

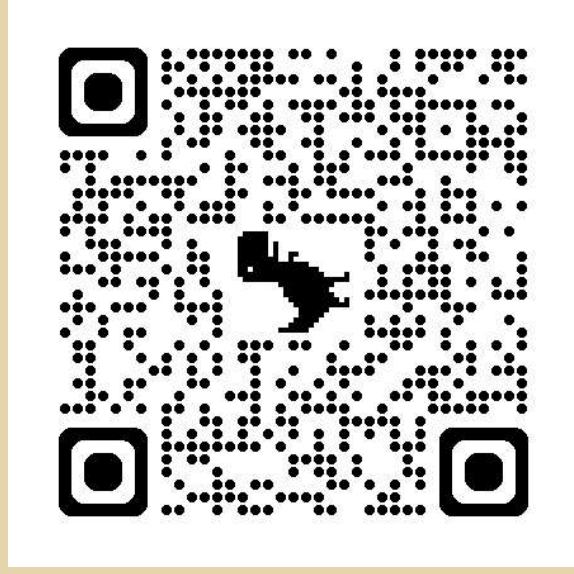
Présentation du guide de synthèse et d'expérience

Licia **Bocaletti** (ANS) – Salvatore **Milanta** (ANS) – Alexandra **Costa** (SCML)



Have a look!

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



WWW.HOLD-MY-HAND.EU



EXPERIENCE SYNTHESIS GUIDE



EMBRACING THE END
AS A NATURAL PART OF LIFE

A Guide to conscious anticipation of End-of-Life



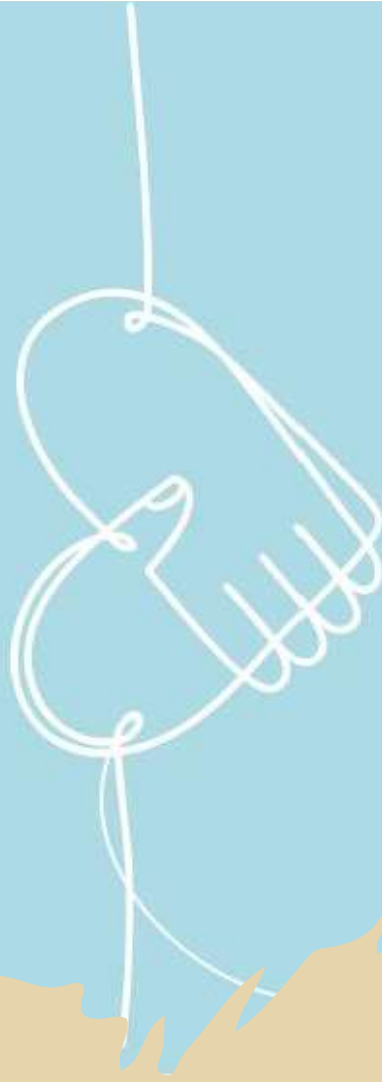
- It is a **support tool** to help readers reflect and anticipate issues related to the end of life

- The guide includes **8 themes** considered relevant for reflection, related to anticipating the end of life

- Associated with each topic, there are **useful tips and good practices**

- It is available in EN-FR-IT-SWE-PT

EXPERIENCE SYNTHESIS GUIDE



EMBRACING THE END
AS A NATURAL PART OF LIFE

Topics

The **8 themes** included in the Guide:

- Talking about death with my loved ones
- Advanced care planning
- Estate planning
- Practical aspects of the end of life
- Spiritual needs related to the end of life
- Funeral Wishes
- Anticipatory grief or living (preparatory) grief
- Dignity, empathy and humility



EXPERIENCE SYNTHESIS GUIDE



EMBRACING THE END
AS A NATURAL PART OF LIFE



Glossary

The Guide includes a Glossary, explaining some key concepts associated with the end of life, such as:

- **Conscious anticipation of the end of life**
- **Introspection about the end of life**
- **Advance health care directives**
- **Tripartite dialogue**
- **Euthanasia...**

And it ends with useful contacts at local level

EXPERIENCE SYNTHESIS GUIDE



EMBRACING THE END
AS A NATURAL PART OF 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



