



# Narrative review: what constitutes contemporary, high-quality end-of-life care and can lessons be learned from medieval history?

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**Background and Objective:** In modern Britain, palliative and end-of-life care is governed by quality standards and guidance, which should consider spiritual and psychological needs. However, there are significant gaps in provision of services which was highlighted during the coronavirus disease 2019 (COVID-19) pandemic where many individuals and families suffered profound spiritual and existential distress. Significant gaps remain in the provision of services to support patients with spiritual and psychological needs which can affect the management of physical symptoms. During the medieval period in Western Europe, it was important to prepare well for death throughout life. It has been suggested that lessons may be learned from medieval preparations for death which might benefit those approaching end-of-life in contemporary society. It is therefore timely to consider medieval attitudes to death and reflect on how these might inform modern end-of-life care. The objective of this review is to synthesise literature addressing modern end-of-life care in the UK and contrast this with literature on preparations for death during the medieval period in Western Europe. Our aim is to determine whether there is wisdom to be gained from history which could inform our approaches to end-of-life care today.

**Methods:** Using online databases and broad keyword searches along with experts in the field of medieval history, we identified literature and translations of texts with a focus on preparations for death during both periods. These were narratively synthesised and discussed.

**Key Content and Findings:** A key finding is that the medieval attitude to death was as an integral part of life, whereas in modern society death is not usually considered until the situation arises. The review highlights a need for a better understanding of the individuality of spiritual and existential needs during end-of-life care in modern society, which will vary according to individual choice, culture, societal group, religion, and belief.

**Conclusions:** The lessons we can learn from our medieval counterparts include the need for lifelong and individual preparations for the end of life, with emphasis on spiritual needs. Alongside palliative interventions, we need to take time to appreciate what gives individuals spiritual support and provide the resources to facilitate this.

**Keywords:** End-of-life care; dying; medieval; historical; review

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## Introduction

### Background

In modern Britain, end-of-life care is defined as the final 12 months of life (1), and is a period when palliative, rather than curative, treatment is given. The modern hospice movement started with Dame Cicely Saunders [1918–2005], who opened St Christopher's Hospice in 1967. Initially, hospice care was a nurse-orientated environment, but the need for medical input eventually led to the establishment of modern palliative care as a specialty in 1987. From the beginning, Dame Cicely Saunders recognised that psychological issues were a core aspect of care. She defined 'total pain' as encompassing physical, psychological, social, spiritual, and practical struggles (2,3) and stated that the emphasis of end-of-life care should be "Living until you die" (4). Today, end-of-life care is directed and measured by quality standards and guidance, approved by The National Institute for Health and Care Excellence (NICE) (5) and used in palliative care settings both within the hospice sector and primary care. This guidance includes a holistic needs assessment, which involves consideration of "...all aspects of a person's wellbeing, their spiritual and health and social care needs" and would normally be overseen by a generalist medical team unless the patient requires specialist palliative care (5). However, access to holistic needs assessment and psychological support has been shown to be patchy and inequitable across the United Kingdom (UK) (6,7).

Modern living is increasingly dominated by advances in technology and medicine, including specialised palliative care provision and increased potential for prolonging life. This has changed the way families and communities function and interact, leading to changes in attitudes and beliefs (religious and secular) surrounding death and dying. Historically, attitudes to death were very different and it is useful to explore historical approaches to death and dying to help us understand the integration of death into everyday lives and how this promotes an emphasis on the spiritual needs of those reaching the end of their lives.

Examination of the medieval era in Europe (c. 450 AD – 1500 AD) might suggest that high rates of mortality meant that death was an everyday occurrence and therefore possibly regarded as a banal event; when in fact, death was

at the centre of medieval life. During the medieval period, approximately 90% of people worked the land as serfs who paid rent to overlords. Most people were poor and lived in small, interdependent village communities. The Latin Christian church was central to life for both rich and poor. During this time, the first European universities were established, and physicians were trained but had strong ties to towns and cities, and to the Christian Church, especially in northern Europe. Generally, only the rich could afford the care of the university-trained practitioner. During this time, the purpose of life was regarded as a preparation for death and the afterlife in Christianity, although across Europe there was a diversity of beliefs. Orthodox Christianity (8), Judaism (9,10) and Islam (11,12) had important beliefs to consider and had their own rituals and traditions in preparation for, and following, death. Even within Christianity there were variations in belief and ritual depending on wealth, culture, location, and tradition. Medieval Christianity was not necessarily the homogenous culture that is portrayed by authors such as Dickerson *et al.* (13).

The 15<sup>th</sup> century *Ars Moriendi* (the Art of Dying Well) is a body of Catholic literature of unknown authorship but was probably written in southern Germany. It provided information on what was required for a Christian 'good death' during the medieval period (14,15). This followed on from earlier guides to dying and death which originated in a monastic context (16,17). Whereas the *Ars Moriendi* was probably aimed at the elite of society, mendicant friars (usually Dominican or Franciscan) also provided end-of-life care for poorer people, and every town in Europe had either an alms-house or small hospital providing support and preparation for death (18–20).

It has been suggested by others that lessons may be learned from medieval preparations for death which might benefit those approaching end-of-life in contemporary society (16,21–23). Such approaches have been adapted and utilised within the Dutch and Belgian palliative care systems but not widely adopted. Understanding of the '*Ars Moriendi*' could provide useful and forgotten tools for shaping an understanding of what is needed for high-quality end of life care. Other, less well-known guidance could also provide useful insights from historical sources.

