

Annex

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...at the end of life

A GUIDE TO CONSCIOUS ANTICIPATION OF END-OF-LIFE

EXISTING GOOD PRACTICES AND TOOLS



Co-funded by
the European Union





This document has been developed by the Erasmus+ Hold my Hand partnership:

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2. Introduction and methodology

The project “Hold my hand - HMMH” is funded under the Erasmus+ Programme and it is implemented in four countries: Belgium, Italy, Sweden and Portugal. The project aims to share, discuss, educate around the issues connected with advanced planning in end-of-life care.

The first project result “Experience Synthesis Guide” aims to collect information about the current legal situation in partner countries; good practices and tools that can be further exploited in the project as well as to identify training needs in the field.

More specifically task nr.2 refers to the identification and sharing of materials/tools related to the themes of support and awareness of anticipation of end-of-life care available in partner countries.

To achieve this goal the partnership adopted the following methodology:

- ANS, as leader of this task, developed a methodological guide for the identification and description of each practice
- Each partner organization conducted a desk-research with the goal to identify at least 3 good / promising / best practices¹ referring to awareness rising and/or educational tools targeted to the general population with the goal to inform them about anticipation of end-of-life care and describe them according to a common template.
- The definition we adopted were the following:

Promising practice²: An intervention is considered to be a Promising Practice when there is sufficient evidence to claim that the practice is proven effective at achieving a specific aim or outcome, consistent with the goals and objectives of the activity or program

Good practice³: strategies, approaches and/or activities that have been shown through research and evaluation to be effective, efficient, sustainable and/or transferable, and to reliably lead to a desired result.

Best practice⁴: an intervention, method or technique that has consistently been proven effective through the most rigorous scientific research (especially conducted by independent researchers) and which has been replicated across several cases or examples.

- ANS summarised the results of the research in a summary report

¹ <https://www.homelesshub.ca/solutions/best-promising-and-emerging-practices>

² <https://www.homelesshub.ca/solutions/best-promising-and-emerging-practices>

³ https://ec.europa.eu/migrant-integration/page/what-are-good-practices_en

⁴ <https://www.homelesshub.ca/solutions/best-promising-and-emerging-practices>



3. Summary of research results

Overall, 16 tools have been identified and described by partners.

While the selected tools often address different goals at the same time, we could try to classify them around the following **main purposes**:

- Providing lay-man information about the legislation in place in the country of concern in relation to advanced care planning (practices nr. [1](#) – [2](#) - [18](#))
- Supporting individuals in self-reflecting about their end-of-life care wishes and arrangements, discussing them with family members (practices nr. [2](#) – [4](#) – [5](#) - [10](#) - [11](#) - [12](#) - [13](#) – [14](#) – [15](#) – [16](#) – [17](#) – [18](#))
- Supporting individuals in making informed choice about their end-of-life care preferences and write them down to be used by caregivers (practice nr. [3](#) - [6](#) - [9](#) - [18](#))
- Supporting family members in getting prepared for the death of a beloved one (practice nr. [7](#) - [8](#) - [10](#))

In terms of **thematic**, the practices cover the following topics:

- Anticipating end-of-life care (practices nr. [1](#) – [4](#) - [5](#) - [9](#) - [10](#) - [18](#))
- Anticipating practical issues related with end of life (practices [11](#) - [12](#) - [18](#))
- Estate planning (practices [6](#) – [14](#))
- Talking about death with loved ones (practices nr. [2](#) – [4](#) – [5](#) - [10](#))
- Anticipatory grief and living grief (practices [8](#) – [10](#))
- Funerals (practices nr. [7](#) - [15](#))
- Dignity, empathy & humility (practices nr. [2](#) - [3](#))
- Spiritual and philosophical issues related to the end of life (practices nr. [13](#) - [16](#) - [17](#))

These experiences are based on different means such as videos, leaflets / brochures, cards, note-book to be completed on line of in paper.

Authors of the tools are mostly NGOs, professional organizations or health-care providers.

Although this was not the aim of our research, it is interesting to mention that during the research process, partners also came across the concept of “bad practice”, meaning behaviours which are performed repeatedly although not providing positive results.

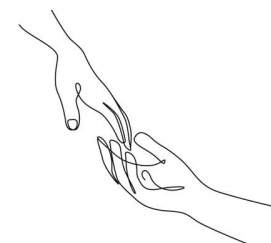


4. Detailed descriptions of collected good practices



1. How to make your advanced directives

Title	“Maramao perché sei morto?” [Literally: Maramao, why did you die? – it’s the title of a famous Italian song from 1939 by Trio Lescano. The text talks about some kittens desperate for the death of Maramao, a cat they were in love with, and they wonder how such a thing could have happened to a character who had everything he needed for a comfortable life]. Subtitle: How to make your advanced directives
Location	Italy
Organisation(s)	Associazione Luca Coscioni
Website	https://www.youtube.com/watch?v=ePyxL_7xRaY
Available language(s)	Italian with subtitles automatically translated by Youtube
Date of development	January 2023
Type of tool	Digital
Purpose	Awareness rising / information
Topic(s) covered	<ul style="list-style-type: none">✓ what is anticipation of end-of-life care✓ why it is important to think in advance about your end-of-life care✓ what is the legislation in place✓ what are the procedures to formalize your end-of-life care wills✓ what kind of choices you can make in advance
Overview	<p>A video to illustrate the importance of living wills and offer all the information to be able to do it immediately.</p> <p>“Grandfather, do you think you are going to die?” With this question, a little girl, starting from the experience of her cat’s death, involves her grandfather on the subject of the bio-will, and explains to him in a light and delicate way the importance of being able to express one’s choices in advance in terms of health treatments, to prevent others, like her, from having to decide for him.</p> <p>An animated video, simple and clear, and a social communication campaign, to explain to citizens what a living will is, how to do it and where to file a living will.</p>



