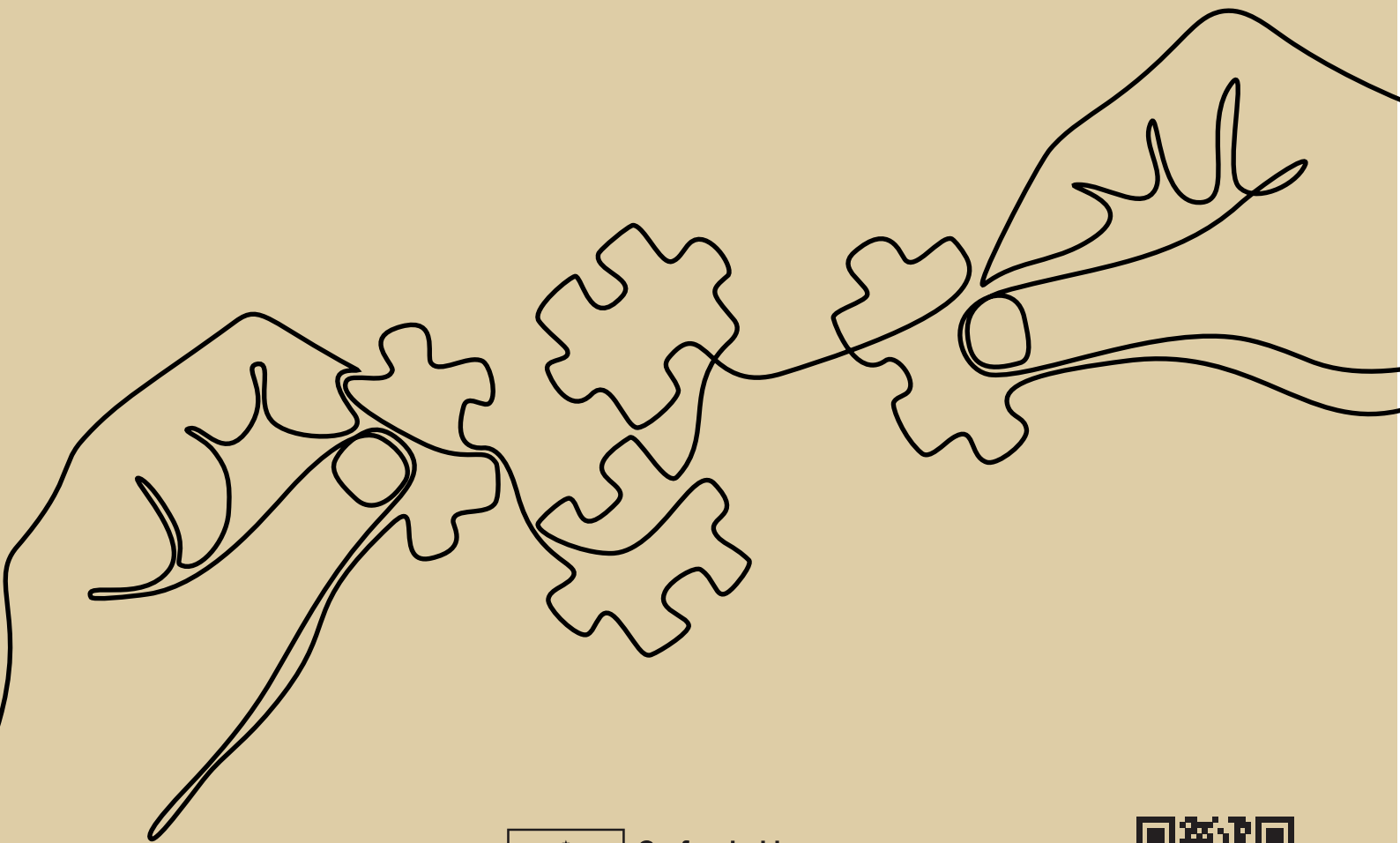




RECOMMENDATION REPORT



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1. The Hold my Hand project

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

The project “Hold my hand - HMH” 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, including issues such as:

- Advanced care planning / proxy nomination
- Will and testaments
- Digital heritage
- Organization of funerals
- Life-stories and memories

And much more.