**Table 1** Search strategy summary

Items	Specification
Date of search	14 July 2023–18 August 2023
Databases and other sources searched	MEDLINE (via OVID), EmBASE, CINAHL, JSTOR, The International Medieval Bibliography ( <a href="https://www.brepols.net/series/imb-o">https://www.brepols.net/series/imb-o</a> ), Regesta Imperii OPAC ( <a href="http://opac.regesta-imperii.de/lang_en/">http://opac.regesta-imperii.de/lang_en/</a> )
Search terms used	Broad searches of each database were conducted using keywords and free text. Medical databases were searched using MeSH descriptors  Keyword/free-text search: “good death”, “dying well”, “death and dying”, “end of life”, “Ars Moriendi”  MeSH descriptors: “Death”, “Attitude to death”, “Palliative care”
Timeframe	All literature from inception to August 2023
Inclusion criteria	Searches were restricted to English-language texts and translations only
Selection process	C.A.P., E.J.C., A.T.P., and I.M. conducted searches and assembled the data. Literature was searched independently. Consensus was achieved through discussion
Additional considerations	Expert opinion within the author team was consulted for seminal texts

### ***Rationale and knowledge gap***

Despite huge advances in modern medicine over the past century, end-of-life care and symptom management are still not optimal for many patients. The biomedical paradigm, which promotes a view of the body in a mechanistic way, where the mind and body are separate entities, remains a significant influence in modern medicine, resulting in a medicalised approach with its emphasis on quantitative outcomes and indicators (24). This approach diminishes the importance of the psychological, spiritual, existential, and emotional needs of patients and carers which are nevertheless an essential part of achieving both high quality death (23,25), and an acceptance of it (26). We ask whether this can be improved by incorporating wisdom from history to inform a more holistic approach within the context of post-pandemic 21<sup>st</sup> century Britain.

### ***Objectives***

This narrative review discusses and synthesises literature addressing modern end-of-life care in the UK, highlighting gaps in the provision of high-quality holistic care and inequalities in access to it. This is contrasted with literature on what was regarded as a well-prepared death during the medieval period in Western Europe. We examine attempts to modernise and apply the principles found in the *Ars Moriendi* and debate whether there is other wisdom to be gained from history which could inform our approaches to

end-of-life care today. We present this article in accordance with the Narrative Review reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-552/rc>).

### **Methods**

Literature for this narrative review was sourced from a broad keyword search of relevant online databases, including MEDLINE (via OVID), EmBASE, CINAHL, The International Medieval Bibliography (<https://www.brepols.net/series/imb-o>), Regesta Imperii OPAC ([http://opac.regesta-imperii.de/lang\\_en/](http://opac.regesta-imperii.de/lang_en/)) and JSTOR to identify key articles and reviews, limited to texts in the English language, or translations. Broad key search terms included “end of life”, “dying well” and “good death” (*Table 1*). Experts in the fields of palliative and end-of-life care and medieval history were also consulted to identify seminal works which would contribute to our discussion. Some of the historical texts were translations from Latin and other medieval languages. Literature was included if it considered preparations for death with a focus on spiritual (religious or secular), emotional or psychological wellbeing as well as physical health and care needs. Literature was critically assessed for its suitability for inclusion and for its quality and impact. Included articles were narratively synthesised and compared with other evidence, identifying any inconsistencies or contradictions.

**Table 2** Conditions required for a good death (24)

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Relief from physical pain and symptoms
Effective communication and relationships with health-care providers
Performance of cultural, religious, and spiritual rituals
Relief from emotional distress and psychological suffering
Autonomy with regards to treatment-related decision making
Dying at the preferred place
Not prolonging life unnecessarily
Awareness of the deep significance of what is happening
Emotional support from family and friends
Not being a burden on anyone
Right to terminate one's life

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## Modern and medieval end-of-life care examined

### *Modern end-of-life care*

Recent evidence from studies, systematic reviews and reports provides a contextual background to modern end-of-life care and the constraints imposed by limitation of resources and the recent global coronavirus disease (COVID-19) pandemic. Evidence also reveals the continued existence of inequalities for marginalised and minority societal groups.

### Evidence from systematic reviews

In 2021, Zaman *et al.* published a systematic review of systematic reviews (conducted in 2020), asking the question: 'what would it take to die well?' (24). The authors considered the conditions required for a 'good death'. Data was extracted from 13 reviews, including 7 studies from the United States of America, 2 from Canada and one each from UK, Australia, Singapore, and Colombia. Thirteen themes were extracted (Table 2).

Zaman *et al.* argue that in the modern-day context suffering at end-of-life may be related to the commonplace medicalisation of death. Three of these conditions (relief from physical pain and other symptoms, not prolonging life unnecessarily and the right to terminate one's own life), are at least in part influenced by the availability (or not) of medical interventions. The modern era has also seen ongoing legal and ethical debates about assisted dying, although these are outside the scope of the current review. Zaman *et al.* concluded that many

of the identified conditions required for a good death could be offered towards the end-of-life without the need for costly medicalised infrastructure or specialised knowledge. Recent evidence suggests that better quality of end-of-life care is more likely to be achieved with good continuity of primary care as evaluated by the opportunity to see a preferred general practitioner (27), which would provide an opportunity to meet Zaman's condition of effective communication and relationships with healthcare professionals.

More recently, Wang *et al.* considered a 'good death' specifically from the perspective of patients with advanced cancer (28). Their systematic review of 4 qualitative studies from Taiwan, Hong Kong, Sweden and England, found 7 synthesised factors; (I) being aware of cancer, (II) pain and symptom management, (III) dying well, (IV) being remembered after death, (V) individual perspectives of a good death, (VI) individual behaviours to lead a good death and (VII) culture and religions. These authors highlight that the process of a 'good death' is initiated from the time of diagnosis (28), justifying the current drive for earlier integration of palliative care support. Wang *et al.* view a good death as being shaped by both external factors such as the medical care for symptom management plus the internal attributes of the person such as their individual perceptions and behaviours; reiterating the position that a holistic approach encompassing physical and psychosocial support is needed to promote a good death experience (29-31).

### Spirituality and the needs of the dying patient

The Lancet Commission report on the value of death in 2022 responded to the imbalances and paradoxes surrounding dying in 21<sup>st</sup> century. The report proposed several principles to address these imbalances and over-medicalisation of death and dying (32). These principles included a recognition that dying is a spiritual event, not just a physiological phenomenon, and that it has meaning and value. The importance of families and communities in this process was also recognised. Spirituality is a very personal characteristic and encompasses all that makes us human; what gives us joy, sadness, hope and despair. Nevertheless, spirituality is still one of the most neglected areas of palliative care (33) and if it remains unaddressed, can affect management of other symptoms (34).

