

ISSUE FOCUS

Dying With Dignity and the Human Rights of Older Persons

ASEM Global Ageing Center





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We would like to express our gratitude to the AGAC Issue Focus Advisory Group—Jung-Hwa Ha at Seoul National University; Sabine Henning at the United Nations Economic and Social Commission for Asia and the Pacific; Mijin Lee at Konkuk University; and Margaret Young at the Global Alliance for the Rights of Older People. They provided general guidance on the outline and theme of this report.

Valuable insight and input were provided by the contributors to this issue—Dae Seog Heo at Seoul National University College of Medicine; Derya Nur Kayacan at the Turkish-German University; Rob Jonquière at the World Federation of Right to Die Societies; and Atsushi Asai and Hua Xu at Tohoku University Graduate School of Medicine.

We hope that this edition will inspire advocates for the human rights of older persons around the world and contribute to improving their quality of life and death, particularly with respect to the controversial issue of assisted dying, a matter of potential importance to everyone of us. It appears that the only thing we can agree on at the moment is the desire for a dignified ending. We urge the international community to discuss the issue in depth.

It is an exceptional honor to work with Issue Focus team members and collaborators and the global community to advance the human rights of older persons, ASEM Global Ageing Center's fundamental ambition. We thank you for your unwavering support with the cause.



Eun-Hee Chi

Executive Director, ASEM Global Ageing Center (AGAC)

AGAC ISSUE FOCUS ADVISORY GROUP

The AGAC Issue Focus Advisory Group is a group of experts focused on ageing and the human rights of older persons. They advise on the themes and topics of Issue Focus publications and provide feedback on the volumes. The advisors share their insights and views, bringing to bear expertise from around the world. Issue Focus addresses issues and agendas of ageing that are relevant to all ASEM partners.

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ISSUE FOCUS

CONTENTS

1	INTRODUCTION	Eunsun Lee
5	The Challenges of End-of-Life Care for Older Persons: A Human Rights Perspective	Dae Seog Heo
17	European Perspective on the Right to Die	Derya Nur Kayacan
29	Assisted Dying for Older People in the Netherlands: An Historical and Ideological Analysis	Rob Jonquière
41	Voluntary Assisted Dying: Japanese Perspectives	Atsushi Asai, and Hua Xu
53	APPENDIX · About ASEM	

INTRODUCTION

Eunsun Lee

ASEM Global Ageing Center

Omnes una manet nox. The notion that dying is an equalizer may appear valid at first glance; however, a closer look at our world reveals a different story. When 80 countries were analyzed across five categories to determine the quality of death of their citizens, wealthier countries dominated the top spots. (The United Kingdom was ranked the highest, followed by Australia and New Zealand.) The five categories on which the measurement was based were palliative and healthcare environments, availability of human resources (such as end-of-life care workers), affordability of care, quality of care, and levels of community engagement (such as public awareness and volunteering) (Economist Intelligence Unit, 2015). Regarding, for instance, access to analgesics for palliative care—such as an opioid morphine-equivalent—the situation is drastically and unjustifiably unequal; the estimated percentage of need that was considered to be adequately met was 0.2% for Afghanistan, 0.2% for Nigeria, and 0.8% for Haiti, compared with 870% for Western Europe, 1890% for Australia, and 3150% for the United States. Overall, individuals who died experiencing serious health-related suffering in 2015 were largely from developing countries (more than 80% of the people), and the majority of them did not have sufficient access to palliative care or pain medication (Knaul et al., 2018).

When Living Feels Hard

Even within countries, inequality exists in end-of-life care, particularly for vulnerable groups (e.g., ethnic minorities; homeless, imprisoned, and LGBTQ+ people; older people with frailty or dementia; people with lower socioeconomic status; people with disabilities or non-cancer diagnosis; and people with mental illness) (Dewhurst et al., 2023; Edwards et al., 2021; Hospice UK, 2021). Furthermore, in regions where universal health coverage is lacking, the high expense of end-of-life care treatment may push families into poverty (Sallnow et al., 2022).

With these abject realities in front of them, both domestically and globally, the public has been exposed to debates about assisted dying, with its demand linked to lost autonomy and dignity, degraded quality of life, dependency on others, and present and anticipated future suffering (Health Canada, 2023; Oregon Health Authority, 2023). However, although various polls have been conducted to gauge public opinion (e.g., Yun et al., 2022), the public's understanding of assisted dying appears to be less than ideal (Dying Well APPG, 2021). Attitudes change significantly, however, once people become aware of the complexities of the issue (Mangino et al., 2021), and the validity of the survey methodology has frequently been questioned (Magelssen et al., 2016).

Four Stories

The debate around older people's dying with dignity raises issues of cost (e.g., public funding that should be invested in palliative care) and potential societal impact (e.g., a shift in perspective on the meaning of life and the rationality of suicide). These issues, as well as injustices in current end-of-life provision, should certainly concern everyone. We believe that the public should be provided with an opportunity to participate in deliberation, which is "the process by which individuals sincerely weigh the merits of competing arguments in discussions together" (Fishkin, 2009, p. 33). In addition, they should be able to do so on an equal footing. This edition is our attempt to assist the process; we do not pretend to have been able to address all aspects of the debate.

It should be clear that we neither support nor oppose the definitions of dying with dignity, and the views, that are expressed in the four articles published in this edition. However, we wish to convey sincere respect to our contributors for their willingness to bear the burden of presenting their ideas in the public sphere, and for their courage in thereby facing public scrutiny and consultation.

Heo surveys key issues of end-of-life care for older people, calling for societal understanding and possible consensus. He points out that the terminology currently in use regarding dying with dignity does not serve the issue well—for example, what do we mean by death with dignity or natural death in the first place?—and that the ambiguity thus produced among professionals and the general public may reduce the quality of care for people at the end of their lives. Heo's comprehensive review covers unclear terminology problems; life-sustaining treatment decisions and their legal frameworks; hospice and palliative care; useful but potentially conflicting principles of medical ethics in medical decisions; and the ethical, legal, and cultural debates surrounding physician-assisted suicide and active voluntary euthanasia. He emphasizes that older people have the right to adequate information, authority in medical decisions, and decent treatment.

Kayacan summarizes practice in Switzerland and the Netherlands in relation to the right to die, and examines major cases filed to the European Court of Human Rights on this issue. Both the Netherlands and Switzerland have greater experience with assisted dying than other European countries; however, Kayacan suggests there are still concerns that arise. In Switzerland, for instance, lack of regulation may become a source of concern. She explains that when evaluating cases, the Court considers both Article 2 of the European Convention on Human Rights, which is about the right to life, and Article 8 of the Convention, which is about the right to respect for private and family life. She notes that, in most cases, the Court has taken a procedural approach, giving member states the margin of appreciation.

Jonquière shares aspects of the Dutch experience as the world's first country to legalize assisted dying, as well as elements of his own experience as a medical practitioner. His article opens with Huib Drion's argument for self-determined endings for older people, and continues with the intimate, poignant story of his involvement with a particular patient's desire for euthanasia; the cultural, political, legal, and societal interaction and process that led up to the passing of the Dutch law of Termination of Life on Request and Assisted Suicide (Review Procedures) Act in 2002; misunderstandings regarding assisted dying practices; and current ongoing debates in the Netherlands. Jonquière argues that palliative care is not an alternative to assisted dying and highlights Drion's idea that older people should be entitled to determine the ending of their lives.

Asai and Xu take us through a legal, sociological, and cultural analysis of Japanese attitudes to assisted dying. The issue of dying with dignity is either under-discussed or avoided. The authors invoke relevant incidents, as well as mass media products, such as *the Legacy of Dr. Death* and *Plan 75*, which might have had a substantial influence on public opinion. They say that Shintoism and Confucianism, in addition to the collectivist tendencies in Japanese society, have so far provided grounds for opposing assisted dying in Japan. However, Asai and Xu argue that the moment to discuss the issue has come and suggest that the Australian model would be a suitable place to start.

We acknowledge that the topic we are discussing here is weighty and that, in this copy of Issue Focus, we are reflecting only a portion of its size and significance. We accept that, like everyone, we need greater knowledge and wisdom, but we believe that this can only be gained through inclusive and thoughtful discussion. This report is neither about *vindicata liberatio* nor about *culturae mortis*. It is about the human struggle at *finis vitae sed non amoris*. We intend, and hope, that this edition will serve as the impetus for difficult but necessary deliberation at home, in the community, in society, and around the world.

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The Challenges of End-of-Life Care for Older Persons: A Human Rights Perspective

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The process of dying frequently takes place in and around medical institutions, involving both terminally ill patients and older people nearing the end of their lives. The fact that populations around the world are aging is a challenge to healthcare systems since longevity increases vulnerability to chronic illnesses, which necessitate complex and costly care. In other words, the aging trend increases the prevalence of chronic diseases, possibly stretching healthcare resources to the limit.

The medical establishment aims to extend life. Yet there is a need to keep a balance between quality and duration of life. Making the decision to discontinue treatment for older patients at the end of their lives is fraught with ethical quandaries. In addition, ambiguities in terminology and regulation make end-of-life care choices more complex, with varying legal frameworks globally. Decisions for life-sustaining treatments need to be shared among healthcare experts, the patient, and their family. In many circumstances, advance directives are useful because they allow patients to express their preferences regarding life-sustaining treatment, aligning medical decisions with personal values.

It can be challenging to decide when to stop aggressive treatment and focus on comfort care. There is no one-size-fits-all answer to this question, and decisions should be made on a case-by-case basis, taking all relevant factors into account. The establishment of principles guiding end-of-life decisions has extended beyond medical ethics to encompass broader societal concerns.

The concept of dying with dignity is related to the human rights of older people. However, while passive voluntary euthanasia is generally accepted around the world, legalizing active voluntary euthanasia raises ethical and cultural concerns. Advocates view active

voluntary euthanasia as an extension of personal autonomy, alleviating suffering and giving patients some control over their final days. Opponents emphasize the sanctity of life and express concern about the risk of abuse and the degradation of medical ethics. Variations in cultural, ethical, and legal concepts highlight the intricate nature of determining active voluntary euthanasia as a human right. Ultimately, addressing end-of-life care for older persons requires dealing with ethical, legal, and sociological concerns, as well as safeguarding autonomy and respecting human dignity.

Terminology

Having a peaceful, dignified death or dying naturally is a shared aspiration for most individuals. Nevertheless, reaching a consensus on the parameters of a dignified death presents considerable difficulties. While unanimity exists around the desirability of a painless demise, divergent viewpoints persist regarding the ethical application of modern medical interventions. The absence of societal accord within the realm of end-of-life care partly emanates from the ambiguity that clouds the relevant terminology.

Throughout history, the term euthanasia has been widely employed. Euthanasia denotes the deliberate act of terminating an individual's life to alleviate suffering, which commonly arises from terminal illness or agonizing pain. Rather than encapsulating a singular practice, euthanasia is more accurately conceived as an overarching expression encompassing an array of practices, each representative of distinct forms of the concept. These may be categorized as voluntary versus involuntary based on intention and active versus passive based on action (Australian Human Rights Commission, 2016).

