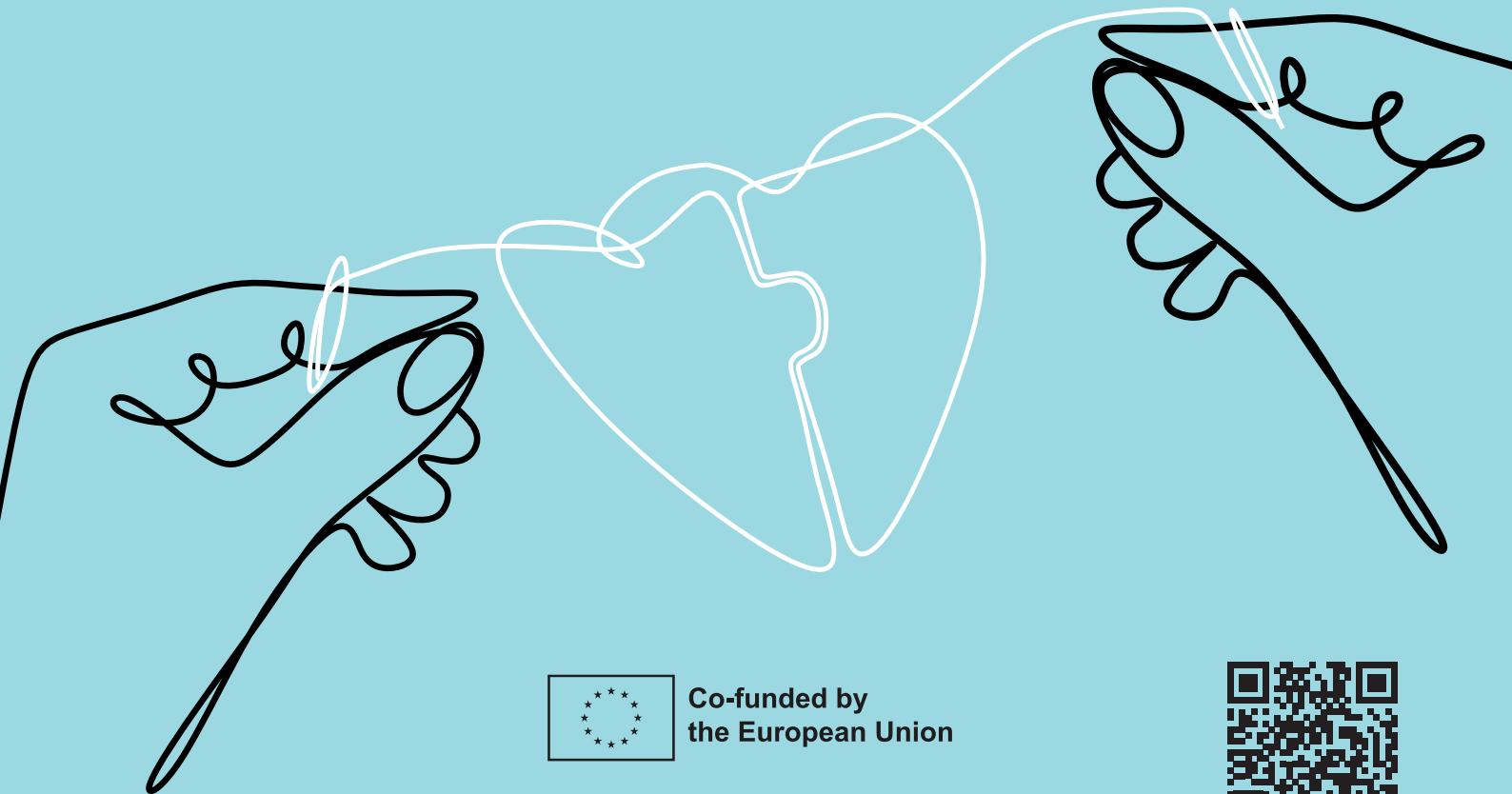




A GUIDE TO CONSCIOUS ANTICIPATION OF END-OF-LIFE

Synthesis Guide



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Introduction

Death is an inevitable part of life yet remains a taboo topic in many cultures and societies. The fear, discomfort, and stigma associated with death often prevent open and honest conversations about this universal human experience. However, overcoming these taboos is crucial for fostering healthy attitudes and practices related to death and dying.