Richardson argued that dying individuals from all cultures and religions want to experience death with dignity, having ensured that their legacy is as they would want it (34). The only difference being how they go about

achieving this. In modern times, dying is often a battle against physical symptoms, which the medical profession is trained to prioritise (21,23). Despite this emphasis on death as a physiological phenomenon, health care professionals, particularly those trained in palliative care, are acutely aware of the importance of the psychological and spiritual needs of the dying patient and are well placed to help patients and their families explore these issues (34-37). However, barriers to the provision of this type of support include the availability of trained staff, adequate time for health professionals to address spiritual concerns, lack of privacy and poor continuity of care (34). It is therefore difficult, in our modern multicultural society, for healthcare professionals to attend to the wellbeing of patients who might have diverse cultural, religious or spiritual needs (38).

### Access to palliative end-of-life care

Across the UK there are inequalities in access to high-quality end-of-life care with a large proportion of individuals from different ethnic and minority societal groups being unable to spend the remainder of their lives in a place, or manner of their choice (39). Hospice care remains largely the domain of white, middle-class people with little representation from minority ethnic groups and LGBTQ+ communities (40-42). There is also inequitable provision of high-quality palliative care for patients suffering from psychiatric illnesses with or without other terminal conditions (43,44). This leaves already marginalised groups disproportionately impacted by lack of access to high quality end-of-life care.

Even for those who do receive support, this tends to take the form of (often Christian) religious support (via chaplaincy), counselling and pre-bereavement or bereavement support for families (34). Some hospices have psychological and psychiatric support, but this is not common and recent surveys have revealed significant gaps in screening and provision which may contribute to distress, anxiety, and depression, which can adversely affect symptom management (6,7,45). Frequently, the voluntary sector provides support services such as outpatient groups and complementary therapy sessions, but this is variable and depends entirely upon the voluntary network and expertise available.

### Impact of the COVID-19 pandemic

The COVID-19 pandemic highlighted widespread gaps and deficiencies in provision of psychological and spiritual support in the modern era (46). In the UK alone, there were more than 130,000 excess deaths reported in the

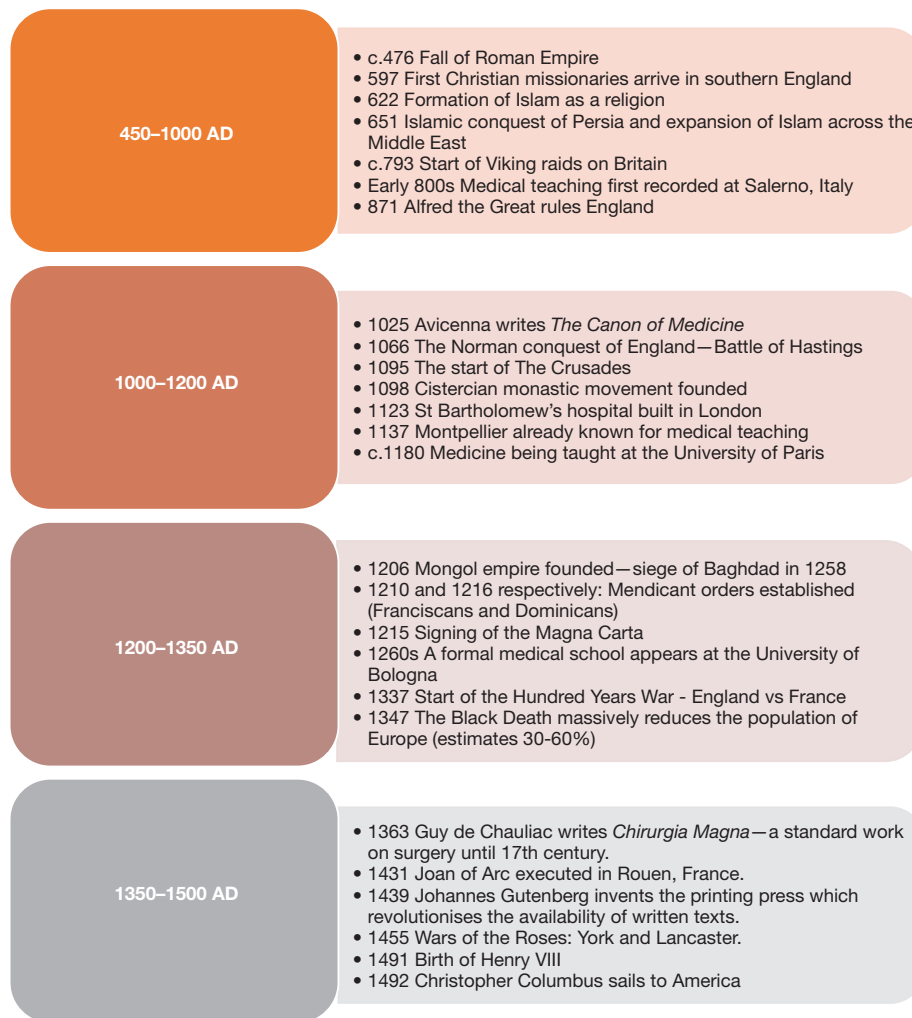
period March 2020 to June 2022 with a disproportionate number of these within ethnic minority communities (47). This placed a huge burden on end-of-life care which was exacerbated by the closure of all but essential services. During the period January 2020 and September 2021, there were 57,000 more home deaths than expected, and an estimated 8,000 fewer hospice inpatient deaths (47). During this time, dying alone and isolated with no choices about how and where death would occur became a stark reality for many people. The delivery of care has also changed because of the pandemic, with many more episodes of palliative care being delivered within the home setting or online (48). Remote delivery of care further served to heighten disparities and depersonalise the experience for some individuals and isolated family members (49). Since the global pandemic and subsequent economic downturn, health services across the UK have been deeply affected. Ever-widening variations and inequity in access to high quality palliative care have been highlighted, together with a lack of resources and poor integration of services for those with life-limiting conditions (50).