The target groups of the project are:

- Adult population
- Relatives / Informal carers likely to be involved in accompanying end-of-life cares
- (Non-)professionals from social or medical backgrounds likely to be called upon in the context of accompanying end-of-life cares
- (In)formal carers likely to be involved in accompanying end-of-life care

In detail, its objectives are:

- To work on the development of a culture addressing the issue of end-of-life preparation 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.

This document aims to summarise some of the lessons learnt in the implementation of the project and to share a set of recommendations that the partnership drew from them, with the purpose of contributing to the European political debate around these issues.



2. The European context

The transnational cooperation implemented in the framework of the project, clearly highlighted the fact that there are still many differences across Europe around the issue of end-of-life care and advanced planning, both from a legal as well as from a cultural perspective.

Nevertheless, there are also several European and International frameworks in place that contribute to create a common background in which project activities were actioned.

Palliative care

In the European Union, palliative care is regulated by a series of guidelines and recommendations, which seek to ensure the quality and accessibility of these services throughout the territory. Directive 2011/24/EU on "the exercise of patients' rights in cross-border healthcare" states that patients have the right to receive adequate and effective palliative care in any Member State of the European Union. In addition, the Prague Declaration of 2013 reiterated the European Union's commitment to ensuring access to palliative care, and its availability across the continent.

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

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

Informed consent and right to refuse care

While each European Member State might have regulated them in more detail, there are general principles in relation to informed consent which are underpinned by The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No 164), also known as "Oviedo Convention". This Convention has been signed by the vast majority of the EU MSs, with the exception of Austria, Germany, Ireland and Malta. These principles are:

- Right to informed consent
- Right to privacy of health information
- Right to know and not to know



Organ donations

Member States have different systems in place to seek people's consent to donate their organs after death. While responsibility for framing health policies and organising and delivering care lies primarily with the EU Member States, the EU has nevertheless addressed organ donation and transplantation.

EU rules on organ donation and transplantation are set out in Directive 2010/45/EU (the 'European Organs Directive') that lays down the quality and safety standards for organs intended for transplantation, covering all stages of the process – from donation, procurement and handling to transplantation.

Moreover, the European Parliament has adopted own-initiative resolutions on various aspects of organ donation and transplantation: in its 2008 resolution it stressed that one highly effective way to increase organ availability was to provide the public with more information and it called for the introduction of a European donor card. In its 2012 resolution on voluntary and unpaid donation of tissues and cells, Parliament stressed, among other things, the importance of nonremuneration, consent, and protection of living donors' health, underlining the need for anonymity, traceability and transparency.

3. Positions and recommendations

In the above-described EU context, the partnership would like to recommend European stakeholders:

To implement actions to promote the public discourse around end of life

Research evidence¹ suggests that a lack of engagement with palliative care and advance care planning could be attributed to a lack of knowledge, presence of misconceptions and stigma within the general public. Barriers to engagement in discussions have been found to include topics such as death and dying are considered a social taboo, posing an increased risk of distress for loved ones; and a misconception that this is only for those at the end of life rather than future planning. Therefore, there is a need for a

¹ Black R, Hasson F, Slater P, Beck E, McIlpatrick S. Building public engagement and access to palliative care and advance care planning: a qualitative study. *BMC Palliat Care*. 2024 Apr 12;23(1):98. doi: 10.1186/s12904-024-01420-8. PMID: 38605315; PMCID: PMC11010379.



public health approach to ACP, to enable and support individuals to engage in conversations about their wishes and make decisions surrounding their future care.

Our recommendations in this regard include:

Finance public communication campaign on media

A public health approach to end-of-life care expands the reach and effectiveness of end-of-life care services by engaging communities. It can address a greater range of needs including social, psychological and spiritual needs, and do so more comprehensively. It can also raise awareness about death, dying, loss and care.