Reasons for selecting the practice	<p>This short (4 min.) animated video explains in simple terms what is an advanced directive, why it is important, which are the advantages and how it can be implemented according to the Italian legislation.</p> <p>It is colourful and joyful in the music and mood and the voice to the grandfather character was provided by a popular actor, therefore it is recognisable by the audience.</p> <p>It also suggests a way to introduce the topic with family members (linking it to the death of a pet).</p>
Impact	The tool registered 9.732 views so far.
Transferability	Although it makes specific reference to the Italian legal framework, the tool is transferable when it comes to the sections in which it is highlighted the importance of being able to choose how one would like to be cared for and accompanied to death.
Additional info	-
Contacts for further information	<p>https://www.associazionelucacoscioni.it/</p> <p>info@associazionelucacoscioni.it</p>



2. The conversation project

Title	The conversation project - Your Conversation Starter Guide
Location	USA
Organisation(s)	Institute for Healthcare Improvement
Website	https://theconversationproject.org/wp-content/uploads/2020/12/ConversationStarterGuide.pdf
Available language(s)	English, Spanish, Chinese
Date of development	2021
Type of tool	Digital
Purpose	<ul style="list-style-type: none">✓ Form / template✓ Self-reflection tools✓ Guidelines (“how to”)
Topic(s) covered	If and how to discuss this topic with your beloved ones
Overview	<p>This booklet is the first of a series of resources dedicated to help individuals having conversations with the important people in their life about your – or their – wishes for care through the end of life.</p> <p>It suggests questions and prompts to go through:</p> <ul style="list-style-type: none">• What matters to you in life• How you prefer to approach health care issues, now and when you will approach your end-of-life• Identifying with whom and in which context you would like to start a conversation• Suggestions on how to begin the conversation and topics that could be discussed
Reasons for selecting the practice	Starting a conversation about end-of-life care and death is often difficult and somehow embarrassing. It might be useful to be supported in preparing and then starting it.



	<p>The tool is very practical, offers step-by-step instructions, forms to fill, it can be printed or filled-in online and it contains references to other similar tools focusing on issues such as nominating a care proxy or preparing a living will.</p>
Impact	<p>More than 600,000 people, from all 50 states and 160+ countries, have downloaded the Conversation Starter Guide.</p> <p>More than 1,800,000 people have visited The Conversation Project website since its 2012 launch.</p>
Transferability	<p>This tool doesn't make any reference to the specific context of the USA, therefore it is highly transferable. Moreover, it is very simple as it doesn't contain reference to specific medical or care treatments / procedures.</p> <p>The combination of self-reflection questions together with prompt for conversation makes it very practical and useful for anyone intending to prepare him/herself to write own advanced directives.</p>
Additional info	-
Contacts for further information	<p>conversationproject@IHI.org</p> <p>https://theconversationproject.org/</p>



3. Dignity therapy at end-of-life care

Title	Dignity Therapy at End-of-Life
Location	Canada
Organisation(s)	Dignity in Care
Website	https://www.dignityincare.ca/en/dignity-therapy-at-end-of-life.html
Available language(s)	English
Date of development	Information not available
Type of tool	Digital
Purpose	Intervention
Topic(s) covered	If and how to discuss this topic with your beloved ones
Overview	<p>Dignity Therapy was developed by Dr. Harvey Max Chochinov to assist people dealing with the imminent end of their lives.</p> <p>This brief intervention can help conserve 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.</p> <p>Dignity Therapy (DT) is a brief, individualized, narrative psychotherapy developed to reduce psychosocial and existential distress, and promote dignity, meaning, and hope in end-of-life patients. During a 30-to-60-minute session, the therapist asks a series of open-ended questions that encourage patients to talk about their lives or what matters most to them. The conversation is recorded, transcribed, edited and then returned within a few days to the patient, who is given the opportunity to read the transcript and make changes before a final version is produced. Many choose to share the document with family and friends.</p>



Reasons for selecting the practice	This is a psychotherapeutic intervention and, as such, can only be implemented by qualified professionals. On the other hand, the approach it is based on can be helpful for the HMH project purposes since it integrates a reflection on how a person wishes to be cared and accompanied in end-of-life with an opportunity for him/her to think about his/her legacy and ultimately to sustain a sense of meaning, purpose and self-worth.
Impact	The first clinical trial using Dignity Therapy has affirmed the value of this method for patients and families. For example, 91% of patients said they were satisfied or highly satisfied; 86% found it helpful or very helpful. More data available here: https://www.dignityincare.ca/en/dignity-therapy-at-end-of-life.html
Transferability	This is a psychotherapeutic intervention and, as such, can only be implemented by qualified professionals. Nowadays it is applied internationally and therefore practitioners might be found in many different countries.
Additional info	-
Contacts for further information	dignityincare@umanitoba.ca https://www.dignityincare.ca/en/



4. The Anticipated Life and Care Project (PAVS) and its supports

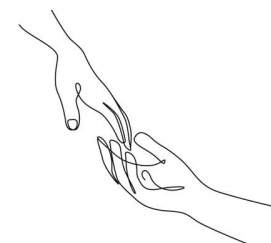
Title	Le Projet anticipé de vie et de soins (PAVS) et ses supports The Anticipated Life and Care Project (PAVS) and its supports
Location	Belgium
Organisation(s)	UNESSA
Website	http://unessa.be/Homepage/Projets/PSPA-(1)/PSPA-Documentation.aspx
Available language(s)	French
Date of development	2021
Type of tool	<ul style="list-style-type: none"> ✓ Digital ✓ Paper format ✓ videos
Purpose	<ul style="list-style-type: none"> ✓ Awareness rising / information ✓ Form / template ✓ Self-reflection tools
Topic(s) covered	<ul style="list-style-type: none"> ✓ what kind of choices you can make in advance ✓ if and how to discuss this topic with your beloved ones
Overview	<p>The Anticipated Life and Care Project (PAVS) was developed by UNESSA, the federation of reception, accompaniment, help and care for people.</p> <p>The PAVS takes up the essence of the Personalized Anticipatory Care Project (PSPA) created by Pallium, the Palliative Care Platform of Walloon Brabant. The PSPA is a "process by which a person, in consultation with his or her relatives and carers, formulates in advance objectives and choices about how he or she would like to be cared for if he or she were no longer able to take care of them. This process can lead to advance directives.</p> <p>The PAVS contains the essential information of the therapeutic project on one double-sided page. This sheet is intended to be a tool for transmitting information from one institution to another, from one care centre to another. In all circumstances, and in the event that the resident</p>



