puts the person in a situation of dependence on a third party or technological support for the performance of elementary activities of daily living, with certainty (or high probability) that these limitations will persist over time without the possibility of cure or significant improvement;
- Serious and incurable disease – life-threatening, advanced and progressive, incurable and irreversible disease, which causes suffering of great intensity.

Medically assisted death can only occur in one of the following ways:

- medically assisted suicide – when the patient self-administers lethal drugs, albeit under medical supervision;

- Euthanasia – When lethal drugs are administered by the doctor or health professional qualified for this purpose.

However, it should be noted that medically assisted death can only occur through euthanasia provided that medically assisted suicide is not possible to perform due to the physical disability of the patient. The latter does not have the right to choose between medically assisted suicide or euthanasia, contrary to what resulted from an earlier proposal, which, by way of interpretation, could allow this possibility.

Procedure

The request is made in writing by the patient and addressed to a guiding physician chosen by the applicant. That doctor is in charge of coordinating all information and assistance to the patient, that is, he is the main interlocutor, issuing within 20 working days, a reasoned opinion on the respective requirements. The guiding physician also provides information and clarification about the clinical situation of the patient, the treatments applicable to his case, namely in the area of palliative care and its prognosis. If the patient's decision stands, it shall be recorded in writing.

If the opinion of the guiding physician is not favorable to medically assisted death, the procedure is canceled and terminated. But it can be restarted upon a new request for opening. On the other hand, if the opinion of the guiding physician is favorable, he proceeds to the consultation of another doctor (specialist in the disease), who confirms (or not), among other situations provided for in the law, the diagnosis of the clinical situation or the serious and incurable nature of the disease. It should be noted that the opinion of the specialist doctor must be carried out within 15 working days.

If the opinion of the specialist doctor is favourable, the patient is informed of this by the guiding physician, who confirms again whether the patient's will is maintained.

During the process, the opinion of a doctor specializing in psychiatry is mandatory in the following situations:

- if there are doubts about the patient's ability to request medically assisted death;
- faced with the possibility of psychic disturbance or medical condition that affects their decision-making. If the psychiatry specialist confirms some of these situations, the procedure is canceled.

Still, if the opinions are favorable, the guiding physician sends a copy of the Special Clinical Registry to the Committee for Verification and Evaluation of the Clinical Procedures of Medically Assisted Death, requesting an opinion on compliance with the procedure. If it is favourable, the guiding doctor informs the patient, confirming once again whether this is his wish.

The request can be revoked at any time, which implies the cancellation of the clinical procedure.

The Implementation of the procedure

The supervising physician combines the day, time, place (chosen by the patient; it may be in the National Health Service establishments or in the duly licensed private sector) and the method to be used. It should also inform and enlighten the patient about the methods available to carry out medically assisted death. For example, the self-administration of lethal drugs by the patient or the administration by the doctor (or health professional qualified for this purpose, although under medical supervision) when the patient is unable to do so due to physical disability. In this regard, the law does not clarify who is responsible for attesting to the physical incapacity of the patient or who ensures medical supervision during the act. The regulation of the law is awaited to confirm whether these issues are covered.

If the patient becomes unconscious before the scheduled date for the procedure, it is interrupted and does not take place, except if he regains consciousness and maintains the decision.

Life insurance

Medically assisted death is not an exclusion factor under an insurance contract. However, once the clinical procedure has been initiated, it is not possible to amend the clauses designating beneficiaries.

The Directorate-General for Health will make available on the internet an area with information on medically assisted death relating to information on clinical procedures, forms and documents, and applicable legislation.

https://dre.pt/dre/detalhe/lei/22-2023-213498831

The Advance Directive of Will (DAV) in Portugal is regulated by Decree-Law no. 25/2012, of 16 February, which establishes the legality of advance directives of will, also known as "living wills". The DAV is a legal instrument that allows citizens to express their preferences regarding the health care they wish or do not wish to receive, in case of inability to express their will.

https://www.ers.pt/pt/utentes/perguntas-frequentes/faq/diretiva-antecipada-de-vontade-em-cuidados-de-saude/

Policy framework

Despite been recently approved, it is important to highlight that euthanasia is still a controversial topic and divides opinions in Portuguese society, and there are still organizations that oppose the practice of euthanasia for ethical, moral, and religious reasons.

After two political vetoes by the President of the Republic and two leads in the Constitutional Court, the decriminalization of medically assisted death was approved. Marcelo Rebelo de Sousa was forced to promulgate the decree.

In this way, euthanasia becomes legal in Portugal, with the approval of the diploma of the decriminalization of medically assisted death, with 129 votes in favor, 81 against and one abstention. This total far exceeded the 116 votes needed for the confirmation of the diploma.

The parliamentary discussion of medically assisted death began three legislatures ago, after the delivery in the Assembly of the Republic of a petition with 8400 signatures calling for the decriminalization of euthanasia, following a manifesto of the civic movement "Right to Die with Dignity". But the issue would only go up to votes in May 2018. Although all the bills were then voted down, the Social Party was five votes away from approval and was promised a new round for the next legislature.

The decriminalization of medically assisted death would be approved in general for the first time in early 2020. It was the beginning of the current legislative process: three years and three months of back-and-forth between the Assembly of the Republic, the São Bento Palace and the Ratton Palace, seat of the Tribunal Constitucional, until finally on May 16, 2023, the President of the Republic was forced to enact.

On the other hand, the Advance Will Directive (DAV) has also been debated and regulated mainly in the field of health and the rights of the sick person.