We recommend public stakeholders at micro-meso and macro level to invest in the promotion of public campaigns to contrast the stigma around death and dying and to raise awareness about the importance of advanced care planning for all ages.

Support the availability of books, movies, theatre plays around the issue of end of life

Humanities can be of great help in initiating a public discourse around death and dying. Indeed movies, books, theatre plays addressing either adults or children / teen-agers provide a useful medium for facing death as the users can identify with characters and follows a story while, at the same time, distancing themselves enough to feel safe in experiencing the related emotions.

We recommend the implementation of programmes aiming to encourage the availability of books, movies, theatre plays around the issue of end of life and their use in educational and awareness rising programmes at community level.

Promote the inclusion of the topic of death in school curricula

Many children grow up in a culture that try to avoid grief and denies the inevitability of death. However, according to statistics, many students have experienced the passing of family members and friends. By creating transparency through education, death, dying and the disposal of the dead can all become part of the everyday. And by normalising death within schools, it may well be that students can help their families to fear less and make more informed decisions about the end of their lives.



We recommend the inclusion of death-education in school curricula at every grade. Death and dying by its very nature, lend itself to a multidisciplinary approach. The topic could be integrated into various learning areas including the Social Studies, Science or Literature curriculum.

To implement actions to ensure information and education about death to the general public

According to the Institute of Medicine (IOM) report *Approaching Death* (IOM, 1997) “a continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to dying patients and families, and the obligations of communities to those approaching death”. Moreover, talking about end-of-life offers the opportunity to avoid situations in which families don’t know how to best help or support their dying loved one, the dying person feeling frightened and distressed, and the issue of people dying without leaving traces of their actual wills – leaving the family unsure about how to handle end-of-life stages.

Our recommendations in this regard include:

Develop lay-man educational resources about end-of-life preparation

The availability of free, understandable and accessible educational resources for adults can ensure that everyone interested and willing to initiate an introspective process and / or a family discussion can find a starting point to do so.

We recommend the development of targeted educational resources around the different aspects of advanced end-of-life planning. In this regard, the modules developed within the Hold My Hand project, available in different languages, can be a useful tool: <https://holdmyhandmodules.eu>

Include end-of-life related issues in informal adult education programmes (i.e. death café, third-age universities educational offer etc.) and in health education campaigns

When we think about death, and even more if we are in older age, a series of processes are set in motion, including an increase in thoughts about the proximity and arrival of death, which allows for a clearer



appreciation of the fact that life is limited and a greater awareness of mortality. Education is an instrument that can be used to address situations that may generate emotional or physical discomfort, such as the issue of death. It is therefore essential to provide training for elderly people, aimed at demystifying the fear of death and making it no longer a taboo subject.² For example, Death Café approach can be a useful strategy to improve both death and grief literacy levels.³

We recommend that death and grief literacy is promoted in the context of adult education offer. This can be encouraged for example by including it as a priority topic in the context of funding programmes at local, national but also European level (i.e. Erasmus+). Hold my Hand is an example of an Erasmus+ project dealing with these issues.

Promote the availability of services where people can turn to have information and counselling about end-of-life preparation

Anticipating end-of life entails planning for a variety of issues (including for ex. advanced care directives, patrimonial dispositions through wills and testaments, funeral planning etc.) which are related to national legislations and might imply the need to initiate different bureaucratic processes. Moreover, for some individuals addressing these issues might be difficult and they might feel the need of support in processing their emotions, fears, and concerns relating in a safe space. Accessible support services offered by public entities or NGOs can be very helpful.

We recommend to promote the availability of tailored, easily accessible, face-to-face and/or online services, possibly free of charge, offering initial information and advice about all the aspects of end-of-life planning.

