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Parte II

Settori

Giurisprudenza e legislazione amministrativa

Giurisprudenza e legislazione canonica e vaticana

Giurisprudenza e legislazione civile

Giurisprudenza e legislazione costituzionale e comunitaria

Giurisprudenza e legislazione internazionale Giurisprudenza e legislazione penale Giurisprudenza e legislazione tributaria

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Parte III

Settori

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E-mail: *info@pellegrinieditore.it* Sito web: *www.pellegrinieditore.it* 

Direzione scientifica e redazione

I Cattedra di Diritto ecclesiastico Dipartimento di Giurisprudenza Università degli Studi di Napoli Federico II Via Porta di Massa, 32 Napoli – 80133

Tel. 338-4950831

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Faith teachings and legal aspects on end-of-life decisions. An overview of controversial issues in contemporary Western societies

Insegnamenti delle fedi religiose e aspetti giuridici riguardo alle decisioni di fine vita. Una panoramica di questioni controverse nelle società occidentali contemporanee

FABIO FRANCESCHI

#### ABSTRACT

To what extent do the views of religions and religious groups on end-of-life (EoL) issues affect their regulation in Western legal systems? What difficulties do national legislators encounter in regulating end-of-life? What are the peculiarities of the Italian situation? Is it possible to affirm that the privileged position recognized in Italy to the Catholic Church has influenced (and to what extent) the solution settled by the Italian legislator for end-of-life issues? The essay aims to answer these questions. More precisely, it focuses on the analysis of the influence of the views and teachings of religious groups both on individual choices and on the current Western regulatory framework concerning end-of-life decisions (with specific regard to euthanasia and assisted suicide), as well as on extent to which the legal regulation of end-of-life issues at national and supranational level must be consistent with the ideological postulates and positions of the secular state, especially in the context of the growing multi-ethnic, multicultural and multireligious evolution of contemporary Western societies.

#### KEYWORDS

End-of-life decisions; Ethical dilemmas; Legal standards; Religious teachings; Western societies

#### Riassunto

In che misura le opinioni delle religioni e dei gruppi religiosi sulle questioni di fine vita (EoL) influenzano la loro regolamentazione nei sistemi giuridici occidentali? Quali difficoltà incontrano i legislatori nazionali nella regolamentazione delle decisioni di fine vita? Quali sono le peculiarità della situazione italiana? È possibile affermare che la posizione privilegiata riconosciuta in Italia alla Chiesa cattolica abbia influito (e in che misura) sulla soluzione delineata dal legislatore italiano per le questioni di fine vita? Il saggio si propone di rispondere a queste domande. Più precisamente, si concentra sull'analisi dell'influenza delle opinioni e degli insegnamenti dei gruppi religiosi sulle scelte

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individuali e sull'attuale quadro normativo occidentale concernente le scelte di fine vita (con specifico riguardo all'eutanasia e al suicidio assistito), nonché sulla misura in cui la disciplina giuridica delle questioni di fine vita a livello nazionale e sovrannazionale debba risultare coerente con i postulati ideologici e con le posizioni dello Stato laico, specialmente nel contesto della crescente evoluzione multietnica, multiculturale e multireligiosa delle società occidentali contemporanee.

#### PAROLE CHIAVE

Decisioni di fine vita; questioni etiche; religione; diritto; società occidentale

TABLE OF CONTENTS: 1. Political, legal and ethical aspects of the end-of-life debate – 2. The influence of individuals' religious beliefs on the approach to the concept of life and death -3. Advances in medical science and endof-life decisions – 4. Right to life v. self-determination. The "right to die" *debate – 5. Regulating end-of-life: a difficult task for State legislators – 6.* Faith at end-of-life. The views and teachings of religious groups on endof-life decisions – 7. The "Position Paper of the Abrahamic Monotheistic Religions on Matters Concerning the End of Life" - 8. Principles, values and practices relevant to the dying patient in contemporary Western societies and the growing trend towards forms of death on request -9. End-of-life issues in Western legal tradition – 10. The case-law of the Strasbourg Court on issues related to end of life – 11. End-of-life regulatory framework in Italy. The Law no. 219 of 2017 – 12. A developing path. Prospects for increasing the legal protection of end-of-life choices in Italy – 13. The influence of Catholic Church on the current Italian legislation on end-of-life – 14. Conclusive remarks.

# 1. Political, legal and ethical aspects of the end-of-life debate

The ethical, religious, social, political and legal aspects of decisions regarding the end of human life are among the most contentious and widely discussed topics in contemporary Western societies, especially as regards the care and treatment of dying patients<sup>1</sup>.

¹ 'End of life' (EoL) is a generic term to refer to the choices at the terminal stage of human life, with specific regard to those situations "in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future": The Council of Europe, Guide on the decision-making process regarding medical treatment in end-of-life situations, December 2014 (https://www.coe.int/en/web/bioethics/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations). For an overview on end-of-life debate in Western world see Gerald Dowrkin, Raymond G. Frey, Sissela Bok (eds.), Euthanasia and Physician

In recent years, end-of-life questions have been the subject of intense public and political debate. National and supranational legislators and courts, scientists and experts in different areas (medicine, ethics, sociology, philosophy, etc.), jurists, religious leaders, civil society organizations and citizens have all assessed controversial issues ranging from the extent of care and support that persons in the last stage of life should receive, including the right to refuse or to withdraw life-sustaining treatments (i.e., different types of treatments that can be used to keep people with serious or terminal illnesses alive), up to the admissibility of a terminally ill person's right to end their life and, if so, under what conditions.

Much controversy has focused on physician-assisted suicide, also called by some supporters "aid in dying". However, the end-of-life debate also involves the broader question of euthanasia, both voluntary and involuntary, including whether and when it is permissible to suspend life-sustaining treatment of someone who is unable to make the decision to himself (patients in persistent vegetative state, for example)³, as well as other issues involving

Assisted Suicide: For and Against, CUP, Cambridge, 1998; Alfonso Aguilar (ed.), What is death? A scientific, philosophical and theological exploration of life's end, LEV, Vatican City, 2009; Daniel Callahan, The Roots of Bioethics: Health, Progress, Technology, Death, OUP, Oxford-New York, 2012; Antonio D'Aloia (ed.), Il diritto alla fine della vita. Principi, decisioni, casi, ESI, Napoli, 2012; Stephen W. Smith, End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process, CUP, Cambridge, 2012; Michael Cholbi, Jukka Varelius (eds.), New directions in the ethics of assisted suicide and euthanasia, Springer, Dordrecht, 2015; Margaret P. Battin (ed.), The Ethics of Suicide: Historical Sources, OUP, Oxford-New York, 2015; Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford Handbook of Ethics at the End of Life, OUP, Oxford-New York, 2016; Mauro Ronco (ed.), Il "diritto" di essere uccisi: verso la morte del diritto?, Giappichelli, Torino, 2019; Sue Westwood (ed.), Regulating the end of life: death rights, Routledge, London-New York, 2022.

<sup>&</sup>lt;sup>2</sup> Physician-assisted suicide can be defined as the deliberate and intentional support or facilitation of the death of a terminally ill patient by the physician by providing the means and/or information necessary to enable the patient to perform the life-ending act (usually through the prescription of a drug which, if ingested, causes the person's death).

<sup>&</sup>lt;sup>3</sup> Euthanasia (from the ancient Greek  $\varepsilon v \theta a v a \sigma (a)$ , good death, 'death that benefits the person who dies'), sometimes called 'mercy killing', is the direct, deliberate, and intentional act by a person (ordinarily a physician, but not necessarily) to provide a good death for a patient by administering a lethal agent, in order to alleviate the patient's intolerable and incurable suffering (usually because he is terminally ill and in pain). In terms of the person making the decision, euthanasia can be voluntary or non-voluntary. In voluntary cases, a person requests the end of their life to avoid future suffering, expressly consenting to their own death. A widely accepted definition of voluntary euthanasia is the administration of a drug by a health professional to actively end a person's life at the individual's voluntary request and with their informed consent. Non-voluntary euthanasia occurs when a person is unable to make the decision, due to the nature of their condition, to end their life on their own (usually because they are unconscious, as in the case of young infants or patients in a coma), so the decision is made by a legal guardian. Furthermore, on the basis of the method used to end a life, it is possible to distinguish between active and passive euthanasia. Active euthanasia occurs when a person's death is caused by external intervention rather than natural causes, such as via a lethal injection or the voluntary swallowing of deadly drugs. Passive euthanasia occurs when a person dies as a result of to the deliberate withdrawal of treatment that kept them alive. Thus, a person passively euthanized may die via natural causes even though methods

end-of-life decisions such as advance care directives, standards for surrogate decision making, refusal and withdrawing of life-sustaining treatment, actively hastening death and palliative care, pain management, artificial nutrition and hydration, continuous sedation, therapeutic obstinacy, do-not-resuscitate orders, organ donation, etc.

The main reason for this widespread interest is that end-of-life decisions involve delicate dilemmas, which are not only and primarily medical or scientific, but rather ethical, philosophical and religious dilemmas, as most of the decisions concerning the dying patient are based on personal values and ethics. While the modern approach to dying is highly medicalized, the terminal stage of human life is often a time when spiritual issues emerge, and patients can examine and reaffirm their beliefs to die in peace. From this perspective, end-of-life issues are about the freedom to be oneself, to form deep beliefs and act on them. Furthermore, they have an intrinsic and inevitable legal dimension because any solution to end-of-life questions cannot disregard the regulatory intervention of the law. From a legal perspective, however, it is difficult to establish what may or may not be legal in this context, because end-of-life choices involve ethically sensitive issues such as the right to life, the right to health, the right to human dignity, or the right to freedom and self-determination of the human being. They are all rights guaranteed and protected both at national and supranational level. Therefore, a fair balance needs to be found between these rights<sup>4</sup>.

2. The influence of individuals' religious beliefs on the approach to the concept of life and death

Religious beliefs have always played and still play an intervening role in matters of people's life and health, exerting a significant influence on the ap-

to keep them alive might be available (for instance, a person who has a life-support machine switched off dies via natural causes but only as a result of a decision to allow natural causes to take effect). On these distinctions, see Mark Dimmock, Andrew Fischer, Ethics for A-Level: For AOA Philosophy and OCR Religious Studies, Open Book Publishers, Cambridge, 2017, pp. 123-140 (http://books.openedition.org/obp/4427); Jocelyn Downie, Mona Gupta, Stefano Cavalli, Samuel Blouin, Assistance in dying: A comparative look at legal definitions, in Death Studies, 46 (7), 2022, pp. 1547-1556. The more recently introduced terms "voluntary assisted dying" or "medical assistance in dying" describe both active voluntary euthanasia and physician-assisted suicide. See Graham Grove, Melanie Lovell, Megan BEST, Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide: A Comparative Analysis, in Journal of Religion and Health, 61, 2022, p. 4759.

<sup>&</sup>lt;sup>4</sup> See Giuseppe D'Angelo, The Interface between End-of-Life Care and Religious Rights: Legislation of a Christian or a Secular State?, in Stefania Negri (ed.), Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective, Nijhoff, Leiden-Boston, 2011, pp. 437-454.

proach both to the conception of life and, as far as we are concerned, of the death of human beings, more and perhaps even before the law<sup>5</sup>.

Despite the specific opinions and practices of each of them, religions have indeed a particular sensitivity to problems concerning natural end-of-life events (how individuals perceive death, the process of dying, defining the exact moment of death, and the afterlife), and to the connected needs of protection of human existence and dignity. Whenever possible, religious groups and communities strive to direct their followers towards choices consistent with their own positions. They also try to carry out a function of ethical and social control over the progress of medical science, perceiving the danger that it may progressively invade the personal and unavailable sphere of the individual<sup>6</sup>.

Not by chance, the teachings of faith traditions on euthanasia, assisted suicide, and other end-of-life issues have a significant impact both on patients, especially the terminally ill, and on healthcare professionals, as they act as an element of interpretative conditioning in the end-of-life decision-making process, not without legal implications<sup>7</sup>. As patients and physicians with different religious, cultural, and ethical backgrounds adopt different approaches, the religion and religiosity of both patients and physicians are important in determining end-of-life attitudes and practices. In particular, with the development of the right to therapeutic self-determination, a patient's religious affiliation has become a key component in medical decision-making<sup>8</sup>. Today, religious

<sup>&</sup>lt;sup>5</sup> Shane Sharp, Beliefs in and about God and attitudes towards voluntary Euthanasia, in Journal of Religion and Health, 57, 2018, pp. 1020-1037. In this regard, it is evident that a religious faith's theological teachings do influence societal beliefs, often unconsciously, in any given society where that faith predominates. See also Patricia A. Talone, Feeding the Dying: Religion and End-of-life Decisions, P. Lang, New York, 1996; Michele Aramini, Bioetica e religioni, Paoline, Milano, 2007; Mariam Rawam Abdulla, Culture, religion, and freedom of religion or belief, in The Review of Faith & International Affairs, 16 (4), 2018, pp. 102-115; Antonio Sandu, Ana Frunză, Alexandra Huidu, Bioethical acceptability of Euthanasia in the Greek orthodox religious context, in Journal for the Study of Religions and Ideologies, 19 (57), 2020, pp. 150-165; Gaetano Marcaccio, Identità religiosa e diritto alla salute. Interazioni classiche ed emergenti, in Stato, Chiese e pluralismo confessionale, Rivista telematica (https://www.statoechiese.it), 8, 2021, pp. 17-78.