In 2012, Law no. 25/2012 regulating VAD in Portugal was approved, and since then there has been a growing recognition of the importance of this tool to ensure respect for the rights and dignity of patients in this context.

However, the theme of VAD can also be framed in a broader context of human rights and citizenship, related to individual autonomy and freedom of choice in relation to health care. In this sense, some political currents that value individual freedom and the protection of human rights defend the use and promotion of the Early Will Directive.

In general, the political framework in relation to the Advance Directive of Will in Portugal has been positive and there has been a growing consensus around its importance for the defense of patients' rights and autonomy.

More than 13,000 Portuguese registered their Living Will/DAV in 2022, doubling the number of registrations compared to the previous year.

As of January 9, 2023, the total number of active DAV's/Widowed Wills exceeded 34,500, of which more than 12,000 were granted by men and more than 22,500 by women. In either gender, the age groups with the highest number of active registrations are between 65 and 80 years and between 50 and 65 years.

Sweden

Legal Framework

In Sweden, palliative care is governed by various laws and guidelines.

The most important are:

- Patient Act (Patientlagen): This law guarantees the right of all patients to receive adequate health care, including palliative care. It also stresses the importance of involving patients in decision-making and providing care of a high-quality
- Social Services Act (Socialtjänstlagen): This law requires municipalities to provide palliative care services to all residents who need them. This includes home care, hospital care, and support for family members and caregivers
- Health and Medical Services Act (Hälso- och sjukvårdslagen): This law defines the responsibilities of healthcare providers in Sweden, including the provision of palliative care services. It emphasizes the importance of patient-centred care and the involvement of family members and caregivers
- National guidelines for palliative care: These guidelines provide detailed information on best practices for palliative care in Sweden. They cover a wide range of topics, including symptom management, communication with patients and families, and the provision of spiritual and psychological support
- National Health and Wellness Council: This provides advice on the implementation of national guidelines and regulations related to palliative care. It also monitors the quality of health care offered by providers and makes recommendations for improvements

Sweden has a strong commitment to palliative care and has developed comprehensive laws and guidelines to ensure that all residents receive high-quality, patient-centred care in the final stages of life.

Policy framework

Palliative care in Sweden is part of the wider health system and is influenced by the country's political framework. The Swedish health system is largely decentralized, with responsibility for the provision of health care and funding shared between the central government, regional health authorities and municipalities.

At national level, the Swedish Government is responsible for defining general health policies and providing funding to regions and municipalities. The Government has expressed its commitment to improving end-of-life care and has included palliative care as a priority area in its National Cancer Strategy.

Regional health authorities are responsible for the planning and coordination of health services in their respective regions, including palliative care services. Regional authorities work closely with health care providers and municipalities to ensure that palliative care services are available to all residents who need them.

Municipalities are responsible for providing home care and other support services to patients receiving palliative care. They work closely with regional authorities and health providers to coordinate care and ensure that patients receive high-quality, patient-centred services.

In addition to government policies and funding, palliative care in Sweden is also influenced by professional organizations and patient advocacy groups. These work to raise awareness of the importance of palliative care and promote best practices in the provision of end-of-life care.

The policy framework for palliative care in Sweden emphasizes a patient-centred approach to collaboration between different levels of government and health care providers. This framework has contributed to ensuring that palliative care services are of high quality and are widely available throughout the country.

Early Directives after Death

Just as it is important to define the expectation of health care to be received at advanced stages of a disease, it is equally important for individuals to know the legal and political framework of their own countries, to reflect on their wills, and consider granting advance directives ahead of their deaths. This includes the donation of their organs and tissues, as well as possible donation of their body to science.

Here are the legal and political frameworks of each partner country participating in this project.

Belgium

Legal context

Organ donation in Belgium is governed by the law of February 1987, whose principle is "he who says nothing, consents". It is a tacit agreement, a presumed solidarity through which it is considered that everyone agrees to donate their organs after their death. Organ and tissue donors can be dead or still living, though donations cannot be for profit (in cash). Donors and their family members have no rights over the organ/tissue recipient.

However, since July 2020, there have been new modalities, and the person can choose to donate:

- Their organs (kidneys, liver, heart, lungs, pancreas, intestines and vascularized tissues such as the face) for transplantation
- HCM (Human Body Material - stem cells, skin, corneas, cartilage, tendons, secretions, fluids) for transplantation
- HCM for the manufacture of medicinal products
- HCM for research purposes

Despite this presumed consent, everyone has the right to register their opposition or explicit consent to organ donation or to HCM, which avoids the need for family members to have to make a decision on this matter at such a delicate time as the death of their loved one.

In Belgium, body donation to science is not subject to specific legal regulation. It is approached in a pragmatic way and practiced according to a framework determined by the universities, and transmitted by actors such as the FPS Public Health, the Federation of Notaries or the Municipalities.

Procedure: each university has a specific procedure regarding the donation of a body to science. Information on this subject can be found on their respective websites. However, the process is similar from one university to another.

Note: universities only accept bodies of people who have died in Belgium and who have not undergone an autopsy.

Other conditions can prevent the donation of a body:

- When the circumstances of death (suicide, serious accident, etc.) make it impossible to preserve the body
- In case of infectious or contagious disease
- When a period of 52 hours has elapsed after death

Policy framework

To confirm a person's desire to be an organ donor, an official document is available to complete, which can be obtained from the municipal administration, or directly on http://www.beldonor.be.