Passive voluntary euthanasia pertains to the cessation of medical interventions at the behest of a patient to bring about their demise. Active voluntary euthanasia, on the other hand, arises when medical measures, in response to a patient's request, are employed to expedite their death. Unlike the withholding of treatment in passive voluntary euthanasia, active voluntary euthanasia involves affirmative measures taken to conclude a life. A lethal substance or a large dose of potent painkillers may be provided to assist suicide or directly administered by physicians to hasten death. Euthanasia that is involuntary, whether active or passive, is prohibited because it violates a patient's right to self-determination. During the Nazi era, for example, a vast number of persons with disabilities fell victim to an involuntary euthanasia initiative, a mass extermination scheme.

Within end-of-life care legislation, various terms have been introduced around the world, including the Natural Death Act, Death With Dignity Act, Act Relating to Patient Choice and Control at End-of-Life, End of Life Options Act, Aid in Dying for the Terminally Ill Act, and Medical Assistance in Dying Law. However, the titles of these legislative acts inadvertently

complicate understanding of the legal framework. For example, some may wonder what precisely constitutes natural death or death with dignity. Such subjective language is susceptible to varying interpretations, leading to perplexity.

If a physician abstains from life-sustaining measures that could have been administered but weren't—a case of non-action—it could potentially be construed as passive voluntary euthanasia from a medical perspective. Conversely, if a patient facing a similar scenario declines futile life-sustaining interventions and the physician honors the patient's values or wishes by withholding treatment, the terms death with dignity or natural death might be more fitting.

Navigating the intricate landscape of end-of-life care necessitates clarity in language and ethical guidance. Achieving a consensus on the nomenclature and ethical boundaries of interventions is crucial to fostering a more informed and compassionate approach to the delicate matter of ensuring a peaceful and dignified passage from life.

Medical Decision

Medical staff focus primarily on preserving and improving a patient's health and well-being. Within hospital systems, it has become common practice to employ all available medical interventions, not only for patients whose condition is in fact incurable but also for older people who are nearing the end of their natural lifespan. For patients for whom recovery is impossible and the end of life is near, two distinct options are available: medical interventions focused on extending life through various life-sustaining treatments or palliative care, which prioritizes quality of life and aims to provide comfort and relief.

Medical Conditions Requiring End-of-Life Decisions

The primary groups affected are patients in the terminal stage of an illness or those in a persistent vegetative state. The term terminal patient is applied to those in the final stages of an incurable disease, where standard treatments have proven ineffective and the disease's progression may result in death within a brief period. The assessment of potential recovery is generally based on evaluation by two or more doctors. In the Medicare program in the United States, hospice coverage depends on a physician's certification that an individual's life expectancy is six months or less if the terminal illness runs its normal course (Centers for Medicare & Medicaid Services, 2023). Nevertheless, numerical predictions regarding a patient's remaining lifespan can be imprecise.

The phrase persistent vegetative state (PVS) denotes a condition characterized by the complete absence of higher brain function while brainstem activity endures, enabling automatic breathing and fundamental life indicators even in an unconscious state. Responses to external stimuli, such as swallowing and eye movement, are present. A vegetative state persisting for a minimum of one year in cases of trauma and six months in non-traumatic cases might be deemed permanent (Dyer, 2003). Most legal disputes related to end-of-life decisions involve patients in a PVS.

Passive Voluntary Euthanasia: Decisions on Life-Sustaining Treatment

While interventions such as mechanical ventilation and cardiopulmonary resuscitation are vital for patients facing reversible life-threatening situations, in the terminal phase, these measures merely extend a period of distress. The term treatment is commonly interpreted to mean a medical procedure that must be performed, potentially leading to the misunderstanding that cessation of treatment is inherently unethical. To address this confusion, a neutral term such as end-of-life care is more suitable than life-sustaining treatment. The central concern in clinical practice is not how to halt life-sustaining treatment once it has been initiated, but rather how to facilitate patients or their families to decline such interventions if they are unwanted or likely to be ineffective, thereby enabling physicians to refrain from implementing these measures.

Active Voluntary Euthanasia

For medical professionals, there are two types of active voluntary euthanasia: physician-administered euthanasia and physician-assisted suicide (PAS). Active voluntary euthanasia entails a physician administering a lethal agent (or providing a therapeutic agent at a lethal dose) with the intention of alleviating intolerable, intractable, and incurable pain and allowing the patient to die. PAS refers to a physician's active aid in carrying out a patient's planned suicide, often involving prescribing drugs intended for use in the suicide and potentially offering guidance on their utilization for that purpose. These practices must be distinguished from other ethical-legal matters concerning end-of-life, such as discontinuing treatment upon request from a competent patient or surrogate, ceasing nutrition and hydration, and unintended death resulting from therapies primarily aimed at managing a patient's symptoms.

Hospice and Palliative Care

The World Health Organization (2020) defines palliative care as a medical field aimed at identifying and addressing pain and various physical, psychological, social, and spiritual problems faced by patients and their families due to life-threatening illness. The goals are to prevent and alleviate suffering, enhance the quality of life, and make patients more comfortable as they approach death.

A notable difference arises between terminal patients spending their final days in a large hospital and those receiving hospice and palliative care, whether within a hospice facility or at home. Large hospitals operate within a system that employs cutting-edge medical technology to extend a patient's life, while hospice care focuses on reducing an individual's physical and mental suffering rather than merely prolonging physical life.

For a patient to receive hospice and palliative care, their decision not to undergo life-sustaining treatment when the terminal phase becomes imminent should ideally be made in advance. The optimal scenario involves the patient having a comprehensive understanding of their medical condition and articulating their choice to abstain from life-sustaining treatment in favor of hospice and palliative care.

Ethical Issues

Four principles of medical ethics (beneficence, nonmaleficence, autonomy, and justice) apply to end-of-life care, but they can sometimes be in conflict.

Autonomy

One example of a clash of principles relates to the use of high-dose morphine injections for pain control in terminal cancer patients. Increasing the dosage of morphine can alleviate the patient's pain, which aligns with the principle of beneficence. However, it could also lead to respiratory impairment and potentially shorten the patient's life, which invokes the principle of nonmaleficence. In other words, one medical decision can result in both positive and negative outcomes, creating a double-effect dilemma for the medical practitioner. In such situations, the ethical principle of respect for autonomy becomes helpful in decision-making. To comply with this principle, it is recommended to inform the patient about the benefits and risks of morphine injections and involve them in the decision-making process. The most desirable approach to such decision-making is to reflect the patient's own values. As issues related to life-sustaining treatments became

more prominent, some countries, including the United States, have attempted to address them through legal documents such as advance directives.

Best Interests

Best interests are an additional ethical principle that can be used in end-of-life care. The principle of beneficence is most directly related to the concept of acting in the patient's best interests. Beneficence means doing what is good for the patient. Similarly, the principle of nonmaleficence may require the doctor to avoid providing treatment that is likely to cause more harm than good. And the principle of justice may require the doctor to consider the needs of other patients when making decisions about how to allocate resources.

Best interests allow for decisions to be made based on what is believed to be in the best interests of the patient, even if the patient is unable to express their own wishes. This can be done by considering the patient's values, beliefs, and goals, as well as the medical evidence (Kotzé & Roos, 2022).

Shared Decision-Making

Shared decision-making is an approach to end-of-life care that involves the patient, their family, and their healthcare team working together to make decisions. This approach is based on the principles of autonomy, beneficence, and nonmaleficence. It is important to remember that there is no one-size-fits-all approach to end-of-life care, and the best approach will vary depending on the individual patient and their situation.

Ethical Debates on Active Voluntary Euthanasia

Active voluntary euthanasia is the intentional act of ending a person's life at their request. This is a contentious issue, with strong arguments on both sides of the debate that will be explored in more detail in the final section of this article. Proponents of active voluntary euthanasia argue that it is a way to respect patients' autonomy and give them control over their own deaths; it can help to relieve suffering in terminally ill patients who have no hope of recovery; and it is a more humane way to die than allowing a patient to deteriorate slowly and painfully. Opponents counterargue that taking a person's life, even if they request it, is morally reprehensible; it might lead to abuse, such as pressuring patients

to request euthanasia or euthanizing patients who are not terminally ill; and it could undermine confidence between patients and doctors. The debate over active voluntary euthanasia will most certainly continue for many years. There is no simple solution, and each person must decide where they stand on this issue.

The Legislative Framework

Under the Natural Death Act (NDA) of the United States, people may prepare an advance directive that allows them to refuse life-sustaining medical treatment in the event that they become terminally ill and incapacitated. The NDA was enacted initially in California in 1976 and has subsequently been embraced by all states in the United States.

The history of the NDA is closely linked to the development of medical technology. In the early 1970s, new medical procedures and technologies emerged that could prolong life for people with terminal illnesses. For example, mechanical ventilation is a common medical procedure in intensive care units but is considered an invasive intervention because it requires the insertion of a tube into the airway. This can cause a lot of pain. In addition, such procedures can be costly and do not consistently improve the patient's quality of life. This has led to a growing debate about the right to die. Some have argued that individuals should have the right to refuse life-sustaining treatment, even if it means hastening their death. Others argue that doctors have a responsibility to exhaust all options in an effort to preserve a patient's life, irrespective of the patient's desires.

Despite the creation of documents such as advance directives to reflect a patient's autonomy in end-of-life decisions throughout the decision-making process, disputes could subsequently arise regarding the decisions made. Such disputes could potentially result in legal conflicts if a decision is not supported by a comprehensive legal framework. This highlights the necessity for medical professionals and healthcare institutions to be supported by the formal establishment of decision-making protocols concerning life-sustaining treatment. When doctors experience frequent investigations by law enforcement and prosecuting authorities due to such situations, they can feel obliged to deliver defensive medical care in order to prevent legal conflicts associated with end-of-life care.

Decisions on Life-Sustaining Treatment for Patients With Terminal Illnesses

Acceptance of passive voluntary euthanasia in terminal patients is common in many countries that nonetheless lack a relevant legal structure. Decisions regarding life-sustaining treatment for patients with terminal illnesses have been facilitated through Do-Not-Resuscitate (DNR) policies. However, in some Asian countries that prioritize family-centered decision-making, distinct legal systems have been established. The Palliative and Hospice Care Act of Taiwan in 2000 and the Act on Decisions on Life-Sustaining Treatment of Korea in 2016 enable terminal patients to make decisions about life-sustaining treatment (Kim et al., 2022; Ministry of Health and Welfare of the Republic of China, 2021a). In Japan, end-of-life decision-making has become an increasingly significant issue, given the growth of the super-aged population. Guidelines exist, but no legislation has been implemented (Ozeki-Hayashi et al., 2023).

In terms of advance directives, countries in Asia fall into three groups: (a) well-regulated jurisdictions with a clear set of legal rules (e.g., Israel, Singapore, South Korea, Taiwan, Thailand, and India); (b) semi-regulated jurisdictions, which have regulatory documents or guidelines (e.g., Hong Kong, Iran, Malaysia, the Philippines, and Türkiye); and (c) non-regulated jurisdictions (e.g., China, Japan, Macao, Pakistan, and Saudi Arabia) (Cheung & Dunn, 2023).

Decisions on Life-Sustaining Treatment for Patients in a Persistent Vegetative State

Laws have been formulated in response to the emergence of societal concern about decisions regarding life-sustaining treatment for patients in a persistent vegetative state (PVS). In 1990, the Patient Self-Determination Act was enacted federally in the United States, granting patients the authority to make decisions about life-sustaining treatment not only in cases of terminal illness but also when in a PVS. Similar regulations ensued in other countries. The Mental Capacity Act was passed in the United Kingdom in 2005, followed by the Patients' Rights Act in Germany in 2013 and the Law on Informed Consent and Advance Directives in Italy in 2017.

