

# Caring for Loved Ones at the End of Life

## THE ESSENTIAL ROLE OF PALLIATIVE CARE AND SUPPORT

for Informal Carers



**EURO  
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The end of life is a topic that has been discussed for centuries, with various philosophical and political approaches emerging in different parts of the world. In Europe, the approaches to end-of-life care and palliative care have been shaped by cultural, social and political factors. End-of-life care and palliative care are closely related concepts, but they are not the same thing. Both types of care are focused on improving the quality of life for people who are experiencing serious or life-limiting illnesses, but they differ in terms of their specific goals and the timing of their delivery.

End-of-life care is a type of care that is provided to people who are nearing the end of their lives, typically within the last few months of life. The goal of end-of-life care is to provide comfort and support to the patient and their loved ones during this difficult time. End-of-life care may involve a range of medical and non-medical interventions, including symptom management, emotional support, spiritual care and care planning.

Palliative care, on the other hand, is a type of care that is provided to people who have serious or life-limiting illnesses, regardless of their life expectancy. The goal of palliative care is to improve the quality of life for patients and their families by addressing physical, emotional, spiritual and social needs. Palliative care can be provided at any stage of an illness and can be delivered alongside curative or life-prolonging treatments.

In other words, end-of-life care is a type of palliative care that is specifically focused on people who are nearing the end of their lives, whereas palliative care is a broader concept that can be provided at any stage of an illness. Both types of care are focused on providing comfort, relief from symptoms and support for patients and their families. However, end-of-life care is typically more focused on comfort and support, whereas palliative care may also involve ongoing treatment aimed at prolonging life or improving the patient's condition and well-being.



# Philosophical Approaches to End-of-Life Care

The philosophical approach to end-of-life care is grounded in the belief that dying is a natural process that should be respected and accompanied. The philosophy emphasises the importance of providing compassionate care that meets the physical, emotional and spiritual needs of the dying persons and their families.

In Europe, the philosophical approach to end-of-life care is influenced by a variety of philosophical traditions, including Christian, humanist and existentialist thought. The Christian tradition underscores the importance of delivering care guided by the principles of love, compassion and dignity. Humanist philosophy stresses the significance of respecting the autonomy and dignity of the individual, while existentialist thought highlights the importance of finding meaning and purpose in the face of mortality.



# Political Approaches to End-of-Life Care

The political approach to end-of-life care is concerned with the policies and regulations that govern the provision of care for people at the end of life. In Europe, the approach to end-of-life care is shaped by a range of influences, encompassing factors related to traditions, societal aspects and financial considerations.

One of the most important factors shaping the political approach to end-of-life care in Europe is demographic ageing. As the population ages, the demand for end-of-life care is increasing, placing pressure on healthcare systems to provide adequate care and support. This has led to a focus on developing policies and regulations that ensure access to high-quality end-of-life care for all.

Another important factor shaping the political approach to end-of-life care in Europe is the influence of human rights. In recent years, there has been increasing recognition of the importance of ensuring that people at the end of life have access to care that respects their dignity and autonomy. This has led to the development of policies and regulations that prioritise the provision of compassionate, person-centred care.

In Europe, a fundamental political strategy concerning end-of-life care involves the establishment and enhancement of palliative care services. Palliative care is an approach to care that focuses on relieving suffering and enhancing the quality of life for people who are facing life-limiting illnesses. Palliative care services are designed to provide holistic, person-centred care that meets the physical, emotional and spiritual needs of the dying person and their families.

The development of palliative care services in Europe has been influenced by a number of factors, including the need to improve the quality of end-of-life care, the recognition of the importance of providing care that respects the dignity and autonomy of the dying person and the need to provide care that is cost-effective and sustainable.

The provision of palliative care services in Europe is governed by a range of policies and regulations, including the European Association for Palliative Care (EAPC) Charter on the Rights of Patients with Incurable Cancer, the World Health Organisation's (WHO) guidelines on palliative care and national policies and regulations in individual countries.