<sup>&</sup>lt;sup>6</sup> On the long-standing role of religions in the history of science and medicine see Christian Byk, *Religions, Bioethics and Biolaw*, in Silvio Ferrari (ed.), *Routledge Handbook of Law and Religion*, Routledge, London-New York, 2015, p. 302.

<sup>&</sup>lt;sup>7</sup> It is no coincidence that religiosity is one of the main critical factors associated with people's opposition to the legalization or decriminalization of euthanasia and assisted suicide. See Raishekhar Chakraborty, Areej R. El-Jawahri, Mark R. Litzow, Karen L. Syrjala, Aric D. Parnes, Shahrukh K. Hashmi, *A systematic review of religious beliefs about major end-of-life issues in the five major world religions*, in *Palliative & Supportive Care*, 15 (5), 2017, pp. 609-622.

<sup>&</sup>lt;sup>8</sup> See Puteri N.J. Kassim, Fadhlina Alias, *Religious, Ethical and Legal Considerations in Endog-Life Issues: Fundamental Requisites for Medical Decision Making*, in *Journal of religion and health*, 55 (1), 2016, pp. 119-134.

beliefs are increasingly reflected in decisions about the acceptability of an extreme medical practice, including ending life at the patient's request. In many Western countries, adult patients rely on their religious affiliation to refuse life-prolonging or life-sustaining medical treatments if they so choose, or to withdraw treatment that has already begun<sup>9</sup>. Thus, religious affiliation can significantly affect patient medical decisions and events surrounding the dying process, playing a supportive role in both end-of-life decisions and palliative medical care<sup>10</sup>. At the same time, the clinicians' convictions in religious matters are also important, above all regarding the possible access to conscientious objection to euthanasia and assisted suicide, where provided for by law, or, in any case, to the administration of treatments with outcomes contrary to the teachings of their religion<sup>11</sup>.

Because of this dual impact, it is essential that medical professionals have a basic understanding of how different religious groups perceive death, in order to help them better understand and respect patient behaviours, care goals and treatment decisions towards the end of life. Indeed, today religions play a significant role in the lives of billions of adherents worldwide. Many religious communities are spread across the world, and increasing globalization requires healthcare systems to consider the religious beliefs of a wide variety of ethnic and religious groups when making end-of-life decisions<sup>12</sup>.

Obviously, in dealing with the ethical and legal dilemmas surrounding endof-life choices, clinicians must be sensitive not only to patients' varying religious beliefs and cultural values, but also to developing legal and ethical standards, which vary from country to country and may themselves be influenced by the views and teachings of religious faiths<sup>13</sup>.

<sup>&</sup>lt;sup>9</sup> See Naomi R. Cahn, Amy Ziettlow, *Religion and End-of-life Decision-making*, in *University of Illinois Law Review*, 4, 2016, p. 1736.

<sup>&</sup>lt;sup>10</sup> See Alan Meisel, Legal Issues in Death and Dying: How Rights and Autonomy Have Shaped Clinical Practice, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford Handbook of Ethics at the End of Life, cit., 2016, pp. 7-26.

<sup>&</sup>lt;sup>11</sup> On the importance of religiously motivated claims of conscientious objection in democratic societies cf. Mark R. Wicclair, Conscientious Objection, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford Handbook of Ethics at the End of Life, cit., pp. 87-108; Jason T. Eberl, Protecting reasonable conscientious refusals in health care, in Theoretical Medicine and Bioethics, 40 (6), 2019, pp. 565-81; Pierluigi Chiassoni, Protecting freedom of conscience in a constitutional state, in Claude Proeschel, David Koussens, Francesco Piraino (eds.), Religion, Law and the Politics of Ethical Diversity. Conscientious Objection and Contestation of Civil Norms, Routledge, New York-London, 2021.

<sup>&</sup>lt;sup>12</sup> See Hans H. Bülow, Charles L. Sprung, Konrad Reinhart, Shirish Prayag, Bin Du, Apostolos Armaganidis, Fekri Abroug, Mitchell M. Levy, *The world's major religions' points of view on end-of-life decisions in the intensive care unit*, in *Intensive Care Medicine*, 34, 2008, p. 423.

<sup>&</sup>lt;sup>13</sup> See Puteri N.J. Kassim et Al., *Religious, Ethical and Legal Considerations in End-of-Life Issues*, cit., p. 119. According to the authors, the development of comprehensive ethical codes con-

In this regard, it suffices to consider that end-of-life legal decisions are shaped by many forces outside the law, including religion. Although in a secular context the State is not required to have direct knowledge of religion, nevertheless State law must in some cases take religion into account, due to the importance of individuals' religious beliefs even in the context of secular societies. Specifically, concepts for addressing with legal issues at the end of life are often closely related to culture and religions. Therefore, national legislators should consider the perspectives of major religious traditions within each country in regulating ethically sensitive issues such as euthanasia and assisted suicide, because they have a large impact on public opinion and, consequently, can influence the development of legislation on the matter, even within contemporary secular States<sup>14</sup>.

Not surprisingly, the variety of beliefs, thoughts and religions has long influenced legislation on end-of-life decisions and has largely contributed to the distinct approaches in different countries. Indeed, it can be said that the legal discipline on end-of-life issues is certainly one of the areas of State law most influenced by religions (in Italy, mainly by the Catholic Church).

## 3. Advances in medical science and end-of-life decisions

Advances in medical sciences and the modernization of healthcare are certainly among the main factors that have led to the great intensification of dilemmas and debates on end-of-life decisions in recent years.

The progressive development of biomedical technologies has exponentially enlarged the clinical competence and efficiency of diagnostic medicine in the care and treatment of the patient, especially in the terminal stage of human life. Medical advances have made it possible to significantly lengthen life and to defer the moment of death, even for considerable periods of time, to such an extent never before possible. Above all, they have greatly extended the dying process, through medical actions and procedures that can be used to keep people with serious or terminal illnesses alive (so-called "life-prolonging and life-sustaining treatments", such as breathing, hydration, and artificial nu-

sistent with developing legal standards can offer clear guidance to the medical profession in making proper medical decisions.

<sup>&</sup>lt;sup>14</sup> See Graham Grove et Al., *Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide*, cit., p. 4759; Stephanie Rohlfing-Duoux, Uwe Hellmann (eds.), *Perspectives of law and culture on the end-of-life legislations in France, Germany, India, Italy and United Kingdom*, Nomos, Baden-Baden, 2019.

trition). In addition, new pain-relieving drugs have allowed doctors to alleviate pain (so-called pain relief on terminally ill patients) and, in some cases, to painlessly end patients' lives (for example, through so-called continuous sedation)<sup>15</sup>.

However, the counterpart of these medical actions and procedures aimed at lengthening the dying process is the prolongation of a terminal illness, with inevitable consequences on the quality and dignity of life of dying patients. Despite advances in medical science, prolonged survival is still often associated with pain and suffering for patients due to various organic, mental and emotional dysfunctions. Furthermore, other factors such as loneliness, depression, old age, lack of physical autonomy or the moral and economic burden of care on families can affect the perception that the patients may have of the terminal stage of their life. However, with terminal illnesses there comes a time when it becomes clear that there is no prospect of recovery and that life-sustaining treatments are only prolonging the dying process, often selfdegrading the patient like an appendage of the machine that artificially keeps him alive.

A debate is therefore widespread among doctors, scientists, philosophers, jurists, in which religions often also intervene with their ability to influence society. According to some, insisting on prolonging purely biological human life at all costs (the so-called "therapeutic obstinacy" or "medical futility" 16) is a serious attack on the dignity of the patient, which can sometimes make survival intolerable. Human dignity must be considered inviolable in all phases of life, even in the terminal one<sup>17</sup>. Indeed, the goal of end-of-life care for dying patients is to prevent or alleviate suffering as much as possible while re-

<sup>&</sup>lt;sup>15</sup> The practice of continuous sedation is a way to relieve unbearable suffering in patients at the end of life. However, there are also contentious issues raised by continuous sedation, such as whether it should be restricted to patients with a very short life expectancy, artificial nutrition and hydration, and existential or psychological suffering. See SIGRID STERCKX, RAUS KASPER, Continuous Sedation at the End of Life, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford Handbook of Ethics at the End of Life, cit., pp. 109-125.

<sup>&</sup>lt;sup>16</sup> The expression "therapeutic obstinacy" refers to the initiation or continuation of disproportionate and futile medical actions or procedures with no real benefit to the patient and which have no other purpose than to prolong the person's life when faced with a death irreversible. The same concept is also indicated with the term "medical futility", i.e., the use of medical procedures to maintain the vital function of the terminally ill in order to delay death but by introducing excessive suffering or in a way detrimental to his dignity. See Douglas White, Thaddeus Pope, Medical Futility and Potentially Inappropriate Treatment, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford Handbook of Ethics at the End of Life, cit., pp. 65-86.

<sup>&</sup>lt;sup>17</sup> PAWEL LUKÓW, A Difficult Legacy: Human Dignity as the Founding Value of Human Rights, in Human Rights Review, 19, 2018, pp. 313-329.

specting the patients' wishes and their intrinsic dignity<sup>18</sup>. A positive obligation of States to respect and protect the dignity of a terminally ill or dying person must therefore be affirmed<sup>19</sup>. For this reason, patients in such precarious conditions not only ask for palliative care and pain relief programs or therapies, but, at times, they explicitly ask for assistance in dying, to prevent great physical suffering or to avoid the perceived 'indignity' of a dependent existence<sup>20</sup>.

Accordingly, the advancement of techno-sciences raises the question of the forms and limits of control over life and death, that is, the limits within which individuals can make decisions about themselves, even deciding to put an end to their own existence.

In this respect, different and often irreducibly conflicting ideological positions oppose each other. On the one hand there are the promoters of ethical visions, often of a religious nature, who tend to affirm the absolute intangibility of human life and its natural course (both in relation to procreation, and therefore to the initial phase of human existence, and in its terminal stage, especially in the case of incurable or fatal diseases). On the other hand, there are the supporters of a "secular ethics" more oriented to the protection of individual freedom of conscience, which are instead inclined towards biotechnological progress and its potential impact on the management of events concerning human existence, including the right to "leave at the right time", according to one's ethical or religious beliefs<sup>21</sup>.

<sup>&</sup>lt;sup>18</sup> Indeed, not everything that is technically possible from a medical perspective is also ethically admissible, and unjustified disproportion, beyond what can be considered medically reasonable, is only intended to prolong the agony and suffering of the terminally ill. See Melahat Akdeniz, Bülent Yardimci, Ethem Kavukcu, Ethical considerations at the end-of-life care, in SAGE open medicine, 9, 2021 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7958189/).

<sup>&</sup>lt;sup>19</sup> See The Council of Europe, Parliamentary Assembly, 25 June 1999, Recommendation 1418, *Protection of the human rights and dignity of the terminally ill and the dying (https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=16722)*.

<sup>&</sup>lt;sup>20</sup> DIEGO ZANNONI, Right or duty to live? Euthanasia and assisted suicide from the perspective of the European convention on human rights, in European journal of legal studies, 2, 2020, p. 182. On the relation between human dignity and palliative care cf. Kathleen Benton, Renzo Pegoraro (eds.), Finding dignity at the end of life: a spiritual reflection on palliative care, Routledge, London-New York, 2021.

<sup>&</sup>lt;sup>21</sup> On this distinction see David Solomon, Christian bioethics, secular bioethics, and the claim to cultural authority, in Christian bioethics, 3, 2005 pp. 349-59; Giovanni Fornero, Bioetica cattolica e bioetica laica, Bruno Mondadori, Milano, 2009; Mark J. Cherry, Human Suffering and the Limits of Secular Bioethics, in Ronald M. Green, Nathan J. Palpant (eds.), Suffering and Bioethics, OUP, Oxford-New York, 2014, pp. 337-354; María Casado, Manuel Jesús López Baroni, Handbook of Secular Bioethics. Key issues, Edicions de la Universitat de Barcelona, Barcelona, 2020, pp. 149-175; Michael McCarthy, Mary Homan, Michael Rozier, There's No Harm in Talking: Re-Establishing the Relationship Between Theological and Secular Bioethics, in The American Journal of Bioethics, 20 (12), 2020, pp. 5-13; Jason T. Eberl, Purely Faith-Based vs. Rationally-Informed Theological Bioethics, in The American Journal of Bioethics, 20 (12), 2020, pp. 14-16.