Italy

Legal context

Law No. 91/99 *"Provisions relating to the removal and transplantation of organs and tissues"* requires that every citizen be asked to express their will about organ donation after death, in accordance with the principle that informed silence signifies assent.

According to this principle, those who agree to gift their organs after death are considered donors, and those who disagree are regarded as non-donors. Where the potential donor has not expressed any view on the matter, family members have the option of opposing organ removal.

In the absence of a contrary opinion, the deceased may be considered a donor.

Consent to the donation can be formalized in several ways:

- With the citizen's own particular district Health Service where, as well as explicit consent, explicit dissent can also be registered
- By registering with the Italian Association of Organ Donors (AIDO)

If a citizen does not express their will, the law provides for the possibility of family members (unseparated spouse, '*cohabitant plus uxorio*', adult children and parents) to oppose the removal of organs during the period immediately after death.

In the case of children, it is always the parents who decide. If one of them is against it, the child's organs cannot be removed.

The citizen may change the declaration of will at any time. The last declaration made in the prescribed manner shall always be considered valid.

In conclusion:

- If a citizen has expressed a positive intention to donate during their life, family members cannot oppose
- If a citizen has expressed an unwillingness to donate, there can be no harvesting of organs
- If a citizen has not expressed a view, then harvesting is allowed if family members do not object

Policy framework

To confirm one's desire to be an organ donor, an official document should be completed, either at the municipal administration or on website https://aido.it/.

It is also possible to express one's will regarding organ and tissue donation at the municipality, during the renewal and / or issuance of an Identity Card.

Portugal

Legal context

In Portugal, the donation of organs and tissues for transplantation is regulated by the second version of Law no. 12/2009 of 26 March, which establishes a legal regime of quality and safety relating to the donation, collection, analysis, processing, preservation, storage, distribution and use of tissues and cells of human origin. It transposes Directives of the European Parliament into the domestic legal order.

In Portugal, donation is seen as an altruistic gesture, being considered as one of the greatest acts of kindness among human beings.

Any citizen who does not register in the National Register of Non-Donors (RENNDA) may be an organ donor. That is, according to Portuguese legislation, everyone can be considered a potential donor, as long as they do not express opposition to this in RENNDA.

With the best will in the world, not everyone can be a donor, since it is necessary that death occurs in an Intensive Care Unit of a hospital. Only in these units can the organs be preserved, and all necessary tests for the evaluation of each potential donor carried out.

The organs that can be donated are:

- the kidneys
- the liver
- the heart
- the pancreas
- the lungs

The following can also be harvested from donors:

- osteotendinous tissues (such as bone, tendon, and other osteotendon structures)
- corneas
- cardiac valves
- vascular segments
- skin

If someone does not want to donate an organ or tissue, they must document this in the National Register of Non-Donors (RENNDA), otherwise the possibility of complete donation (of all organs) is usually contemplated given the scarcity of organs for transplantation. By consulting the National Register of Non-Donors (RENNDA) it is possible to understand which organs or tissues may or may not be used.

A living donation is possible if the conditions and requirements established in the legislation are fulfilled in order to guarantee the rights of both parties: freedom of decision, volition, recognition, and altruism. Each case has its particularities, so the doctor responsible for the recipient should always be consulted.

There is no age limit for organ donation. It is the quality and functionality of the organs that determine the possibility of their being used for transplantation.

However, it is mandatory to ensure that the donor does not have any disease or pathology that may be transmitted by the organ or tissues to the recipient. Otherwise, the donation and consequent transplant cannot be performed.

A living donation is allowed if the conditions and requirements established in the legislation are obeyed, namely that the donor

- be 18 years of age or older
- be healthy physically and mentally

(NOTE: For more information see: Portuguese Institute of Blood and Transplantation (IPST))

On the other hand, the donation of a body to science is a civic act of great generosity. Anatomy is one of the fundamental bases of medical education. Its importance results from the indispensable role it plays in the teaching of medical students, as well as in scientific and technical research that leads to the development of medical and surgical treatments for many diseases. Their knowledge requires a thorough study of the human cadaver.

The decision to donate one's body to research and the teaching of anatomy should therefore be considered a vital contribution to the advancement of Medical Science in general, and a commendable civic act.

Every person of legal age has the right to donate their body. To this end, the following documents should be carefully read and the relevant form completed:

https://www.medicina.ulisboa.pt/sites/default/files/inline-files/Informa%C3%A7%C3%A3o.pdf

https://www.medicina.ulisboa.pt/sites/default/files/inline-files/Formul%C3%A1rio.pdf

Policy framework

Organ donation is voluntary and free, and Portuguese law provides for the presumption of consent. In other words, all citizens are considered potential donors unless they have expressed a view to the contrary.

http://www.ipst.pt/files/TRANSPLANTACAO/DOACAOETRANSPLANTACAO/brochura_RENNDA.pdf

The donation of bodies to science is regulated by a set of ethical norms, guaranteeing respect for human dignity and the rights of donors and their families.

In political terms, organ and body donation to science is seen as a matter of public health and the promotion of scientific research, and the Portuguese State has been developing policies and measures aimed at encouraging organ donation and registration in the National Register of Body Donors.

However, despite the advances made in recent years, the rate of organ donation in Portugal is still relatively low compared to other European countries, which points to the need to continue to promote awareness of this cause.

Sweden

Legal context

In Sweden, organ donation is based on presumed consent.