	<p>is unable to express him/herself, this tool allows the nursing staff to ensure a follow-up, among other things, respectful of his/her convictions.</p> <p>These tools should not be considered as administrative documents sensu stricto, they should allow for a dialogue between the patient, his relatives and his carers.</p> <p>A situation is never set in stone, it evolves, a current wish may change in the future, which is why it is important for people who have completed the PAVS to know that they can modify or even delete it at any time.</p> <p>In an ideal world, everyone - who wants to make their wishes and values known in case they are no longer able to express them - should complete a PSPA or a PAVS and not wait until they are in hospital to think about it, as hospital is not the ideal place to do this.</p>
<p>Reasons for selecting the practice</p>	<p>The different materials created around the PAVS are intended to raise awareness, inform, disseminate the philosophy of end-of-life support, and help people on the importance of advance care planning (ACP). The materials are:</p> <ul style="list-style-type: none"> - an animated video that can be shown in a reception hall of an institution, during an awareness-raising session with an audience of elderly people, workers, families, people living in an institution, etc; - information flyers for beneficiaries and professionals - an information poster; - Didactic sheets for professionals accompanying people in the reflection on their end-of-life wishes and the completion of the PSPA and/or PAVS. These sheets explain legislation or therapies in a simple and concise manner. Their themes are by no means exhaustive. The sheets do not replace the dialogue with the doctor and health professionals.
<p>Impact</p>	<p>The Anticipatory Life and Care Project and its tools have been presented at various meetings: internal UNESSA working groups and information sessions, webinars and presentation conferences (hospital sector, mental health, nursing homes, disability, health ministry). These events were attended by doctors, directors of institutions, nurses, social workers, volunteers, palliative care platforms, The aim of these presentations</p>



	<p>was to inform, raise awareness and encourage the above-mentioned stakeholders to implement the philosophy of advance care planning and support by providing them with tools to achieve these objectives. At present, it is not possible to say how many institutions or individuals have already completed their end-of-life wishes.</p>
Transferability	<p>The PAVS is a document that may be of interest to the European project because it contains on one double-sided page the essential elements that health professionals must have at their disposal to take care of a person who is no longer capable of expressing his or her wishes, in order to respect the person's wishes as far as possible. The different sections (administrative data; care plan; end-of-life wishes; wishes for after death) can inspire the HMH project. Nevertheless, it is important to be aware that the PAVS was designed for Belgium, where the regulatory framework for the end of life is governed by various laws dating from 2002 (patient rights, palliative care, euthanasia). It is therefore not possible to take up the PAVS as such, as it needs to be adapted to the different European national contexts. But it can be a source of inspiration.</p>
Additional info	<p>The PAVS is the result of a co-construction carried out with field actors from the different health and support sectors of Unessa: general hospitals, elderly, disability, mental health. It has already been implemented in various places and the feedback is extremely positive. The PAVS fills a real gap in the care of the beneficiary. It allows to highlight the wishes of the person and to consider them in the most holistic way possible. Nevertheless, one should always be cautious with this type of document, which can "freeze" the person at a given moment. This is why we strongly encourage the beneficiary to use this tool with vigilance and to fill in this type of document in dialogue with his/her relatives and carers so that, when the day comes when his/her wishes have to be taken into account, the word of the beneficiary - recorded in the PAVS - can be carried by those who have been close to him/her and who have accompanied him/her in his/her reflection on his/her end-of-life wishes.</p>
Contacts for further information	<p>info@unessa.be therese.hebbelinck@unessa.be</p>

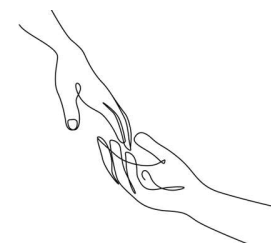


5. AVD

Title	AVD – À vrai dire - "To tell the truth"
Location	Belgium
Organisation(s)	Plateforme des soins palliatifs de Namur
Website	https://www.soinspalliatifs.be/asppn-a-vrai-dire.html
Available language(s)	French
Date of development	2020
Type of tool	<ul style="list-style-type: none">✓ Paper format✓ Card game
Purpose	Self-reflection tools
Topic(s) covered	<ul style="list-style-type: none">✓ why it is important to think in advance about your end-of-life care✓ what kind of choices you can make in advance✓ if and how to discuss this topic with your beloved ones
Overview	<p>"A vrai dire" has its origins in "The GoWish Game", developed by Coda Alliance. The American tool was translated and adapted to Belgian culture and legislation to become the "A vrai dire" tool. It is a card game containing 37 "wish" cards and one "free" card concerning end-of-life wishes. This tool allows for a "third party" approach to end-of-life issues. It can be used alone or with others; during the illness or outside the context of the illness; in training/supervision/place of exchange of words... Its objective is to help the beneficiaries to personally identify their end-of-life desiderata and to initiate/facilitate discussion between 2 or more people, relatives and/or carers</p>
Reasons for selecting the practice	<p>AVD is a tool to tackle the often-difficult topic of the end of life. It seems to us to be a first approach to the essential questions that one must dare to ask oneself when thinking about what one would wish for in the event that one is no longer able to express oneself, and therefore constitutes an interesting prerequisite for the completion of the PAVS. Furthermore, the "card game" format gives an informal aspect to the reflection, which facilitates dialogue between the different protagonists</p>