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A GUIDE TO CONSCIOUS
ANTICIPATION OF THE END-OF-LIFE
LEGAL AND POLITICAL
FRAMEWORKS



ERASMUS+ GA N°2022-1-BE01-KA22D-ADU-00008742



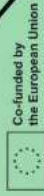
Legal and political frameworks



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



A GUIDE TO CONSCIOUS
ANTICIPATION OF THE END-OF-LIFE
LEGAL AND POLITICAL
FRAMEWORKS



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Legal and political frameworks



For each country, we discuss:

- End-of-life support
- Early Directives after Death
- Representation
- Funerals
- Succession planning



A GUIDE TO CONSCIOUS
ANTICIPATION OF THE END-OF-LIFE
LEGAL AND POLITICAL
FRAMEWORKS



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Legal and political frameworks



...at the end of life

- Basic information for citizens and non-legal experts
- An opportunity to compare own country legal framework with that of the other countries involved



Good practices

18 good practices identified including videos, leaflets / brochures, cards etc... to:

- Get lay-man information about the legislation in place in the country of concern in relation to advanced care planning
- Supporting self-reflections about their end-of-life care wishes and arrangements, discussing them with family members
- Supporting making informed choice about their end-of-life care preferences and write them down to be used by caregivers
- Supporting family members in getting prepared for the death of a beloved ones



A GUIDE TO CONSCIOUS ANTICIPATION OF END-OF-LIFE EXISTING GOOD PRACTICES AND TOOLS



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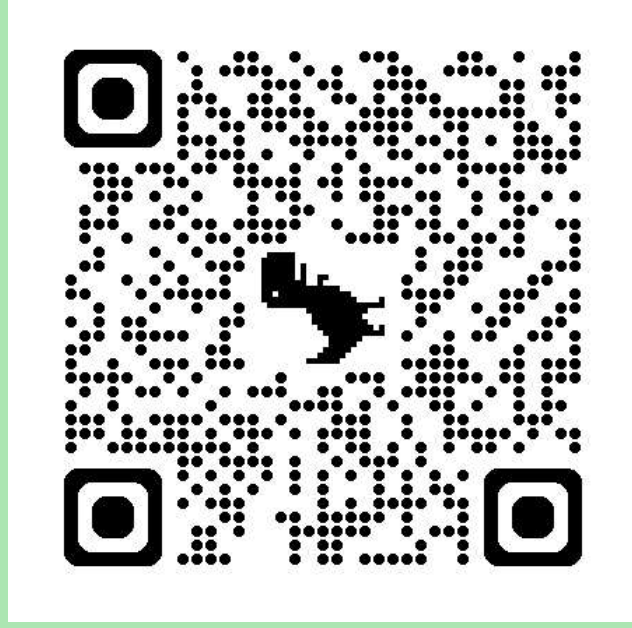
Thematic areas



- Anticipating end-of-life care
- Anticipating practical issues related with end of life
- Estate planning
- Talking about death with loved ones
- Anticipatory grief and living grief
- Funerals
- Dignity
- Spiritual and philosophical issues related to the end of life



Online database



Spiritual needs questionnaire



The questionnaire helps the respondent identifying his/her spiritual needs and to discuss with others how to address them.

Is addressed to persons living with chronic diseases, in older people living in retirement homes, healthy (stressed) persons, and adolescents with chronic diseases and health conditions

Author: Prof. Arndt Büssing, Witten/Herdecke University

Website: <https://tinyurl.com/yvfhvsju>



Life review questions

- Set of life review questions list to help caregivers and nurses to have meaningful conversation with hospice patients.
- The list of questions could also help any person wishing to write his/her life story at any stage of life to anticipate what we leave behind and bear witness to our life experiences.
- **Author:** Continua Hospice Learning
- **Website:** <https://continuaagroup.com/wp-content/uploads/2018/11/Lifetime-Legacies-Life-Review-Questions.pdf>

To conclude

- This WP developed a set of resources aimed to provide to readers basic information in relation to a set of key-areas related with end-of-life anticipation
- The selection of good practices and tools integrates the resources providing concrete examples of methods to support the end-of-life anticipation journey
- These resources integrate and complement the e-learning platform developed in work-package 3
- We rely on your help to disseminate these results and boost their impact!