These acts determine that when decisions about life-sustaining treatment are made for patients in a PVS, the patient's right to self-determination must be respected, even in the face of uncertainty regarding diagnosis or prognosis. Therefore, decisions about life-sustaining treatment are only permitted when taken by patients themselves. Advance directives play an important role and are followed strictly, in a manner similar to the

execution of a will. An individual designated by the patient in advance can participate in the decision-making process as well.

Among Asian states, Taiwan introduced the Patient Right to Autonomy Act in 2019. This distinct legislative act aimed to broaden the eligibility criteria for decisions on life-sustaining treatment to encompass patients in an irreversible coma or PVS, those experiencing severe dementia, and individuals whose condition or suffering is unbearable or lacks a remedy based on the assessment of the overseeing hospital (Ministry of Health and Welfare of the Republic of China, 2021b). However, the act of withdrawing or withholding life-sustaining treatment from patients with PVS is prohibited in South Korea (Heo et al., 2022).

Physician-Assisted Suicide and Active Voluntary Euthanasia by Medical Professionals

When medical professionals prescribe lethal substances to a patient and the patient self-administers them, it is classified as physician-assisted suicide (PAS). The conditions that must be met in order for PAS to be legal vary from jurisdiction to jurisdiction. In some jurisdictions, PAS can apply even when the patient is not in a terminal state but is enduring an incurable, excruciating illness.

Countries that permit PAS include the Netherlands, Belgium, Luxembourg, Switzerland, Canada, Australia (Australian Capital Territory, Victoria, and Western Australia), New Zealand, Austria, Spain since 2021, and Portugal since 2023. Additionally, PAS has been exempt from punishment in Germany since 2020 (Hänel & Goldenberg, 2023). In the United States, PAS is authorized through legislation or legal precedent in Washington, DC, and ten states: the Death With Dignity Act in Oregon, Washington, Maine, and Washington, DC; the End of Life Options Act in California, Colorado, and New Mexico; the Act Relating to Patient Choice and Control at End-of-Life in Vermont; the Our Care, Our Choice Act in Hawaii; and the Aid in Dying for the Terminally Ill Act in New Jersey. In addition, in Montana, medical aid for the dying has been protected by a court ruling since 2009.

Countries that allow euthanasia by medical professionals directly administering lethal substances are restricted to the Netherlands (Termination of Life on Request and Assisted Suicide Act in 2001), Belgium (Belgian Act on Euthanasia in 2003), Luxembourg (Law on Euthanasia and Assisted Suicide in 2009), Canada (Medical Assistance in Dying Law in 2016), Colombia (1997), New Zealand (End of Life Choice Act in 2019), and Spain (Organic Law for the Regulation of Euthanasia in 2021).

Dying With Dignity and the Human Rights of Older Persons

Older persons share many of the same human rights issues as persons with disabilities (British Geriatrics Society, 2020). They have the right to make decisions about their lives, including their care, housing, and finances. Their capacity to make decisions should not be undermined. It is essential to treat older persons with respect and dignity and strongly discourage both discrimination and any action that makes them feel inferior to other people (European Network of National Human Rights Institutions, 2017).

The concept of dying with dignity is a universal entitlement, regardless of age. This means having the autonomy to decide about one's own end-of-life care, which includes refusing treatment and determining the manner and timing of one's death (Reingold & Mora, 2019; UNECLAC, 2017). Consideration of the human rights of older persons becomes essential in discussions about dying with dignity. Older individuals have the right to respectful and compassionate treatment and to exercise authority in decision-making about their care. Several measures can ensure the dignified passing of older individuals; these include disseminating information about end-of-life care choices, honoring the preferences of older individuals concerning their care, offering access to palliative care, and eradicating age-based discrimination.

The question of whether active voluntary euthanasia constitutes a human right is a subject of ethical, legal, and cultural debate. Different countries and regions hold different perspectives on this issue, and the answer may depend on individual beliefs. Here are some key considerations (Australian Human Rights Commission, 2016), as briefly discussed in the previous section.

Arguments in favor of active voluntary euthanasia include the following:

- personal autonomy—Advocates for euthanasia often argue that individuals have the right to make decisions about their lives, including the choice to end their life if they are faced with a terminal illness or unbearable suffering. This perspective emphasizes personal autonomy and the ability to shape one's own destiny.
- relief from suffering—Supporters of euthanasia argue that it offers a compassionate alternative for individuals who are experiencing extreme pain, diminished quality of life, and no realistic hope for recovery. It can be seen as a way to alleviate prolonged suffering.
- dignity in death—Proponents of euthanasia maintain that the right to die with dignity includes the right to determine the timing and manner of one's death, especially when the person's quality of life has significantly deteriorated.

Arguments against active voluntary euthanasia include the following:

- right to life—Opponents of euthanasia often stress the sanctity of human life and argue that intentionally ending a life is morally unacceptable. Certain religious and ethical viewpoints maintain that life should be preserved and safeguarded regardless of circumstances.
- slippery slope—Critics voice concerns about potential abuse and invoke the slippery slope argument, suggesting that legalizing euthanasia might lead to unintended outcomes such as involuntary euthanasia or coercion of vulnerable individuals to choose death.
- medical ethics—Some contend that the role of medical professionals involves providing care, comfort, and support to patients and that actively participating in ending a patient's life contradicts traditional medical principles.
- potential for abuse—Critics raise concerns about the risk of abuse or coercion in cases involving vulnerable individuals who lack access to proper medical care or mental health support or who might feel compelled to opt for assisted suicide due to societal factors.
- legal and cultural variation—Laws and regulations concerning euthanasia exhibit considerable diversity globally. While some countries and jurisdictions have legalized and regulated euthanasia under specific circumstances, others maintain stringent prohibitions.

Whether active voluntary euthanasia is a human right is a complex and contentious issue. Coming to a single view involves balancing personal autonomy, compassion, ethical considerations, and potential risks. Stances on euthanasia vary based on personal beliefs, cultural norms, and legal frameworks. It is important to have open and honest discussions about this issue in order to ensure that the rights of all individuals, including older persons, are respected.

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European Perspective on the Right to Die

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The right to choose the time and manner of one's own death, also known as the right to die, has been a highly debated subject in recent years. Advances in technology and medical innovations have increased life expectancies and provided cures for many previously incurable illnesses. However, the capabilities of medicine do not always provide a quality of life that is acceptable to the patient, and treatments can sometimes prolong life under unacceptable circumstances. Some illnesses might cause unbearable pain without any relief. In other instances, the final phase of certain terminal illnesses can be prolonged due to medical machines that help carry out necessary bodily functions. This might not always qualify as a dignified end for the individual concerned. As concerns over the quality of life and having a dignified death increase, people want to have more control in the final phases of their lives. Rather than a paternalistic approach, in which it was assumed that the physician knew what was best for the patient and took the lead in the decision-making process, the focus of medicine has shifted to a more patient-centered approach (Chin, 2002; Meulenbergs & Schotsmans, 2005). As a result, the patient's definition of what is considered dignified and the patient's wishes and expectations at the end of life have gained more importance.

While there are several types of end-of-life decisions, such as withdrawing life-sustaining treatment or administering increasing doses of pain medication, the right-to-die debate focuses on active termination of life based on the patient's explicit and autonomous request. The right to die is realized through the practices of either euthanasia or assisted suicide. Euthanasia, which etymologically means "gentle and easy death" (Focarelli, 2020, para. 1), refers to the active termination of the patient's life by a third person upon the patient's explicit and autonomous request. Assisted suicide, on the other hand, means the active termination of the patient's life by the patient themselves with the help of a third party. While the final act that causes death is the differentiating factor for these

assisted dying practices, personal autonomy is at the center for both of them. The term assisted dying sometimes refers to euthanasia and sometimes to assisted suicide, or is used as an overall term for both practices (Kayacan, 2022).

As in the practice of most human rights, there are two competing sides to the right-to-die debate. On one hand, the right to die is an expression of personal autonomy and the right to self-determination at the end of life. On the other hand, the practice of the right to die carries an inherent risk of abuse, especially for those who belong to the rather more vulnerable groups of society, such as people with severe or psychological illnesses and people of advanced age. Therefore, for the state, it is a matter of conflicting individual and societal interests that require balancing. Allowing assisted dying practices can unintentionally result in morally questionable outcomes, a phenomenon known as the “slippery slope” (Keown, 2018, p. 68). For example, if one argues that assisted dying must be legalized to prevent unbearable suffering, one must also define what unbearable suffering means. Who will decide which amount of pain is unbearable? If the autonomous request of the patient is at the center, it should be the patient who deems their suffering has reached its limits. But then, if we respect only the autonomous decision of the patient, how do we control the practice of assisted dying? Must we accept any kind of suffering, whether be it physical or psychological? How can we make sure that the request for assisted dying is not influenced by others and that it is actually an autonomous decision? Is it possible to evaluate the sincerity of such a request in cases of patients with psychological illnesses, who can sometimes be more susceptible to others’ opinions? If assisted dying becomes normalized in society through regular practice, can we be certain that patients with advanced age or disabilities will not feel pressure to end their lives in order not to be a burden on their families? The state must consider all of these aspects, as it has a duty both to ensure public health and safety and to protect life—a duty that is particularly important for vulnerable groups in the society.

This article focuses on the right to die from a European perspective. There are currently nine states parties to the European Convention on Human Rights (ECHR or the Convention) that have a permissive approach to the right to die. Switzerland is famous for its assisted suicide organizations, which have been active since the 1990s. The Netherlands and Belgium are the first European states to adopt a law legalizing euthanasia, with Luxembourg following a few years later. The Italian and German Constitutional Courts have given judgements in favor of the right to die, which should, in theory, result in an adaptation of legislation in due course. Spain, Austria, and Portugal have already adopted legal frameworks allowing assisted suicide. The major part of this article will focus on interpretations of the right to die in the case law of the European Court of Human Rights (ECtHR). Before that, however, I will give a brief analysis of the Swiss and Dutch practices, since these two states have the longest experience in assisted dying in Europe and offer valuable insights.

The Swiss Practice of Assisted Suicide

While euthanasia remains prohibited in Switzerland, assisted suicide has been practiced since the 1990s, based on a legal gap provided by Article 115 of the Swiss Criminal Code, which reads as follows:

Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty. (Swiss Confederation, n.d.)

The Swiss assisted suicide organizations, which are non-profit, operate on a voluntary basis within the scope of Article 115, since it does not penalize suicide assistance on altruistic grounds.

Two of the most famous assisted suicide organizations are EXIT (EXIT-Deutsche Schweiz for the German-speaking region and EXIT-Suisse Romande for the French-speaking region) and Dignitas. While EXIT only accepts members who have Swiss citizenship or who reside in Switzerland, Dignitas accepts members from all around the world. In the year 2022, the two EXIT organizations assisted 1,627 suicides and together had a membership of over 187,000 (EXIT-Deutsche Schweiz, 2022; EXIT-Suisse Romande, 2023). Dignitas has 11,856 members of 97 different nationalities, most of whom are from Germany, the United Kingdom, the United States, and France, and has assisted 206 suicides (Dignitas, 2022a, 2022b).