With specific regard to the end-of-life, the key question is the extent to which individuals can dispose of the terminal stage of their existence. In fact, in the Western legal tradition and in most Western systems, while it is possible to affirm the existence of a 'right to life' according to the main supranational instruments on human rights, it is not possible to argue with the same certainty about the existence of a 'right to die'22. This remark raises some questions: Does the right to life imply the right to die? If so, is there a right of human beings to put an end to their own life (i.e., to choose death) when life is no longer deemed dignified? More specifically, does a right to a 'dignified death' exist? Can the right of patients to refuse life-sustaining treatment or medical intervention be interpreted as a right to death on demand? If the existence of this right is recognised, within what limits and under what conditions? In the name of this alleged right, it is possible to authorize a person with a terminal illness, incurable pain or simply lacking the will to continue living, to end his life by submitting himself to voluntary euthanasia or resorting to assisted suicide?<sup>23</sup>

### 4. Right to life v. patient self-determination. The right to die debate

In this respect, two fundamental principles clash and must in some way be balanced and reconciled with each other: the protection of human life, on the one hand, and the autonomy and self-determination of the individual, linked to the right to respect for private life, on the other hand<sup>24</sup>.

The latter has had a constant increase in recent years and has led to the gradual affirmation of the individual's right to choose not only the medical treatment he wishes to receive, with the related patients' right to refuse care,

<sup>&</sup>lt;sup>22</sup> In this regard see XAVIER DIJON, Can the "Right to Die with Dignity" be Classified as a Human Right?, in Death and Dignity: New Forms of Euthanasia. A Catholic Perspective on the Human Right to a Dignified Death, edited by Caritas in Veritate Foundation, FCIV, Chambésy, 2016, pp. 11-32 (http://www.fciv.org); Hans-Georg Ziebertz, Francesco Zaccaria, The Right to Life Questioned. Introductory Remarks, in Hans-Georg Ziebertz, Francesco Zaccaria (eds.), Euthanasia, Abortion, Death Penalty and Religion. The Right to Life and its Limitations: International Empirical Research, Springer Cham, 2019, pp. 1-12.

<sup>&</sup>lt;sup>23</sup> Interestingly, there is a lack of convergence among supporters of the two opposing visions on the concept of human dignity. In fact, "the emphasis on the right to die with dignity can be found both in the writings of those who consider euthanasia at the request of the patient and assisted suicide a dignified way of dying and in the writings of those who consider it the most undignified end conceivable. This shows the ambivalence of the notion 'dignity' across radically opposed positions": Diego Zannoni, Right or duty to live?, cit., p. 190. See also Francesco Francioni, Genetic resources, biotechnology and human rights: the international legal framework, in EUI Working Paper Law, 17, 2006, pp. 1-23.

<sup>&</sup>lt;sup>24</sup> See Diego Zannoni, Right or duty to live?, cit., p. 182 ff.

including life-sustaining treatment<sup>25</sup>, but also the "manner and timing" of his death (i.e., by what means and at what time his life will end), provided he is able to freely decide<sup>26</sup>. Therefore, the extension of the patient's autonomy and self-determination has allowed the individual to decide autonomously on some ethically and religiously controversial issues such as resuscitation, mechanical ventilation, artificial nutrition and hydration, terminal sedation, withholding and withdrawing treatments, and, in some cases, euthanasia and physician-assisted suicide<sup>27</sup>.

However, the availability of advanced medical technologies capable of lengthening the time of death raises questions about the morality of sustaining life versus taking life or allowing someone to die, fostering a worldwide debate on medical care decision-making in end-of-life situations (above all, on euthanasia and assisted suicide), with a variety of opinions on the acceptability and usefulness of treatments from different ethical, philosophical, religious and legal perspectives. For supporters of the "right to life", human life is never available for its intrinsic dignity. Thus, they are hostile to any alteration of the natural course of human existence. Unconditional adherence to the principle of unavailability of the right to life has as a consequence the need to always defend and protect human life, even against the will of the person concerned in situations where the end of life is requested in his presumed best interest<sup>28</sup>. Instead, proponents of individual autonomy and self-determination argue that the ability to choose about the terminal stage of one's life is increasingly

<sup>&</sup>lt;sup>25</sup> It means that a patient who does not want any life-sustaining treatment can refuse it even though the consequence of withdrawing from life-sustaining treatment is that the patient will die right away.

<sup>&</sup>lt;sup>26</sup> Cf. Council of Europe, Assembly debate on 25 January 2012, Resolution 1859 (2012): Protecting human rights and dignity by taking into account previously expressed wishes of patients (http://www.europeanrights.eu/public/atti/1859\_ing.htm), n. 1: "There is a general consensus based on Article 8 of the European Convention on Human Rights (ETS No. 5) on the right to privacy that there can be no intervention affecting a person without his or her consent. From this human right flow the principles of personal autonomy and the principle of consent. These principles hold that a capable adult patient must not be manipulated and that his or her will, when clearly expressed, must prevail even if it signifies refusal of treatment: no-one can be compelled to undergo a medical treatment against his or her will".

<sup>&</sup>lt;sup>27</sup> On the current emphasis on patient autonomy and self-determination, which almost exclusively focuses on preference or choice of individual, see Francesco Salerno, International Protection and Limits to the Right to Self-Determination for the Bio-Technological Strengthening of 'Own Person, in Debora Provolo, Silvio Riondato, Feridun Yenisey, Genetics, Robotics, Law, Punishment, Padua University Press, Padova, 2014, p. 452 ff.; Angela Di Stasi, Perspectives of International and European Law on Dignity and Self-Determination at the End of Life Human Dignity: From Cornerstone in International Human Rights Law to Cornerstone in International Biolaw?, in Stefania Negri (ed.), Self-Determination, Dignity and End-of-Life Care, cit., pp. 1-21: Alan Meisel, Legal Issues in Death and Dying: How Rights and Autonomy Have Shaped Clinical Practice, cit., pp. 7-26.

<sup>&</sup>lt;sup>28</sup> See Diego Zannoni, *Right or duty to live?*, cit., pp. 183-184. In this respect, see also Xavier Dijon, *Can the "Right to Die with Dignity" be Classified as a Human Right?*, cit., p. 17.

perceived as an essential element of individual autonomy<sup>29</sup>. Not all lives are worth living and no one can be forced to live a life that he deems intolerable. Therefore, everyone should have the freedom to choose how and when to die, even by completely refusing medical assistance as it is deemed futile, disproportionate or dehumanizing, or by deciding to withdraw life-prolonging or life-sustaining treatments<sup>30</sup>.

As is evident, the latter vision leads to a 'de-absolutisation' of the value of life, in the sense that life is not always and no longer considered an absolute right<sup>31</sup>. Above all, it supports the growing tendency to affirm a right of individuals to dispose of their own life in certain conditions of incurable illness or intolerable suffering, that is, a right to die. This demand for the right to die, however, has shifted in recent decades and has turned into what some call a 'right to death'. As a result, patients no longer claim only the right to refuse or to withdraw treatment -the right to let themselves die- but also the right to determine the very moment of their own death, even by resorting to active euthanasia and assisted suicide<sup>32</sup>. It follows that unconditional adherence to the principle of self-determination would entail the recognition of everyone's "right to die upon request, provided that their decision is based on their free and informed will" To support this claim, the proponents of the right to death are increasingly calling for a decriminalization or legalization of so-called medically assisted suicide and euthanasia (EPAS) in national laws.

In this respect, however, a few questions need to be raised, and specifically: when would it be possible to request assisted dying? if so, would there be limits and conditions to be respected or would the request of the competent adult be suffice? Many supporters of the morality of assisted dying argue that individuals may only turn to euthanasia or assisted suicide as a 'last resort', meaning that a patient should be eligible for assisted dying after exhausting a prescribed list of treatments or care options. Others, on the contrary, believe

<sup>&</sup>lt;sup>29</sup> DIEGO ZANNONI, *Right or duty to live?*, cit., pp. 183-184. Against the conception of autonomy and self-determination of the individual as independent of all objective values, including any "ontological" dignity, see Bernard N. Schumacher, *Death and Dignity: The Ethical and Social Stakes*, in *Death and Dignity: New Forms of Euthanasia*, cit., p. 36.

<sup>&</sup>lt;sup>30</sup> Cf. Michael Cholbi, No Last Resort: Pitting the Right to Die Against the Right to Medical Self-Determination, in Journal of Ethics, 19, 2015, pp. 143-157.

<sup>&</sup>lt;sup>31</sup> See Diego Zannoni, Right or duty to live?, cit., p. 182.

<sup>&</sup>lt;sup>32</sup> Bernard N. Schumacher, Death and Dignity: The Ethical and Social Stakes, cit., p. 35.

<sup>&</sup>lt;sup>33</sup> DIEGO ZANNONI, *Right or duty to live?*, cit., pp. 183-184. On the "right to die" see Alan Meisel, Kathy L. Cerminara, Thaddeus M. Pope (eds.), *The Right to Die: The Law of End-of-Life Decision-making*, Wolters Kluwer, New York, 2016; Melvin I. Urofsky, Philip E. Urofsky, *The Right to Die*, Routledge, London-New York, 2020; Sue Westwood (ed.), *Regulating the end of life: death rights*, Routledge, London-New York, 2022.

that submitting those who seek for assisted dying to the condition of last resort unjustly infringes their right to refuse treatment or medical interventions, i.e. their right to therapeutic self-determination, which is a fundamental right<sup>34</sup>. From a legal point of view, the key question is whether the right of patients to refuse medical treatment or interventions implies the right to assisted dying as a necessary consequence. This is truly one of the most difficult dilemmas in end-of-life decision-making and the answer can be influenced by many factors, including religious beliefs.

### 5. Regulating end-of-life: a difficult task for State legislators

Legal regulation of end-of-life situations is very much a matter of State law. It results that national legislations must play an intervention role in resolving end-of-life questions. However, these are complex issues for domestic legislators, because the right to life must be balanced with other individual values and human rights standards, equally deserving of protection (dignity and quality of life, right not to suffer in chronic situations of objective irreversibility of the clinical situation, prohibition of inhuman or degrading treatment, autonomy of the incompetent patient, right to respect for private life, etc.).

Not surprisingly, State laws vary greatly in legislative approaches and solutions due to a series of country-specific factors such as dominant ideological traditions or the influence of religions on public opinion and politics, so much so that some legislators even seem to prefer not to make decisions about whether a terminally ill person can decide how and when his life will end<sup>35</sup>.

Regulating the end of life in a more or less permissive way indeed means for State legislators to make a choice, taking a stand in the head-on conflict between respect for individual autonomy and respect for life. This stand is never neutral, but always ideologically oriented, and it is bound to have major and unprecedented impacts not only on an individual level, but also on an institutional and social level. To speak clearly, if the existence of a 'right to end human life in a safe and dignified manner' derives from the need to respect dignity and quality of life, as recognized in the main supranational human rights instruments, then it would be unavoidable to deduce a duty for States of take measures to make this right effective, facilitating death with dignity. However, there is a profound diversity of views on the meaning and con-

<sup>&</sup>lt;sup>34</sup> Consistently, see Michael Cholbi, No Last Resort, cit., pp. 143-147.

<sup>35</sup> See § 9.

tent of this alleged right, and on what should be considered a dignified death. Therefore, there is no international consensus on the right of an individual to decide for himself on his own death, nor on the possibility of admitting the legalization of euthanasia and assisted suicide, for example by ensuring that a patient wishing to commit suicide can obtain a lethal drug. This is why States use contrasting systems to regulate assisted dying, reflecting each country's traditions, current values and ethical principles<sup>36</sup>.

However, in adopting a regulation for end-of-life issues, the law cannot ignore that many decisions of the dying patient are not of a medical-scientific nature but are based on personal and ethical values, and among them, those of a religious nature. It cannot fail to consider that these decisions are linked to the inner dimension, which is the spiritual one, the dimension of everyone's conscience. This means that an influence of individuals' religious beliefs on end-of-life decisions can occur, because patients with a strong religious affiliation at the end of their life are often ethically challenged when making decisions, and they seriously seek religious guidance in these matters.

For State legislators the question is to establish to what extent personal opinions on the meaning of life and its dignity, including those of a religious nature, can be recognized by law. In this regard, there are different and even contrasting opinions on what should or should not be done for the dying patient. This inevitably fuels discussions and conflicts between different viewpoints and makes legislative decisions on end-of-life very difficult. Furthermore, it should be considered that national end-of-life legislation is influenced by each country's model of relations between State and religion<sup>37</sup>. Thus, a theocratic State, a State with an established-church and a secular State tend to provide different legal solutions to end-of-life issues. From this point of view, the countries where euthanasia and assisted suicide have been legalized usually have a higher degree of secularism and atheism than the average. As a result, in the Western world and in developed countries, where the influence of secularization has been greatest, euthanasia and assisted suicide have been admitted in one form or another by some States over the past three decades, including the Netherlands, Belgium, Luxembourg, Switzerland, Colombia, New Zealand, Canada, Spain and various States of the USA and Australia. In developing and Muslim-majority countries, on the contrary, there is usually

<sup>&</sup>lt;sup>36</sup> Obviously, if states decide to regulate end of life, they must put in place procedures that ensure that a person's decision to end his or her life actually reflects his or her free will.