The Swedish Health Board has set up a register for organ donation. Donation rates in Sweden are lower than in other European or North American countries, with only 150 60 160 donors a year from a population of some 15 to 16 million people.

Policy framework

The new European directives for organ and tissue donation, in addition to working-time restrictions, will directly affect infrastructure, clinical care and the general attractiveness of this field.

Government regulations are expected to result in a consolidation of transplant centres in Sweden, with transplant activities in only a few locations in the country.

Maintaining a high level of education is as much a Swedish problem as it is in many other countries. Poor support for health care, beyond the constraints of industry support, requires a readjustment of educational efforts.

Results are monitored in national registries, with open comparisons of quality variables, including graft and patient survival, 30-day mortality, and the number of transplants per million people.

The National Health Council regularly audits the results. All centres actively seek the use of marginal donors to increase the pool of available organs.

Representation

The appointment of a designated representative or proxy can help a patient ensure that their needs are met and decisions respected, even when they themselves are not present or are unable to express their will. This representative, or person of trust, is given the legal authority to make decisions on the patient’s behalf and to ensure that their wishes are fulfilled.

The following paragraphs are the legal and political frameworks of each partner country participating in this project.

Belgium

Legal context

In Belgium, the issue of patient representation was addressed in the 2002 law on patients' rights. However, two important prerequisites must be considered: in all cases, patients remain involved in the exercise of their rights as much as is possible, and as they are able to understand.

In order to appoint a Trusted Person or Representative, the patient must be ABLE to exercise these rights

These notions of power of attorney and trustee are two concepts emanating from the 2002 law, and should not be confused:

The *prosecutor* is a person who represents patients who are no longer in a position to exercise their own rights; they will have been appointed by the patient, when they were still in a position to do so, to take their place until they are again able to exercise their rights. (Law of 2002, art. 14).

The representation of patients or adults who are not able to express their will and exercise their rights is ensured through a cascading system:

- Representative appointed in advance
- Administrator or the person designated by the justice of the peace
- Spouse or partner in a partnership
- Son, of legal age
- Father or Mother
- Sister or brother, of legal age
- Medical team (multidisciplinary)

The trusted person is a person authorized to help provide care to a patient who is still able to exercise their own rights. Support or trusted persons do not exercise rights in place of the patient, but assist them

in the exercise of some of their rights (such as accompanying them to medical consultations, receiving information or consulting the patient's file).

Italy

Legal context

The representation of an individual is governed by the Civil Code, which regulates the representation of assets and consists of two elements

- relationships with third parties
- relationships with those represented

(1) *The legal instrument governing a patient's relationship with third parties is the power of attorney* (art. 1387-1399 of the Civil Code).

Attorneys, when requested, must justify their power and show the document that sets out the source of their representation. They must have the same form of contract as that to be dealt with, (for example, a house purchase is made by public deed, so the power of attorney must be made in the form of a public deed). The power of attorney may be modified or revoked at any time, but the modification or revocation must be made known by appropriate means.

(2) *The relationship between represented and representative is governed by a contract: the agency contract.*

Problems arise when the patient has become incompetent. In this case, the agency contract ends causing uncertainty as to whether the representation is still valid.

It may therefore be necessary for a judge to appoint a *guardian* (in cases of full incompetence), a *semi-guardian* (if the inability is partial) or an *administrator* (in the event that a person is no longer able to look after their own legal affairs, whether competent or not).

The *administrator* may be appointed by the patient while still competent, in anticipation of their eventual future incapacity, either by public deed or notarized private document. It is a form of power of attorney supervised by a judge.

The extent of the legal issues to be handled on behalf of the patient will depend on the need, but can be as great as for a totally incompetent person.

Regarding representation for non-patrimonial acts, but only for those related to the patient's health, the governing article is Law n. 219, 2023. This provides the faculty to appoint a trusted person, the *fiduciary*, who is appointed to act as an assistant and representative in dealings with the physician and health care facilities.

In the case of Advanced Directives, the appointment must be made by public deed, private public deed, or by private deed, and delivered personally to the appropriate civil registry where the document will be registered.

Also, in the event of specific illness, an *intervener* may be appointed to act on behalf of the patient, with a view to giving informed consent, or the refusal or withdrawal of medical treatment. To this end, the patient may choose to have some or all of their medical information redirected to the trustee. The designation may be made verbally or in a way appropriate to the patient's condition but must be documented in writing or by video. In the case of disability, they may use any device that allow them to communicate.

Whichever form is used, it shall be included in the patient's medical record and electronic health record.

Policy framework

In Italy, many regions encourage individuals to make their support administrator known, thereby reinforcing their role, and ensuring that technical support information is updated.

Each region establishes lists at provincial level of individuals available to assume the role of administrator, as well as supporting the creation of advisory structures on legal, economic, social and health issues. A support administrator can turn to these sources for needs related to their work, (such as in the case of Emilia Romagna who died in 20098. Regional Law n. 11).

Portugal

Legal context

In Portugal, the appointment of a representative for a terminally ill patient is regulated by Law no. 25/2012 of 16 July, which establishes a regime of access for the provision of health care, as well as the protection of the patient's rights.

According to Article 9 of that law, patients have the right to choose a person who will represent them in decisions concerning their health when, for any reason, they are not in a position to make these decisions themselves. This choice must be expressed and freely manifested by the patient through a written declaration, which must be signed and dated. The declaration must be delivered to the attending physician, who will include it in the patient's medical record.