There is no legal framework regulating assisted suicide practice in Switzerland, apart from the omission in Article 115 of the Swiss Criminal Code. As long as suicide assistance is provided without selfish motives to a competent adult over the age of 18 who has decided to end their life autonomously, it does not constitute a crime. The Swiss practice as it is today has developed over time in the hands of assisted suicide organizations through custom and relatively few court cases (Hurst & Mauron, 2017). Organizations use sodium pentobarbital (NaP) for suicide assistance, which requires a physician's prescription (Schwarzenegger, 2007). The Swiss Academy of Medical Science (SAMS) prepares guidelines on ethical issues in medicine, which are generally incorporated by the Swiss Medical Association (FMH) into the Code of Professional Conduct for physicians. While these guidelines are not legally binding, failure to follow the Code of Professional Conduct has professional repercussions for physicians. In 2004, SAMS recognized that "consideration for the patient's wishes is fundamental" for the physician-patient relationship and that, even though it is not a medical task, a physician's decision to provide suicide assistance should be respected if certain conditions are met (Swiss Academy of Medical Sciences, 2004, sec. 4.1). SAMS refined these conditions in its 2018 Medical-

Ethical Guidelines on Management of Dying and Death, further amended in 2021 (Swiss Academy of Medical Sciences, 2018, sec. 6.2.1). FMH incorporated these guidelines into the Code of Professional Conduct in 2022 (Swiss Medical Association, 2022). According to the guidelines, the physician must make sure that the patient has *capacity* and *an autonomous wish* to end their own life due to *severe suffering* to which the patient sees *no other acceptable alternative*. A third person, who does not need to be a physician, must confirm the existence of capacity and an autonomous wish for assisted suicide.

SAMS specifically defines capacity in relation to assisted suicide, differentiating it from regular decision-making capacity, which enables the patient to fully understand their prognosis, the available treatment options, and the consequences of their decision (Swiss Academy of Medical Sciences, 2019, sec. 3.9). If the patient suffers from a mental illness, a detailed psychiatric evaluation is necessary (Haas, 2006, para. 6.3.5.2). To determine whether the wish for assisted suicide is autonomous, the physician must conduct at least two meetings with the patient that are at least two weeks apart. All circumstances that might affect the patient's decision must be taken into consideration. The patient's suffering must be severe and intolerable—a subjective assessment that can only be made by the patient. However, there must be some sort of medical indication that makes the patient's suffering and their wish to end their own life comprehensible to the physician. Providing suicide assistance to a physically and mentally healthy person is considered ethically unjustifiable. Furthermore, all alternatives must be discussed with the patient.

Except for the legally non-binding SAMS guidelines, there is no framework that regulates assisted suicide. Although there have been many proposals for legislation, Parliament did not find it necessary to regulate assisted suicide in 2011, and the situation has not changed since (Bundesrat, 2011). This is unfortunate, since the lack of regulation leaves the Swiss practice unsupervised and in the hands of assisted suicide organizations; the only control mechanism is the prescription requirement for NaP.

Practice in the Netherlands

The Netherlands is known for having the most liberal law regarding assisted dying in the world. The foundation for the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (Euthanasia Act), which was adopted in 2001 and came into force in 2002, was laid down by case law with support from the Royal Dutch Medical Association (Kayacan, 2022, pp. 61–77). A case from 1973 regarding a Dutch physician who had assisted the death of her terminally ill mother sparked a nationwide debate on euthanasia, and the Court's lenient judgement set a precedent that led to the Euthanasia Act (Postma, 1973). In a case from 1981, the Court set conditions that would justify assisted suicide (Wertheim, 1981); these conditions were developed over time through further cases and ultimately found their place in the Euthanasia Act.

Euthanasia and assisted suicide are not punishable if the physician follows the due care criteria prescribed under Article 2(1) of the Euthanasia Act. When faced with a request for euthanasia or assisted suicide, the physician must do the following:

- a. be satisfied that the patient has made a voluntary and carefully considered request;
- b. be satisfied that the patient's suffering is unbearable, and that there is no prospect of improvement;
- c. have informed the patient about his situation and his prospects;
- d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
- e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and
- f. have terminated the patient's life or provided assistance with suicide with due medical care and attention. (Marty, 2003, para. 30)

As a control mechanism to supervise euthanasia and assisted suicide practices, the Euthanasia Act requires the physician to consult another physician and report the case to the municipal pathologist. The municipal pathologist will inform the Regional Euthanasia Review Committee (RTE), which will assess whether the physician has fulfilled the due care criteria. If the due care criteria have been met, no further action is necessary. If not, RTE will notify the Board of Procurators General and the Health and Youth Care Inspectorate to trigger an investigation. In 2022, the RTE received 8,720 notifications from physicians that euthanasia or assisted suicide had taken place. Noncompliance with the due care criteria has been found in only 13 of these cases (RTE, 2023).

Article 2 paragraphs 2, 3, and 4 of the Euthanasia Act regulate the euthanasia of minors. Children from ages 16 to 18 may request euthanasia without parental consent if the child is considered to have a reasonable understanding of their interests. However, the parents must always be involved in the decision-making process. Children from ages 12 to 16 may request euthanasia with parental consent if the child is considered to have a reasonable understanding of their interests. Recently, the Netherlands has been discussing euthanasia for minors from ages 1 to 12 (Wilkinson, 2023). However, this is not a new development since the topic of neonatal euthanasia has been discussed since the early 2000s. The Groningen Protocol was written in 2004 to provide guidance on neonatal euthanasia for physicians who faced a dilemma when dealing with infant patients with grievous and incurable medical conditions (Verhagen, 2006). While the Protocol does not legalize or

encourage neonatal euthanasia, it aims to acknowledge extreme and challenging cases in medicine.

It must be noted here that the right to die is based on personal autonomy, expressed as a request to end one's own life. This cannot be the case in minors due to their lack of decision-making capacity. Since the definitions of euthanasia and assisted suicide include the explicit request of the patient as an expression of personal autonomy, termination of life in minors should not be referred to as euthanasia or assisted suicide. While this is the author's and the ECHR's perspective (which will be analyzed further in the next section), right-to-die practice in the Netherlands is primarily focused on the physician's medical duty to take care of their patients and not the personal autonomy of the patient (de Vries, 2004, p. 388; Otlowski, 1997, p. 402). This is not to say that personal autonomy is ignored in Dutch practice. But when the starting point of the discussion is the medical duty to relieve pain, it changes the perspective on euthanasia or assisted suicide and what is considered acceptable practice.

The Right to Die Under the European Convention on Human Rights

There have been only a handful of cases before the ECtHR that deal with the right to die. While not all of the cases will be mentioned here, a few will be discussed briefly in order to provide insight into the ECtHR's perspective on the right to die. When evaluating the right to die, the ECtHR takes into consideration the right to self-determination and personal autonomy protected under Article 8 of the Convention regarding the right to private life and the state's obligation to protect life under Article 2 of the Convention regarding the right to life. These two articles read as follows:

Article 2. Right to Life

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary: (a) in defence of any person from unlawful violence; (b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained; (c) in action lawfully taken for the purpose of quelling a riot or insurrection. (European Court of Human Rights of the Council of Europe, n.d., pp. 6–7)

Article 8. Right to Respect for Private and Family Life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others. (European Court of Human Rights of the Council of Europe, n.d., p. 11)

The ECtHR identified the competing interests embodied in these articles in the very first case it dealt with on the right to die. The *Pretty Case*, decided in 2002, involved a British woman with terminal motor neuron disease who wanted her husband to help her die (*Pretty v. The United Kingdom*, 2002). She argued that the United Kingdom's laws prohibiting assisted suicide violated her right to a private and family life, as protected by Article 8 of the Convention. However, the ECtHR ruled against her, stating that the Convention did not guarantee a right to die, nor did it impose an obligation on the state to facilitate assisted suicide. The ECtHR found that the United Kingdom's blanket ban on assisted suicide did not violate Article 8. The judgement emphasized that the protection of the right to life, outlined in Article 2 of the Convention, allowed states to enact laws prohibiting assisted suicide to safeguard vulnerable individuals (*Pretty v. The United Kingdom*, 2002, para. 74). While the ECtHR recognized the importance of personal autonomy and human dignity protected under Article 8, it maintained that the protection of life was paramount, allowing member states a margin of appreciation in deciding their own policies on sensitive issues such as assisted suicide.

In the *Haas Case* of 2011, the ECtHR explicitly recognized that the right to choose the time and manner of one's own death (i.e., the right to die) was an aspect protected under Article 8 of the Convention. A Swiss national suffering from bipolar disorder sought the right to access a lethal dose of NaP to end his life (*Haas v. Switzerland*, 2011). The physicians he approached were unwilling to prescribe NaP due to the psychiatric nature of his illness, and the Swiss authorities did not waive the prescription requirement. He argued that the Swiss authorities' refusal to waive the prescription requirement violated his right to private life under Article 8 of the Convention. The ECtHR explicitly acknowledged the following:

An individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention. (*Haas v. Switzerland*, 2011, para. 51)

However, the Court said that the positive obligation to protect life under Article 2 required states to ensure that the decision was autonomous and well-considered (*Haas v. Switzerland*, 2011, para. 56). The ECtHR drew attention to the fact that there was no consensus with regard to the right to die among member states. This allowed states a greater margin of appreciation for how to achieve a balance between the right to die and the obligation to protect life. Since the prescription requirement for NaP served this purpose, the ECtHR did not find a violation of the Convention.

In subsequent cases, the ECtHR reiterated the margin of appreciation attributed to member states and mainly restricted itself to a procedural examination. Due to the lack of consensus, it remains the case that it is up to member states to decide how to balance the right to die with the right to life and whether to allow assisted dying (*Koch v. Germany*, 2012, paras 70–71; *Lambert and Others v. France*, 2015, para. 148; *Lings v. Denmark*, 2022, paras 40–44; *Nicklinson and Lamb v. The United Kingdom*, 2015, para. 84).

In a case against Switzerland, a healthy older woman wished to end her life due to what she regarded as its declining quality but was unable to obtain a prescription for NaP (*Gross v. Switzerland*, 2013). The ECtHR identified as the issue for their consideration whether or not Switzerland had regulated assisted suicide with sufficient clarity, meaning under which circumstances physicians could prescribe NaP for assisted suicide. A majority of four out of seven judges found that the lack of clear and comprehensive legal guidelines was a violation of Article 8 of the Convention (*Gross v. Switzerland*, 2013, para. 69). The remaining three judges believed that the SAMS guidelines and Swiss case law provided sufficient clarity that NaP could not be prescribed to a non-terminally ill patient (*Gross v. Switzerland [Chamber]*, 2013, Joint Dissenting Opinion para. 9). This decision was later rendered invalid when the Grand Chamber of the ECtHR dismissed the case after it was discovered that the applicant had managed to obtain a prescription for NaP and had ended her life (*Gross v. Switzerland*, 2014). Nevertheless, the Chamber decision shows that if the state decides to legalize assisted dying, the state must provide clear legal guidelines for its practice.