### *End-of-life care in the medieval period*

Historical information from the medieval era (or Middle Ages) is frequently available from second-hand accounts because many people were illiterate. In Europe, those who had access to an education were either from monastic communities and convents, or the very rich. These texts included biographies, medical texts, and information related to mostly Christian rituals, although there were learned texts from Islamic and Jewish culture. Many of the medical texts were translated into Latin from the 12<sup>th</sup> century (51). These texts were based on the medicine of Galen and Avicenna, set within a strong philosophical framework.

### Introduction and context

In the medieval era birth and death were inextricably linked because of the high child mortality rates and deaths of mothers during or after childbirth. From the fourteenth century, plague brought disease to the whole of society, including rich and poor, and highlighted the importance of good preparation for death, especially during the pandemic known as the Black Death [1347-1352] which it is estimated killed 30-50% of people in Europe, North Africa, and the Middle East. People died quickly, often unprepared, and unable to receive proper burial. However, there were cases of rivers being consecrated in order that they could be used



**Figure 1** Major events during the medieval period.

to dispose of bodies and efforts were made, even with mass graves, to ensure that the dead were given an acceptable burial (52). There were, in fact, multiple global outbreaks of plague from the 13<sup>th</sup> century onwards (53).

A contextual timeline showing some of the noteworthy events during the medieval period is shown in *Figure 1*.

### Dying well in the medieval era

Medieval guides to dying and death originated in a monastic context but eventually became a part of wider pastoral care. The mendicant orders of friars, usually Franciscans and Dominicans, preached within society during the 13<sup>th</sup> century and provided spiritual assistance to the dying (16). During that period, manuscripts such as *La Somme des Vices et Vertus* (The Sum of Vices and Virtues, 1279) were written

by Dominican friar Lawrence of Orleans. Poems such as the *Vers de la Mort* (Verses of Death) by the monk Hélinant of Froidmont were also written during the late 12<sup>th</sup> century to warn individuals to live a pious life or face eternal damnation (54,55).

Medieval life was organised around rituals and practices meant to prepare a person for their death and those of others. Most research has focused on these rituals and on burial and commemoration. Medieval people grieved and felt loss, just as individuals do today. The depth of a father's grief for his dead daughter during the medieval period was eloquently described in the Pearl Poem (56). Also, as with their modern counterparts, dying individuals desired succour, amelioration of pain and other unpleasant symptoms (57-59), and they wanted comfort in the face

of their immediate fears about death (60,61). Christians wanted a 'good death' in their own homes, receiving the last rites and being surrounded by family and friends, although sometimes it was thought that grieving family could distract from a proper pious end (21,62). Despite a lower life expectancy, there was still hope for a long life and a pain free ending. They feared dying without proper preparation for the afterlife and for those left behind (63). Preparation for death not only included confession and other religious rituals, but also the making of wills, settling family and business affairs, and a proper burial. These desires are also evident in literature from other religions, such as Judaism (64). Similarly, in Islamic tradition, proper preparation for the afterlife (*al-ākhirah*) involved making peace with one's neighbours and seeking redemption for sins (65,66).

The 15<sup>th</sup> century *Ars Moriendi* (the Art of Dying Well) provided information for Christians on what constituted a good and holy death during the medieval period (14,15). It was originally produced in long form in c. 1415 and in shorter form in c. 1450 and was a series of block book woodcuts from Germany (long version) and the Netherlands (short version). Although the *Ars Moriendi* included images that could have been understood by the illiterate, it was largely provided as a guide to death for the elite and wealthy. These were the same people who could also have afforded the bedside care of a personal physician able to alert them when their time drew near (67). It explained how to die well according to Christian protocol and teaching and how to avoid various temptations which would lead to an eternity in hell. It is a guide to help prepare for death in the hope that this would shorten the time spent in purgatory and ensure the soul safe passage to heaven.

The doctrine of purgatory initiated a shift in attitudes towards death and the relationship between life and death, and the living were encouraged to meditate upon death (55). The idea of purgatory as an intermediate place between heaven and hell was important in Latin Christianity. Purgatory gave individuals the opportunity to be cleansed of their sins before entering heaven and there was a clear connection between the living and the dead where the living could intercede by offering up prayers, masses, and alms in order to ease the passage of the dead into heaven (55). The aim was to limit time spent in purgatory before going to heaven and righteousness was a small price to pay for the prospect of eternal bliss (68,55,61). Those with the means to do so were known to pay others for intercessory prayers and rituals (55).

### Preparations for death during life

Preparation for death was expected to be done throughout life, as referred to in the Latin phrase: 'Ars moriendi ars vivendi est' (i.e., the art of dying is the art of living). It could therefore be argued that end-of-life was lifelong in the medieval period. The fate of the soul after death was key to understanding attitudes to and preparations for death (and burial) and the rituals that went alongside it (13). The soul was more important than the living body and people were terrified of eternal damnation (Christian religious view). Deathbed confessions were expected, i.e., to make peace with God through the last rites, and the dying individual would ensure that his affairs were in order.

Within the Christian religion, those who had the means would pay for others to offer up prayers for them, even after death, in the hope of lessening their time in purgatory. Poorer people were catered for on All Souls Day on November 2<sup>nd</sup> each year when prayers beseeched God to look kindly on all the dead.

### Medical care for the dying

A lot of medieval medicine has been regarded as palliative rather than curative, providing long term care for the chronically ill such as people suffering from leprosy/Hansen's Disease (69). Being symptom-free was not of primary importance (70), although that is not to say that people did not seek relief from unpleasant symptoms such as pain, and individuals in great pain might have wished for death to provide relief from it (71). Pain relief of some kind was available during this time, as has been found through the discovery of plant-based recipes in the 11<sup>th</sup> Century Old English Herbal, such as Dwale, which was an early anaesthetic, and the use of hemlock and opium (58,72). It is likely that people will have sought relief from symptoms such as pain from a variety of sources, including physicians (if they could afford it), the church, early apothecarists, home remedies and through visits to a local healer or an Anchorite (sometimes termed 'wise woman' or 'cunning person') (73).