<sup>&</sup>lt;sup>37</sup> On the different model of State-religions relationships cf. SILVIO FERRARI, *Models of State-Religion Relations in Western Europe*, in Allen D. Hertzke, *The Future of Religious Freedom: Global Challenges*, OUP, Oxford-New York, 2012, pp. 202-214.

no form of recognition of euthanasia and assisted suicide, and such practices are generally considered suicides when patients consent to the procedure, and homicides when physicians execute the procedure.

6. Faith at end of life. The views and teachings of religious groups on end-of-life decisions

Given that religious beliefs play a significant role in shaping individuals' beliefs about end-of-life decisions, it is helpful to briefly review the official teachings of major world religions regarding life, suffering and death, to understand how (and to what extent) they can influence the legal framework in domestic laws.

Despite differences in the teachings of individual religious faiths, most religions oppose any form of euthanasia, physician-assisted suicide, and other efforts by health care professionals to hasten a patient's death. While not all religions have official teachings and rules on all of these issues, most of the religions widespread across the Western world -thus, for example, the Abrahamic monotheistic religions and, with some differences, Hinduism, and Buddhism, which are the five major world religions in terms of numbers of adherents- consider both euthanasia and medically assisted suicide as acts in contradiction with the value of human life<sup>38</sup>.

However, some distinctions need to be made among end-of-life care. In fact, there are many different types of life-sustaining treatments that can be used to keep people with serious or terminal illnesses alive, more or less invasive. Not all life-prolonging medical interventions fall within situations in which end of life is sought in the person's alleged best interest: cases which, in a broad sense, are covered by the notion of euthanasia (or by the broadest

world religions cf. Hans Henrick Bülow et Al., *The world's major religions' points of view on end-of-life decisions in the intensive care unit*, cit., pp. 423-430; *Religious Groups' Views on End-of-Life Issues*, edited by Pew Research Center, 2013 (https://www.pewresearch.org/religion/2013/11/21/religious-groups-views-on-end-of-life-issues/); Susan M. Setta, Sam D. Shemie, *An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death*, in *Philosophy, Ethics, and Humanities in Medicine*, 10 (6), 2015, pp. 1-22; Naomi R. Cahn et Al., *Religious and End-of-life Decision-making*, cit., pp. 1713-1736; Puteri N.J. Kassim et Al., *Religious, Ethical and Legal Considerations in End-of-Life Issues*, cit., p. 119-134; Raishekhar Chakraborty et Al., *A systematic review of religious beliefs about major end-of-life issues in the five major world religions*, cit., pp. 609-622; Graham Grove et Al., *Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide*, cit., pp. 4758-4782; Maria D' Arienzo, *Fine vita e diritit religiosi*, in Pierlugi Romanello (ed.), *Deliberare de morte. La scelta di morire tra bioetica, diritto e religione*, Editoriale scientifica, Napoli, 2022, pp. 75-88.

one of "medical assistance in dying", which includes both active voluntary euthanasia and physician-assisted suicide). Thus, allowing something to happen -letting a patient die of natural causes by removing artificial life support, for example- is different from actively hastening death<sup>39</sup>. Some religions tend to admit some less invasive forms of treatment (such as medically assisted nutrition and hydration, for example), but limit or reject other forms based on their religious beliefs to prevent unnecessary and unwanted invasive treatments in the terminal stage of life. Most religions consider the so-called "Do not resuscitate" (DNR) orders admissible<sup>40</sup>, as well as the so-called "Do not intubate" (DNI) orders<sup>41</sup>. Palliative care and pain management programs are generally permitted<sup>42</sup>.

In any case, an analysis of the positions of the major world religions on frequently encountered end-of-life medical situations (EoL) shows the existence of a clear opposition to euthanasia and physician-assisted suicide based on themes common to all these religious faiths, generally attributable to the belief of "an external locus of morality and the personal hope for a better future after death that transcends current suffering"43.

Regarding Christian denominations<sup>44</sup>, almost all Christian churches are firmly opposed to medically assisted suicide and any form of active euthanasia, deeming morally wrong and unacceptable to take a human life, even

<sup>&</sup>lt;sup>39</sup> From this point of view, there is a substantial distinction between active and passive euthanasia, that is, between a conscious decision to end life and to let a life end by itself. However, the line between the two is not always clearly defined.

<sup>&</sup>lt;sup>40</sup> The expression "Do not resuscitate" (DNR) is used to indicate the possibility for the patient in case of cardiac arrest to refuse chest compressions, cardiac drugs or the placement of a breathing tube, even preventively. Indeed, resuscitation can avoid death. However, its counterpart is the prolongation of a terminal illness, usually with an increase in the patient's suffering. Therefore, DNR orders have been the subject of intense debate not only in emergency medicine and in the legal field, but also from the point of view of religions.

<sup>&</sup>lt;sup>41</sup> The expression "Do not intubate" (DNI) indicates that treatments involving chest compressions and heart medications may be allowed, but placement of a breathing tube may not.

<sup>&</sup>lt;sup>42</sup> Palliative care focuses on relieving pain at the end of life but does not help extend life. Therefore, palliative care may be administered even for patients who do not want to be kept alive.

<sup>&</sup>lt;sup>43</sup> Graham Grove et Al., Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide, cit., p. 4758.

<sup>&</sup>lt;sup>44</sup> Despite some divergences of opinions and points of view among the various Christian groups (from Mormons and Jehovah's Witnesses to Lutherans, Roman Catholics and Orthodox Christians), within the doctrinal texts and in some specific officially authorized documents of the Christian churches it is possible to identify some common principles on end-of-life issues, which have their main source in the teachings of the Holy Bible dealing with creation, human values, suffering, death, hope and resurrection. See Graham Grove et Al., Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide, cit., p. 4768 ss. See also H. Tristram Engelhardt jr, The foundations of Christian bioethics, Swets & Zeitlinger, Lisse, 2000.

if to relieve the suffering caused by an incurable or fatal disease<sup>45</sup>. Indeed, Christianity teaches that human life is sacred. Death is perceived as the separation of the eternal spirit from the physical body, and it is considered part of the earthly cycle of life (there is a "time to be born and a time to die": Eccl. 3:2). Therefore, one should never take a life, even one's own, because life is a gift from God. Only God should determine when life ends. Human beings lack the authority to decide when life ends, because this is the Creator's decision. Consequently, destroying life created in God's image is contrary to core Christianity teachings.

According to the teachings of the Catholic Church, we are only the administrators, not the Lords of the life that God has entrusted to us as a gift<sup>46</sup>. Consequently, the existence of a right to kill oneself must be denied: living is a duty, even for those who are sick and suffering. This is why the Roman Catholic Church firmly prohibits physician-assisted suicide and active euthanasia. More specifically, Catholics believe that euthanasia is wrong and sinful because it overlocks the sanctity of life<sup>47</sup>. It substitutes man for God in choosing who dies and when, and this is not admissible<sup>48</sup>. Therefore, whatever its motivations and means, direct euthanasia "is morally unacceptable"<sup>49</sup>. Even the Orthodox Churches clearly reject euthanasia and assisted suicide, considering them grave sins, which are not permitted under any circumstances. According to Orthodox teachings, acceptance of the diseases that God has allowed into our lives is an important part of the life of the faithful and opens the Orthodox

<sup>&</sup>lt;sup>45</sup> See LISA S. CAHILL, Suffering: A Catholic Theological-Ethical View, in RONALD M. GREEN, NATHAN J. PALPANT (eds.), Suffering and Bioethics, cit., pp. 231-248.

<sup>&</sup>lt;sup>46</sup> Cf. Congregation for the Doctrine of the Faith, Declaration *lura et bona* on Euthanasia, 5 May 1980.

 $<sup>^{47}</sup>$  The Second Vatican Council, Pastoral constitution on the Church in the modern world *Gaudium et Spes*, 7 December 1965, 27.

 $<sup>^{48}</sup>$  Sacred Congregation for the Doctrine of the Faith, Declaration  $\it Iura\ et\ bona$ , cit.; John Paul II, Encyclical Letter  $\it Evangelium\ vitae$ , 25 March 1995, 65.

<sup>&</sup>lt;sup>49</sup> Catechism of the Catholic Church, LEV, Vatican City, 2003, 2277. See also Congregation for the Doctrine of the Faith, Letter Samaritanus bonus on the care of persons in the critical and terminal phases of life, 22 September 2020, § V, 1. For an overview of catholic teachings on end-of-life issues cf. Hazel Markwell, End-of-life: a catholic view, in Lancet, 366 (9491), 2005, pp. 1132-1135; H. Tristram Engelhardt Jr, Ana Smith Iltis, End-of-life: a Traditional Christian view, cit., pp. 1045-1049; Marco Canonico, La posizione della Chiesa cattolica riguardo al fine vita, in Diritto e Religioni, 1, 2018, pp. 309-336; Michael McCarthy, Mark Kuczewski, Reframing Care in End-of-Life Care: Helpful Themes from a Catholic-Christian Understanding of Death, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford handbook of ethics at the end of life, cit., pp. 330-340; Ralph Weimann, Bioethical challenges at the end of life: an ethical guide in catholic perspective, Angelico Press, New York, 2022.

Christian to spiritual growth<sup>50</sup>. As a result, any death caused by human decisions must be considered as an insult to God<sup>51</sup>. As for the Protestant churches, Protestantism is characterised by a great diversity of views and the absence of an official doctrine in the field of bioethics. Thus, Protestant Christian churches present a less unified view on end-of-life situations than the Catholic and Orthodox churches. This is a result of the great diversity among Protestant Christianity, with over a hundred recognized Protestant Christian churches and with new forms emerging regularly. However, these churches usually tend to oppose euthanasia and assisted suicide. For example, the Anglican Church, one of the largest branches of the Protestant church, explicitly took a stand against euthanasia already during the 1998 World Bishops' Conference in Lambeth<sup>52</sup>. The Evangelical Lutheran Church in Germany has developed advance directives for end-of-life choices, but strongly rejects active euthanasia. Even the Baptist churches have repeatedly spoken out against euthanasia and assisted suicide, reiterating their incompatibility with the sanctity of human life; while the world's largest association of Pentecostal churches, the Assemblies of God, has released specific documents discussing the issue of EPAS and confirming its opposition to the practice. However, dissenting voices also exist within Protestantism: thus, for example, the theologians of the Reformed tradition in the Netherlands defend active euthanasia<sup>53</sup>.

At the same time, Christian denominations generally allow life not to be sustained at all costs when there is no hope of recovery. Although belief in

<sup>&</sup>lt;sup>50</sup> Antonio Sandu et Al., Bioethical acceptability of Euthanasia in the Greek orthodox religious context, cit., p. 152.

<sup>&</sup>lt;sup>51</sup> Therefore, "as a principle the withholding and withdrawing of therapy is not allowed and should a fully conscious patient request an omission of treatment (that might save him), it is the moral obligation of the physician to try to persuade him to consent to that treatment. Alleviation of pain is allowed if medication is given in doses that are not certain to lead to death. Withholding or withdrawing of artificial nutrition is not allowed even if there is no prospect of recovery": cf. The Holy Synod of THE CHURCH OF GREECE, BIOETHICS COMMITTEE, Press release, 17 August 2000. Basic positions on the ethics of transplantation and euthanasia (http://www.bioethics.org.gr). However, the possibility of discontinuation of artificial support (for example, ventilation therapy) in a brain-dead person is generally accepted. For more details, see Nikolaos Hatzinikolaou, Prolonging life or hindering death? An orthodox perspective on death, dying and euthanasia, in Christian Bioethics, 9, 2003, pp. 187-201.

<sup>&</sup>lt;sup>52</sup> See Cinthia B. Cohen et Al., Faithful living, faithful dying: Anglican reflections on end-of-life care, Morehouse Publishing, Harrisburg, 2000.

<sup>53</sup> For further details, see Susan M. Setta et Al., An explanation and analysis of how world religions formulate their ethical decisions on withdrawing treatment and determining death, cit., pp. 9-11; Graham Grove et Al., Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide, cit., p. 4771; GERMANA CAROBENE, Dilemmi del fine vita nel confronto tra approccio scientifico e prospettiva religiosa (cattolica-protestante), in BioLaw Journal-Rivista di BioDiritto, 3, 2016, pp. 105-122; Luca Savarino (ed.), Eutanasia e suicidio assistito. Una prospettiva protestante sul fine vita, Claudiana, Torino, 2021.

miracles and the sanctity of life may prolong an individual's desire for care at the end of life, even when healing is deemed impossible by medicine, there is no moral obligation to extend the act of dying by extraordinary means if the person has no reasonable expectation of recovery. Thus, Christian denominations generally agree to refuse unnecessary life-prolonging therapies or artificial means if burdensome, dangerous, extraordinary, or disproportionate to the expected outcome and do not compel prolongation of life by unreasonable means. Moreover, although pain at the end of life may have the special meaning of participating in Christ's suffering on the cross, they accept the use of pain-relieving drugs (analgesia and sedation) to relieve terminal suffering, even in cases where they might contribute to hastening death as an unintended side effect, provided it does not consciously take away a person's life or opportunity for repentance<sup>54</sup>. This is the reason why DNR orders are generally permitted if the interventions are futile or burdensome<sup>55</sup>.