Impact	<p>In everyday life, this tool is used by people who are ill or not, carers, informal carers, etc. It is most often presented in nursing homes to professionals or to a group of residents, sometimes during "family" evenings in nursing homes. It has also been presented in a medical home, a geriatric Glem (i.e. hospital environment), training courses for the elderly sector, to a group of people (citizens) wishing to draw up their advance directives, to teachers, and to students (nurses and carers) from various universities during courses on communication, ethics, etc.</p> <p>AVD opens the floor, opens the field of possibilities. As previously mentioned, it is a good preliminary to the drafting of advance directives. Moreover, it questions practices, develops ethics, gives meaning to the work, and is a mediator between the different stakeholders.</p>
Transferability	<p>AVD seems to be more easily "transferable" than the PAVS at the European level because the 37 "wishes" stated can "globally" be found in the different geographical areas. It is therefore an interesting source of inspiration for HMM. The "game" aspect is particularly important for addressing painful issues. And the tool makes it possible to act as a "third party" so as not to address painful issues head-on with one's loved ones.</p>
Additional info	<p>It should also be noted that the original tool "The GoWish Game" has been translated into several languages and is used to convey a culture of anticipating end-of-life wishes throughout the world. See https://codaalliance.org/resources-for-all/#flag</p>
Contacts for further information	<p>info@asppn.be https://codaalliance.org/resources-for-all/#flag</p>



6. And after me ... Instructions to my relatives

Title	Et après moi ... Instructions à mes proches And after me ... Instructions to my relatives
Location	Belgium
Organisation(s)	Notaire.be
Website	https://www.notaire.be/famille/la-protection-de-mes-proches/les-declarations-de-volonte-anticipees
Available language(s)	French
Date of development	2020
Type of tool	<ul style="list-style-type: none">✓ Digital✓ Paper format
Purpose	Form / template
Topic(s) covered	<ul style="list-style-type: none">✓ what kind of choices you can make in advance✓ whom you can / should choose to be your proxy / reference person
Overview	<p>24-page booklet to be completed. It is a compilation of instructions to be left to one's relatives. This brochure 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.</p> <p>This booklet, to be completed, aims to facilitate the organisation of your funeral, the drafting of your declaration of inheritance and the the liquidation of your estate. It can be completed alone, with a relative or with your notary. It is important to update these data regularly, according to your wishes or taking into account the evolution of your heritage</p>
Reasons for selecting the practice	It is a concise document and the notaire.be website provides all the information needed to complete the document. It is a reference site in Belgium for notarial matters. This document allows relatives to have all the useful information after the death and to avoid difficulties related to the administrative aspects of the aftermath of the death.



Impact	Briefly elaborate the impact of the tool and results of evaluation (if available)
Transferability	The document is easily transferable to other European national contexts.
Additional info	It is not a will but a supporting document. It is imperative that you do not put this document in your bank safe-deposit box as it is sealed on your death
Contacts for further information	www.notaire.be



7. Children and funerals

Title	Children and Funerals
Location	United Kingdom
Organization(s)	St. Christopher's Hospice
Website	https://www.stchristophers.org.uk/wp-content/uploads/2015/11/StChris_Candle_Children_and_funerals.pdf
Available language(s)	English
Tool type	<ul style="list-style-type: none"> ✓ Digital ✓ Paper format
Purpose	<ul style="list-style-type: none"> ✓ Increased awareness/information ✓ Academic Background ✓ Form / template ✓ Self-reflection tools ✓ Guidelines ("how to do")
Topic(s) covered	<ul style="list-style-type: none"> ✓ what kind of information should be provided to decrease the psychological impact on the child after the death of a loved one; ✓ How to prepare the child for the death/funeral of a loved one; ✓ what are the procedures to prepare a funeral; ✓ what kind of choices you can make when a loved one dies; ✓ if and how to discuss this topic with children.
Overview	This brochure was written to help families think about children when a funeral is organized, why they should have the opportunity to go and how to answer some of their questions.
Reasons to choose the practice	<ul style="list-style-type: none"> • It is important to invest early in the preparation and awareness of the child/young population on these topics, in order to naturalize death as a process that is part of life; • The difficulty that the family has in managing/dealing with these issues when it comes to the child/young population.



	<ul style="list-style-type: none">• Anticipation of end-of-life care should include a holistic view of the person and, as such, the preparation of their loved ones, including their children/young people in the family.
Impact	Parents and caregivers want to do what's best for their children, and it's very hard to know what's best for them when a death happens. This tool is a practical support and guidance for families, professionals and anyone concerned about a child who may go through grieving processes.
Transferability	The brochure includes information which are mostly not country-specific, therefore the potential transferability is high.
Contacts for more information	info@stchristophers.org.uk

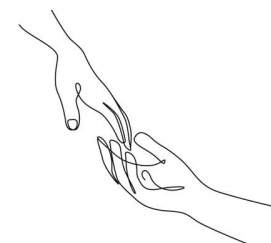


8. Tutorials for Informal Caregivers in Pediatric Palliative Care

Title	Tutorials for Informal Caregivers in Pediatric Palliative Care
Location	Portugal
Organisation(s)	Attitude - Social Solidarity Association
Website	https://attitude.org.pt/cuidados-paliativos-pediatricos/tutoriais/
Available language(s)	Portuguese
Date of development	2021
Type of tool	✓ Digital
Purpose	<ul style="list-style-type: none">✓ Awareness rising / information✓ Education✓ Self-reflection tools✓ Guidelines (“how to do”)
Topic(s) covered	<ul style="list-style-type: none">✓ activities of daily living (hygiene care in bed, hygiene care, positioning, etc.)✓ use of devices (tracheostomy, catheter, ventilation, nasogastric tube, etc.)✓ home adaptations/accessibility✓ communication of bad news✓ symptom control✓ loss and grief management✓ Caregiver's self-care
Overview	<p>ATTitude - IPSS, made available 19 didactic tutorials, to support informal caregivers of children in pediatric palliative care situations.</p> <p>Among these tutorials, two topics are particularly relevant for the HMH topic, namely:</p> <ul style="list-style-type: none">- Module 5 – Management of grief and loss- Module 7 – Taking care of the carer