Relief from symptoms was often synonymous with 'miracle' cures and the sudden recovery of the moribund was a common theme (71,74). There are testimonies such as accounts of the miraculous recovery of newborn infants who were thought to be dead at birth (75) and the miraculous healing of children with seemingly fatal injuries (76), although in the latter case the author discusses the interweaving of natural healing and sacred factors in these 'miracle' events.

Medieval families or extended families would usually

live together in the same dwelling, and during the plague, families were conflicted between remaining with the dying person and inevitably becoming infected themselves or leaving in an attempt to avoid infection. They would flee if they could or alternatively shut themselves up with other family members. Individuals rarely lived alone in the Middle Ages, and those who did were probably subject to stigma and financial hardship (77), unlike the modern period when the 2022 census data showed over 8 million people in England and Wales over 16 living alone, representing a third of all households (78). A bad death in the medieval era occurred when the individual had no thoughts of eternal salvation or died before receiving the last rites without confessing/contrition, without making peace with friends, relatives and neighbours or being intestate or in debt (63).

### Final preparations for death

For Christians, even unexpected deaths (*Mors improvisa*) were prepared for if possible, and not feared. Even lay people prepared when death was thought to be near (79). A confession to a layperson was preferable to nothing in an emergency, "...even to a woman if a man is not available." Lay people were reminded about this during the plague of the mid-14<sup>th</sup> century because so many of the clergy were struck down by the disease (80).

Deathbeds were public occasions with family and friends present (81). They were expected to gather at the dying individual's bedside. Phillipe Ariès wrote about death: "It was also a public ceremony. The dying man's bedchamber became a public place to be entered freely" (82). Within Jewish and other religious traditions, death was also a very public occasion (64).

Medieval preparations for death throughout the lifecycle were carried out against the backdrop of a mostly poor society suffering from untreatable infections and trauma from environmental hazards and a lack of access to hygiene and medicines. People were aware of the need for hygiene, but the cost of fuel to heat hot water for bathing and cleaning was expensive and therefore inaccessible for most. Nevertheless, it has been argued that the ritual, prayer, and beliefs about a better afterlife reduced the fear of death (83), although it is difficult to source information about these rituals for the poor of society.

### Can history inform modern practice in end-of-life care?

The *Ars Moriendi* and other religious practices provided guides and principles to follow within a Christian tradition

and belief-system. At the outset, it would seem difficult to adapt and apply the principles to modern society with so many diverse cultures, social groups, and religious beliefs.

Within the Dutch and Belgian healthcare systems the principles of holistic and spiritual care within the medieval *Ars Moriendi*, were modernised, and put into practice in palliative care settings (22). However, Leget and other authors have not considered any other medieval evidence for end-of-life care, such as that provided by the friars to the poor in society, or the care and preparations for death within other religious contexts, such as Buddhism, Judaism and Islam, or marginalised societal groups. It is also important to recognise that Leget's article was published very soon after the Belgian Euthanasia Act and was received into a society where the palliative care sector was still coming to terms with this significant shift in policy.

Leget's approach was to apply the *Ars Moriendi* to five modern secular themes: Autonomy, Pain Control (suffering), Attachment and Relations, Guilt and Evil and The Meaning of Life (hope) (22). These secular principles have since been utilised effectively within the Dutch and Belgian health systems, where spiritual and emotional aspects of palliative care are recorded in a file after an individual discussion with each patient, thus providing autonomy and choice about the manner of their death (22). Despite this, there remains a lack of a commonly shared view on a good death across other European countries, although there is a general understanding that for every individual a good death will be different. Leget has since argued that change is needed not just at the micro level of the patient, but at the wider cultural level where a shift is needed, especially in the absence of a shared spiritual belief system (23). It is in the wider cultural environment that the dying person can anchor themselves and avoid the loneliness and isolation of dying, which was highlighted so starkly during the COVID-19 pandemic.

These issues were explored in a systematic review in 2016 where other authors discussed parallels between the medieval *Ars Moriendi* and modern literature about end-of-life (16). The concept of death anxiety is discussed, and it is suggested that in the modern days of secularism and presence of a wide range of religions and belief-systems, the tools for coping with death anxiety are frequently absent or insufficient. This is discussed by Ruys who considers gradual modification of the *Ars Moriendi* so that it no longer puts the fear of hell into dying, as this serves to be counterproductive for achieving a good death (62), a view supported by Gerrard and Petley as already



discussed (83).

The elements of a good death have more recently been examined by Collier and Chapman, who went on to discuss how the COVID-19 pandemic had brought death and dying back into focus and suggest that policy and practice should shift towards ‘matters of care’ (70). Pollock and Seymour also advocate a process of responding to ‘care need’ but caution against making a ‘good death’ a matter of policy because it ends up being a form of social control and results in a loss of autonomy and choice (84). Recognition of individual needs, beliefs and culture requires a uniquely individual approach.

The impact of poverty and deprivation merit consideration here as they are significant in affecting how, where, and sometimes when people die. A critical review by Rowley *et al.* revealed that there are gaps in our understanding of dying within poverty and deprivation, especially within the context of other social determinants and prejudice such as racism, sexism, homo/transphobia, and ableism (85). We need to be aware that by defining what a ‘good death’ looks like we are immediately marginalizing those who have different belief systems or cultures. For example, in some religions and cultures, suffering and pain are important and provide a means of showing godliness. In a study of South Asian communities in the UK, participants gained internal strength from their faith and used religiously accepted methods of pain relief with great significance as they believed this to be a blessing (86). Coret *et al.* recognised that most of our ideas on a good death come from cancer studies and these might not be relevant for those with other diseases with more uncertain trajectories, such as heart disease or dementia (29). They also observe that a good death should not be the medicalised, often negative modern experience but rather a peaceful, comfortable time, where the dying person is not alone and where dying is not prolonged unnecessarily.