As an alternative to this declaration, patients may also complete and submit an Advance Directive of Will (DAV).

The appointed representative shall have the right to receive information on the patient's state of health, and be consulted on decisions concerning the care to be provided. It should be noted that the

appointment of a representative does not imply any loss of the patient's ability to make decisions regarding their own health. The representative should always respect the wishes and preferences of the patient and, in case of doubt, consult the health professionals who provide care.

If patients are no longer able to express their will, a 'Regime of the Accompanied Adult' may be put in place through the Court or Public Prosecutor's Office.

This Regime, approved by Law No. 49/2018 of August 14, allows any person who, for reasons of health, disability or behaviour, is unable fully and consciously to exercise their rights or fulfil their obligations, to request from the Court the necessary accompanying measures. It also allows them to choose who they would like to accompany or represent them in making decisions of a personal or patrimonial nature.

Accompanying measures may also be requested by the Public Prosecutor's Office, the spouse, the unmarried partner, or any successor of the person in need.

Any adult can choose their "companion" in advance and this will must be respected. Subsequent monitoring of the adult aims to ensure their well-being, their recovery, the full exercise of their rights and fulfilment of their duties, apart from legal exceptions or those determined by a judge.

https://www.ministeriopublico.pt/perguntas-frequentes/protecao-de-adultos

In summary, the appointment of a representative for terminally ill patients is allowed by law, provided that they clearly convey their intent through a written declaration, which must be delivered to the attending physician, or alternatively by completing their ADLW.

The representative shall have the right to receive information on a patient's state of health and to be consulted on decisions concerning the health care to be provided.

If the patient is not able to express their will, a Legal Regime of the Accompanied Adult may be affected through the Court or Public Prosecutor's Office.

Policy framework

In Portugal, the political framework regarding the appointment of a representative for terminally ill patients can be understood from several points of view. In general terms, the appointment of such a representative is seen as an important measure to ensure the dignity, autonomy, and rights of these patients, as well as ensuring a more humane and empathetic approach to medical care. This appointment can be made by patients themselves or, in their absence, by their closest relatives or by the Court.

In political terms, the issue of appointing a representative for terminally ill patients can be seen as part of a broader debate about the role of the state in ensuring access to quality health care for all citizens, regardless of their financial, social or health status.

In this sense, the appointment of representatives for long-term patients is an important instrument to ensure a more humane and patient-centred approach to medical care, as opposed to a technical or impersonal view of medicine.

In general, it can be said that the political framework regarding the appointment of representatives for terminally ill patients in Portugal is favourable from a legal, social, and political point of view. There is a growing consensus in Portuguese society on the importance of guaranteeing the dignity and rights of terminally ill patients, as well as on the need to adopt a more humane and empathetic approach to medical care.

Sweden

Legal Framework

In Sweden, the law provides for the appointment of a representative or trusted person to make decisions on behalf of those who cannot act for themselves due to illness or disability, including at the end of life.

The Health and Medical Services Act (Hälso- och sjukvårdslagen) provides for the appointment of a legal guardian (förvaltare) for people unable to make decisions about their own medical care, including end-of-life care. Guardians are appointed by a court and have the authority to make decisions on behalf of those they represent. They act in the best interest of the patient, whose desires, values and beliefs they must take into account.

In addition to the legal guardian, the law also allows for the appointment of a trusted person or trustee to make decisions on behalf of those who are unable to act for themselves due to illness or disability. Trustees may be appointed by the person they represent or by the court, and have the authority to make decisions about the patient's medical care, finances, and other personal matters.

The law also recognizes the importance of advance care planning, which allows individuals to make decisions about their medical treatment and end-of-life care in advance. An individual may appoint a representative or a trusted person to make decisions on their behalf if they become unable to make their own decisions.

Policy Framework

In Sweden, there are policies and guidelines regarding the appointment of a representative or trustee for a person at the end of life. Some of these include:

Legal guardianship: The National Council for Health and Welfare has issued guidelines on legal guardianship, which provide information on the appointment of a legal guardian to a person who is unable to make decisions about their own medical care, including end-of-life care. The guidelines underline the importance of appointing someone who can make decisions in the best interest of the person they represent

Trusted persons: The Swedish Association of Local Authorities and Regions (SALAR) has developed guidelines on the appointment of a trusted person to make decisions on behalf of those unable to decide for themselves due to illness or disability. The guidelines emphasize the importance of ensuring that the trustee is trustworthy, capable, and willing to take on the responsibilities of the role

Early care planning: The National Health and Wellness Board has also issued guidelines on advance care planning, which encourage individuals to appoint a trusted representative, or person to make decisions on their behalf if they become unable to make their own decisions. The guidelines underline the importance of ensuring that the designated person understands a patient’s wishes and values, and is willing to act in their best interest

These policies and guidelines aim to ensure that the appointment of a trusted representative is carried out in a responsible and compassionate manner, recognizing the importance of appointing someone who can make decisions in the best interests of the person they represent, and of ensuring that that person's wishes and values are respected.

Funerals

A person who is aware of the legal and political environment of their own country, and who anticipates the funeral arrangements they may want, can help to ensure that their wishes are respected upon their deaths. It also eases the emotional and financial burden on their loved ones, and ensures that their spiritual or religious beliefs are upheld.

Here is a summary of legal matters regarding funerals in each partner country of this project.

Belgium

Legal Framework

In Belgium, funerals are regulated by the Civil Code and local legislation.

The deadline for arranging a funeral is usually between the 1st and 6th day after the death certificate is issued. However, funeral regulations differ from region to region.