Reasons for selecting the practice	<ul style="list-style-type: none">• It is an informative/educational tool, simple and didactic, whose playful character, promotes and facilitates the participation and involvement of the family in the provision of health care.• The training of informal caregivers is essential and indispensable, especially in a context of chronic, incurable and progressive disease.• Usually, the main role of the family/caregiver is to provide support and security, either through affection and understanding, or seeking, above all, to ensure the comfort and well-being of their loved ones, in a context of illness. However, in the face of a situation of severe and progressive disease, it is necessary to consider the need for (re)adaptation to the disease condition, and consequently to the need that emerges, for a greater and more complex provision of care, often leading the family/caregiver to have to seek to know how and what to do.• If themes, such as the anticipation of end-of-life care, palliative care, death, etc. in the adult population, is still a taboo and a paradigm to be consolidated in civil society in general, when it comes to pediatric care in this area, it becomes even more urgent to invest in the dissemination of information in this area, as well as in the construction of pedagogical and easily accessible tools.
Impact	<ul style="list-style-type: none">• This tool is still relatively recent (2021), so it continues to be disseminated and is available on the aTTitude platform.• It can be applied in the scope of training, education and qualification, by various intervention groups, whether social, clinical, pedagogical, family and/or institutional.• Target Groups: families, caregivers, children/young people, professionals, volunteers.
Transferability	Although it is spoken in Portuguese, it does not address specific cultural aspects. It can be a downloadable and/or adaptable tool. Inconvenience: Subtitled only in Portuguese
Contacts for further information	Rua Xavier Araújo Loja 6 D Lisbon, Portugal +351 211 398 273 hello@attitude.org.pt

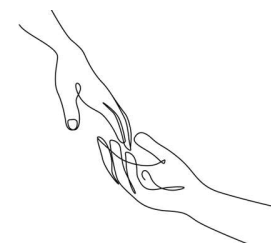


9. Advance Healthcare directive (DAV)

Title	Advance Healthcare directive (DAV) – Support forms
Location	Portugal
Organization	Ministry of Health - Health Regulatory Authority
Website	https://www.ers.pt/pt/utentes/perguntas-frequentes/faq/diretiva-antecipada-de-vontade-em-cuidados-de-saude/
Available language(s)	Portuguese
Development date	2012
Tool type	<ul style="list-style-type: none">✓ Digital✓ Paper format
Purpose	✓ Form/template
Topic(s) covered	✓ what kind of choices you can make in advance
Overview	The Advance Healthcare directive (DAV) in the field of health care, namely in the form of a living will (TV), is the document where a person of legal age and capable, can, in a free and enlightened way, register in advance the health care that he wants, or does not want, receive if, for some reason, you are unable to express your will personally and autonomously, that is, in a situation of near death or physical or mental disability. [Cf. Law no. 25/2012, of 16 July]
Reasons to select the practice	The AVD represent the autonomy of the patient, thus guaranteeing the power to make decisions about their health and their life. The form supports the interested party in including all the necessary information, guiding him/her in the choices that can be made.
Impact	<p>More than 13,000 Portuguese registered their living will in 2022, doubling the number of registrations compared to the previous year.</p> <p>By January 9, 2023, the total number of active DAV's/Living 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.</p>



Transferability	In Portugal, it can be translated and/or completed in a foreign language, provided that it is accompanied by a certified translation. [Cf. Ordinance no. 96/2014, of 5 May]
Additional information	
Contacts for more information	https://spms.min-saude.pt/wp-content/uploads/2014/06/Rentev_form_vo.4.12.pdf



10. Dying matters

Title	Dying Matters Hospice UK
Location	United Kingdom
Organisation(s)	Hospice UK
Website	Homepage Hospice UK
Available language(s)	English
Date of development	-
Type of tool	<ul style="list-style-type: none"> ✓ Digital ✓ Paper format
Purpose	<ul style="list-style-type: none"> ✓ Awareness rising / information ✓ Education ✓ Guidelines (“how to”)
Topic(s) covered	<ul style="list-style-type: none"> ✓ what is anticipation of end-of-life care ✓ why it is important to think in advance about your end-of-life care ✓ what kind of information you should collect to be able to make an informed choice ✓ what kind of choices you can make in advance ✓ if and how to discuss this topic with your beloved ones
Overview	<p>Dying Matters 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, to reduce the associated stress, stigma, and social isolation.</p> <p>Hospice UK is the national charity for hospice and end of life care. They work to ensure everyone affected by death, dying and bereavement gets the care and support they need.</p>
Reasons for selecting the practice	Dying Matters has three simple purposes; to share stories of those impacted by death, dying and bereavement, provide useful resources and have regular Dying Matters campaigns which acts as awareness raising and educational.