# Typology of places of death

A comprehensive classification of places of death is essential for making well-informed decisions, allocating resources effectively, developing policies, and continually enhancing end-of-life care services. This, in turn, contributes to an improved overall quality of care for individuals approaching the end of their lives.

The European Association for Palliative Care (EAPC) has established a European typology for places of death. Grounded in the notion of “care settings,” this typology identifies six overarching categories that encompass various settings where individuals may experience the conclusion of their lives:



## **Hospital:**

This category includes all types of hospitals, including general hospitals, specialised hospitals and hospice units within hospitals.



## **Home:**

This category includes the patient’s own home, as well as the homes of relatives or friends where the patient may be staying.



## **Nursing home or residential care facility:**

This category includes nursing homes, residential care facilities and other types of long-term care facilities.

**Hospice:**

This category includes inpatient hospice facilities, as well as hospice services that provide care in the patient's home or other community settings.

**Acute palliative care unit:**

This category includes specialised palliative care units that provide short-term, acute care for patients with complex symptoms or other palliative care needs.

**Other:**

This category includes all other types of care settings that do not fit into the above categories, such as prisons, homeless shelters and other institutional settings.

The EAPC typology provides a useful framework for understanding the different care settings where people may die in Europe. It highlights the diversity of care settings and emphasises the need for high-quality palliative care to be available in all of these settings, regardless of where

the patient is located. By understanding the different care settings where people may die, policymakers, healthcare professionals and other stakeholders can work together to ensure that patients receive the appropriate care and support to meet their needs and preferences at the end of life.

# Role of informal carers in the context of end of life and palliative care in Europe

Informal carers play a critical role in the provision of end-of-life and palliative care in Europe. Informal carers are individuals who provide care - usually unpaid - to a family member or a friend with a chronic illness, a disability or any other long-lasting care needs, outside a professional or formal framework. In the context of end-of-life and palliative care, informal carers may provide emotional, practical and physical support to patients and their families.

The role of informal carers in end-of-life and palliative care can be complex and challenging. Informal carers may experience a range of emotional and physical stressors, including grief, anxiety and fatigue. However, they can also provide valuable support to patients and their families, helping to improve quality of life and ensure that patients receive care that is aligned with their wishes and values.

In Europe, informal carers are recognised as an important resource for the provision of end-of-life and palliative care. A number of policies and initiatives have been developed to support informal carers in their role, including:

## Respite care

Informal carers may require a break from their caregiving responsibilities to rest and recharge. Respite care provides temporary relief and can be provided in the home, hospice, or other care facilities. This allows informal carers to take a break from their caregiving duties and helps to prevent carer burnout.

## Education and training

Informal carers may benefit from education and training programs to help them develop the skills and knowledge necessary to provide effective care. These programs may cover topics such as symptom management, communication and emotional support.



## **Emotional support**

Informal carers may experience emotional stress and require support. This can be provided through counselling services, support groups, or peer-to-peer support networks.

## **Financial support**

Informal carers may face financial burdens as a result of their caregiving responsibilities. Financial support measures such as allowances, tax breaks, or subsidies for respite care can help alleviate these burdens.

## **Flexibility in the workplace**

Many informal carers also have work responsibilities. Providing flexible working arrangements, such as reduced hours or telecommuting, can help them manage their caregiving responsibilities while also fulfilling their work obligations.

## **Recognition and appreciation**

Informal carers often feel undervalued and unrecognised for their contributions. Recognizing and appreciating their efforts through public recognition, efforts to increase awareness, targeted workplace initiatives, or alternative methods of recognition can help to increase their sense of self-worth and provide motivation to continue providing care.

Overall, providing specific support measures to informal carers in the context of end-of-life and palliative care is essential to help them manage the complex emotional and physical demands of their role. By providing adequate support to informal carers, we can help to ensure that patients receive high-quality care that is compassionate, patient-centred and aligned with their wishes and values. However, the support measures mentioned above frequently appear tokenistic or are challenging to access.