To begin with, death must be declared by the family doctor or the doctor on duty (if death occurs at home). The death must be reported to the municipality within 48 hours, together with the death certificate.

Every death must be declared, for marital status purposes, but also to obtain authorization for burial or cremation, along with authorization to carry the coffin.

Anyone can arrange the funeral themselves, or they can hire an undertaker.

A burial plot should be requested at the local authority of the municipality where the remains will be buried. If a plot is not requested, the grave can be removed after 10 years.

Municipalities are responsible for the management of cemeteries and their funerals, and may establish specific rules for burial and cremation.

Cremation has been allowed in Belgium since 1933, but it is important to note that written permission is required, either from the deceased or their family, in order to carry out cremation.

Since 2001, the ashes of the deceased can be scattered, preserved, or buried on private land, if the deceased has specified so in writing.

Finally, it is important to note that Belgium recognizes freedom of religion and belief, which means that funerals can be celebrated according to the beliefs and traditions of the deceased's family.

An individual may at any time inform the civil registry of their municipality (or commune), in writing, of their last will and testament. This may include the desired funeral method and ceremony, the destination of the ashes, as well as mentioning the existence of a funeral contract.

For each region, there is a Declaration of Last Will and Testament about the type of grave, the rite and the funeral contract.

Policy Framework

Local authorities are responsible for the management and maintenance of cemeteries as well as the granting of graves. They may also lay down safety, health and aesthetic rules and standards for funerals.

At the regional level, policies can be implemented to encourage or regulate the practice of cremation, the protection of the environment during burials, or the payment of funeral expenses of people in financial distress.

Finally, at the federal level, policies can be set to regulate the funeral practices of different religions and beliefs, or to ensure the protection of consumer rights in the funeral industry.

Funeral policy in Belgium is decentralized but framed by national laws and regulations that guarantee respect for the rights of individuals and families, and the promotion of sustainable and environmentally friendly funeral practices.

Italy

Legal Framework

In Italy, funerals and related matters are regulated by national law number DPR 285/90, also known as the Mortuary Police Regulations

The rules relating to the death certificate are laid down:

by special law No. 578 passed in 1993; by standards for the determination and certification of death and the regulation on "methods of verification and certification of death"; by a decree of the Ministry of Health No. 594, approved in 1994, with subsequent modifications and integration (ss.mm.ii.)

Cremation is governed by law No. 130 passed in 2001, which allows for:

- dispersal of the ashes, normally only in specially-defined areas within cemeteries or on private land with the owner's permission. They may be buried, or scattered on mountains or at sea
- the delivery of the cinerary urn to family members
- ballot box cemeteries
- cremation free of charge (where the deceased is destitute)

The Mortuary Police Regulations also protect the dignity of the deceased with provisions that punish the defamation of corpses and graves, and the invasion or disturbance of a funeral or funeral service (art. 407-413).

Political Framework

Local authorities are responsible for the management and maintenance of cemeteries as well as the granting of graves. They can also establish safety, health and aesthetic rules and standards for funerals and provide for people in financial difficulties.

Portugal

Legal Framework

In Portugal, the legislation regarding the funerals of terminally ill patients is governed by Decree-Law No. 411/98 of 30 December, which establishes the legal regime for the removal, transport, inhumation,

exhumation, transfer and cremation of corpses, as well as some of these acts relating to bones, ashes, dead foetuses and anatomical pieces, and also the change of location of a cemetery.

Funerals should be carried out with the utmost respect and dignity, ensuring that the corpse is treated appropriately and that all sanitary standards are met.

Funeral services must be provided by duly authorized companies that comply with all legal standards and requirements, including safety, hygiene, and public health standards.

Where death occurs at home, it is necessary to notify the local health authority, so that it can take the necessary measures to ensure public health and compliance with sanitary standards.

It should be noted that there are guidelines for support in cases of destitution and / or financial difficulty, which may result in a subsidy for funeral expenses and / or social customs.

https://eportugal.gov.pt/servicos/obter-informacoes-sobre-o-servico-de-funeral-social

Policy Framework

In Portugal, the issue of funerals of terminally ill patients is generally treated as a public health issue and therefore within the framework of health policy.

Health policies in Portugal are managed by the Ministry of Health, with the help of other entities and organizations involved in the provision of health care to the terminally ill. However, the funeral of a terminally ill patient can also have ethical and moral implications, giving rise to broader political discussions on the topic.

Some political parties in Portugal may have different perspectives on the issue, depending on their political, philosophies and personal beliefs. In general, public opinion tends to be in favour of guaranteeing citizens a dignified and respectful funeral.

Most people believe that terminally ill patients deserve more care and special attention, including help with funeral planning and emotional support for their families and loved ones. However, the implementation of specific policies on funerals for these patients may vary depending on the practices and resources available in different regions of the country, as well as the personal preferences and beliefs of the individuals involved.

It is therefore important that there is an open and ongoing dialogue between government, health organisations and civil society to ensure that the needs of terminally ill patients are adequately met.

Sweden

Legal Framework

In Sweden, the law relating to funerals is mainly governed by the Funeral Law (Begravningslagen). This defines the rights and responsibilities of individuals, funeral directors and local authorities.

Some key provisions of the Funeral Law include:

Right to organize a funeral: The law gives close relatives the right to arrange a funeral for the deceased. If there are no close family members, local authorities can take responsibility for the arrangements.