Breaking the taboos surrounding death is a gradual process that requires collective effort from individuals, communities, and institutions. By normalizing conversations about death, through education, challenging cultural and religious beliefs, encouraging advance care-planning, fostering grief-support and embracing alternative funeral practices, we can create a more open and compassionate approach to death and dying. Ultimately, loosening these taboos can lead to a healthier, more informed, and more accepting relationship with this natural part of the human experience.

Anticipating end-of-life issues and planning for the future can be valuable at any age, as it allows individuals to have control over their healthcare decisions, ensure their wishes are respected, and prepare for the eventualities that may arise.

Individuals can engage in advance care planning, regardless of age. This includes creating a living will, naming a healthcare proxy, and discussing preferences for medical care and interventions. It's never too early to have conversations with loved ones about end-of-life wishes and to document those wishes in legal documents to ensure they are honoured.



This document is a support tool to help you anticipate and reflect on end-of-life issues

The guide you are reading was produced within the framework of the Erasmus + *Hold My Hand* project. For more information, see the project description on page 19.

It highlights eight themes linked to the anticipation of end-of-life issues.

- Talking about death with loved ones
- Advance care planning
- Estate planning
- Preparing for the end of life & its practicalities
- Spiritual needs related to the end of life
- Funeral wishes
- Anticipatory grief & living grief
- Dignity, empathy & humility

Pictograms will guide you through the document:



LEGAL + POLICY FRAMEWORK
More information if you click on pictogram



HELPFUL TIPS



FOCUS OF ATTENTION

GOOD PRACTICES

For each theme, you will find best practices (information tools, documents to fill in, videos, etc.) presented in a box of this type.

For each best practice, a flag indicates the language available.

QR codes give you direct access to these tools.

Two reference documents (available on our website: www.hold-my-hand.eu) can help you go further and find more information:

- Legal and policy Frameworks
- Collection of good practices

This guide is an information document and does not replace the advice of specialists such as doctors, lawyers, notaries, etc.

Key concepts surrounding the end-of-life

CONSCIOUS ANTICIPATION OF END OF LIFE

This refers to the deliberate and thoughtful process of preparing oneself psychologically, emotionally and materially for one's own death. This involves becoming aware of mortality, reflecting on one's wishes and preferences for end-of-life care, and planning one's wishes regarding medical decisions, financial arrangements and funeral arrangements. The aim of this approach is to enable a more peaceful death that respects personal dignity, while relieving the emotional and logistical burden that can fall on loved ones.

INTROSPECTION ABOUT END-OF-LIFE

Introspection about the end of life involves deep personal reflection and examination of one's thoughts, emotions, and beliefs. It is a process of exploring and gaining insight into one's fears, hopes, desires, and values as they relate to this universal experience.

HEALTH CARE ADVANCE DIRECTIVES

These are legal documents that allow a person to state in advance the health care decisions they would accept or refuse. These decisions only come into effect if the person is unable to communicate their own wishes. Different countries may have differing procedures to register these documents.

TRIALOGUE

This refers to a three-way collaborative conversation or discussion between patient, family, and medical staff. It typically takes place in healthcare settings and aims to facilitate open communication, shared decision-making, and a mutual understanding regarding the patient's care, treatment, and overall well-being.

LIFE STORY

This is a narrative or personal account of an individual's life experiences, memories, and significant events. It encompasses the individual's unique journey, values, relationships, and accomplishments, providing an opportunity to reflect on their life's meaning and legacy.

HEALTHCARE PROXY

A legal document that designates one person to make medical decisions on behalf of another in the event that they become unable to make decisions for themselves. The appointed healthcare proxy has the authority to advocate for the individual's medical treatment preferences and to ensure that their wishes are respected.