In a recent case, the ECtHR evaluated Belgium's legal framework for euthanasia (*Mortier v. Belgium*, 2022). The Belgian Act on Euthanasia of May 28, 2002, legalizes euthanasia under similar conditions as the Dutch Euthanasia Act and sets a similar review procedure: The Federal Commission for Control and Evaluation of Euthanasia (CFCEE) supervises compliance with due care criteria in euthanasia and assisted suicide cases (Belgian Ministry of Justice, 2002). In the Mortier case, a woman who had been suffering from depression for over 40 years ended her life by euthanasia. Her son, who was only notified after the euthanasia took place because his mother did not want to contact him, claimed that the state had failed to fulfill its duty to protect life under Article 2 of the Convention. The physician who had carried out the euthanasia was also the co-chair of the CFCEE

that reviewed the case. The son's request to see his mother's file was refused by the CFCEE, and the decision with regard to his complaint against his mother's physician was not disclosed due to the confidentiality of the proceedings. Mortier's son also lodged a criminal complaint against the physician, but the prosecutor's office found that the euthanasia of his mother complied with the law.

For the first time, the ECtHR dealt with the question of whether a euthanasia regulation complied with the state's obligation to protect life under Article 2 of the Convention. ECtHR evaluated the *a priori* and *a posteriori* euthanasia procedures separately. The Belgian Euthanasia Act provides safeguards to ensure the autonomous and well-considered nature of a euthanasia request. Especially when the case concerns a patient suffering from mental illness, the Euthanasia Act lays down additional requirements such as a waiting period and consultation with another physician. The ECtHR found that there were sufficient safeguards in the pre-euthanasia procedure to ensure the protection of life as required by Article 2 and, in the case at hand, that these safeguards were followed (*Mortier v. Belgium*, 2022, paras 153, 165). With regard to the *a posteriori* safeguards, the ECtHR had a different view.

According to Article 6 of the Belgian Euthanasia Act, the CFCEE consists of 16 members who are physicians, lawyers, and experts in incurable illness. Reports of euthanasia cases that are submitted to the CFCEE have two sections: The first section contains personal information on the participating physicians and the patient, and the second section contains the factual circumstances. Evaluation of the case is done based on the second section, which does not contain any personal information, in order to maintain confidentiality. Personal information is only revealed when the CFCEE finds it necessary with a majority vote. Therefore, if the case belongs to one of the physicians sitting as a member of the CFCEE, the physician is expected to remain silent and act in a manner that does not influence the decision. The ECtHR did not find leaving the matter to the physician's discretion sufficient to guarantee the independence of the CFCEE regardless of whether Mortier's physician, who was also the co-chairman of the CFCEE, had actually influenced the decision (*Mortier v. Belgium*, 2022, paras 177–178). Furthermore, the criminal investigation that was opened after the son's complaint had lasted over three years, and there was hardly any investigative action undertaken during that period (*Mortier v. Belgium*, 2022, paras 179–180). The ECtHR found that Belgium had failed to fulfill its obligation to protect life under Article 2 of the Convention in light of the CFCEE's lack of independence and the nature of the criminal investigation (*Mortier v. Belgium*, 2022, paras 184–185).

Conclusion

The European perspective on the right to die reflects a nuanced balance between individual autonomy and the protection of vulnerable individuals, with divergent legal frameworks and ethical considerations guiding the approach of each state. Among the 46 states parties to the ECHR, only seven have legalized assisted suicide or euthanasia, while the constitutional courts of two other states have given the green light.

In a number of cases dealing with the subject, the ECtHR has limited itself to a primarily procedural approach. While the importance of striking a balance between the protection of life and the respect for personal autonomy has been emphasized numerous times, it is left to the discretion of the member states to decide how to achieve this balance. There is no obligation under the Convention to provide access to assisted suicide or euthanasia. But if states decide to allow assisted dying, then they must make sure that there are adequate safeguards and clear guidelines as part of their obligation to protect life under Article 2 of the Convention.

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Assisted Dying for Older People in the Netherlands: An Historical and Ideological Analysis

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Huib Drion, a Dutch lawyer, civil law professor at Leiden University, and vice president of the Dutch Supreme Court, would have never imagined the impact his article “Self-Willed End of Life for Older People,” which was published in a major Dutch newspaper in 1991, would have on the debate over end-of-life decisions in the Netherlands and around the world. In his piece, he argued that many older people would find great peace of mind if they could have access to a means to end their lives in an acceptable manner at a time when this seemed right in light of what life might have in store for them (Drion, 1991). It was the first time, as far as I know, that the emphasis was laid explicitly on the suffering of older people, during a period when euthanasia was drawing increased public attention and sparking debate in the Netherlands. In the course of time, his writing proved to be a turning point in Dutch euthanasia discussions.

The Dutch define euthanasia as the deliberate termination of life by someone else at the recipient’s explicit request. Physician-assisted suicide (PAS), on the other hand, is defined as termination of life by the person concerned (who commits suicide) with the assistance of a physician (who prescribes drugs). Many medical decisions at the end of life (e.g., terminal sedation, non-treatment decisions, involuntary termination of life), which are sometimes mistaken for a form of euthanasia, are not euthanasia and thus are not regulated by the law concerning euthanasia or PAS in the Netherlands. In this article, I will frequently use the term euthanasia to refer to both types of end of life. The distinction between euthanasia and PAS is made only when necessary, despite the fact that euthanasia accounts for the vast majority of the practice. It should also be noted that, because of the many different cultures and juridical systems in the world, the term *assisted dying* is generally preferred over other terms (WFRtDS, n.d.a).

Bep: A Patient's Story

All through the ages and all over the world, people who have suffered unbearably or lived intolerably have turned to their doctors for help, pleading, "Doctor, please do something. This is no life anymore." And doctors have acted on such requests out of compassion, effecting a humane and dignified termination of suffering. Where the result of such assistance was the death of the person—generally, doctors were not supposed to terminate lives but to treat ill patients—such help had to occur in secrecy.

Bep, a patient in my family doctor's practice, was a former district nurse who was born in 1924. Her medical history was extensive, with diagnoses such as Hodgkin's disease, breast cancer, and lastly, at the age of 55, ovarian cancer with metastases to the lymph glands. We reviewed the options following this horrible, deadly prognosis, and at that point, she decided to pursue treatment aggressively—her glass was always half full. Also, had she not already triumphed over two earlier malignant diseases?

The treatment consisted of the most aggressive chemotherapy available, which she endured for three months. After those months, she had not only dropped more than 15 kilograms in weight, but the tumor had also grown even larger than before. She made a firm decision and stopped the treatment. This was the first time she brought up the topic of euthanasia with me. She was quite clear about what she expected for the rest of her life, about the later stages of her life with that disease, and about what she regarded as an unacceptable quality of life. As a nurse, she knew exactly what to expect and was also well aware of the ongoing public and professional debate in the Netherlands at the time.

Her condition deteriorated rapidly, revealing the malignant nature of her disease. That was the moment she mentioned euthanasia again, this time as a possibility for herself. When I asked her when she would want it, she said, "When I am completely bedridden and dependent on others for every movement I want to make, that is when dying is less dreadful to me than living on" (personal communication, 1978–1979). I told her I would be ready to help her die through euthanasia when the time came. I continued to give her all of the terminal care I used to provide to patients in similar circumstances: regular home visits; treatment of pain, sickness, and discomfort; and constant conversations about her state of life and mind. The moment she said she dreaded had come and gone: She assured me that it was not as bad as she had anticipated. And she described a new set of conditions, to which we once again agreed. To make a long story short, she changed her mind about what made her life intolerable three times in the period following that first time.

The last limit came: With a bunch of fresh snowdrops on her night table, her final moment was near at hand. We sat down for one last conversation, about her life, her disease,

and the process of her death. We talked about how her trust in me to help her die in a dignified way at her self-chosen moment allowed her to push her limits beyond what she had ever thought feasible. And that, in fact, had made her live far longer than she had ever expected.

On a Tuesday morning in the early spring of 1979, four days after that final conversation, and more than six months after her first serious euthanasia request, her partner called and told me that Bep believed the time had come. I went, sat down for an emotional farewell, and gave her the final injections: a barbiturate overdose to induce a deep coma, followed by an overdose of the medication for complete muscle relaxation. Bep died quietly, with a smile on her face, within two minutes. I had lost a friend, which was heart-wrenching, but I was also happy to have been the good practitioner who helped his patient and complied with one of the most difficult and most intimate wishes she could ask for.

The Dutch Law of Assisted Dying

Based on the Dutch culture of tolerance, openness, and transparency, Dutch doctors started to practice life termination on request (i.e., euthanasia) in the 1960s and even reported such cases to prosecutors. The Dutch gradually developed a legal framework through a number of vital and important court cases that went up to the Supreme Court and encouraged doctors to report their euthanasia cases using the principle of opportunity (i.e., the public prosecutor's right to decide whether to prosecute or not, another Dutch phenomenon). The Royal Dutch Medical Association officially recognized and endorsed the framework created by this body of case law in 1984 by issuing guidelines for the practice of euthanasia (Angell, 1996; Rietjens et al., 2009).

Pro-choice campaigners in the Netherlands have highlighted the right to self-determination as the key underlying principle for requesting a good death (*ευθανασία* in Greek) since the beginning of the public debate about assisted dying. Soon, attitudes and principles shifted to focus on mercy and medical perspectives. And the medical perspective, in particular, was not only essential, since doctors were almost always involved, but it also offered lawyers and legislators ample opportunity to connect medical and juridical arguments in such a way that the law would fit both judicial and medical practice. In the debates leading up to the passing of the Dutch law *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* of 2002, it was clear that, just like doctors, even lay campaigners emphasized the role of doctors, since doctors had time and again fulfilled their (illegal) duty of complying with the cries for help of their suffering patients, assisting them to die in a humane way.

It was thus not unexpected that the main grounds for considering or discussing euthanasia, let alone performing it, could be found in cases where suffering had become somatically unbearable and hopeless and where doctors provided relief with appropriate medication. Until today, the majority of now-legal euthanasia or PAS cases have involved terminal cancer patients (e.g., 57.8% in 2022) (RTE, 2023).

However, in his original article, “Self-Willed End of Life for Older People,” lawyer Huib Drion (1991) had emphasized non-medical situations specific to older people. Looking back on the turmoil he caused in the public debate, he observed that the problem of old people’s suicide was not primarily medical in nature (personal communication, 1992). People’s personal judgments concerning dignity, their need for independence, and their unwillingness to burden their environment with the consequences of their old age mattered in this context. The most essential point, according to him, was that older people should be able to determine whether or not their lives were complete and whether continuing to live would diminish the fullness of life.

This new view on assisted dying, as well as broad public interest in the right to die for anybody who thought their life was no longer worth living for whatever reason, posed strategic challenges for all campaigners for a self-determined end of life. Many doctors who were already hesitant about the whole issue of terminating people’s lives were not looking forward to assisting in cases that did not fall under the purview of medicine. Politicians immediately realized the importance of the difference in core principles (mercy versus self-determination) of medical and non-medical issues, claiming that only the medical perspective would allow for the legalization of assisted dying. Pro-choice campaigners, such as the Dutch Right to Die Society NVVE, identified that there were strategic problems in advocating for a law that would respect Huib Drion’s viewpoint equally and concurrently with the medical position.

In the public, professional, and political debates about assisted dying, the issue was discussed from the medical perspective only: The law would solely enable doctors—not even nurses—to act in circumstances of unbearable and hopeless suffering. Using the principle of medical necessity in the middle of a medical conflict of duties, doctors’ practice would need to be founded on an objective medical opinion that justified euthanasia or PAS. The Supreme Court’s decision in the controversial case of 86-year-old former senator Edward Brongersma, whose suffering was existential (i.e., he was tired of life) rather than medical, supported the medical perspective. According to the Supreme Court ruling (de Rechtspraak, 2002), doctors who assist with suicide in cases where the patient’s suffering is not primarily due to a medically classified disease or disorder, that is, a clinically diagnosed disease or condition, but stems from the fact that life has become meaningless for the patient, are acting outside the scope of a physician’s expertise.