Promoting information and education of social and health care professionals

Generally speaking, in the context of medical education there is still a lack of adequate training for health professionals about how to provide superior, or even competent, care for dying patients. This might reflect a medical culture that still defines death as failure and ignores care for dying people as a

² Martínez-Heredia N, Soriano Díaz A, Amaro Agudo A, González-Gijón G. Health Education as a Means of Addressing Death in the Elderly. *Int J Environ Res Public Health*. 2021 Jun 21;18(12):6652. doi: 10.3390/ijerph18126652. PMID: 34205630; PMCID: PMC8296413.

³ Laranjeira, C., Dixe, M. A., Querido, A., & Stritch, J. M. (2022). Death cafés as a strategy to foster compassionate communities: Contributions for death and grief literacy. *Frontiers in Psychology*, 13, 986031.



source of professional accomplishment and personal meaning.⁴ Improving the capacity of health care professionals to provide end-of-life care might have a positive impact on dying patients and their families as well as improving the coping skills of staff working in close contact with death and grief.

Our recommendations in this regard include:

Include end-of-life care in standard curriculum for all health and social care professionals and promote the availability of continuous professional development opportunities in this regard

The increasing hospitalization of death and dying means that health care professionals are increasingly involved in the assessment and support of patients and caregivers experiencing a range of losses, but they often report feeling inadequately prepared to do so⁵. Indeed, studies show that in most countries, there are severe deficiencies in quantity and quality regarding the education of this care, especially clinically⁶. Similarly, studies suggest that, like medicine and nursing, social work students have insufficient training—both didactic and practical—to provide the best care at the end of life⁷.

We recommend to include in the standard curricula for health and social care workers qualifications a compulsory and evidence-based training around end-of-life care and anticipation. The issue should also be included in the offer of continuous professional development programmes for these professionals.

Ensure the availability of counselling / psychological support programmes for health and social care professionals dealing with death

It is well recognised that healthcare workers can experience physical and emotional exhaustion as a result of cumulative grief and associated compassion fatigue which can have an impact both on

⁴ Institute of Medicine (US) Committee on Care at the End of Life; Field MJ, Cassel CK, editors. *Approaching Death: Improving Care at the End of Life*. Washington (DC): National Academies Press (US); 1997. 8, Educating Clinicians and Other Professionals. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK233588/>

⁵ Sikstrom L, Saikaly R, Ferguson G, Mosher PJ, Bonato S, Soklaridis S. Being there: A scoping review of grief support training in medical education. *PLoS One*. 2019 Nov 27;14(11):e0224325. doi: 10.1371/journal.pone.0224325. PMID: 31774815; PMCID: PMC6880967.

⁶ Taheri-Ezbarami, Z., Jafaraghaee, F., Sighlani, A.K. et al. Core components of end-of-life care in nursing education programs: a scoping review. *BMC Palliat Care* 23, 82 (2024). <https://doi.org/10.1186/s12904-024-01398-3>

⁷ Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board; Foley KM, Gelband H, editors. *Improving Palliative Care for Cancer*. Washington (DC): National Academies Press (US); 2001. 9, Professional Education in Palliative and End-of-Life Care for Physicians, Nurses, and Social Workers. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK223527/>



individual level and well as on the organization as a whole. However, despite these serious impacts, according to research most organisations often fail to support healthcare workers experiencing cumulative grief or compassion fatigue.⁸

We recommend policy and decision makers as well as human resource managers and directors of services employing health and social care professionals to consider including bereavement support and death education programmes for their staff.

4. Conclusion

These recommendations summarise the lessons learnt by the Hold My Hand partnership in the implementation of the project, as well as the feedback received by citizens, professionals and informal carers reached out through project activities. We hope they can be a starting point for further discussion at policy level across Europe.

⁸ O'Sullivan, D., Stone, G., Mahomed, H., O'Reilly, P., Stewart, P., Noonan, H., & Murphy, A. M. (2019). Bereavement Counselling for Healthcare Workers in the Aftermath of Child Death.

WWW.HOLD-MY-HAND.EU