BREAKING TABOOS ABOUT DEATH

This involves challenging and dismantling the norms and beliefs that surround death, encouraging open conversation, and addressing the silence and discomfort often associated with the subject. It involves promoting awareness and the understanding of death as a natural part of life, allowing for more meaningful discussions, improved care, and better end-of-life support for individuals and their families.

EUTHANASIA

This is the act of deliberately ending the life of a person suffering from an incurable or painful disease at his or her request. In Europe, euthanasia is currently legal in six countries: Belgium, the Netherlands, Luxembourg, and more recently Germany, Spain and Portugal

ESTATE PLANNING

This is a process aiming to set up a plan that establishes what happens to one's assets and obligations after death. It also clarifies how a person wants their affairs to be handled in the event they are unable to handle them on their own for any reason.

WILL

A Will is a legally binding document that makes clear a person's wishes for the distribution of their assets and wealth after their death. Legislation varies from country to country, and there are many different types of will and regulations concerning the assets that may be distributed and to whom.

FINAL DISPOSITION

This term refers to what should happen to a person's remains after they have died. It includes the method of disposition chosen, such as cremation or burial, and other associated issues such as the scattering of ashes or in-ground burial. It might also include other aspects of farewell rituals and ceremonies, linked perhaps to religious or personal beliefs.

PALLIATIVE CARE

The holistic care of patients with advanced, progressive or incurable illness. It focuses on the management of pain and other distressing symptoms, and the provision of psychological, social, and spiritual support to patients and their families. Palliative care is independent of diagnosis or prognosis and can be provided at any stage of a patient's illness, not just in the last few days of life. The objective is to help individuals live as well as possible until they die, and do so with dignity.

END OF LIFE

Patients are deemed to be 'approaching the end of life' when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive or incurable illnesses; those with general frailty and co-existing conditions; those at risk of dying from a sudden acute crisis due to an existing issue, and those with life-threatening conditions caused by sudden catastrophic events.

RESPIRE CARE

Temporary relief and support for caregivers of individuals with serious illnesses or at the end of life. Respite care allows caregivers to take a break while ensuring the patient's needs are still met.

THOSE CLOSE TO THE PATIENT

Anyone nominated by the patient, close relatives (including parents if the patient is a child), partners, close friends, paid or unpaid carers outside the healthcare team, independent advocates or others who are interested in the patient's welfare. It may include, in some circumstances, attorneys for property and financial affairs and other legal proxies.

BEREAVEMENT

This refers to the period of mourning and grief that follows the death of a loved one. It involves emotional, psychological, and social reactions to the loss, and the adjustment to life without the deceased.

FUNERAL AND RITUALS

Funerals and rituals are cultural and social practices that honour and commemorate the deceased. These ceremonies can vary based on cultural, religious or personal beliefs, providing an opportunity for family and friends to gather, pay respects, and support one another.

LEGACY AND REMEMBRANCE

Legacy refers to the impact a person leaves behind, whether it be through accomplishments, relationships, or contributions to society. Remembering and honouring the deceased person's legacy can bring comfort and provide an ongoing connection to their memory.

CONTINUED BONDS

The concept of continued bonds recognizes that relationships with the deceased can continue even after death. This may involve maintaining connections through memories, rituals, storytelling, or other symbolic practices, fostering a sense of ongoing connection and support.

GRIEF JOURNEY

This is the personal journey of mourning and healing after the loss of a loved one. Bringing with it a range of emotions, it means adapting to life without the deceased, and finding ways to remember, honor, and integrate this loss into one's life.