As for the Jews, they believe that life is a precious gift from God. Since a person's life belongs to God, so it is up to God to decide when it should end. Thus, according to Jewish law, the directive to preserve human life generally prevails over other considerations, including the desire to alleviate pain and suffering, since death is a natural process that must be permitted and accompanied. This means that doctors and healthcare professionals must work

<sup>&</sup>lt;sup>54</sup> JOHN PAUL II, Apostolic Letter Salvifici doloris, 11 February 1984, 5.

Among Christian denominations, the Catholic Church recognizes that a dying person has the moral option to refuse extraordinary treatments that provide only a precarious or painful extension of life (Catechism of the Catholic Church, cit., 2278; JOHN PAUL II, Encyclical Letter Evangelium vitae, cit., 65: Congregation for the Doctrine of the Faith, Letter Samaritanus bonus, cit., V. 2), Nevertheless, the suspension of futile treatments must not involve the withdrawal of therapeutic care: thus, it is not lawful "to suspend treatments that are required to maintain essential physiological functions, as long as the body can benefit from them": Congregation for the Doctrine of the Faith, Letter Samaritanus bonus, cit., V, 2. In this regard, the main distinction or criteria for legitimate withholding or withdrawing of life-sustaining treatment is whether the treatment is considered proportionate or disproportionate. This means that patients can legitimately refuse treatment that doesn't give a reasonable hope of physical or spiritual benefit, such as resuscitating someone who is at the very end of life. Applying this criterion, the Catholic Church usually deems hydration, nutrition, thermoregulation, proportionate respiratory support, and the other types of assistance needed to maintain bodily homeostasis and manage systemic and organic pain as ordinary care that must be administered (cf. Thomas A. Shannon, Nutrition and Hydration: An Analysis of the Recent Papal Statement in the Light of the Roman Catholic Bioethical Tradition, in Christian Bioethics, 12, 2006, pp. 29-41). For a dissenting position in Catholic bioethics see Christopher Tollersen (ed.), Artificial Nutrition and Hydration. The New Catholic Debate, Springer, Dordrecht, 2008. More aggressive interventions, however, such as cardiopulmonary resuscitation and endotracheal intubation, are not considered obligatory if they do not offer a reasonable chance of leading to a state of well-being or if they would be excessively burdensome. Similarly, the Church of Jesus Christ of Latter-day Saints teaches that when someone is dying, it is acceptable to forgo excessive or extraordinary therapies and to allow a person to die from natural causes. Similar positions are supported by the Assemblies of God, the Evangelical Lutheran Church and other Christian denominations.

to keep people alive for as long as possible, and they shouldn't do anything to hasten death. All three major Jewish movements -Orthodox, Conservative and Reform- prohibit euthanasia, suicide and assisted suicide, even in the case of painful and terminal illnesses. However, Jewish law allow a person to renounce medical care if his life is about to end and he is suffering unnecessarily, as there is no hope of recovery. Most Jewish thinkers, rabbis, and philosophers (except for the Orthodox and some conservative rabbis) believe that nutrition and hydration are unnecessary if death is imminent, and they allow that a dying person can interrupt treatment or remove life-support systems that are impeding the natural process of dying if excessive suffering will result from the short remaining life<sup>56</sup>. Similarly, according to Jewish teachings orders not to resuscitate and not to intubate are permitted if the interventions are only aimed at delaying the dying process and healing is impossible to achieve.

As for Islam, it sanctifies life and considers any act of taking one's life a sin. Therefore, it categorically forbids any form of suicide and any action that may help another to kill himself. Indeed, Muslims cannot kill or be complicit in the killing of another, except in the interest of justice. Therefore, all Islamic doctrines consider both assisted suicide and euthanasia prohibited, because human life is sacred and is given by God (Allah), who decides how long each of us will live and when he will die. Human beings have no right to end their life. Death must be accepted as part of the overall divine plan. During illness and at the terminal stage of life, medical care should always be sought. Belief in the sanctity of life can be considered a valid reason for prolonging aggressive care. However, while hastening death is not admitted, Islamic thinkers concede that suffering should be alleviated if possible, and generally believe that the terminally ill need not employ extraordinary means and technologies to delay death<sup>57</sup>. When death is inevitable the patient should be allowed to die without unnecessary procedures. Therefore, if the patient has an imminent fa-

<sup>&</sup>lt;sup>56</sup> Thus, for example, most Jewish religious and ethical thinkers writing on bioethics agree that Judaism would permit the cessation of life-sustaining therapy in the case of a dying person who is in a coma or vegetative state. See Elliot N. Dorff, End-of-life: Jewish perspectives, in Lancet, 366, 2005, pp. 862-865; VARDIT RAVITSKY, A Jewish perspective on the refusal of life-sustaining therapies: culture as shaping bioethical discourse, in The American Journal of Bioethics, 4, 2009, pp. 60-62. For the Orthodox Jewish perspective see John Loike, Muriel Gillick, Stephan Mayer, Kenneth Prager, The critical role of religion: Caring for the dying patient from an Orthodox Jewish perspective, in Journal of Palliative Medicine, 13 (10), 2010, pp. 1267-1271; REGINA PROSSER, DIANE KORMAN, AKIVA Feinstein, An Orthodox Perspective of the Jewish End-of-Life Experience, in Home Healthcare Nurse, 30 (10), 2012, pp. 579-585.

<sup>&</sup>lt;sup>57</sup> On the meaning in the Islamic tradition of end-of-life suffering as a way to purify previous sins see Abdulaziz Sachedina, Human Suffering through Illness in the Context of Islamic Bioethics, in Ronald M. Green, Nathan J. Palpant (eds.), Suffering and Bioethics, cit., pp. 296-308.

tal illness, it is considered permissible to refuse or withdraw unnecessary medical treatment (i.e. treatment that no longer provides comfort or its risks prove greater than its benefits). In particular, the withdrawing of life-sustaining treatments is permitted if doctors determine that brain death has occurred, or in cases where there is no hope of recovery. It should mean that it is permissible to turn off life support for patients believed to be in a persistent vegetative state. This is because all mechanical life support procedures are considered temporary measures. Obviously, while turning off a life-support is allowed, hastening death with the use of specific pain-killing drugs is not allowed as this would correspond to euthanasia. Regarding DNR orders, some Muslims believe that do not resuscitate orders represent a soft form of euthanasia that is strictly prohibited in Islam. However, according to most interpreters, DNR can be regarded as congruous with respect for human dignity and allowed if resuscitation efforts will be futile, in order to allow the natural process of death<sup>58</sup>.

As for Buddhists, they generally oppose assisted suicide and euthanasia. Indeed, Buddhism teaches that it is morally wrong to destroy human life, including one's own, even if the intention is to end suffering. Respect for life is fundamental to Buddhists, although that life is not lived in optimal physical and mental health. However, Buddhists also believe that life should not be preserved at all costs, and that it is not right and necessary to make every effort to preserve the life of a dying person. This means, for example, that while a terminally ill person should not be denied basic care, he or she may be refused care that may prove futile or unduly burdensome. Thus, forced prolongation of life and resuscitation are generally not favoured. Buddhists believe in reincarnation and that past life acts (karma) influence future suffering through the cycle of rebirths with the goal of ending the cycle and attaining nirvana. Since a person's state of mind at time of death determines the type of rebirth he or she will experience, Buddhists rather strive to allow for peaceful preparation

<sup>&</sup>lt;sup>58</sup> For further details, see Abdulaziz Sachedina, End-of-life: the Islamic view, in Lancet, 366, 2005, pp. 774-779; Naser Aghababaei, The Euthanasia-Religion Nexus: Exploring Religious Orientation and Euthanasia Attitude Measures in a Muslim Context, in OMEGA- Journal of Death and Dying, 66(4), 2013, pp. 333-341; Mohammed Ali Al-Bar, Hassan Chamsi-Pasha, End-of-life care, in Mohammed Ali Al-Bar, Hassan Chamsi-Pasha, Contemporary Bioethics: Islamic Perspective, Springer Cham, 2015, pp. 243-260; Mahmud Adesina Ayuba, Euthanasia: A Muslim's perspective, in Scriptura: Journal for Biblical, Theological and Contextual Hermeneutics, 115, 2016, pp. 1-13; Mohammad Mustaqim Malek, Noor Naemah Abdul Rahman, Mohd Shahnaz Hasan, Luqman Hail Abdullah, Islamic considerations on the application of patient's autonomy in end-of-life decision, in Journal of Religion and Health, 57, 2018, pp. 1524-1537; Mohammed Madadin, Houria S. Al Sahwan, Khadijah K. Altarouti, Sarraa A. Altarouti, Zahra S. Al Eswaikt, Ritesh G. Menezes, The Islamic perspective on physician-assisted suicide and euthanasia, in Medicine, Science and the Law, 60, 2020, pp. 278-286.

for death. Therefore, they may wish to avoid certain drugs and treatments intended to artificially prolong life<sup>59</sup>.

As for the Hindus, they believe in reincarnation and that the soul goes through a cycle of successive lives (samsara), until liberation from reincarnation, pain and suffering occurs and enlightenment (moksha) is achieved. Hindus also believe that karma affects the form of rebirth a person will experience, as well as that suffering is integral part of life and is the result of previous actions in this or a previous life<sup>60</sup>. Thus, if an individual evades karma by taking some action to stop suffering, he will bear the consequences in the next life, because the action of delaying suffering can increase negative karma in the next life. By enduring suffering, a Hindu can repay the debt incurred for past negative behaviour. Death is perceived as a natural experience. Indeed, Hindus believe that death should come at a natural and proper time. Thus, artificial prolongation of life is often not favoured, especially in the case of aggressive medical or mechanical interventions when the prognosis is poor. While there is no formal Hindu teaching on assisted suicide or euthanasia, there is a general concern in Hinduism that ending a person's life prematurely may negatively impact their karma in passing from this life to the next<sup>61</sup>. DNR orders are widely accepted, especially if interventions will delay the inevitable or interfere with natural death. However, according to some interpreters Hinduism can justify euthanasia through the Gandhian interpretation of ahimsa, provided that all methods of alleviating the patient's pain and suffering have been exhausted<sup>62</sup>.

<sup>&</sup>lt;sup>59</sup> For more information on Buddhist viewpoint on the end-of-life issues see MICHAEL BARNES, Euthanasia: Buddhist principles, in British Medical Bulletin, 52, 1996, pp. 369-375; Damien Keown, End of Life: The Buddhist View, in The Lancet, 366, 2005, pp. 952-955; Andrew J. McCormick, Buddhist ethics and end-of-life care decisions, in Journal of social work in end-of-life & palliative care, 9 (2-3), 2013, pp. 209-225.

<sup>60</sup> Karma guides Hindus on how to live their life. The law of karma is a moral law of cause and effect and determines life cycles and rebirth. The concept of karma focuses on the belief that good and bad occurrences in one's life are caused by actions over the course of multiple lifetimes. This doctrine strongly influences the attitude of Hindus towards life, as they consider all life events as the result of karma. See Sujatha Shanmugasundaram, Margaret O'Connor, Ken Sellick, Culturally competent care at the end-of-life. A Hindu perspective, in End-of-life Care, 4, 2010, pp. 26-31; Susan Thrane, Hindu end-of-life death, dying, suffering and Karma, in Journal of Hospice and Palliative Nursing, 12 (6), 2010, pp. 337-342; Mohsin Choudry, Aishah Latif, Katharine G. Warburton, An overview of the spiritual importance of end-of-life care among the five major faiths of the United Kingdom, in Clinical Medicine, 1, 2018, pp. 23-31.

<sup>&</sup>lt;sup>61</sup> See Shirley Firth, End-of-life: A Hindu view, in The Lancet, 366, 2005, pp. 682-686; Namita Nimbalkar, Euthanasia: The Hindu Perspective, January 2007 (https://www.vpmthane.org/Publications/Bio-Ethics/Namita%20Nimbalkar.pdf).

<sup>&</sup>lt;sup>62</sup> Ercan Avci, A comparative analysis on the perspective of Sunni Theology and Hindu Tradition Regarding Euthanasia: The impact of belief in resurrection and reincarnation, in Journal of Religion

7. The "Position Paper of the Abrahamic Monotheistic Religions on Matters Concerning the End of Life".

An interesting contribution on the subject can now be found in a joint declaration by the three Abrahamic Religions (Christians, Jews, Muslims) regarding end-of-life decisions, such as euthanasia, assisted suicide and palliative care, signed in the Vatican City on 28th October 2019<sup>63</sup>.