The EAPC typology for places of death has important implications for informal carers who provide care to loved ones at the end of life. Depending on the care setting, informal carers may face different challenges and may require different types of support to effectively care for their loved ones. Here are some examples of how support to informal carers could be adapted to the six categories of care settings identified by the EAPC:



## Hospital

Informal carers may face a number of challenges when caring for a loved one in the hospital, such as navigating complex medical systems and dealing with the stress of a hospital environment. In this setting, support to informal carers could include education and training on navigating the hospital system, emotional support and practical assistance with tasks such as coordinating care and communicating with healthcare providers.



## Home

When caring for a loved one at home, informal carers may face challenges related to managing complex symptoms, coordinating care and dealing with the emotional strain of caregiving. In this setting, support to informal carers could include training on symptom management, respite care to provide relief for carers and emotional support from healthcare professionals or support groups.



## Nursing home or residential care facility

When a loved one is receiving care in a nursing home or residential care facility, informal carers may need support in navigating the facility's policies and procedures, coordinating care with healthcare providers and dealing with the emotional impact of placing a loved one in a care facility. In this setting, support to informal carers could include education and training on navigating the care facility, emotional support and practical assistance with tasks such as coordinating care and communicating with healthcare providers.



## Hospice

In hospice settings, informal carers may require support in managing complex symptoms, dealing with the emotional strain of caregiving and navigating the hospice system. In this setting, support to informal carers could include education and training on symptom management, emotional support and practical assistance with tasks such as coordinating care and communicating with hospice staff.



## Acute palliative care unit

In this setting, informal carers may require support in managing complex symptoms, dealing with the emotional strain of caregiving and navigating the acute care system. In this setting, support to informal carers could include education and training on symptom management, emotional support and practical assistance with tasks such as coordinating care and communicating with healthcare providers.



## Other

Informal carers who are providing care in non-traditional care settings may require support in navigating unfamiliar environments, coordinating care with healthcare providers and dealing with the emotional strain of caregiving. In this setting, support to informal carers could include education and training on navigating the care setting, emotional support and practical assistance with tasks such as coordinating care and communicating with healthcare providers.

# Insights on the current policy developments in Europe related to end-of-life care and palliative care

In recent years, there has been an increasing focus on improving the provision of end-of-life care and palliative care in Europe and a number of policy developments have emerged as a result. Some of these policy developments include:

**The development of national strategies for palliative care:** Many European countries have developed national strategies for palliative care, which outline the goals and priorities for improving the provision of care. These strategies often include measures to increase access to palliative care services, improve training for healthcare professionals and enhance public awareness of palliative care.

**The promotion of advance care planning:** Advance care planning is a process that involves discussions between patients, their families and healthcare professionals about their preferences for end-of-life care. Many European countries are promoting the use of advance care planning as a way of ensuring that patients receive care that is aligned with their wishes and values.

**The development of palliative care networks:** Palliative care networks are collaborative partnerships between healthcare providers, patients and their families, aimed at improving the provision of palliative care. Many European countries have established palliative care networks as a way of enhancing the coordination of care and improving access to services.

**The integration of palliative care into mainstream healthcare:** There is growing recognition of the importance of integrating palliative care into mainstream healthcare and many European countries are taking steps to ensure that this happens. This includes improving training for healthcare professionals, developing guidelines for the provision of palliative care and integrating palliative care services into hospitals and primary care settings.

**The use of technology to improve access to palliative care:** There is increasing interest in the use of technology to improve access to palliative care services, particularly in rural areas. This includes the use of telemedicine, mobile apps and other digital tools to support patients and their families.

Overall, there is a growing recognition of the importance of improving the provision of end-of-life care and palliative care in Europe and a number of policy developments are emerging as a result. These developments are aimed at enhancing the quality of care, improving access to services and ensuring that patients receive care that is respectful, compassionate and dignified.