Choice of funeral director: The family or close relatives may choose a funeral director to arrange the funeral. These must be licensed and follow certain regulations regarding the treatment of human remains and other aspects of funeral arrangements.

Cremation and burial: The law provides for both cremation and burial as options for the disposal of human remains. If the deceased has not expressed a preference, the family or close relatives can choose whether to cremate or bury the body.

Religious and cultural considerations: The law requires funeral arrangements to consider the religious and cultural context of the deceased and any wishes expressed in relation to the funeral.

Law relating to cemeteries: The law provides for regulations governing the use of cemeteries and the maintenance of graves.

Funeral funding: The law provides for government subsidies to cover the cost of basic funeral arrangements for individuals who do not have the means to pay for them.

Funeral law aims to ensure that funerals in Sweden are held with respect and dignity and that the rights and wishes of the deceased and their families are upheld.

Political Framework

In Sweden, there are policies and guidelines that advise on the arrangements and conduct of funerals. Some of these include:

Environmental considerations: The Swedish Association of Local Authorities and Regions (SALAR) has developed guidelines on environmentally sustainable funerals, which encourage undertakers and families to consider the environmental impact of funerals. This may include options such as the use of biodegradable materials and the reduction of energy consumption

Religious and cultural matters: Sweden's National Education Agency has developed guidelines on religious and cultural considerations at funerals. These provide information on various practices and customs and how they can be incorporated into funeral arrangements

Personalization of funerals: The Swedish Association of Funeral Directors has developed guidelines on the personalization of funerals, which encourage undertakers and families to create unique and meaningful arrangements that reflect the personality and interests of the deceased

Accessibility: The Swedish Association for the Rights of Persons with Disabilities has developed guidelines on accessibility at funerals, which provide information on how to make funeral services accessible to people with disabilities

Funeral etiquette: The Swedish Church has developed guidelines on funeral etiquette, which provide information on proper behaviour and conduct during funerals

These policies and guidelines aim to provide guidance on how to organize and conduct funerals in a respectful and meaningful manner, in light of environmental, religious, cultural and personal considerations.

Succession planning

Succession planning is important because it can help ensure that a person's estate is distributed according to their wishes, minimize taxes to be paid by heirs, protect the estate, and ensure that health care wishes are respected. In addition, it can help reduce the stress of loved ones and avoid family conflicts.

Here are the legal and political frameworks of each partner country participating in this project.

Belgium

Legal Framework

In Belgium, succession planning is governed by the Civil Code and the law of 31 July 2017. This law fundamentally reformed the succession system in Belgium, introducing, among other things, the possibility of planning for inheritance during one's lifetime.

Succession planning can take different forms, such as the drawing up of a will or a donation between spouses. The rules relating to these different forms of succession planning are laid down in the Civil Code and may vary according to an individual’s personal and family situation.

The 2017 Act also introduced a family wealth protection mechanism, which allows spouses and cohabiting partners to protect part of their wealth for their direct descendants. This protection can take the form of a legacy in favour of the descendants or a shared donation.

In the event of a dispute between the heirs, the Civil Code provides for rules of common law for the division of the estate. If the heirs are unable to reach an agreement, a notary may be appointed to affect a judicial division.

In short, succession planning in Belgium is governed by legal provisions that offer individuals various ways to organize their assets in advance. The Civil Code sets out customary law rules for the division of inheritance, while the 2017 law introduced new rules to protect family assets.

Political Framework

The policy framework for succession planning in Belgium focuses mainly on promoting early succession planning. The Belgian Government encourages citizens to organize their inheritance in advance to avoid family conflicts and the high costs of an unprepared succession.

To facilitate estate planning, the government has put in place measures such as providing information and guides on the various planning options, as well as tax reductions for lifetime donations.

The government also encourages the use of mediation to resolve family disputes related to inheritance. Mediation is a dispute resolution process that allows the parties to reach a mutually satisfactory agreement without going to court.

In addition, the protection of family property introduced by the 2017 law aims to secure the interests of direct descendants and preserve family assets for future generations.

Finally, the Belgian succession planning policy aims to ensure a certain fairness in the distribution of assets between heirs. The Civil Code provides rules on the distribution of inheritance according to the relationship and personal situation of the heirs.

In summary, the Belgian policy framework for succession planning focuses on promoting advance planning, encouraging mediation to resolve family disputes, and protecting family property. The rules for the distribution of an inheritance aim to ensure a certain equity between the heirs.

Italy

Legal context

Succession planning in Italy is largely governed by the civil code.

The inheritance can pass:

- by means of a will
- by law, in the absence of a will

Planning can also begin during a person's life by making donations, which in the Italian legal system is considered an advanced disposition of inheritance.

In fact, the estate to be distributed to heirs at the time of death is the value of the deceased's assets, less any donations already made and outstanding debts

In Italy, except in severe cases, spouses, ascendants, and descendants must have at least part of the inheritance, varying according to who and how many of them are alive at the time of succession. This part may represent up to 3/4 of the estate to be inherited.

When inheritance debts are greater than the applicable credits, the civil code allows for "*reserved acceptance*" of the inheritance, (*beneficio d'inventario*), where a beneficiary's liability for the deceased's debt is capped at the actual amount inherited.

This kind of acceptance is obligatory for incapacited people.

Trust funds are a recognized tool in Italy but are not regulated by national law. Despite numerous bills on the subject, the legal system is still deficient in the civil regulation of trusts. Nevertheless, they are in use thanks to the adoption of the Hague Convention (1 July 1985), effective from 1 January 1992. This is a multilateral treaty in which signatory States have established common legal provisions related to the recognition of trusts.