Pentaris and Thomsen conducted a qualitative study examining the strong relationships between cultural and religious identities and the experience of dying, and how these identities must be considered on an individual basis in end-of-life care if the needs of the dying patient are to be met (87). This requires a shift in organisational culture and changes in social policy in addition to bottom-up changes in professional attitudes to, and understanding of, diverse cultures and religious practices. This suggests that changes in the training of healthcare professionals should include holistic approaches to end-of-life care and cultivate a person-centered understanding of individual needs within

different religious, cultural, and societal contexts.

## Conclusions

We have described and discussed literature considering approaches to end-of-life care and preparation for death both during the medieval era and modern day. Although medieval sources are largely based on Latin Christianity, we have observed similar principles in end-of-life care and preparation for death within other religions and communities.

A key point that has arisen during this review is the need for an understanding of death as an integral part of life. We suggest that there is a need to re-familiarise our society with death and dying and this understanding should be implemented from an early age. Currently in the UK, there is a policy recommendation for grief and death education within schools at an age-appropriate level, but this is not yet an essential part of the curriculum, even though, almost every child has experienced some form of grief before the age of 16 (88). Particularly during the COVID-19 pandemic, children and families were exposed to death and bereavement on a huge scale and many were unprepared for it, as reported by the UK Commission on Bereavement (<https://bereavementcommission.org.uk/>).

Secondly, we suggest that there is a training requirement for health professionals in better understanding the individuality of spiritual and existential needs during end-of-life care, which will vary widely according to individual choice, culture, societal group, religion, and belief (89).

In summary, the lessons we can learn from our medieval counterparts include the need for lifelong and individual preparations for the end of life, with more emphasis on spiritual needs, especially when it is known for certain that an individual is facing death. Alongside any necessary palliative medical intervention, we also need to take time to appreciate what gives individuals spiritual support and provide the resources to facilitate this.

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## References

1. MarieCurie. What is end of life care? London, UK: Marie Curie; 2022 [updated 1 May 2023]. Available online: <https://www.mariecurie.org.uk/help/support/terminal-illness/preparing/end-of-life-care>
2. Richmond C. Dame Cicely Saunders. *BMJ* 2005;331:238.
3. Wood J. Cicely Saunders, 'Total Pain' and emotional evidence at the end of life. *Med Humanit* 2022;48:411-20.
4. Saunders C. The evolution of palliative care. *J R Soc Med* 2001;94:430-2.
5. NICE. End of life care for adults. End of life care. London UK: National Institute for Health and Care Excellence; 2011, updated 2021.
6. Paley CA, Keshwala V, Arango MF, et al. editors. Evaluating provision of psychological assessment and support in palliative care: A national survey of hospices in England. *Prog Palliat Care* 2024;32:11-21.
7. McInnerney D, Candy B, Stone P, et al. Access to and adequacy of psychological services for adult patients in UK hospices: a national, cross-sectional survey. *BMC Palliat Care* 2021;20:31.
8. Steindorff L. Death, Burial and Remembrance: The Christian Orthodox Tradition in the East of Europe. In: Booth P, Tingle E, editors. *A Companion to Death, Burial, and Remembrance in Late Medieval and Early Modern Europe, c 1300-1700*. Leiden, The Netherlands: Brill, 2020:225-48.
9. Rubin SS. Loss and mourning in the Jewish tradition. *Omega (Westport)* 2014-2015;70:79-98.
10. Reif SC, Lehnardt A, Bar-Levav A. *Death in Jewish Life: Burial and Mourning Customs Among Jews of Europe and Nearby Communities*. Berlin: De Gruyter; 2014.
11. Halevi L. *Muhammad's Grave: Death Rites and the Making of Islamic Society*. New York: Columbia University Press; 2011:416.
12. Lange C. *Paradise and Hell in Islamic Traditions*. Cambridge: Cambridge University Press; 2015.
13. Dickerson MGA, Conlon D, Raeburn T. *Ars Moriendi: An Overview of Approaches to the Art of Dying, Grief and Loss for Nurses Working in Mental Health*. *Issues Ment Health Nurs* 2023;44:27-34.
14. Rylands WH, Bullen G. *The Ars Moriendi (editio princeps, circa 1450): a reproduction of the copy in the British Museum*. London: Holbein Society; 1881:86.
15. Unknown. *The Ars Moriendi, editio princeps*. In: Rylands W, editor. *The Ars Moriendi: a reproduction of the copy in the British Museum*. London UK: Wyman and Sons; circa 1450.
16. Espi Forcén F, Espi Forcén C. *Ars Moriendi: Coping with death in the Late Middle Ages*. *Palliat Support Care* 2016;14:553-60.
17. Paxton FS. *Signa mortifera: death and prognostication in early medieval monastic medicine*. *Bull Hist Med* 1993;67:631-50.
18. Davis AJ. *The Medieval Economy of Salvation: Charity, Commerce, and the Rise of the Hospital*. New York: Cornell University Press; 2019:336.
19. Watson S. *On Hospitals: Welfare, Law and Christianity in Western Europe, 400-1320* Oxford, UK: Oxford University Press; 2020:376.
20. Henderson J. *The Renaissance hospital. Healing the body and healing the soul*. New Haven, US: Yale University Press; 2006. xxxiv + 458 p.
21. Thornton K, Phillips CB. Performing the good death: the medieval *Ars moriendi* and contemporary doctors. *Med Humanit* 2009;35:94-7.
22. Leget C. Retrieving the *ars moriendi* tradition. *Med Health Care Philos* 2007;10:313-9.
23. Leget CJW. *A New Art of Dying as a Cultural Challenge*. *Studies in Christian Ethics* 2016;29:279-85.
24. Zaman M, Espinal-Arango S, Mohapatra A, et al. What would it take to die well? A systematic review of systematic