Talking about death with loved ones

Talking openly about death is not morbid, but rather a courageous act that shatters the taboo surrounding it. It allows for meaningful conversations, fosters understanding, and encourages preparation, leading to a healthier relationship with mortality. - Caitlin Doughty



- Consider using a dedicated tool (such as cards or a booklet) to help you with introducing the issue to your family
- You can decide not to talk about death if you don't feel comfortable with doing so
- Choose the right time and place. Avoid discussing death during emotionally charged situations or when there are distractions
- Be empathetic, patient, and respectful of others' feelings and perspectives. Use sympathetic language and tone to convey your thoughts and concerns
- Take the initiative to start the conversation. Express your intentions in a calm and straightforward way. For example, you could say, "I've been thinking about our future and want to discuss my end-of-life wishes with you"
- Listen and encourage questions
- Share your wishes. Be specific and detailed and consider putting them in writing, such as in a living will or an advanced directive
- Respect differences. Understand that your loved ones may have different opinions or beliefs about death and end-of-life care

The Conversation Project

This booklet is dedicated to helping individuals have conversations with the important people in their lives about their wishes for end-of-life care. It is a very practical tool, offering step-by-step instructions and forms to fill, and can be printed or filled-in online.

Institute for Healthcare Improvement



À vrai dire - "To tell the truth"

This is a card game containing thirty-seven "wish" cards and one "free" card concerning end-of-life wishes. It can be used alone or with other people, during or outside the context of an illness. It aims to help participants identify their end-of-life preferences and to begin or facilitate discussions with other people, friends, relatives or carers.

Palliative care platform of Namur



Dying Matters

This is Hospice UK's flagship national campaign. Working in partnership with grassroots communities around the UK, it aims to get people talking and sharing stories openly about dying and grief, so as to reduce the associated stress, stigma, and social isolation. There are many resources such as:

- 'Things to do before you die'
- 'Supporting bereavement'
- 'Let's talk about dying'
- 'Talking about dying with people affected by dementia'
- Talking about dying with children'

Hospice UK



Life story

The life story is not only a story of what happened, but also a story of what was meaningful to us. - David Epston

- Consider writing down the most significant aspects of your life you would like to pass on to your heirs
- You can use the 'questions' document to help you. (Check good practice below)
- You can write your life story by yourself or with the help of a relative or professional
- You do not have to answer every question or explain all aspects of your life – the choice is yours
- Writing your life story takes time. Be ready for multiple sessions



Lifetime Legacies: Life Review-Questions

These "Life Review- Questions" will help you to start writing your life story, with prompts ranging from Childhood, Adolescence, and Adulthood, to Older Adulthood and other General Questions.

Continua Hospice Learning



My Life booklet

Document containing both administrative and legal data and a form on the person's life. The second part is an invitation to introspection, which will facilitate the dialogue with your relatives and will also allow you to share a little of your story (Your values, important events, your personality, ...)

Énéo



Advance care planning

Advance directives are a way to ensure that the healthcare choices we make reflect our values and preferences even when we are unable to make our own decisions. They are a way to plan ahead and make our wishes known before we face a medical crisis. - Barbara Coombs Lee



The European Union states that patients have the right to receive adequate and effective palliative care in any Member State. The European Health Committee has highlighted the need to integrate this palliative care with the psychological and spiritual aspects of patient care and to provide support for the family. However, concerning advance care planning there are many difference between laws among the European Union Countries.



- You can refuse care
- You can always change your mind and/or modify your anticipated directives
- Doctors must give you all the information (effects and potential consequences)
- Your anticipated directives will be used ONLY if you are no longer able to express your wishes
- Share your anticipated directives with your relatives or caregivers, and let them know who you appoint to represent you ("trusted person")
- Tell your relatives where you keep your advance directives



The right to palliative care is acquired in the 4 partner countries. BUT euthanasia is only legal in Belgium (since 2002) & is in process of legalisation in Portugal (2023). The documents for advance directives are therefore different between countries.

Representative



The proxy is a person who represents you when you are no longer able to exercise your rights. You can appoint your representative in advance, otherwise the courts will appoint one for you. The criteria for these appointments may vary from country to country.