# How are end-of-life and palliative care regulated across the EU?

End-of-life and palliative care are regulated across the European Union (EU) through a combination of national and EU-level policies and regulations. While healthcare is primarily a national responsibility, the EU has a role in supporting member states in ensuring access to high-quality care.

At the national level, each EU member state has its own regulatory framework for end-of-life and palliative care. These frameworks may include legislation, guidelines and standards that govern the provision of care. For example, some countries have established legal frameworks for advance care planning, while others have guidelines for the use of opioids for pain relief at the end of life.

At the European level, palliative care has been on the agenda of intergovernmental organisations since the 2000s:

The Council of Europe has issued several recommendations on palliative care: a recommendation on the organisation of palliative care (Recommendation Rec 24, 2003), a recommendation on the “Promotion of Human Rights of Older People” and an explanatory memorandum on Palliative Care (Council of Europe, 2014).

The World Health Organisation Regional Office for Europe issued a recommendation on “Better Palliative Care for Older People” in 2004, guidelines on “Palliative Care for Older People: Better Practices” in 2011 and a recommendation on “Strengthening of palliative care as a component of integrated treatment within the continuum of care” in 2014.

At the EU level, there are several key policy documents that guide the provision of end-of-life and palliative care. These include:

**The European Charter of Patients’ Rights:** The European Charter of Patients’ Rights sets out a number of principles that are relevant to end-of-life and palliative care, including the right to be treated with dignity and respect, the right to be involved in decisions about care and the right to access high-quality healthcare.

**The EU Framework for National Strategies on Palliative Care:** The EU Framework for National Strategies on Palliative Care was adopted in 2008 and provides guidance to member states on the development of national strategies for palliative care. The framework outlines a number

of key priorities for improving the provision of care, including improving access to services, enhancing the quality of care and promoting public awareness of palliative care.

**The Cross-Border Healthcare Directive:** The Cross-Border Healthcare Directive, adopted in 2011, provides EU citizens with the right to access healthcare services in other member states. This includes the right to access end-of-life and palliative care services.

**The EU Health Programme:** The EU Health Programme is a funding programme that supports the development of EU-level policies and initiatives in the field of health. The programme has supported a number of initiatives related to end-of-life and palliative care, including research projects, conferences and training programmes for healthcare professionals.

Overall, while healthcare is primarily regulated at the national level in the EU, there are a number of European/ EU-level policies and initiatives that support the provision of high-quality end-of-life and palliative care services. These policies and initiatives aim to improve access to care, enhance the quality of care and promote public awareness of the importance of compassionate end-of-life care.

However, a lot remains to be done so that high-quality end-of-life care is available and accessible to all in practice. Palliative care needs are still rarely fully covered, especially in the case of older people with complex chronic conditions. This situation derives from the fragmentation of our care systems, the lack of a person-centred approach and the late identification of palliative care needs. A recent research project funded by the European Union<sup>1</sup> provides an analysis of the situation and proposes a new model of palliative care based on training, early integration and personalised pathways.

In conclusion, the philosophical and political approaches to end-of-life care and palliative care in Europe are shaped by a variety of factors, including cultural, social and economic factors. The development of palliative care services in Europe has been a significant advancement in the provision of end-of-life care. Palliative care services provide holistic, person-centred care that meets the needs of the dying persons and their families and are designed to relieve suffering and enhance the quality of life.

However, despite the progress made in the development of palliative care services in Europe, there are still challenges that need to be addressed. These challenges include improving access to palliative care services, addressing the financial and workforce challenges facing the provision of care, ensuring that care is delivered in a way that respects the cultural and religious beliefs of the dying persons and their families and acknowledging the important role played by informal carers via adequate support measures.

Overall, the philosophical and political approaches to end-of-life care and palliative care in Europe are grounded in a shared belief in the importance of providing compassionate care that meets the needs of the dying persons and their families. By continuing to work towards improving access to high-quality end-of-life care, we can ensure that everyone has the opportunity to receive care that is respectful, compassionate and dignified.

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1. [InAdvance Project \(2019-2023\)](#)



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