The Brongersma case was remarkable in that the judicial decision process (1998–2002) not only paralleled but was also inextricably linked to the parliamentary debate (1999–2002) on the euthanasia law. Lower court verdicts in the case (an acquittal of the doctor involved in helping Brongersma to die, to start with, which was appealed vehemently by the Public Prosecution Office) influenced markedly the parliamentary debate, while political comments and statements about what should and should not be covered by the new law were clearly mirrored in the final Supreme Court ruling in 2002. This upheld a Court of Appeals judgment that limited the possibility of legal euthanasia by bringing in (or putting more emphasis on) a medically classifiable disorder as a *conditio sine qua non* (Sheldon, 2003).

The history of euthanasia law in the Netherlands dates back to 1886, when the Dutch government drafted a penal code that declared euthanasia and assisted suicide liable to punishment (articles 293 and 294) (Government of the Netherlands, n.d.). Those articles are still valid under current legislation and have only been slightly amended in their use of words, not necessarily in the essence of their meaning. The first euthanasia case was brought to court in 1959, but it was only the 1972 Postma case (regarding a doctor who assisted her mother's death after receiving multiple, clear requests for euthanasia) that attracted attention from the media and thus from the public and professionals. The Postma case is considered to be the formal start of the Dutch debate on end-of-life decisions, a debate that has focused primarily on the legitimacy of euthanasia and assisted suicide when administered by a physician.

Another two cases (Schoonheim in 1984 and Chabot in 1993) resulted in judicial acquittals; but even before Chabot, the Dutch government, under pressure from growing public interest, had decided to investigate how practice had developed. As is customary when dealing with complex and sensitive matters, a state committee (known as the Remmelink Commission) was formed; in 1990, it organized the first large-scale scientific survey among doctors. The survey revealed the reality of euthanasia practice: The number of cases shown in the result was enormous, far exceeding what could be considered an exception (Onwuteaka-Philipsen et al., 2003). A bill on assisted dying started to be prepared, based on both practice and case law; because it was thought to be simply codifying established practice since the Postma case of 1972, the projected bill was expected to gain ready acceptance in Dutch society, both public and professional. After a new political coalition came to power in 1998, without religious political representatives for the first time in nearly 40 years, the long-discussed bill was introduced in Parliament in 1999, discussed through 2000 and 2001, and finally adopted in 2001, to take effect in April 2002.

It had taken more than 25 years for the Netherlands to become the world's first country to have conditionally legalized doctors' assistance in dying at the request of patients. (To be exact, it was the Northern Territory of Australia that legalized euthanasia first, but

because it is a territory rather than a state, the federal government of Australia could have invalidated the regulation and effectively did so within six months in 1997.) It was a genuine product of Dutch culture (comparable with our drug, prostitution, and LGBTQ+ policies), in which problematic, even penal, situations are tolerated and largely accepted as long as they occur in complete transparency and in line with established regulations (see Table 1 for the legal due care criteria).

Table 1

Termination of Life on Request and Assisted Suicide (Review Procedures) Act

Key Criteria^a
<ul style="list-style-type: none"> • Voluntary and Well-Considered Request^b <p>The patient should not be pressed to ask, and the request should not be made on the spur of the moment.</p>
<ul style="list-style-type: none"> • Unbearable and Hopeless Suffering <p>The patient defines what they consider unbearable, and the doctor defines hopelessness, after explaining and offering alternatives (e.g., optimal palliative care) to make the patient’s suffering bearable. As such, both the patient and the physician must come to the conclusion that euthanasia is the only viable option.</p>
<ul style="list-style-type: none"> • Consultation With a Second, Independent Doctor <p>The doctor must examine the patient and ensure that the criteria are met.</p>
<ul style="list-style-type: none"> • Good Medical Practice by Adhering to the Golden Standard of Medication <p>Barbiturate coma induction followed by muscular relaxation is considered a good practice.</p>

Note. The law, formally known as the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, is a codification of the criteria developed by professional guidelines, verdicts, and case law. Its principle is consistent with the Dutch ethos of democratic toleration. Physicians who administer euthanasia or PAS are required by law to report the case so that a review committee in their locality can assess it. The review committee (which has five regional chapters) includes a medical professional, an ethicist, and a lawyer who is the chair. The committee receives the obligatory report from the doctor who performed the euthanasia and assesses it against the legal criteria. It delivers the verdict to the doctor within a short period of time, up to six weeks maximum, and only sends cases to the public prosecution service and health care inspectorate when the legal due care criteria are not met (RTE, 2020). If the review committee to which the case is reported makes a careful enough assessment, I believe most cases are unlikely to be prosecuted.

^a Even though euthanasia is still a crime, if a doctor complies with the request and meets the criteria, the doctor will be exempt from punishment and will be considered to have acted outside of the penal code.

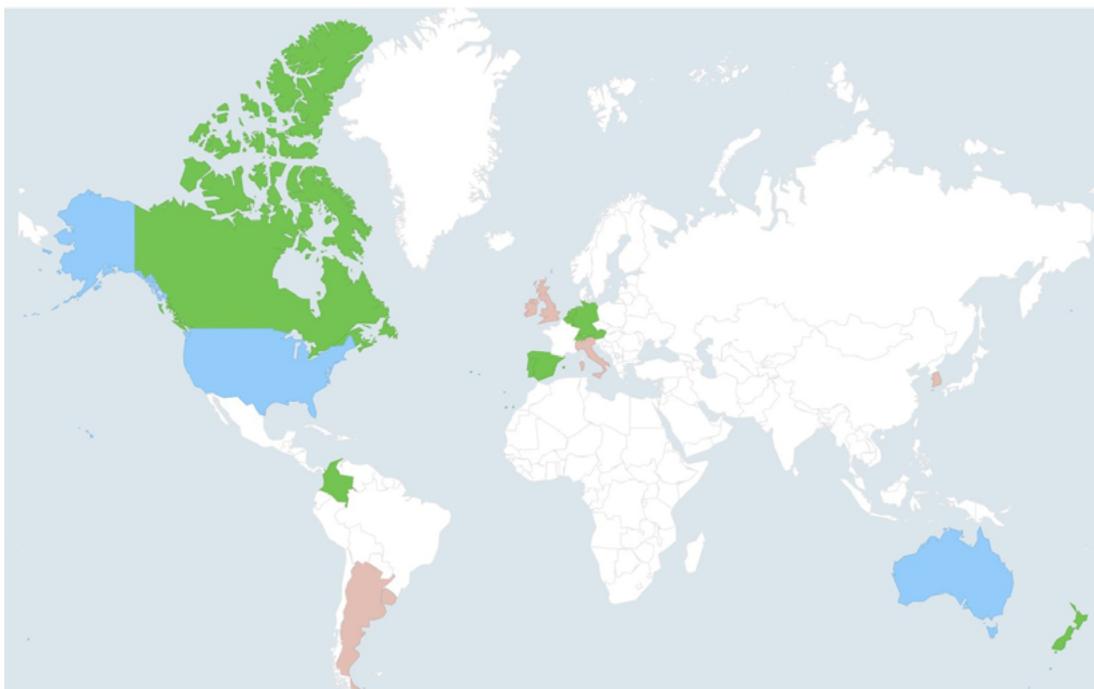
^b The law makes provision for a situation in which the patient can no longer ask for euthanasia themselves but made a living will while they could. A form of euthanasia statement is legally equivalent to a request.

Some Facts and Misconceptions About Assisted Dying and Future Directions

As one of the few countries with a law involving assisted dying in the world (WFRtDS, n.d.b) (see Figure 1), the Netherlands conducts a national evaluation of its Termination of Life on Request and Assisted Suicide (Review Procedures) Act every five years. The fourth report of 2022 is the most current (Government of the Netherlands, 2023). The surveys in the report are internationally renowned for the quality of their data, which provides a true picture of practice and developments in the Netherlands. These results, in combination with the figures presented by the review committees in their obligatory annual reports, underline developments both in numbers and cases. The percentage of assisted deaths has slightly increased from 1.9% of all deaths in 1990 to 5.1% in 2022 (Onwuteaka-Philipsen et al., 2003). However, the majority of euthanasia or PAS deaths were still due to terminal oncologic conditions, and eight out of ten cases were performed by family doctors at home rather than in hospitals (RTE, 2023).

Figure 1

The Current State of Assisted Dying Around the World



Note. Assisted dying is allowed in the green areas but not in the white areas. Legal developments are taking place in the pink areas. Assisted dying is only legal in a few parts in the blue areas. From *World Map*, by the World Federation of Right to Die Societies, 2023 (<https://wfrtds.org/worldmap/>). Reprinted with permission.

When discussing the dignity of older persons, the sick, and the dying, it is inevitable to address various medical decisions around the end of life. In this paper, however, I believe it is an absolute requirement to rectify misinterpretations and explain the background and principles of the Dutch approach, because the Dutch way of making such judgments, both in general and in relation to legally transparent active termination of life in particular, will contribute significantly to debates around this issue. Alternative ideas incorporating palliative care on the one side and euthanasia on the other may deepen these discussions.

Some of the myths about assisted dying include that older or incapacitated people in the Netherlands are afraid of visiting hospitals or nursing homes. As described in the previous section, euthanasia is only permissible under strict conditions. Furthermore, the majority of euthanasia cases are performed in the patient's home (RTE, 2023). Another misunderstanding is that legalizing euthanasia poses particular risks to the vulnerable in our society (e.g., older people, people with disabilities, and socially or economically disadvantaged groups). On the contrary, international research reports that assisted dying has been used primarily by white, well-to-do, and highly educated persons (Battin et al., 2007; California Department of Public Health, 2019; Redelmeier et al., 2021). Another common misconception is the slippery slope argument, which states that doctors would perform end-of-life procedures outside of the regulations once euthanasia was tolerated. However, it should be noted that the rate of termination of life without request has decreased from 0.8% in 1990 to 0.3% in 2015 (Onwuteaka-Philipsen et al., 2003; van der Heide et al., 2017).

The issue of palliative care—or rather, the lack of proper palliative care provision—is brought up frequently in discussions of the 2002 Dutch law. It is important to understand that palliative care was not as developed in the Netherlands at the time the euthanasia debate started. Els Borst, the minister who successfully brought the euthanasia law into being, also initiated the development of palliative care in the Netherlands; immediately after euthanasia was legalized, her ministry provided funds and developed the necessary structures.

Although that progression parallels the further development of Dutch euthanasia practices, palliative care or sedation has never been, and must never be, seen as an alternative to assisted dying: Palliative care, or sedation, is aimed at a comfortable, though brief, end of life before dying, whereas euthanasia is intended at the termination of life on request. It has become clear that, thanks to increased attention to end-of-life decisions in general, current practice places the Netherlands, together with Belgium, which has also legalized euthanasia, at the top of palliative care providers in Europe, both in terms of quality and quantity. Euthanasia and palliative care are now viewed as complementary rather than competitive: Euthanasia cannot be practiced without the availability of good palliative care, and optimal palliative care cannot be given without the option of euthanasia.