With this statement the three Abrahamic monotheistic religions clarified their firm opposition to any form of euthanasia, as well as physician assisted suicide, because "they fundamentally contradict the inalienable value of human life, and therefore are inherently and consequentially morally and religiously wrong and should be forbidden without exceptions"64. Moreover, they asked to ensure that the patient's will no longer be a burden for society and families, even from a financial point of view, do not induce him "to choose death rather than wanting to receive the care and support that could allow him to live the time he has left in comfort and tranquillity"65. Finally, the signatory religions encourage a qualified and professional presence of palliative care everywhere and for everyone, since there is a moral and religious duty "to provide comfort, effective pain and symptoms relief, companionship, care and spiritual assistance to the dying patient and to her/his family"66. Indeed, the function of palliative care is to "achieving the best quality of life for patients suffering from an incurable and progressive illness, even when their illness cannot be cured, thus expressing the noble human devotion of taking care of one another, especially of those who suffer"67.

It is certainly a very significant document, with few precedents. Based on the arguments articulated in the position paper, Abrahamic monotheistic religions promote mutual understanding, share common goals, and are in full agreement in their approach regarding beliefs, values and practices that are relevant to the dying patient. This effort is aimed at providing their proposal about the right balance between conflicting values to be sought in solving end-of-life issues, trying to oppose the growing diffusion of a secular ethics in medical care at the end of life, which tends to focus only on the physical aspects

and Health, 58, 2019, pp. 1770-1791.

<sup>&</sup>lt;sup>63</sup> See Position Paper of the Abrahamic Monotheistic Religions on Matters Concerning the End of Life, Vatican City, October 28th, 2019, p. 4 (https://www.academyforlife.va).

<sup>64</sup> Ivi, p. 7.

<sup>65</sup> Ibidem.

<sup>66</sup> Ivi, p. 9.

<sup>67</sup> Ivi, p. 8.

of medical care, neglecting the spiritual and religious needs of patients. For this reason, the Abrahamic religions, in reaffirming their commitment to support laws and policies that protect the rights and dignity of the dving patient. in order to avoid euthanasia and promote palliative care, appeal to "all policymakers and health-care providers to familiarize themselves with this wideranging Abrahamic monotheistic perspective and teaching in order to provide the best care to dying patients and to their families who adhere to the religious norms and guidance of their respective religious traditions"68, also committing themselves "to involving the other religions and all people of goodwill"69.

8. Principles, values and practices relevant to the dying patient in contemporary Western societies and the growing trend towards forms of death on request.

There is no doubt, however, that the issue remains delicate. As already mentioned, in dealing with end-of-life decisions the right to life must indeed be balanced with other fundamental human rights and values, such as dignity and quality of life. When someone chooses not to seek treatment, knowing that refusal will shorten his life, it is usually because he is choosing what he believes will be a better quality of life, rather than a longer life which may be less pleasant. But to what extent is this choice admissible in order not to conflict with the right to life?

Aware of these difficulties, religions are committed to offering their own contribution to the search for a balance between the sanctity of life and individual autonomy, without renouncing their own teachings on the subject. However, current secular humanistic values and practices on end-of-life are not always in compliance with the principles, values and practices of religious communities relevant to the dying patient. The former push more and more towards a recognition of the "right to die" of the terminally ill patient; more precisely, towards the admissibility of wide chances for resorting to 'death on request', immediate or deferred through advance care directives. This can happen with different forms and modalities, which vary depending to the choices of individual jurisdictions, ranging from the admission of active and passive euthanasia and assisted suicide up to milder forms of 'accompaniment of dying', but which in any case tend to deny any form of therapeutic obstinacy (or medical futility), that is, of unwanted suffering for the terminally ill.

<sup>68</sup> Ivi, p. 10.

<sup>69</sup> Ibidem.

This is not surprising. In fact, the primary justification for legalizing euthanasia and assisted suicide in domestic jurisdictions is the relief of pain and suffering. This vision "is based on the one hand, on a certain understanding of the notions of dignity, autonomy, and 'quality of life', and on the other hand, on a consequentialist, utilitarian ethics, accompanied by an ethics of subjective desires, interests and preferences"70. Although suffering cannot be considered the foundation of human rights, it certainly constitutes a factor that contributes decisively to their recognition and effective protection. Human rights norms, in fact, are primarily aimed at preventing forms of human suffering. This means that there is a moral duty of States to prevent suffering<sup>71</sup>. For this reason, according to supporters of the secular ethics, euthanasia and assisted suicide are to be considered legitimate pain-relieving interventions or medical treatments, and therefore should be legalized. In this regard, however, there is no consensus among the interpreters. According to many, in fact, euthanasia and assisted suicide cannot be considered as such. Therefore, they should not be allowed, and must remain punishable under States criminal law<sup>72</sup>.

On these issues, in any case, as well as on the legal, ethical and political implications of death and dying, debates and controversies are increasingly heated today. For right to life's supporters, the denial of the possibility of resorting to euthanasia and assisted suicide contributes to the protection of the lives of vulnerable persons. On the contrary, for promoters of EPAS the ban on assisted dying violates the rights of a significant number of individuals to life, to freedom from torture or inhuman or degrading treatment and to private life. These debates are not new in the Western world, of course. However, over the past three decades end-of-life issues have received growing attention and involvement from both the media and the judicial, political and academic debate, within which contrasting views and opinions have emerged on what should or should not be done for the dying patient, fostering discussions between distinct and often opposing visions, especially when there are dramatic cases that draw the attention of the media and public opinion (as in the cases of little Charlie Gard and, more recently, Archie Battersbee in the United Kingdom).

In these cases, the law is consistently invoked by both sides to support the opposing arguments. So the question is: what should be the role of the law in a secular state?

<sup>&</sup>lt;sup>70</sup> Bernard N. Schumacher, Death and Dignity: The Ethical and Social Stakes, cit. p. 35.

<sup>&</sup>lt;sup>71</sup> See Roberto Andorno, Cristiana Baffone, *Human Rights and the Moral Obligation to Alleviate Suffering*, in Ronald M. Green, Nathan J. Palpant (eds.), *Suffering and Bioethics*, cit., pp. 182-200.

<sup>&</sup>lt;sup>72</sup> See Margaret Somerville, *Exploring Interactions between Pain, Suffering, and the Law*, in Ronald M. Green, Nathan J. Palpant (eds.), *Suffering and Bioethics*, cit., pp. 201-228.

Answering this question is not easy, especially when the law is required to regulate situations on which individuals take a moral stance, such as end-of-life issues. In fact, law is never morally neutral. Underlying our apparently and often supposedly neutral precepts and legal systems there is a basic morality which is the result of a set of outside factors that have settled over time, and which influence the law in every society (among these, religious beliefs)<sup>73</sup>. This hidden morality, which obviously varies State by State, is pervasive precisely because of its supposed neutrality. In other words, in every place and in every time the law always represents the mirror of the society it regulates, since it reflects the degree of cultural, social, political and legal evolution of a country at that moment. This is why the law operates as it does within a certain legal system, or, in some cases, why it does not operate, being unable or perhaps deeming it preferable not to take a position on ethical issues that would undermine its alleged neutrality.

Abstractly, according to the postulates of liberal legal systems, it could be said that the task of law in a secular society should be to stop before the individual conscience, without invading or replacing it in an authoritarian way in end-of-life decisions. In the secular perspective that should characterize most of the legal systems of Western countries, the individual conscience should receive the widest possible protection by the law. Thus, according to one's freely formed conscience, everyone should be free to decide whether to continue living even suffering from an incurable disease, or to choose whether to make the pain stop, deciding how and when to end one's life. As it is an internal conflict affecting the terminally ill, every decision should be entrusted to their freely formed conscience, while governments should make a commitment to patients approaching end of life, ensuring access to personalized care which focuses on the preferences, beliefs and spiritual needs of the individual, without legal impositions by the State. For believers, religion can certainly provide precious support in guiding personal choices (as mentioned, the effort to provide a peaceful death consistent with the teachings of faith is present and important for all religious communities, so much so that most religions provide guidance and rituals to comfort and direct patients at the end of life). However, the task of law is to protect everyone, believers and non-believers alike, ensuring respect for the widest possible range of individuals' personal choices, without prejudice to public interests and the fundamental rights and freedoms of others. This means that the law must always balance individual rights and freedoms with each other and with the collective interest, evalua-

<sup>73</sup> See Mario Ricca, Pantheon. Agenda della laicità interculturale, Torri del Vento, Palermo, 2012, p. 18 ss.

ting the impact and long-term consequences of legislative choices on society.

From this point of view, despite the importance of individual autonomy and self-determination, it would be limiting to identify the role of law in a secular State only with the need to protect individual conscience. The secular State is not an agnostic State, i.e. a neutral State indifferent to ethical values. The secular State has its ethical foundation in the values and legal principles enshrined in its fundamental laws, which are usually identified with national constitutions, and which in the Western world coincide with the rights enshrined in the main international declarations on human rights. When these values and legal principles conflict with each other, the law must adopt a compromise position, i.e., a position that recognizes and accommodates the competing values, whilst also restoring a measure of coherence to the law.

It should also be noted that there is not just one type of secular State, an abstract model, but as many types of secular State as there are concrete manifestations, each with its own specific connotations and with its own model of relationship with religious organizations, characterized by a more or less extensive influence of religions in society according to the history of each country. Suffice it to consider, in this regard, the different models of secularism implemented in France and Italy, both secular States but with a very different approach to the role of religion within society and their respective legal systems. As far as we are concerned, this different connotation has a significant impact on the regulation of ethically sensitive issues such as end-of-life decisions and explains the great variety of solutions adopted in Western legal systems.

Given the lack of an abstract model of a secular State, it is therefore very difficult to establish what the role of law should be in a secular society, regardless of concrete conditioning within it, including those of a religious nature.

## 9. End-of-life issues in Western legal tradition.

As proof of this difficulty, it should be noted that end-of-life issues are treated differently in Western countries, even by those members of the European Union or the wider Council of Europe. There are significant divergences on the current Western end-of-life regulatory framework, with various choices regarding advance care directives, medically assisted nutrition and hydration, active and passive euthanasia, physician assisted suicide, do not resuscitate orders, etc.<sup>74</sup>.

<sup>&</sup>lt;sup>74</sup> For an international comparison of assistance in dying regimes see Samuel Blouin, Murielle Pott, Assistance in dying: Conditions for international comparison, in Death Studies, 46 (7), 2022,

This lack of homogeneity depends on the absence of a defined regulatory framework on the subject at international and supranational level. All international human rights treaties clearly affirm the protection of the 'right to life', but do not contain an explicit 'right to die'75. Experts and scholars from various areas – philosophers, jurists, sociologists, theologians, etc. – have debated whether the right to life can be interpreted as including a 'right to end one's life'. However, according to the current standards of human rights law this right does not seem admissible, nor does it seem possible to admit a 'right to die with dignity'. As a result, many States in the Western world have introduced legislations that allow patients to choose medical treatments that prolong, shorten, or interrupt life in certain end-of-life situations, with a greater or lesser degree of autonomy and protection for dying patients depending by the cases<sup>76</sup>. Yet only a small number of countries have regulations that allow people to end their own lives. In most countries any form of active euthanasia and assisted suicide is strictly prohibited and criminalized by law<sup>77</sup>.

Interestingly, solutions for end-of-life issues mainly come from jurisprudence. In developing legal solutions for end-of-life issues, jurisprudence has mostly played a key role, in some cases replacing the inertia of legislators. Almost everywhere, the debate on the end-of-life questions has evolved from concrete case-law. Based on the jurisprudential decisions, many national legislators then introduced a more or less extensive regulatory framework within

pp. 1541-1546.

<sup>&</sup>lt;sup>75</sup> Among the main ones, cf. United Nations, Universal Declaration of Human Rights (UDHR), 10 December 1948, Article 3; International Covenant on Civil and Political Rights (ICCPR), 16 December 1966, Article 6; Convention on the Rights of the Child, 20 November 1989, Article 6; Convention on the Rights of Persons with Disabilities, 13 December 2006, Article 10; COUNCIL OF EUROPE, Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), Article 2: American Convention on Human Rights, 22 November 1969, Article 4.1. Under international human rights law, full recognition of the right to life creates both negative and positive obligations for states. It means that states must not only refrain from undertaking actions that violate the right to life but must also actively work to create the necessary conditions to protect this right.

<sup>&</sup>lt;sup>76</sup> Most Western states recognize the right of both competent and incompetent adult patients to refuse unwanted life prolonging or life-sustaining treatments. Competent patients can request treatment suspension or withdrawal in the informed consent process. The rights of incompetent patients can be exercised on their behalf by a family member or other surrogate decision-maker based on the patient's previously expressed wishes and best interests. Regarding the decision-making ability of incompetent patients, cf. Mark Aulisio, "So what do you want us to do?" Patient's Rights, Unintended Consequences, and the Surrogate's Role, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford handbook of ethics at the end of life, cit., pp. 27-41.