Advance directives for post-death

You can make advance directive for :

- Donating your organs
- Donating your body to science

Organ donation is a remarkable opportunity to give the gift of life to others, leaving a legacy of compassion and generosity that transcends our own mortality. Dr. Thomas Starzl



In the 4 partner countries (IT, BE, PT, SW) there is a presumed commonality regarding organ donation. If someone does not want to donate their organs, they can register as a non-donor. Equally, they may wish to register as a donor in order to support their choice and to avoid opposition from the family. Remember:



- To be sure that your will is respected, it is best to register officially as a donor ('donation register')
- You can always change your mind
- Communicate your wishes with your family

The Anticipated Life and Care Project (PAVS)

The PAVS contains the essential details of the patient's care plan on one double-sided page, and is intended to be a tool for conveying information from one institution or care centre to another. In the event that residents are unable to express themselves, this tool allows the nursing staff to ensure a consistent follow-up, and to respect their wishes.

UNESSA



Anticipated Directive of Will (DAV)

The DAV in the field of health care is the document whereby people of legal age and sound mind can freely register in advance the health care that they want or do not want to receive in the event of physical or mental incapacity, or of being near death.

Health Regulatory Authority



How to make your advanced directives

A short, animated video explains advanced directives in very simple terms, their importance, advantages, and how they can be implemented according to Italian law.

Associazione Luca Coscioni



Estate planning

Making a will is a crucial step in ensuring that your legacy is preserved, your loved ones are protected, and your wishes are respected. It is a responsible act of preparation that reflects your commitment to planning for the future and taking care of those you leave behind. - Suze Orman



Each country has a specific legal framework covering estate planning and succession. It is important to be aware of the applicable rules & the level of protection for legal direct heirs in each country.



- Ensure that your estate plan & will respect the formalities of your country
- Anticipating issues with your heirs could help avoid family conflicts
- Discuss the rules of succession with your heirs.
- Be aware that if you make a will, there are rules of obligation for heirs
- When your heirs receive your inheritance, it also includes your debts. Your heirs can disclaim the inheritance to avoid your debts
- Regularly review and update your estate plan if your circumstances change
- Seek professional help to make sure your estate plan & will are comprehensive, legally sound and aligned with your goals

And after me ... Instructions to my relatives

This 24-page booklet is a list of instructions to be left to your relatives. It is divided into 8 sections:

- My identity
- Organising my funeral
- People to be informed
- My family
- My assets
- What I have recently received or given
- My last wishes
- Resource persons for the liquidation of my assets
- Additional asset data.

One of the aims of this document is to facilitate the drafting of your declaration of inheritance & the liquidation of your estate.

Notaire.be



Your will-planning worksheet

This booklet will help you to note down important information and questions before seeing a legal conveyancing professional & drawing up your will.

- Simple will planner
- Work out the value of your estate
- Decide who you'd like to provide for
- If you have dependent children, choose guardians
- Make a note of any question

British Red Cross



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End-of-life practicalities

There are some aspects that people forget to think about when anticipating the end of their lives.



- Have you considered documenting important contacts, contracts or accounts?
 - What are your preferences regarding privacy?
 - Are there certain things you'd prefer people not to find after your death? (personal diaries, documents, correspondence or belongings)
 - Do communicate your wishes regarding privacy and confidentiality to someone you trust
 - How should your digital presence be handled after your death?
- You can ask estate administrators to ensure that your digital assets and accounts are managed according to your preferences

Life book

An easy and safe way to record the practical details of your life. In this booklet, you can write important and useful information about your life, ranging from who insures your car to where you store your passport and other important documents. In case you need someone to sort things out for you, having everything they could possibly need in one place will help keep things simple.

Age Concern



See The good practice
"My Life booklet" Page 7

Döstädning – Death cleaning


This is a Swedish practice designed to help individuals prepare for their eventual death. It deals with getting rid of all the stuff we have accumulated that we may no longer need, so that no one else has to do it for us after we pass. It includes for example reflecting on what we still need and what can be donated or sold. It is a gradual process that can help us to start thinking about and planning for our own deaths. Moreover, an important part of "Death Cleaning" is involving others and it becomes a good time to share with our families what we would like to happen after our passing.

The practice started to be popular beyond Sweden after the publication of a book in English named "The Gentle Art of Swedish Death Cleaning: How to Free Yourself and Your Family From a Lifetime of Clutter" written by Margareta Magnusson.