- reviews on the conditions for a good death. *Lancet Healthy Longev* 2021;2:e593-600.
25. Rentfro D. A Good and Holy Death: *Ars Moriendi* and the Battle of Wit versus Truth. *New Blackfriars* 2022;103:730-44.
  26. Zimmermann C. Acceptance of dying: a discourse analysis of palliative care literature. *Soc Sci Med* 2012;75:217-24.
  27. ElMokhallalati Y, Chapman E, Relton SD, et al. Characteristics of good home-based end-of-life care: analysis of 5-year data from a nationwide mortality follow-back survey in England. *Br J Gen Pract* 2023;73:e443-50.
  28. Wang G, Xiao J, Chen Z, et al. Good death from cancer-the patient view: systematic review of qualitative studies. *BMJ Support Palliat Care* 2023. doi: 10.1136/spcare-2022-004146.
  29. Coret M, Martimianakis MAT. Conceptualizations of "good death" and their relationship to technology: A scoping review and discourse analysis. *Health Sci Rep* 2023;6:e1374.
  30. Miyashita M, Morita T, Sato K, et al. Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manage* 2008;35:486-98.
  31. Curtis JR, Patrick DL, Engelberg RA, et al. A measure of the quality of dying and death. Initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002;24:17-31.
  32. Sallnow L, Smith R, Ahmedzai SH, et al. Report of the Lancet Commission on the Value of Death: bringing death back into life. *Lancet* 2022;399:837-84.
  33. Quinn B, Connolly M. Spirituality in palliative care. *BMC Palliat Care* 2023;22:1.
  34. Richardson P. Spirituality, religion and palliative care. *Ann Palliat Med* 2014;3:150-9.
  35. Batstone E, Bailey C, Hallett N. Spiritual care provision to end-of-life patients: A systematic literature review. *J Clin Nurs* 2020;29:3609-24.
  36. Wierstra IR, Liefbroer AI, Post L, et al. Addressing spiritual needs in palliative care: proposal for a narrative and interfaith spiritual care intervention for chaplaincy. *J Health Care Chaplain* 2023;29:64-77.
  37. Chahrour WH, Hvidt NC, Hvidt EA, et al. Learning to care for the spirit of dying patients: the impact of spiritual care training in a hospice-setting. *BMC Palliat Care* 2021;20:115.
  38. Wong K, Camacho JHS, Dulani S, et al. Honoring Long-Lived Cultural Beliefs for End-of-Life Care: Are We Prepared in the Modern Western Society? *Cureus* 2022;14:e30313.
  39. HospiceUK. Equality in hospice and end of life care: challenges and change. London: Hospice UK; 2021.
  40. Leget C. Spirituality in Palliative Care. In: MacLeod RD, Van den Block L, editors. *Textbook of Palliative Care*. Cham: Springer International Publishing; 2019:689-99.
  41. Best MC, Vivat B, Gijsberts MJ. Spiritual Care in Palliative Care. *Religions* 2023;14:320.
  42. Tobin J, Rogers A, Winterburn I, et al. Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Support Palliat Care* 2022;12:142-51.
  43. Trachsel M, Irwin SA, Biller-Andorno N, et al. Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks. *BMC Psychiatry* 2016;16:260.
  44. Chochinov HM, Martens PJ, Prior HJ, et al. Comparative health care use patterns of people with schizophrenia near the end of life: a population-based study in Manitoba, Canada. *Schizophr Res* 2012;141:241-6.
  45. Chapman EJ, Pini S, Edwards Z, et al. Conceptualising effective symptom management in palliative care: a novel model derived from qualitative data. *BMC Palliat Care* 2022;21:17.
  46. Willis KD, Rao SR, Normen M, et al. Same storm, different boat: The global impact of COVID-19 on palliative care. *Psychooncology* 2023;32:148-54.
  47. APPG. The Lasting Impact of COVID-19 on Death, Dying and Bereavement. London, UK: APPG; 2023.
  48. Keeble E, Scobie S, Hutchings R. Support at the end of life: The role of hospice services across the UK. London: Research report, Nuffield Trust, 23/05/2022.
  49. Chunara R, Zhao Y, Chen J, et al. Telemedicine and healthcare disparities: a cohort study in a large healthcare system in New York City during COVID-19. *J Am Med Inform Assoc* 2021;28:33-41.
  50. HSIB. Variations in the delivery of palliative care services to adults. Healthcare Safety Investigation Branch; July 2023.
  51. Glaze F. Authority: Trusting the Text in the Early Middle Ages. In: McCleery I, Cooter R, editors. *A Cultural History of Medicine. 2: A Cultural History of Medicine in the Middle Ages*. London, UK: Bloomsbury Publishing; 2021:177-202.
  52. Arcini C, Price TD, Cinthio M, et al. Living conditions in times of plague. In: Lagerås P, editor. *Environment, Society and the Black Death. An interdisciplinary approach to the late-medieval crisis in Sweden*. Oxford: Oxbow Books; 2016:104-40.