Impact	Impact assessment for 2022 is here: Hospice UK Impact Report 2022.pdf (hukstage-new-bucket.s3.eu-west-2.amazonaws.com)
Transferability	Dying Matters provides resources and grants that are aimed at community-led arts and culture projects, with a focus on equality and inclusion, and which approach the subject of dying in an innovative or creative way. They look for activities which take place in communities, outside of formal healthcare settings, which help make it easier for people to talk about death and dying. This approach can be transferred in various settings and takes into consideration of different gender/age.
Additional info	Dying Matters produces 5 resources that is updated regularly and covers some very important areas: <ol style="list-style-type: none">1. Things to do before you die [single page version] [professional print version]2. Supporting bereavement [single page version] [professional print version]3. Let's talk about dying [single page version] [professional print version]4. Talking about dying with people affected by dementia [single page version] [professional print version]5. Talking about dying with children [single page version] [professional print version] Examples of some projects funded: 1,000 Conversations about Death: a video game revolution Hospice UK (55) East African Education Foundation hosts comedy end of life and grief event - YouTube 'Uncovering': the project pushing for change Hospice UK
Contacts for further information	National guidelines for end of life care For professionals (mariecurie.org.uk)



11. Lifebook

Title	LifeBook
Location	UK
Organisation(s)	Age Concern
Website	id204608-0321-age-uk-lifebook.pdf (ageuk.org.uk)
Available language(s)	English
Date of development	January 2022
Type of tool	<ul style="list-style-type: none"> ✓ Digital ✓ Paper format
Purpose	<ul style="list-style-type: none"> ✓ Awareness rising / information ✓ Education ✓ Form / template ✓ Self-reflection tools ✓ Guidelines (“how to”)
Topic(s) covered	<ul style="list-style-type: none"> ✓ why it is important to think in advance about your end-of-life care ✓ what are the procedures to formalize your end-of-life care wills ✓ what kind of information you should collect to be able to make an informed choice ✓ what kind of choices you can make in advance ✓ whom you can / should choose to be your proxy / reference person ✓ if and how to discuss this topic with your beloved ones
Overview	The LifeBook is a free booklet where you can write important and useful information about your life, from who insures your car to where you put your passport and other important documents.
Reasons for selecting the practice	Sometimes it's easy to misplace important documents and information, so Age Concern developed the LifeBook to help those that are in the cusp of end of life find exactly what they need without searching. The LifeBook will not only help to be more organised but could also be invaluable to a family member or a friend if they need to find important information about a loved one in an emergency.



	<p>Many people have documents in different places and with different people. Banks, solicitors, and Independent Financial Advisers are all quite likely to hold some of your paperwork. The LifeBook divides up into the following sections:</p> <ul style="list-style-type: none">• Personal details (Full name/date of birth)• Documents (Important documents such as passport, will)• Life contacts (friends and family)• Financial (Bank details/credit cards)• Possessions (Ranging from your home, car)• Final wishes (funeral arrangements)
Impact	<p>With so many things to remember, it can often seem overwhelming trying to keep on top of it all when one is trying to deal with the end of life. But with the Age UK LifeBook, you know where everything is when you need it. The LifeBook lets you keep all the important information you might need in one place. It's one of those things your future self will thank you for. Whether you need to dig out some information about a pet or an energy supplier, you'll know exactly where to find it. But it's not something that's just going to help you. Letting people, you trust know about the LifeBook can make their life that bit easier down the line too. In case you need someone to sort things for you on your behalf, having everything they could possibly need in the same place will help keep things simple.</p>
Transferability	<p>The LifeBook could be used in multiple setting it is a great template for those who are end of life and wish to keep all their key information in one document in an organised manner. It also has instructions on how to manage confidential information such as passwords to bank accounts. The LifeBook has been designed to cover everything – but that doesn't mean you need to sit down and fill it all out in one go. There might be things you can fill out quickly, but there might be other sections that require a bit more time. Of course, what you fill out and when is totally up to you.</p>
Additional info	<p>LifeBook is particularly helpful for people who would like to be looked after at home during the final stages of their life</p>
Contacts for further information	<p>End of life planning Age UK</p>

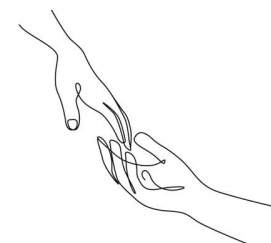


12. Döstdning - Death cleaning

Title	Döstdning - Death cleaning
Location	Sweden
Organisation(s)	-
Website	https://www.nbcnews.com/better/health/what-swedish-death-cleaning-should-you-be-doing-it-ncna816511
Available language(s)	English
Date of development	-
Type of tool	✓ Other (practice)
Purpose	✓ Guidelines (“how to”)
Topic(s) covered	✓ How to prepare for end-of-life
Overview	“Death cleaning” is a practice designed to essentially help individuals prepare for death and it deals with getting rid of all the stuff they have accumulated that they don’t need anymore — so that no one else has to do it for them after they pass. It includes for example reflecting on what we are still needing and what can be donated or sell.
Reasons for selecting the practice	<p>It is a gradual process that can help to start thinking and planning for own death. Moreover, an important piece to Swedish Death Cleaning is involving others and it becomes a good time to share with family own wishes after passing.</p> <p>It can support well-being: the practice belongs to the concept of psychologically minimalism, which is based on the idea that happiness doesn’t come from stuff, but rather from relationships and experiences. According to psychologists, when you get rid of the excess stuff surrounding you, you can better identify on those things that are really important to you and what brings you pleasure in your life.</p>
Impact	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 the Swedish author Margareta Magnusson.
Transferability	The practice is based on suggestions / advices that can be implemented by anyone, therefore it is highly transferable.
Additional info	https://www.nbcnews.com/better/health/what-swedish-death-cleaning-should-you-be-doing-it-ncna816511
Contacts for further information	-