Spiritual and philosophical issues related to the end-of-life

It is important to remember that spirituality is a personal and unique experience, and there is no right or wrong way to explore it. Trust your own spiritual journey and choose the resources and approaches that best resonate with you. Don't hesitate to seek help from professionals or spiritual guides if you feel the need.

 The World Health Organization & the European council highlights the importance of providing psychological, emotional and spiritual support for patients and families.

The European Association for Palliative Care (EAPC) define Spirituality as 'the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.'

Spiritual Needs Questionnaire

This is a questionnaire to help identify spiritual needs and provide appropriate support and assistance to those who complete it. The thirty questions are divided into four main areas: Religious needs, Existential needs, Inner Peace needs, and Giving needs.

Herdecke University



H.O.P.E Questions

The HOPE questions cover the basic areas for spiritual assessment. 'H' pertains to a patient's basic spiritual resources, such as sources of hope, without immediately focusing on religion. 'O' and 'P' inquire about the importance of organized religion in patients' lives and the specific aspects of their personal spirituality and practices that are most helpful. 'E' pertains to the effects of a patient's spirituality and beliefs on medical care and end-of-life issues.

Brown University



Funerals wishes

Funerals are a ritual of transition that mark the passage from the realm of the living to the realm of the dead. They are a time for reflection, contemplation, and reconciliation, a moment to confront our mortality and celebrate the legacy of those who have gone before us. - Aristotle



The European Convention of Human Rights guarantees the right to choose the funeral ceremony that best suits the belief and traditions of individuals & families.



- If you wish, you can organize everything yourself with a funeral director or leave the planning to your loved ones
- If you have a funeral contract, inform your relatives
- If you have any special wishes for your funeral arrangements, don't forget to let your family know

Funeral and farewell wishes

This worksheet is designed to stimulate users to think of the kind of funeral and farewell they might like; and ensure that those who may be responsible for the events know their wishes. It includes a checklist of aspects which can be taken into account when planning for a funeral, such as financial arrangements, burial options, rituals and ceremonies.

Hearth and soul funerals



Children and funerals

This brochure was written to help families think about children when a funeral is planned, why they should have the opportunity to attend and how to answer some of their questions. Parents and caregivers want to do the right thing for their children, but it can be difficult to know what is best for them when a death occurs. This tool is a practical guide for families, professionals and anyone caring for a child who may be going through a grieving process.

St. Christopher's Hospice



Anticipatory grief & living grief

Anticipatory grief occurs before death – either one's own, or the anticipated death of a loved one.

Anticipatory grief is the profound sorrow arising when we are faced with the imminent loss of a loved one. It is a unique form of grieving that allows us to process and prepare for the inevitable, while navigating the complex emotions that arise as we anticipate the future without our beloved. - Alan Wolfelt



- Allow yourself to feel and express the emotions that arise, whether it be fear, sadness, anger, or confusion
- Surround yourself with a supportive network (loved ones, friends, therapist)
- Take time to reflect on your life, your values, and your legacy. Consider writing down your thoughts, memories and wishes
- Take care of your physical, emotional, and mental well-being. Make sure to prioritize self-care by eating well, getting enough rest, engaging in activities that bring you comfort, and seeking professional help if needed
- Practice Mindfulness to help you manage anxious or distressing thoughts about the future. Try relaxation techniques, such as meditation or deep breathing, to help you stay grounded in the present

Remember that anticipatory grief is a unique and individual experience, and it is OK to cope with it in your own way. Give yourself the space and grace to process your emotions and seek support when needed

Tutorials for Informal Caregivers in Pediatric Palliative Care

19 tutorials designed to support informal caregivers of children in paediatric palliative care. The fifth module is about Management of grief and loss. This is an informative and educational tool, simple and playful in character, promoting and facilitating the family's involvement in the provision of health care.

Attitude - Social Solidarity Association



Dignity, empathy & humility

Dignity, humility, and empathy are crucial principles in palliative & end-of-life care.