53. Green MH. The Four Black Deaths. *The American Historical Review* 2020;125:1601-31.
54. McCulloch F. The Art of Persuasion in Hélinant's "Vers de la Mort". *Stud Philol* 1972;69:38-54.
55. Moreira I. Purgatory's Intercrossers: Bishops, Ghosts, and Angry Wives. In: Pollard RM, editor. *Imagining the Medieval Afterlife*. Cambridge Studies in Medieval Literature. Cambridge: Cambridge University Press; 2020:133-52.
56. Andrew M, Waldron R. *The Poems of the Pearl Manuscript: A Prose Translation*. Exeter, UK: University of Exeter Press; 2007.
57. Paley EG, Johnson MI, Paley CA. Understanding pain in modern society: insights from attitudes to pain in the Medieval Period. *Front Pain Res (Lausanne)* 2023;4:1162569.
58. Carter AJ. Dvale: an anaesthetic from old England. *BMJ* 1999;319:1623-6.
59. Carter AJ. Narcosis and nightshade. *BMJ* 1996;313:1630-2.
60. Ocker C. The Motion of Another's Death: Grief and Mourning. In: Booth P, Tingle E, editors. *A Companion to Death, Burial, and Remembrance in Late Medieval and Early Modern Europe, c 1300–1700*. Leiden, The Netherlands: Brill; 2020:368-92.
61. Raeburn G. Death and dying. In: Broomhall S, Lynch A, editors. *The Routledge History of Emotions in Europe 1100-1700*. 1 ed. London UK: Routledge; 2019:200-15.
62. Ruys JF. Dying 101: Emotion, Experience, and Learning How to Die in the Late Medieval artes moriendi. In: McNamara R, McIlvenna U, editors. *Medieval and Early Modern Emotional Responses to Death and Dying*. 31. Australia: Parergon; 2014:55-79.
63. van 't Land K. Long life, natural death. The learned ideal of dying in late medieval commentaries on Avicenna's Canon. *Early Sci Med* 2014;19:558-83.
64. Horowitz E. The Jews of Europe and the moment of death in medieval and modern times. *Judaism: A Quarterly Journal of Jewish Life and Thought* 1995;44:271.
65. Bagheri A. End of Life Issues: An Islamic Perspective. In: Emmerich N, Mallia P, Gordijn B, et al. editors. *Contemporary European Perspectives on the Ethics of End of Life Care*. Cham: Springer; 2020:93-103.
66. Schultz M, Baddarni K, Bar-Sela G. Reflections on palliative care from the Jewish and Islamic (with capital letters) tradition. *Evid Based Complement Alternat Med* 2012;2012:693092.
67. McCleery I. Medical Perspectives on Death in Late Medieval and Early Modern Europe. In: Krötzel C, Mustakallio K, editors. *On Old Age: Approaching Death in Antiquity and the Middle Ages*. Turnhout: Brepols; 2011:277-92.
68. Daniell C. *Death and Burial in Medieval England 1066-1550*. London: Routledge; 1997:264.
69. Brenner E. Between palliative care and curing the soul: medical and religious responses to leprosy in France and England, c. 1100 - c. 1500. In: Yoshikawa N, editor. *Medicine, Religion and Gender in Medieval Culture*. Cambridge, UK: D.S. Brewer; 2015:221-4.
70. Collier A, Chapman M. Matters of care and the good death - rhetoric or reality? *Curr Opin Support Palliat Care* 2023;17:208-13.
71. Kuuliala J. Infirmity and Death Wishes in Medieval French and Italian Canonisation Processes. In: Jones L, Varlik N, editors. *Death and Disease in the Medieval and Early Modern World: Perspectives from across the Mediterranean and Beyond*. Health and Healing in the Middle Ages. York: York Medieval Press; 2022:201-20.
72. Brunsch SH. Analgesic remedies in the Middle Ages. *Schmerz* 2007;21:331-8.
73. Licence T. Anchorites, Wise Folk and Magical Practitioners in Twelfth-Century England. *History* 2021;106:709-26.
74. Edwards JC. Medical and Spiritual Healing of Death and Disease in Medieval Miracle Stories. In: Jones L, Varlik N, editors. *Death and Disease in the Medieval and Early Modern World. Perspectives from across the Mediterranean and Beyond*. York: York Medieval Press; 2022:177-200.
75. Nissi J. Death in a Birth Chamber: Birth Attendants as Expert Witnesses in the Canonization Process of Bernardino of Siena. In: Katajala-Peltomaa S, Kuuliala J, McCleery I, editors. *A Companion to Medieval Miracle Collections*. Leiden: Brill; 2021:226-48.
76. Craig L. Describing death and resurrection: medicine and the humors in two late medieval miracles. In: Bowers B, Keyser L, editors. *The Sacred and Secular in medieval Healing: sites, objects, and texts*. AVISTA Studies in the history of Medieval technology, science and art. Oxon, UK: Routledge; 2016:103-42.
77. Schmidt A, Devos I, Blondé B. Introduction Single and the City: Men and Women Alone in North-Western European Towns since the Late Middle Ages. In: De Groot J, Devos I, Schmidt A, editors. *Single Life and the City 1200–1900*. London: Palgrave Macmillan UK; 2015:1-24.
78. *Families and households in the UK: 2022* London, UK:

- Office for National Statistics (ONS); 2023 [updated 18 May 2023. Statistical bulletin]. Available online: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2022>.
79. Lahtinen A, Korpiola M. Introduction: Preparing for a Good Death in Medieval and Early Modern Northern Europe. In: Lahtinen A, Korpiola M. *Dying Prepared in Medieval and Early Modern Northern Europe. The Northern World*. Leiden, The Netherlands: Brill; 2017:1-17.
  80. Horrox R. Document 87: A shortage of clergy. In: Horrox R, editor. *The Black death (Manchester medieval sources series)*. Manchester, UK: Manchester University Press; 1994:271-3.
  81. Gray M. Deathbed and Burial Rituals in Late Medieval Catholic Europe. In: Booth P, Tingle E, editors. *A Companion to Death, Burial, and Remembrance in Late Medieval and Early Modern Europe, c1300–1700*. Leiden, The Netherlands: Brill; 2020:106-31.
  82. Ariès P. *Western Attitudes Toward Death: From the Middle Ages to the Present*. Translated by Patricia M. Ranum. London, UK: Johns Hopkins University press; 1974.
  83. Gerrard CM, Petley DN. A risk society? Environmental hazards, risk and resilience in the later Middle Ages in Europe. *Natural Hazards* 2013;69:1051-79.
  84. Pollock K, Seymour J. Reappraising 'the good death' for populations in the age of ageing. *Age Ageing* 2018;47:328-30.
  85. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. *Palliat Care Soc Pract* 2021;15:26323524211033873.
  86. Clarke G, Crooks J, Bennett MI, et al. Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study. *BMC Palliat Care* 2023;22:90.
  87. Pentaris P, Thomsen LL. Cultural and Religious Diversity in Hospice and Palliative Care: A Qualitative Cross-Country Comparative Analysis of the Challenges of Health-Care Professionals. *Omega (Westport)* 2020;81:648-69.
  88. Dawson L, Hare R, Selman L, et al. Let's talk about death: All children in England should receive grief education at school. Bristol, UK: University of Bristol; 2023:Contract No.: 85.
  89. Murnane S, Purcell G, Reidy M. Death, dying and caring: exploring the student nurse experience of palliative and end-of-life education. *Br J Nurs* 2023;32:526-31.

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