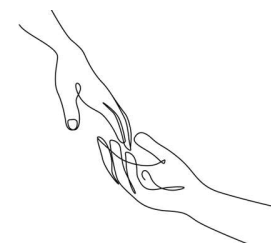


13.H.O.P.E. questions

Title	H.O.P.E. questions
Location	USA
Organisation(s)	Brown University
Website	-
Available language(s)	English
Date of development	-
Type of tool	✓ Other (questions)
Purpose	✓ Other (specify) – questions for incorporating a spiritual assessment into the medical interview
Topic(s) covered	✓ Spirituality issues related with end of life
Overview	<p>The HOPE questions cover the basic areas of inquiry for physicians to use in formal spiritual assessments.</p> <p>H, pertains to a patient's basic spiritual resources, such as sources of hope, without immediately focusing on religion or spirituality.</p> <p>O and P, refer to areas of inquiry about the importance of organized religion in patients' lives and the specific aspects of their personal spirituality and practices that are most helpful.</p> <p>E, pertains to the effects of a patient's spirituality and beliefs on medical care and end-of-life issues.</p>
Reasons for selecting the practice	<p>The HOPE questions were developed as a teaching tool to help medical students, residents and practicing physicians begin the process of incorporating a spiritual assessment into the medical interview. These questions have not been validated by research, but the strength of this particular approach is that it allows for an open-ended exploration of an individual's general spiritual resources and concerns and serves as a natural follow-up to discussion of other support systems.</p>

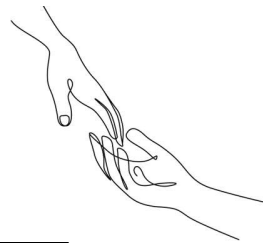


	Although developed for professionals, these questions might be used also within an informal conversation with family members to explore spiritual issues related with end-of-life
Impact	According to a survey conducted in the UK with 177 GPs, the HOPE tool was viewed as acceptable to use with patients by 65% of participants, although its limitations were acknowledged. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0276281
Transferability	The practice is totally transferable as it is based on a set of questions to open a discussion.
Additional info	https://www.aafp.org/dam/brand/aafp/pubs/afp/issues/2001/0101/p81.pdf
Contacts for further information	-



14. Your will-planning worksheet

Title	Your will-planning worksheet
Location	UK
Organisation(s)	British Red Cross
Website	https://www.redcross.org.uk/-/media/documents/get-involved/guide-legacy-will-planner.pdf?la=en&hash=400C75B9C8B920ED5FoE17A129038B37E36D6907
Available language(s)	English
Date of development	-
Type of tool	✓ Worksheet
Purpose	✓ Other (specify) – forms to support the user in start thinking about its estate planning
Topic(s) covered	✓ Estate-planning
Overview	This worksheet is designed to help the user get prepared for a conversation with a solicitor to prepare his/her will. It helps to note down important information as well as questions to be asked to make sure that his/her desires and intentions are then worded in a legally valid way.
Reasons for selecting the practice	It is a simple instrument which helps self-reflection in relation to the value of real estate's one's possess, the persons he/she would like to provide for and a basic glossary.
Impact	No information available.
Transferability	The practice is easily transferable as it doesn't refer to a specific local legislation disciplining inheritance, but rather it helps reflecting on general issues which might be the basis for an informed dialogue with other family members and legal professionals.

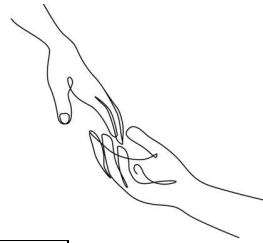


Additional info	-
Contacts for further information	redcross.org.uk/mywill



15. Funeral and farewell wishes

Title	Funeral and farewell wishes
Location	UK
Organisation(s)	Hearth and soul funerals
Website	https://www.heartandsoulfunerals.co.uk/wp-content/uploads/2018/08/funeral-farewell-wishes-web.pdf
Available language(s)	English
Date of development	2018
Type of tool	✓ Worksheet
Purpose	✓ Other (specify) – forms to support the user in start thinking about their desired funeral arrangements
Topic(s) covered	✓ Funerals
Overview	This worksheet is designed to stimulate the user to think of the kind of funeral and farewell he/she might like; and ensure that those who may be responsible for the events know their wishes
Reasons for selecting the practice	It includes a checklist of aspects which can be taken into account when planning for a funeral in relation to different aspects, such as financial arrangements, burial options, rituals, ceremony etc.
Impact	No information available.
Transferability	The practice is transferable although in some parts might refer to the legislation in place in the UK and therefore might need some adaptations to local contexts.
Additional info	To support the completion of the document, users can be referred to the book “We Need To Talk About The Funeral – 101 Practical Ways To Commemorate And Celebrate A Life, written by Jane Morrell and Simon Smith of Heart & Soul Funerals” which can be purchased from the organization’s website.



Contacts for further information	https://www.heartandsoulfunerals.co.uk/
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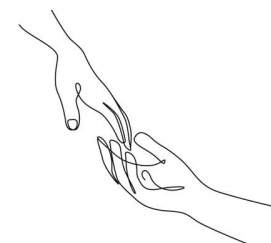


16. The Spiritual Needs Questionnaire

Title	The Spiritual Needs Questionnaire
Location	Germany
Organisation(s)	Prof. Arndt Büssing, Witten/Herdecke University
Website	https://tinyurl.com/yvfhvsju
Available language(s)	German, English, Italian, French, Spanish, Portuguese, Brazilian Portuguese, Polish, Danish, Lithuanian, Croatian, Chinese, Japanese, Korean, Indonesian, Farsi (Iran)
Date of development	2010
Type of tool	Questionnaire
Purpose	✓ Other (specify) – identification of spiritual needs of persons living with chronic diseases, in elderly living in retirement homes, healthy (stressed) persons, and adolescents with chronic diseases and health conditions
Topic(s) covered	✓ Spirituality issues related with end of life
Overview	For many persons confronted with chronic diseases, spirituality/religiosity is an important resource for coping. However, patients often report unmet psychosocial and spiritual needs in social and health care contexts. The questionnaire helps the respondent identifying his/her spiritual needs and to discuss with others how to address them.
Reasons for selecting the practice	The SpNQ was developed to assess patients' unmet existential/spiritual needs in a structured and standardized way. It is first of all a resource-oriented diagnostic instrument that allows both, communication and documentation. Although conceived for a clinical setting, the questionnaire could also be used to support a conversation within the family context for planning support options
Impact	The tool has so far been translated into numerous languages and is widely used as a valid and reliable instrument to assess a wide range of spiritual needs of patients with chronic diseases, elderly, adolescents, and healthy person. See: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8484079/