<sup>&</sup>lt;sup>77</sup> Some countries are currently debating whether or not to allow their citizens to end their lives at certain conditions. Among them, Italy. See below, §§ 11-12. For further details, see STEPHANIE ROHLFING-DIJOUX, UWE HELLMANN (eds.), Perspectives of law and culture on the end-of-life legislations in France, Germany, India, Italy and United Kingdom, Nomos, Baden-Baden, 2019.

individual countries (with significant differences between civil law systems and common law systems). Thus, while in some States the case-law guidelines have been transposed into law, and in some cases even integrated to introduce a complete discipline on end-of-life issues, in other jurisdictions the legislation was mainly aimed at opposing and limiting the jurisprudential solutions, as they are deemed inconsistent with the evolution of social consciousness within the country. Furthermore, not all jurisdictions have deemed it necessary or appropriate to dictate a regulatory framework on the end-of-life, preferring to leave it up to judges to find solutions to dilemmas about the legitimacy of euthanasia, assisted suicide and other critical decisions in medical treatment in the terminal stage of life.

In any case, the problem for lawmakers, both at a supranational and national level, has been to find a balance between the need to recognize the importance for the comfort of care, for dying with dignity and for the preservation of personal autonomy until death, while taking care to limit voluntary control of the end of one's life<sup>78</sup>.

As regard Europe, the Member States of the Council of Europe were far from having reached a consensus as regards the right of an individual to choose how and when to end his life<sup>79</sup>. Among European States, while it is possible to find a general consensus on the importance of the value of personal auto-

<sup>&</sup>lt;sup>78</sup> See Ben White et Al., International Perspectives on Reforming End-of-Life Law, in Ben White, Lindy Willemott (eds.), International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence, CUP, Cambridge, 2021, pp. 250-276.

<sup>&</sup>lt;sup>79</sup> The Council of Europe has dealt specifically with end-of-life issues on several occasions. The most important document on the matter is the "Convention on Human Rights and Biomedicine" (CHRB), a European treaty on patients' rights signed in Oviedo in 1997, which constitutes the first legally binding international text designed to preserve human dignity, rights and freedoms, through a series of principles and prohibitions against the misuse of biological and medical advances. See COUNCIL OF EUROPE, Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (so-called Oviedo Convention), (ETS No. 164), Oviedo, April 1997 (https://www.coe.int). The CHRB provides that a person must give the consent for treatment expressly, in advance, except in emergencies, and that such consent may be freely withdrawn at any time. The treatment of persons unable to give their consent, such as children, people with mental illness or unconscious patients, may be made only if it can produce a real and direct benefit to their health. In recommending that States respect and protect in all respects the dignity of the terminally ill or dying, the Convention does not in any way legitimize euthanasia and assisted suicide, but rather supports the prohibition of intentionally taking the life of the terminally ill or dying. A dedicated Committee on Bioethics has been set up to facilitate the implementation of the CHRB principles. In addition, see also COUNCIL OF EUROPE, Assembly debate on 25 June 1999, Resolution 1418: Protection of the human rights and dignity of the terminally ill and the dying (http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=16722); Assembly debate on 25 January 2012, Resolution 1859: Protecting human rights and dignity by taking into account previously expressed wishes of patients (http://www.europeanrights.eu/public/atti/1859\_ing.htm). According to the Resolution 1859 euthanasia (defined as the intentional killing by act or omission of a dependent human being for his or her alleged benefit of her) must always be prohibited.

nomy, on the need to respect the wishes of an adult patient able of expressing his own will (thus, on the so-called 'passive euthanasia', i.e. on the possibility of refusing or withdrawing treatment: the majority of European States seem to allow the withdrawal of artificial life-sustaining treatment), there is instead no consensus on the admissibility of 'active euthanasia' and 'physician assisted suicide'80. In particular, there are only a few jurisdictions characterized by a clear propensity to guarantee as much as possible the free expression of the principle of individual therapeutic self-determination, which has represented the basis for the recognition of wide possibilities for recourse to 'death on request', also in the form of active euthanasia (in Europe, active euthanasia is permitted by, among others, the Netherlands, Belgium, Luxembourg and, more recently, Spain)81. The vast majority of the European States seem to place greater importance on the protection of the individual's life than on his right to put an end to it, as evidenced by the existence of legislations which severely limit the faculty to dispose of human life, and in any case frame it within rather rigid schemes, which highlight the exceptionality of the condi-

<sup>80</sup> It should be remembered that the European Convention on Human Rights (ECHR) does not provide for the right to die, and Article 2 of the ECHR only concerns the right to life. In this regard, see Stevie Martin, Assisted suicide and the European Convention on Human Rights, Routledge, London-New York, 2021.

Euthanasia has been legal in Belgium, the Netherlands and Luxembourg since 2002 (see JOHN GRIFFITHS, HELEEN WEYERS, MAURICE ADAMS, Euthanasia and Law in Europe. With Special Reference to the Netherlands and Belgium, Hart Pub Ltd, Oxford, 2008; GERRIT KIMSMA, Physician-Assisted Death in the Netherlands, in Stuart J. Youngner, Robert M. Arnold (eds.), The Oxford handbook of ethics at the end of life, cit., pp. 343-365). In 2021 Spain also decriminalized active euthanasia, thus giving anyone affected by a serious and incurable disease or a chronic and disabling condition the possibility to seek assistance in death and thus avoid unbearable suffering: see TAMARA RAQUEL VELASCO SANZ, PILAR PINTO PASTOR, BEATRIZ MORENO-MILÁN, LYDIA FRANCES MOWER HANLON, BENJAMIN HERREROS, Spanish regulation of euthanasia and physician-assisted suicide, in Journal of Medical Ethics, Published Online First: 30 July 2021 (doi: 10.1136/medethics-2021-107523); CARLOS MARIA Romeo Casabona, La ley orgánica reguladora de la eutanasia y la adaptación del código penal, in BioLaw Journal-Rivista di BioDiritto, 2, 2021, pp. 283-314; Mercedes Martínez-León, Jorge Feijoo VELAZ, DANIEL QUEIPO BURÓN, CAMINO MARTÍNEZ-LEÓN, Estudio médico legal de la Ley Orgánica de Regulación de la Eutanasia en España en comparación con el resto de los países que regulan la eutanasia y/o el suicidio asistido, in Revista Española de Medicina Legal, 48, 4, 2022, pp. 166-174. Where legally admitted, rules about who can access euthanasia and assisted suicide vary, ranging from strict criteria related to terminal illness and suffering to those with minimal regulations other than patient autonomy and capacity (Grove et Al., Perspectives of Major World Religions regarding Euthanasia and Assisted Suicide, cit., p. 4759). However, in all jurisdictions laws and safeguards were put in place to prevent abuse and misuse of these practices. Prevention measures "have included, among others, explicit consent by the person requesting euthanasia, mandatory reporting of all cases, administration only by physicians (with the exception of Switzerland), and consultation by a second physician": Josè Pereira, Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls, in Current Oncology, 18 (2), 2011, pp. 38-45. For a comparison with the US legal system cf. ROBERT S. OLICK, Decisions Near the End of Life, in AMIRALA S. PASHA (ed.), Laws of Medicine. Core Legal Aspects for the Healthcare Professional, Springer, Cham, 2022.

tions legitimizing the exercise of the faculty (common law countries in general, France, Italy). In the middle there are jurisdictions in which the regulation of the end-of-life situations is characterized by a moderate opening, in the sense of a recognition not only of passive euthanasia, but also of assisted suicide under the existence of certain conditions, usually quite severe (this is the case of Switzerland, Austria, to some extent of Germany)<sup>82</sup>.

Are these bans in line with current international human rights standards? Or is there room to argue that such standards also protect a 'right to die with dignity', which would legitimize at least some forms of euthanasia and assisted suicide?

### 10. The case-law of the Strasbourg Court on issues related to end of life.

A specific interest to end-of-life issues can also be found in the jurisprudence of the European Court of Human Rights ("the Court"), which has dealt with them in some cases<sup>83</sup>.

In its judgments, the "Court" has mainly focused on Articles 2 and 8 of the European Convention on Human Rights (ECHR), which respectively protect the right to life and the right to respect for private life, as well as, more recently, the freedom of expression guaranteed by art. 10 of the Convention<sup>84</sup>.

<sup>82</sup> Assistance in suicide has been decriminalized in some European states, at least in part. For example, Switzerland does not allow euthanasia, but considers assisted suicide a tolerated civil act. According to the Federal Criminal Code, physicians can prescribe lethal drug and assisted suicide is not punishable if a provider without a selfish motive assists a person with decision-making capacity. For further details, cf. Marc A. Berthod, Alexandre Pillonel, Dolores A. Castelli Dransart, L'assistance au suicide en Suisse: l'émergence d'un «modèle d'inconduite», in Swiss Journal of Sociology, 46, 2020, pp. 1-17; SAMUEL BLOUIN, The impossibility of contesting in the name of religion? Comparative perspective on assistance in dying in Quebec (Canada) and the Canton of Vaud (Switzerland), in Claude Proeschel, David Koussens, Francesco Piraino (eds.), Religion, Law and the Politics of Ethical Diversity, cit., pp. 157-174; NATASIA HAMARAT, ALEXANDRE PILLONEL, MARC-ANTOINE BERTHOD, Dolores Angela Castelli Dransart, Guy Lebeer, Exploring contemporary forms of aid in dying: An ethnography of euthanasia in Belgium and assisted suicide in Switzerland, in Death Studies, 46 (7), 2022, pp. 1593-1607. In Austria, a law on assisted suicide was approved by Parliament in December 2021. With the law, for the first time, the state at least partially respects the individual's right to self-determination in the terminal stage of life. Moreover, assisted suicide is not reserved only for the terminally ill. See LAMISS KHAKZADEH, Assisted Suicide in Austria - the new legal framework, in BioLaw Journal-Rivista di BioDiritto, 1, 2022, pp. 135-143.

<sup>&</sup>lt;sup>83</sup> The case-law of the European Court of Human Right is available at <a href="https://www.echr.coe.int/pages/home.aspx?p=caselaw/hudoc&c">https://www.echr.coe.int/pages/home.aspx?p=caselaw/hudoc&c</a>. For a brief review of the case-law of Strasbourg Court see European Court of Human Rights, Guide on Article 2 of the Convention – Right to life, 31 August 2022, pp. 18-19 (<a href="https://www.echr.coe.int/Documents/Guide\_Art\_2\_ENG.pdf">https://www.echr.coe.int/Documents/Guide\_Art\_2\_ENG.pdf</a>); Factsheet – End of life and the ECHR, October 2022 (<a href="https://www.echr.coe.int/Documents/FS\_Euthanasia\_ENG.pdf">https://www.echr.coe.int/Documents/FS\_Euthanasia\_ENG.pdf</a>).

<sup>&</sup>lt;sup>84</sup> For an analysis of the Court's decisions, see Gregor Puppinck, Claire de La Hougue, The

According to the Strasbourg judges, Article 2 of the ECHR contains a clear affirmation of the duty of the Council of Europe's Member States to protect life and requires them to refrain from inflicting death, since the "sanctity of human life" is one of the fundamental values of the Convention<sup>85</sup>. Therefore, when questioned on the existence of a right to death, the "Court" clearly stated that no right to death, either at the hands of a third party or with the assistance of a public authority, can be derived from Article 2 of the ECHR. Indeed, the right to life "..could not, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die"86. Nor does the right to life, according to the ECHR, "create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life"87.

Based on this premise, several judicial proceedings have addressed the legitimacy of the refusal of medical treatment with various outcomes, focusing on the right to respect for private life (art. 8 ECHR)88. By virtue of the latter, the Court recognized the centrality of the individual's personal autonomy and self-determination in the medical decision-making process, which is closely connected to the fundamental importance attributed to the patient's will by the domestic laws of the Member States of the Council of Europe, as well as

right to assisted suicide in the case law of the European Court of Human Rights, in The International Journal of Human Rights, 18 (7-8), 2014, pp. 735-755; Stefania Negri, Ending life and death, in André Den Exter (ed.), European Health Law, Maklu Uitgevers N.V., Apeldoorn, 2016, pp. 219-241; Daria Sartori, End-of-life issues and the European Court of Human Rights. The value of personal autonomy within a 'proceduralized' review, in Questions of International Law, 52, 2018, pp. 23-43; AREND CORNELIS HENDRIKS, End-of-life decisions, Recent jurisprudence of the European Court of Human Rights, in ERA Forum, 19, 2019, pp. 561-570; DIEGO ZANNONI, Right or duty to live? Euthanasia and assisted suicide from the perspective of the European convention on human rights, cit., pp. 181-212.