Preserving dignity involves recognizing and respecting the unique worth, autonomy, and self-identity of each patient, regardless of their health. It involves treating them with respect, compassion, and sensitivity, and valuing their beliefs, values, and choices. Dignity also includes maintaining patient privacy, confidentiality, and autonomy in decision-making, even in the face of difficult choices about care options or end-of-life decisions.

Empathy is the ability to understand and share the emotions of others. It helps caregivers see the world through the eyes of their patients, and to respond with compassion, kindness, and understanding. It involves active listening, showing genuine concern, and providing emotional support.

Humility is the recognition of one's own limitations and a willingness to learn from others. In palliative care, humility involves acknowledging that patients and their families are experts in their own experiences, needs, and preferences. It means listening actively and attentively to patients, their families, and the interdisciplinary team, and valuing their input in the care planning process.

Practicing humility in palliative care fosters a collaborative and patient-centered approach, where the care team works in partnership with patients and their families to provide the best possible care.

Dignity Therapy at End-of-Life

To assist people dealing with the imminent end of their lives. This brief intervention can help preserve the dying patient's sense of dignity by addressing sources of psychosocial and existential distress. It gives patients a chance to record the meaningful aspects of their lives and leave something behind that can benefit their loved ones in the future. Dignity Therapy (DT) is a brief, individualized, narrative psychotherapy developed to reduce this distress, and promote dignity, meaning, and hope in end-of-life patients.

Dignity in Care



e-platform presentation

Within the framework of the project, an e-learning platform composed of 5 modules has been created in order to familiarize the adult population and (non-)professionals with the themes of Accompaniment, Awareness and Anticipation of the end of life, whether this be near or far. The training modules follow a lifelong-learning approach and are available in the 4 partner languages (FR, IT, PT, SW) as well as in English.

5 Modules

LET'S TALKABOUT DYING.

IN ANTICIPATION..... OF DEATH

HOLD MY HANDAT THE END OF LIFE

POST.....DEATH

ROLE OF PROFESSIONALS

Hold my Hand project

In the 20th century, the notion of death and dying became a symbol of medical failure and taboo. More recently, ageing populations and the Covid-19 health crisis have highlighted a need to reappropriate issues related to illness, suffering and the end of life. The Hold My Hand project aims to share, discuss, debate, and educate on issues related to anticipating and raising awareness about the end of life.

Hold My Hand is a project co-funded by the Erasmus + programme and involving 4 European partners from Belgium, Italy, Portugal and Sweden. The duration of the project is from November 2022 to the end of October 2024.

Project objectives :

- To work on the development of a culture addressing the issue of end-of-life support with full awareness
- To produce socio-pedagogical tools for the adult population in order to help them address the issue of the end-of-life with their families and health professionals
- To facilitate the transmission of information between the person at the end of life, their relatives and care institutions.

Target groups:

- Adult population
- Relatives likely to be involved in accompanying people/patients at the end of their lives
- (Non-)professionals from social or medical backgrounds likely to be called upon in the context of accompanying people/patients at the end of their lives
- (In)formal carers likely to be involved in accompanying people/patients at the end of their lives

<https://hold-my-hand.eu/>



Some Useful addresses & contacts

BELGIUM

Portail des soins palliatifs de Wallonie

<https://www.soinspalliatifs.be/>

federation@fwsp.be

Fednot: Fédération Royale du Notariat belge asbl

<https://www.fednot.be/>

www.notaire.be

fednot@fednot.be

Association pour le droit de mourir dans la dignité

www.admd.be

info@admd.be

CEFEM Asbl

<https://cefem.be/>

info@cefem.be

ApSoDe

<https://apprivoisersondeuil.be/>

apprivoisersondeuil@gmail.com

Solidarité fin de vie

www.solidaritefindevie.be/

contact@solidaritefindevie.be

Ecoute Eveil

<http://ecouteveil.be/>

ecouteveilnamur@gmail.com

Everlife

<https://ever-life.be/>

assistance@ever-life.be



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