The law to be applied is chosen by the settler ('*disponente*') within the jurisdictions that provide regulation of the trust. Where this is not the case, the trust is regulated by the law with which it maintains the closest ties.

The trust is sometimes used as a property planning tool for people with disabilities due to its tax treatment.

Law No. 112 of 22 June 2016 (the so-called "After Us" Act) provides for exemption from inheritance and gift tax for property and rights placed in a trust fund or encumbered by a destination restriction, and for those earmarked for special funds established for persons with severe disabilities.

Portugal

Legal Framework

In Portugal, the legal framework in relation to the management of assets and wills of patients at the end of life is regulated by the Civil Code and the Law for the Protection of Persons with Disabilities. The Civil Code, in Article 2021, allows a person in full use of their mental faculties to dispose freely of their property after death, by means of a will.

The will can be made orally, in writing, or through a closed will, and must respect certain formalities provided for by law.

However, the Law on the Protection of Persons with Disabilities, in Article 89, provides that such individuals, including those who are terminally ill, may have restrictions on their legal capacity. In such cases, the management of the estate and the will may be subject to judicial supervision or the appointment of a guardian or trustee to exercise legal representation of the person concerned.

In addition, the Palliative Care Act, passed in 2011, establishes the right of terminally ill patients to receive quality palliative care aimed at alleviating suffering and improving their quality of life. This care must be provided in an adequate and humane manner, respecting the will and dignity of the sick person, in anticipation of the management of their estate.

In summary, in Portugal, the management of assets and wills of terminally ill patients is regulated by the Civil Code and the Law for the Protection of Persons with Disabilities, and the will of the sick person must be respected, provided that they are in full use of their mental faculties and / or their will has been expressed in advance in writing.

Political Framework

In Portugal, the management of assets and wills of terminally ill patients is regulated by various laws and legal norms. First, the Portuguese Constitution provides for the right to health protection and the guarantee of access to health care, as well as the right to personal integrity and private autonomy. These rights are fundamental to the protection of patients at the end of life, and for ensuring that they can make their own decisions regarding the management of their assets and property.

Portuguese legislation also contains measures to protect these patients, such as the legal representative or guardian in cases where patients cannot make their own decisions. In addition, the law allows terminally ill patients to make a will, in which they can arrange for disposal of their assets after their death.

However, it is important to note that the management of assets and wills of terminally ill patients can be a controversial topic, especially in cases where there are family conflicts or divergent interests. In such cases, it is important that the rights and wishes of the patient concerned, and the applicable legal rules, are respected, and that there is fair and adequate management of their assets.

Sweden

Legal Framework

In Sweden, succession planning for the end of life is governed by a number of laws and regulations, including the Succession Code (Ärvdabalken) and the Health and Medical Services Act (Hälso- och sjukvårdslagen).

The Succession Code sets out rules for the distribution of a person's property after his or her death, including provisions on inheritance and wills. The code provides for a person's assets to be distributed

according to certain rules in the absence of a valid will. The code also defines the rights of surviving spouses, children, and other relatives in relation to inheritance.

In addition to the Succession Code, the Health and Medical Services Act regulates end-of-life care in Sweden. This includes provisions for advance planning of care, which allows individuals to make decisions about their medical treatment and end-of-life care in advance. The law also defines the rights of patients to receive palliative care, which aims to improve the quality of life of people with life-limiting diseases.

The laws on succession planning for people at the end of life in Sweden aim to ensure that they have the opportunity to make informed decisions about their care, and that their assets are distributed according to their wishes after their death.

Policy Framework

In Sweden, there are various guidelines and policies related to estate planning for people at the end of life. Some of these include:

Advance care planning: The National Health and Wellness Board has issued guidance on advance care planning, which encourages individuals to make decisions about their medical treatment and end-of-life care in advance. The guidelines recommend that healthcare professionals facilitate these discussions with patients and provide information on available options

Palliative care: The National Council on Health and Wellness has also issued guidelines on palliative care, which emphasize the importance of providing a holistic service that meets the physical, emotional, and spiritual needs of the patient. The guidelines recommend that healthcare professionals work closely with patients and their families to develop individualized care plans that meet their specific needs

End-of-life decision-making: The Swedish Association of Local Authorities and Regions (SALAR) has developed guidance on end-of-life decision-making, which advises health professionals on how to deal with complex ethical issues that may arise in end-of-life care. The guidelines highlight the importance of involving patients and their families in decision-making and ensuring that their wishes are respected

Wills and succession planning: The Swedish Bar Association provides information and guidance on wills and succession planning. They recommend that people consult a lawyer to ensure that their wishes are legally binding, and that their assets are distributed according to their will after their death

These guidelines and policies aim to ensure that end-of-life care and estate/succession planning are approached with sensitivity and compassion and that the patient's rights and wishes are respected.

4. Conclusions

In general, reflecting on the legal and political frameworks of each partner country of this project, it is possible to identify a number of differences, most likely associated with cultural nuances and the level of development.

However, it is also clear that the legislation of each partner is based on previously existing international and/or European standards and directives.

This support document has the sole purpose of being an informative guide, and each person should look to the legislation in force in their own country.

Informed choices lead to more conscious decisions, as well as ensuring that a person's wishes can be fulfilled and sustained according to the laws of their own country.

Hold My Hand

...at the end of life