Immediately after the 2002 law was passed and assisted dying was made available on request for seriously ill patients, pro-euthanasia campaigners adapted their goals. The debate now focuses more on three groups of people for whom a self-chosen end of life has previously been completely out of reach: (a) people with dementia who have formulated an adequate advance directive; (b) patients with a chronic psychiatric illness who have come to the end of meaningful treatment; and (c) older people who, for a variety of reasons, judge their lives to be complete. To achieve proper, feasible solutions for these three groups, various ideas, in addition to the medical perspective, need to be discussed.

One perspective proposes adding the criterion of *irreversible loss of personal dignity* to the criterion of *hopeless and unbearable suffering*. While suffering is central to the doctor, loss of dignity is paramount to the patient. The problem here is not so much physical as it is social and emotional, with a severe loss of self-reliance and control over one's personal life.

A second alternative viewpoint considers introducing counselors into the dying process. Because end-of-life discussions encompassed by the euthanasia law start with the suffering caused by illness, doctors occupy a central position in the law. When such suffering is no longer the only criterion, it is only natural that another group of (possibly non-medical) professionals, namely, end-of-life counselors, be allowed to give assistance.

The final consideration relates to the person who wishes to end their life. In our euthanasia law, this person does not hold the strongest of positions: Their voluntary and well-considered request for assistance in dying is conditional on it being granted; in the end, it is the doctor who makes the decision. According to the alternative view, people nearing the end of their lives should be allowed, in all circumstances, to make well-considered choices on how they wish to die.

This wider range of possibilities for dying with dignity, rather than being limited to traditional euthanasia, reflects a commitment to the emancipation of the human being facing death. Their role in determining how they want to die must be consolidated.

Huib Drion-like arguments that go beyond the medical perspective may be recognizable here. Moving toward the self-determination principle and incorporating the dignity criterion have opened the way to thinking about termination of life on request for otherwise healthy older persons who consider their lives to be complete.

This is currently being debated in the Netherlands, although legislation is not expected in the near future. Practice along the lines of the still-unchanged law is broadly accepted and carried out carefully most of the time: In the past 20 years, only around 0.15% of all reported cases were deemed erroneous, with only one resulting in prosecution leading to acquittal (RTE, 2023).

In essence, the main takeaways from Dutch approaches and developments, in my opinion, are the following:

- For the past 40 years or more, the Dutch practice of toleration and the legalization of assisted dying (i.e., euthanasia and PAS) have shown no sign of creating a dangerous slippery slope.
- The availability of assisted dying sometimes prolongs rather than shortens life.
- Assisted dying must be regarded as an act to relieve suffering rather than one to end life.

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Voluntary Assisted Dying: Japanese Perspectives

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Throughout the last decade, there has been ongoing discussion in Japan about issues related to medical decision-making and end-of-life stages, including voluntary assisted dying (VAD) and discontinuation of life-sustaining treatments, from both ethical and cultural perspectives (Asai, 2022; Asai et al., 2018, 2023; Asai, Okita, & Bito, 2022; Asai, Okita, Tanaka, et al., 2022; Asai & Fukuyama, 2023; Masaki et al., 2014). In this article, we will discuss the legal situation, social events, famous cases, and the ethical pros and cons of VAD in Japanese society. Where appropriate, we will refer to the situation surrounding VAD in Australia as well as Confucianism-based cultures. VAD is defined here as practices that include all forms of assisted suicide in general, physician-assisted suicide, and voluntary active euthanasia administered by physicians (Asai & Fukuyama, 2023).

Legal Background on VAD and Life-Prolonging Treatment in Japan and Cases in the 1990s

No laws or official guidelines govern VAD in Japan (Asai et al., 2023; Asai & Fukuyama, 2023). According to Japan's penal code, "solicitation of suicide," "assistance in suicide," "commissioned murder," and "consensual homicide" are all illegal (Murakami, 2020). Moreover, there has been very little discussion on the matter of dying with dignity (Nagao, 2020). A legislative bill on the termination of life-sustaining measures has yet to be sent for deliberation by Parliament, due to strong opposition that has prevented it from being submitted to the Diet (Nakazawa et al., 2019; Nishi, 2021). As of October 2023, advance directives (i.e., a legal document that directs actions for a person's health if the person is

unable to decide for themselves due to disease or disability) are not enforceable in law, and there are only guidelines for the process of end-of-life care in Japan.

Three active euthanasia cases from 1991, 1995, and 1996, in which physicians gave terminal patients with malignant tumors potassium chloride to stop their hearts or muscle relaxants to stop their respiration, as well as the 1998 Kawasaki Kyodo Hospital case, in which a comatose patient in respiratory failure who had suffered from status asthmaticus was given muscle relaxants and had their ventilator turned off, brought the issue of euthanasia to public attention (Komatsu, 2004; Nakazawa et al., 2019; Suda, 2010; Yomiuri Shimbun, 2003). The common link between these four cases is that the patient was diagnosed to be in a terminal or clinically braindead state; they were not conscious when the drugs that led to their deaths were administered; and they had not expressed clear, premeditated requests for this course of action. Accordingly, all of these cases represent acts that fall within the scope of physicians' non-voluntary assisted dying (Asai et al., 2023). After they were sent to the prosecutor, the cases were either dismissed or the physicians were found guilty of murder but given a suspended sentence (Akabayashi, 2002).

On March 28, 1995, at the trial of a Tokai University Hospital case that had happened in 1991, when a physician administered potassium chloride to a patient in response to the demands of the patient's family and the patient died, the Chief Justice of the Yokohama District Court pronounced four new legal requirements for "physician-assisted voluntary euthanasia" (Akabayashi, 2002; Nakazawa et al., 2019):

- The patient must be experiencing unbearable physical suffering.
- The patient's death must be unavoidable and imminent.
- Every possible palliative treatment and care to ease the patient's physical suffering must have been provided, and no alternatives must have been available.
- The patient must have expressed a clear and voluntary desire to have their life shortened.

However, since Japanese court decisions are based neither on precedents nor antecedents, and because these requirements were ruled at an incidental level in one regional court, they carry no official legal significance (Asai et al., 2023).

Recent Events in Japan (2016 Onwards)

Even after the 1998 Kawasaki Kyodo Hospital case began to receive coverage in the press in 2002 and the conviction was confirmed by the Supreme Court in 2009, VAD-related cases still did not become a major public issue for some time. In 2016, however, a notable incident related to euthanasia occurred. Satoshi Uematsu, a former care worker at the

Tsukui Yamayuri Garden, a care facility for people with disabilities in Sagami-hara City, Kanagawa Prefecture, killed 19 residents. He was sentenced to death on March 31, 2020, but consistently attested that euthanasia was his motive for murder (Amamiya, 2020; Shinoda, 2018a, 2018b). The people he killed were unable to communicate, Uematsu said—defined by him as those who could not indicate their name, age, or address, and diagnosed again by him as mentally disabled. He stated that people in similar conditions should be euthanized—a view criticized as eugenicist thinking that is discriminatory toward people with disabilities (Amamiya, 2020; Shinoda, 2018a, 2018b). In our view, this was clearly not a case of voluntary euthanasia; it was slaughter. What happened at Tsukui Yamayuri Garden was undoubtedly an unforgivable act (Asai, 2022).

Discussion of assisted dying, however, is surfacing more frequently in popular culture. In 2017, Sugako Hashida, a well-known Japanese screenwriter, announced her wishes in an essay compilation entitled *Please Let Me Die by Euthanasia*. Hashida claimed in her book, “I don’t want to lie in bed and wait for death, whether in the hospital or at home. I don’t want to spend time just waiting to die, even if there is no pain” (2017, p. 131). The book became a bestseller in Japan. It should be noted that, whereas many readers expressed support for her decision to die by euthanasia, others voiced their opposition and concern.

A novel by Japanese novelist Shichiri Nakayama, *The Legacy of Dr. Death*, was published in the same year as Hashida’s book. This novel was made into a film, entitled *The Legacy of Dr. Death: Black File* (Fukagawa, 2020). In the novel, detectives in a police murder investigation department try to arrest a mysterious person, self-named “Dr. Death,” who has set up a euthanasia request website. Dr. Death receives requests from people who want to die due to severe illness-related suffering (i.e., the requester is a patient) or those who want to end the painful dying process of their family member (i.e., the requester is a member of the patient’s family); the patient in question is then euthanized directly by Dr. Death. Dr. Death states on his site that this mission was inspired by an American physician, Jack Kevorkian, who performed 129 assisted suicides and one active euthanasia between 1989 and 1998, earning him the title of “Dr. Death.” That is, Dr. Death, a fictitious character in Nakayama’s novel, inherits Kevorkian’s real-life nickname (Asai, 2022; Nakayama, 2017).

In 2017, Yoichi Miyashita, a Japanese journalist living in Europe, published a book on the state of assisted suicide and euthanasia around the world. In his subsequent book, *A Japanese Who Accomplished Euthanasia*, published in 2019, he reported in detail the story of the overseas travel suicide of Mina Kojima (who will be introduced in the next section). These two books gained wide public interest in Japan (Miyashita, 2017, 2019). Finally, a cultural empirical study of end-of-life decisions comparing Dutch and Japanese attitudes was published in 2020. In that study, when asked for their preferred medical decision at the end of life if they were to become terminally ill, 18% of the 1038 Japanese surveyed preferred to actively end their lives (Groenewoud et al., 2020).

More recently, a film called *Plan 75* was released in Japan (Hayakawa, 2022). The film is set in Japan in the year 2025, when the Diet has passed and implemented “Plan 75,” a system that gives people the right to choose life or death when they reach 75 in a super-aging society with a declining birthrate. In the film, the hostility of young people toward older people has become stronger than ever: The young consider older people to be a heavy burden on society. The film shows assaults on older persons by the young becoming more frequent and being wrongfully justified. For example, a young man who attacks a nursing home and kills several older persons says the following:

The overabundance of old people is putting pressure on the country’s finances, and young people are bearing the brunt of it all. I guess that old people don’t want to be a nuisance to society any more. I believe that Japanese people have always been proud to die for their country. I sincerely hope that this courageous action of mine will trigger everyone to have a frank discussion and make the future brighter. (Hayakawa, 2022)

The main protagonist in *Plan 75*, Michi Kakutani, is 78 years old, has lost her husband, has no relatives, is suddenly laid off work because of her advanced age, and has no place to live. Given her circumstances, she elects to have euthanasia administered by the Japanese government.

The film was highly acclaimed in Japan, and its message, that the socially vulnerable should not be driven to death for the economic convenience of society and the government, was well received. However, we believe that portraying VAD solely as a means of eliminating older people, because they are viewed as a burden on society, is one-sided. It may also convey the false impression that the economically impoverished and socially vulnerable are being forced to die in order to cut the government’s welfare budget. Issues such as inadequate social welfare and the lack of a safety net are essential factors that may push a person to consider VAD, as shown in the film; however, it is also true that the film does not depict the full scope of VAD, possibly not reflecting adequately the patient’s thoughts on the meaning of life.

Recent VAD Cases in Japan

VAD cases, which were infrequently reported until recently, have occurred in Japan in close succession over the last few years. The following three examples are summaries of VAD cases detailed in “Voluntary Assisted Death in Present-Day Japan: A Case for Dignity,” a report published in *Clinical Ethics* (Asai & Fukuyama, 2023).