Transferability	The practice is transferable since so far it has been translated in different languages and widely used as a valid and reliable instrument to assess the spiritual needs of patients with chronic diseases, elderly, adolescents and healthy persons. According to the author, the instrument is applicable also to non-religious persons who also have spiritual needs, particularly needs for inner peace and generativity while it is of relevance also for religious persons who score higher on explicit religious needs
Additional info	Note that the instrument is © Arndt Büssing and permission is required to copy or publish
Contacts for further information	http://www.spiritualneeds.net/

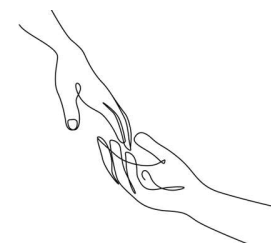


17. Lifetime legacies: Life Review questions

Title	Lifetime legacies: Life Review questions
Location	USA
Organisation(s)	Continua Hospice Learning
Website	https://continuagroup.com/wp-content/uploads/2018/11/Lifetime-Legacies-Life-Review-Questions.pdf
Available language(s)	English
Date of development	-
Type of tool	✓ Questionnaire
Purpose	✓ Life review is essential to allow person/patient to reflect on their lives, process their experiences, and impart wisdom to their loved ones.
Topic(s) covered	✓ Life story – Talking about death with loved ones
Overview	Continua developed a life review questions list to help caregivers and nurses to have meaningful conversation with hospice patients. The 51 questions are divided in various thematic: Childhood- Adolescence- Adulthood- Olderadulthood- General Questions. Utilizing these questions can enhance the quality of care provided and create a positive and supportive environment for both patients and their families. 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.
Reasons for selecting the practice	It is a list of questions. This tool is simple, not too long, easy to access and use. This tool can be used by anyone who has questions about their life and wants to leave a testimony, a life story. It can also help people who are terminally ill and their formal or informal carers to have meaningful conversation. This list of questions can also help to open a dialogue with one's family.
Impact	The tool can be a support to help people to reflect about their experiences of life and what they would like to impart to their loved ones. To write a life



	<p>story it can be difficult to know where and how to start. The life story makes it possible to reweave one's life, give meaning, leave a trace, bear witness...</p> <p>This tool can also be used by those accompanying a person at the end of life to facilitate meaningful patient conversations.</p>
Transferability	<p>The practice was first created for nurses & caregivers to accompany hospice patients. However, the list of questions can be use by any persons who would like to write or talk about his/her life story. It can transferable and it is not restricted to a cultural or national context.</p>
Additional info	
Contacts for further information	<p>https://continuagroup.com/article/lifetime-legacies-life-review-questions/</p>



18. My life booklet

Title	My life booklet
Location	Belgium
Organisation(s)	Énéo
Website	https://www.eneo.be/wp-content/uploads/2023/01/20230130-Mon-carnet-de-vie-Web.pdf
Available language(s)	French
Date of development	Last update June 2022
Type of tool	<ul style="list-style-type: none">✓ Digital✓ Paper format
Purpose	<ul style="list-style-type: none">✓ Awareness rising / information✓ Form / template✓ Self-reflection tools
Topic(s) covered	<ul style="list-style-type: none">✓ what is anticipation of end-of-life care✓ why it is important to think in advance about your end-of-life care✓ what is the legislation in place✓ what are the procedures to formalize your end-of-life wills✓ what kind of information you should collect to be able to make an informed choice✓ what kind of choices you can make in advance✓ whom you can / should choose to be your proxy / reference person
Overview	<p>My life booklet is a very complete 80-page document. It contains a section on administrative and legal data and a more intimate section on the person's life. The document includes practical information as well as spaces to be filled in on the different topics covered:</p> <p>Personal data, emergency contacts, finances and assets, health, my end of life; after death, ...</p> <p>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.</p>



Reasons for selecting the practice	<p>It is a very complete tool that allows a global reflection on many aspects related to the end of life. The emphasis is on anticipation and overlaps with most of the themes addressed in the Hold My Hand project. This tool facilitates both the transmission of information with the family and/or carers. It also facilitates the discussion with the relatives. Moreover, there is a lot of useful information available.</p>
Impact	<p>It is a useful tool for the person and especially for the relatives. It allows for a centralisation of useful information in order to be able to respect the end-of-life choices of the person concerned but also to facilitate the practical aspects linked to the end of life or after death.</p>
Transferability	<p>It is a tool that can be very interesting for other countries and most of the forms to be filled in can be transferred to other contexts. However, for the first part on administrative and legal data, the information available is related to Belgium and may therefore be different in other countries. The interest of this tool is the centralisation of a large number of aspects related to the end of life in a single document.</p> <p>The second part related to the life story is quite transferable to other contexts.</p>
Additional info	
Contacts for further information	<p>https://www.eneo.be/</p>



4. Conclusions

This document collects a series of tools developed in Europe, UK and Canada which have been recognized by partner organizations as relevant in terms of innovativeness, response to a specific need of the public, transferability and impact.

This research, while addressing interested parties to existing tools which might be of inspiration for adaptation and use in own organizations, will also support the development of Hold my Hand resources thus avoiding replication and making sure that they are complementary about the existing offer.



...at the end of life