The Case of Susumu Nishibe

In January 2018, the body of Susumu Nishibe, a 78-year-old man, was found in the Tama River in Tokyo, where he had committed suicide by drowning. Nishibe was a nationally renowned critic in politics and had previously stated in several of his books that he was determined to take his own life. He indicated that he refused to die in a hospital because he would resent being dictated to by others at the end of his life. Nishibe had been widowed for several years and suffered from a very painful spinal condition, a skin disease, and neuralgia in his right hand that prevented him from writing. In April 2018, two of his acquaintances of 20 years were arrested by the Tokyo Metropolitan Police for assisting his suicide (Asai & Fukuyama, 2023; Egawa, 2020; Kondo, 2021; Murakami, 2020; Nishibe, 2018; Sankei Shimbun, 2018a, 2018b). They were convicted of assisting suicide and sentenced to two years in prison, suspended for three years.

The Case of Mina Kojima

In November 2018, Mina Kojima, a 51-year-old woman affected by multiple system atrophy, died by suicide with the help of the Swiss assisted suicide organization called Life Circle. She wanted to end her life before she became bedridden. In March 2018, she made multiple suicide attempts, either by hanging herself or by drug overdose, but failed. In August 2018, she registered with Life Circle and, on November 25, arrived in Switzerland with her two sisters. After completing the formalities, she died by suicide through an intravenous drip of a lethal drug on November 28 (Amamiya, 2020; Asai & Fukuyama, 2023; Miyashita, 2019; Murakami, 2020; Nishibe & Tomioka, 2018). To the best of our knowledge, Kojima's two sisters were not charged in regard to this case.

The Case of Yuri Hayashi

At the end of November 2019, two doctors euthanized Yuri Hayashi, aged 51, at her request, at her house in Japan. She had been diagnosed with amyotrophic lateral sclerosis (ALS) in 2011. She became bedridden in her later days and decided not to have a tracheotomy. Hayashi wanted to end her suffering and pleaded on social media for help to be euthanized. Following that, in 2018, she contacted the two doctors and requested that she be euthanized. These doctors were charged with commissioned murder in July 2020, and the case is still pending (Chabot, 2021; Egawa, 2020; Furuta, 2020; Murakami, 2020; Nishinippon Shimbun, 2020; Suzuki, 2020).

The common factors in these cases are that the patients presented a clear and premeditated request for death; until the moment before death, the patients were in a fully conscious state; they were not in the terminal stage; they had physical and emotional suffering from which no recovery was possible; and the necessary medical care and caregiving were being provided (Asai et al., 2023; Asai & Fukuyama, 2023).

Pros and Cons of VAD in Contemporary Japan

In this section, we will discuss the pros and cons of VAD in Japan so far, with a focus on the arguments against VAD that prevail (Asai, 2022; Asai et al., 2023; Asai & Fukuyama, 2023). The ethical arguments in favor of VAD in Japan are no different from those in other countries, including respect for self-determination, desire for autonomy and control of one's own life, freedom from pain, the right to die, compassion and mercy, death with dignity, and the utility of a wide range of stringent and practical safeguards (Asai et al., 2023). Below, we summarize some of the objections to VAD that have often been voiced in Japan. Some are common to other countries and cultures, while others may be views that strongly reflect Japanese culture and social conditions and those of other East Asian countries.

Opponents of legalizing VAD often argue that because life is sacred, patients have no right to decide on their own death (Wu & Chassang, 2020). Japanese culture embodies an intense respect for the supremacy of life or sanctity of life, rooted in Shintoism (an indigenous Japanese religion based on animism and the belief that gods exist in everything) and Confucianism. Death is regarded as the ultimate impurity and is a serious taboo; any discussion of death is still highly discouraged and met with great resistance. Furthermore, there is no definite concept of an afterlife in Shintoism and Confucianism (Asai et al., 2018, 2021; Wang et al., 2022). Traditional medical ethics also require physicians to value every life and try their best to prevent death (Wang et al., 2022).

It is often argued that death is not an event solely for the person who opts for VAD in Japan (Asai et al., 2023; Asai & Fukuyama, 2023). According to Wang et al. (2022), Confucianism holds that the family is the most fundamental unit in social organization, emphasizing the importance of interpersonal relations and viewing death as a family concern. In other words, a life is shared with the family, not owned by an individual. Thus, anti-individualism (which posits that human thoughts are influenced by both internal and external factors) exists in Japan as well as in other cultures under the influence of Confucianism. In particular, Wang et al. argue that Confucianism emphasizes *xiao* (filial piety) as a virtue to be held above all else, requiring care, obedience, and devotion toward one's parents and older family members; if one's life ended prematurely, the children would suffer both private

and public moral condemnation (Wang et al., 2022). For example, in Japan, the family of a patient who dies of VAD might suffer more than if the patient had died of illness, because death from VAD is perceived as an artificial and unnatural type of death, and the bereaved family may find it more difficult to accept.

In addition to this familism, Japan has a collectivist tendency that makes individuals members of a larger constituency. The Japanese are likely to make decisions based on an other-oriented tendency (i.e., heteronomy rather than autonomy) (Asai, Okita, & Bito, 2022). Japanese people tend to read the atmosphere of the group to which they belong, feel pressure from that atmosphere, and refrain from doing what they really want to do; or they take in the intentions of others in advance, especially those of higher status than themselves, and make choices that satisfy the superior's intentions. In this context, the atmosphere refers to a very powerful invisible force that keeps people from doing what they genuinely want to do; this can be regarded as the absolute criterion of judgments concerning one's actions (Asai, Okita, & Bito, 2022).

For these reasons, it is often claimed that a person wishes to opt for VAD only out of concern for others, or people opt for VAD as a result of peer pressure in a discriminatory atmosphere (Asai, 2022; Asai et al., 2023; Asai & Fukuyama, 2023). Opponents of VAD argue that the implementation of VAD in Japan should not be permitted because the Japanese tend to act out of consideration for the wishes and burdens of others rather than through pure and authentic self-determination, and that the perception of oneself as a burden on others can be a primary reason for requesting VAD. In other words, opponents argue that VAD inevitably becomes non-voluntary in Japanese culture (Asai et al., 2023).

Opponents of VAD also claim in general that, in Japanese society, people of weaker social standing and those with disabilities are more likely to feel greater social pressure than is the case with the general population, and that even if they genuinely wish to continue living, they may choose to die a non-voluntary death under such pressure. In such cases, social pressure is based on eugenicist thinking and implies that these individuals should not be a nuisance to society; they should not use up medical and welfare resources; and they should not be a burden to their families (Asai, 2022; Asai et al., 2023). Finally, a common argument in Japan is that it is not acceptable to even begin a discussion on VAD when there is still discrimination against people with disabilities and a lack of adequate palliative care (Asai et al., 2023; Asai & Fukuyama, 2023).

Future Directions

All of the opinions asserted against VAD in Japan today that were discussed above have a point. But if people are suffering, the option of not starting a discussion on the topic is unacceptable. To protect the right to life of the vulnerable and, at the same time, respect the decision-making of those who wish for immediate death due to unbearable suffering, the dialogue on VAD legislation must begin urgently. Postponing or simply not discussing the topic makes it difficult to discover or create common ground (Asai et al., 2023; Asai & Fukuyama, 2023). To this end, we have explored currently used models that can serve as a springboard to launch discussions. In particular, we believe the Australian model for VAD to be a very useful starting point for discussion in Japan.

In Australia, VAD will be legal in all states by the end of 2023. Although there are minor differences from state to state, at the moment, it is basically the safest and most compassionate system in the world (Hunt, 2023). Below, we provide a summary of the system in Victoria, the first state in Australia to legalize VAD (Close et al., 2021; Hunt, 2023; McDougall & Ko, 2021; McDougall & Pratt, 2020; Minami, 2018; Sellars et al., 2022; Victorian Department of Health in Australia, 2019; White et al., 2021; Willmott et al., 2022).

First, to be eligible, a patient must be 18 years or older, with decision-making capacity, have an incurable, advanced, and progressive disease that leaves them with a prognosis of six months or less to live (or one year in the case of a patient with neurodegenerative disease), and have a disease that is generating suffering that cannot be relieved in a manner that the person deems tolerable. Second, in order to access assisted dying, a patient must have made a formal request on three occasions, each of which must be separated by nine or more days. The physician must not initiate the discussion about VAD; only the patient deciding to seek VAD can ask for it. Third, a patient must undergo evaluations by two independent physicians to assess eligibility. Any physician assigned to evaluate eligibility must have undergone training on VAD. Physicians are not obligated to participate in VAD, and their right to conscientious objection is respected. The default would be for a person to self-administer the medication required for VAD (i.e., physician-assisted suicide). Finally, at each stage of the process, mandatory reporting is enforced, a system is established to ensure review and monitoring, a prospective approval and oversight process is used, and a governmental permit is needed.

Access to the system, however, remains problematic, as it is sometimes difficult to find doctors and facilities that implement VAD, but there are no signs of abuse of the system so far. In addition, no conclusion has been reached on how patients with dementia or mental illness will be treated under this system (Hunt, 2023). In a survey conducted in Queensland, where VAD has been legal since January 2023, more than 70% of physicians

were in favor of the system, although less than one-third of physicians indicated that they would be in charge of implementing VAD for their patients. Many physicians also found it difficult to confidently assess a patient's decision-making capacity (Orth et al., 2023). Although there are some practical problems, this well-balanced system with stringent safeguards in place will provide useful information for Japan as well as other East Asian countries to begin considering the social permissibility of VAD.

Conclusion

In the last scene of the novel *The Legacy of Dr. Death* that we discussed in an earlier section, the protagonist's daughter says the following in regard to euthanasia:

It is the same compassion that makes us think that we don't want to let family members die or that we don't want to let them suffer. The root is the same: compassion. Longevity does not unconditionally bring about happiness for humanity. The motivation is the same. It is the approach that differs. (Nakayama, 2017, pp. 292–293)

We agree with this statement. Some people wish to let a loved one die out of compassion, while others wish to sustain their lives as long as possible out of the very same compassion. There will be no easy answer or consensus on which approach is more ethical (Asai, 2022). However, we argue that it is critical to start or continue discussing VAD issues, no matter how challenging this may be.

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The initial ASEM partnership in 1996 consisted of 15 EU member states, 7 ASEAN member states, China, Japan, Korea, and the European Commission. Today, ASEM comprises 53 partners: 30 European and 21 Asian countries, the European Union, and the ASEAN secretariat.

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ASEM GLOBAL AGEING CENTER (AGAC)

ASEM Global Ageing Center (AGAC) is a specialized international institution based in Seoul that operates as a global hub for coordinating a wide variety of agendas surrounding the human rights of older persons for ASEM partners. The center aims to address various issues confronted by ASEM partners regarding the human rights of older persons and ultimately contribute to the promotion and protection of human rights of older persons through policy research, cooperation, awareness-raising and education, and information sharing.

AGAC ISSUE FOCUS

AGAC Issue Focus is a biannual periodical that aims to address ageing and human rights issues in a timely fashion. The publication introduces relevant ASEM partner policies and responses to a wider audience in order to promote information sharing and awareness-raising and ultimately enhance ASEM partner cooperation. Each report focuses on a distinct theme that highlights current major concerns to do with ageing and the human rights of older persons in Asia and Europe.

For more information, visit the AGAC website (www.asemgac.org).

The logo for the ASEM Global Ageing Center (AGAC) features the letters 'AGAC' in a bold, white, sans-serif font. The letters are closely spaced, with the 'A' and 'G' overlapping slightly. The 'A' is on the left, followed by 'G', 'A', and 'C' on the right.

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