<sup>85</sup> See Pretty v. The United Kingdom (Application no. 2346/02), ECtHR, 29 April 2002, § 39 (Refusal to give undertaking not to prosecute husband for assisting wife to commit suicide). In this case, the Court recognized the legitimacy of the prohibitions placed on assisted suicide by the UK Suicide Act 1961, and that consequently the refusal of the Prosecutor to grant immunity to Ms. Pretty's husband for assisting in her suicide was not disproportionate and could be justified as "necessary in a democratic society". In a similar sense see Haas v. Switzerland (Application no. 31322/07), ECtHR, 20 January 2011 (Refusal to make medication available to assist suicide of a mental patient), concerning the authority's refusal to make medication to assist the suicide of a mental patient. In this case the Court, reiterating that the Convention must be read as a whole, affirmed that Article 8 of the ECHR must be interpreted in its conjunction with Article 2, which "creates for the authorities a duty to protect vulnerable persons, even against actions by which they endanger their own lives". Therefore, it obliges the national authorities to prevent an individual from taking his own life if the decision has not been made freely and with full understanding of what is involved (§ 54).

<sup>86</sup> Pretty v. The United Kingdom, cit., § 39.

<sup>88</sup> See Daria Sartori, End-of-life issues and the European Court of Human Rights. The value of personal autonomy within a 'proceduralized' review, cit., p. 40.

by international instruments<sup>89</sup>. In this respect, the Strasbourg Court observed that while there is no a common consent among the Member States regarding the right of an individual to choose how and when to end his life (more specifically, regarding the right to suspend artificial life-sustaining treatments, although most States seem to allow it), there is instead a general consensus on the fundamental importance of the patient's wishes in the end-of-life decisionmaking process, however expressed. Therefore, due to the recognition of the States' sovereignty in the protection of the individual's life, the Court held that in end-of-life decisions the States must be granted a margin of appreciation "not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and their personal autonomy"90. It means that it is primarily for the national authorities to verify whether the decision to suspend treatment is compatible with national legislation and the Convention, and to establish the patient's wishes in accordance with national law<sup>91</sup>.

Following the recognition of this wide margin of appreciation in end-of-life situations, some scholars have argued that the European Court of Human Rights has seemed to progressively delineate a 'right to assisted suicide', as such falling within the right to respect for private life (Article 8 of the ECHR). In fact, in case *Koch v. Germany* (2012), the Court acknowledged that an individual's right to decide in which way and at which time his or her life should end, provided that he or she was in a position freely to form his or her own

<sup>&</sup>lt;sup>89</sup> See Council of Europe, Resolution 1859: Protecting human rights and dignity by taking into account previously expressed wishes of patients, cit., no. 1.

<sup>90</sup> See Lambert and Others v. France (Application no. 46043/14), ECtHR, 5 June 2015 (Decision to discontinue nutrition and hydration allowing patient in state of total dependence to be kept alive artificially). According to the Strasbourg judges, however, this margin of appreciation is not unlimited, and it is for the Court to verify whether States have complied with its obligations under Article 2 (§§ 147-148). Concretely, in addressing the question of the administering or withdrawal of medical treatment, the Court must evaluate the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2, and whether account had been taken of the applicant's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel and the possibility to approach the Courts in the event of doubts as to the best decision to take in the patient's interest (Ivi, § 143). For the application of the so-called "Lambert criteria" cf. Gard and Others v. the United Kingdom (Application no. 39793/17), ECtHR, 27 June 2017, § 83 (Decision to withdraw life-sustaining treatment for infant child suffering from fatal genetic disease); Afiri and Biddarri v. France (Application no. 1828/18), ECtHR, 23 January 2018, § 31 (decision to withdraw treatment in the case of a minor in a vegetative state); Parfitt v. the United Kingdom (Application no. 18533/21), ECtHR, 21 April 2021, § 37 (Withdrawal of treatment from a five-year old in a permanent vegetative state and discontinues interim measure).

<sup>91</sup> Haas v. Switzerland, cit., § 55; Lambert and Others v. France, cit., §§ 147-148.

will and to act accordingly, was one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention<sup>92</sup>. Consequently, it has seemed possible to some to assert the existence of a positive obligation on States to take measures to facilitate the act of suicide with dignity<sup>93</sup>.

Nonetheless, this conclusion is clearly denied by the decision in the recent case of Lings v. Denmark, with which the Court of Strasbourg rejected the application of Mr. Lings, a former Danish doctor who was sentenced in 2019 of two assisted suicides and one attempted assisted suicide, procuring or recommending drugs<sup>94</sup>. In deciding the case, the Court clarified that "there is no support in the Court's case-law for concluding that a right to assisted suicide exists under the Convention, including in the form of providing information about or assistance that goes beyond providing general information about suicide"<sup>95</sup>. Thus, the Court held that in the present case it was necessary to recognize a wide margin of appreciation in individual States, as well as the fact that the matter of assisted suicide concerned morals issues and comparative law research which enabled the Court to conclude that the Member states of the Council of Europe were far from having reached a consensus on this issue<sup>96</sup>.

The European Court's fear of an excessive opening towards the right to assisted suicide does not seem extraneous to this decision. The lack of a European consensus on EPAS indeed seems to suggest to judges a certain prudence in recognizing the right to die with dignity, to avoid risks at stake of a gradual normalization of the right to die<sup>97</sup>. In fact, the wide recognition of the right to

<sup>&</sup>lt;sup>92</sup> Koch v. Germany (Application no. 497/09), ECtHR 19 July 2012, § 51-52 (Refusal by the German courts to examine the merits of an application by a man whose wife had just committed suicide in Switzerland after having attempted unsuccessfully to obtain authorisation to purchase a lethal substance in Germany). Similarly, cf. Gross v. Switzerland (Application 67810/10), ECtHR, 14 May 2013 (Failure to inform Court of applicant's death in proceedings concerning her ability to obtain drug enabling her to commit suicide).

<sup>&</sup>lt;sup>93</sup> See Gregor Puppinck et Al., The right to assisted suicide in the case law of the European Court of Human Rights, cit., p. 737 ff.

<sup>&</sup>lt;sup>94</sup> Cf. Lings v. Denmark (no. 15136/20), ECtHR, 12 April 2022 (Justified and proportionate conviction and suspended prison sentence imposed on pro-euthanasia physician for assistance and advice to specific persons on how to commit suicide). See Nicolas Bauer, For the ECHR, there is no right to assisted suicide (https://eclj.org/euthanasia/echr/pour-la-cedh-il-nexiste-aucun-droit-ausuicide-assiste).

<sup>95</sup> Lings v. Denmark, cit., § 52.

<sup>&</sup>lt;sup>96</sup> Ivi, § 60. Regarding consensus, see also §§ 26-32.

<sup>&</sup>lt;sup>97</sup> This lack of consensus is considered as paradoxical by Daria Sartori, End-of-life issues and the European Court of Human Rights. The value of personal autonomy within a 'proceduralized' review, cit., p. 43, "considering the consensus which de facto exists about passive euthanasia [...]. There is no reason for not setting limits to personal autonomy when it comes to the refusal of life-saving and the withdrawal of life-sustaining treatments, while setting stringent limits when euthanasia or assistance in suicide are involved". On the unreasonableness of forecasting different legal treatments for the

die with dignity could constitute the prelude to the possibility of a wide resorting to active euthanasia, even beyond the boundaries of incurable disease or intolerable suffering, in cases such as dementia or depression, or in a state of advanced physical or mental decrepitude, or simply to old age, nullifying the meaning of the recognition of the right to life contained in Article 2 of the Convention. The consequences of this decision must be carefully weighed, of course<sup>98</sup>. This risk is clearly underlined by some scholars, both supporters of religious and secular views<sup>99</sup>.

## 11. End of life regulatory framework in Italy. The law no. 219 of 2017

Italy has not had legislation on end-of-life for a long time, also due to the strong opposition of the Catholic Church and its influence in Italian society and politics. However, due to some judicial cases that have divided interpreters and public opinion end-of-life issues have also received great attention in recent years, becoming the subject of a growing debate, as had happened in the past for issues concerning the beginning of life (abortion, medically assisted procreation, etc.).

Not unlike other European and Western countries, the debate has also developed in Italy around the freedom to refuse or withdraw treatments through advance care directives (also called 'living wills'), as well as the admissibility of assisted suicide and active euthanasia, both criminalized by law<sup>100</sup>.

From a legal perspective, the question has been raised whether end-of-life

suspension of life-sustaining treatments on the one hand and euthanasia on the other, see also Cecilia Wee, *Confucianism and Killing versus Letting Die*, in Wanda Teays, Alison Dundes Renteln (eds.), *Global Bioethics and Human Rights. Contemporary Perspectives*, Rowman & Littlefield, Lanham-Boulder, New York-London, 2014, p. 249.

<sup>&</sup>lt;sup>98</sup> In *Gross v. Switzerland*, cit., the applicant was not suffering from a terminal illness. She claimed her right to die to avoid the decline of her physical and mental faculties as a result of her advanced age.

<sup>&</sup>lt;sup>99</sup> See Diego Zannoni, Right or duty to live?, cit., p. 182: "The legalisation of euthanasia and assisted suicide, initially proposed for exceptional cases, could become a method of resource-led population control in a society marked by a progressively aging population and restricted healthcare expenditure. The basic concern is that legalisation could lead to certain conditions being considered generally unworthy of protection, which could ultimately culminate in a kind of 'duty to die', by which vulnerable groups would be disproportionately affected" (p. 182). In this respect, see also Luciano Eusebi, Dignità umana e indisponibilità della vita. Sui rischi dell' asserito "diritto" di morire, in Enrico Furlan (ed.), Bioetica e dignità umana, Franco Angeli, Milano, 2009, p. 218.

<sup>&</sup>lt;sup>100</sup> For an ethical-juridical framework on the end-of-life debate in Italy see Italian Committee for Bioethics (ICB), *Bioethical reflections on Physician-assisted suicide*, 18 July 2019 (https://bioetica.governo.it/en/opinions/opinions-responses/bioethical-reflections-on-medically-assisted-suicide/). See also Marzio Barbagli, *Alla fine della vita*. Morire in Italia e in altri paesi occidentali, il Mulino, Bologna, 2018.

decisions can be placed among the choices attributable to individual freedom; above all, to what extent the personal views of the meaning of life and its dignity that inspire the decision-making process on medical care in end-of-life situations, as well as the underlying motivations (also of a religious nature), can be recognized by domestic law. Following some controversial judicial cases (Welby, Englaro, DJ Fabo, among these), it was discussed whether the Italian legal system imposes the protection of life even when, according to some, it could no longer be considered as such, as in the case of patients in persistent vegetative state. Specifically, it was asked: 1) whether it can be considered a right not to receive life-prolonging treatment in some extreme cases. such as, for example, in situations of objective irreversibility of the clinical situation (so-called "right to switch off the life-support machine"): 2) if so. who is entitled to express this will, especially in cases of the patient's inability to express his consent to the withdrawing of life-sustaining treatments; 3) how should healthcare professionals behave in this case, i.e. if they are required to respect the choices of the patient or his legal guardian, or if there is room for a legitimate refusal by doctors to requests for rejection or interruption of life-prolonging treatment. As it easy to understand, these are very sensitive questions, in which the religious (or non-religious) convictions of individuals, both of patients and clinicians, can play a determining role.

Several bills have been presented to the Italian Parliament over time by various political parties to introduce a regulatory framework for end-of-life decisions aimed at guaranteeing the right to self-determination of people in the terminal stage of life, with regard to the right to refuse or suspend treatment, including through advance care directives. These bills have had contents of greater or lesser extent depending on the case: some aimed at regulating only access to palliative care and pain therapy, others the terms and conditions of advance care directives and of life-support treatments, still others the introduction of forms of active euthanasia and assistance in dying<sup>101</sup>.

<sup>&</sup>lt;sup>101</sup> Law no. 38 of 15 March 2010 ("Provisions to guarantee access to palliative care and pain therapy") provides for access to palliative care and pain therapy by the patient to ensure treatment and assistance in the end of life, respecting the dignity and autonomy of the human person, equity in access to assistance, the quality of care and its appropriateness in this delicate stage of existence. For an overview of the attempts at end-of-life regulation in Italy, see Giovanna Razzano, Dignità nel morire, eutanasia e cure palliative nella prospettiva costituzionale, Giappichelli, Torino, 2014; Denard Veshi, GERALD NEITZKE, Living wills in Italy: ethical and comparative law approaches, in European Journal of Health Law, 22, 2015, pp. 38-60; Germana Carobene, Sul dibattito scientifico e religioso in tema di "fine vita": accanimento terapeutico, stato vegetativo ed eutanasia, in Stato, Chiese e pluralismo confessionale, Rivista telematica (https://www.statoechiese.it), 9, 2015, pp. 1-22; Luca E. Perriello, Living wills and end-of-life decisions: the Italian case, in Diritto delle successioni e della famiglia, 3, 2016, pp. 691-714; FEDERICA BOTTI, The "gattopardesca" (ir) reformability of religious law in matters of end of life, in Il Diritto ecclesiastico, 3-4, 2017, pp. 533-540.

However, only in December 2017 did the Italian Parliament approve the law no. 219, named 'Provisions on informed consent and advance care directives' 102, and the question was finally resolved, albeit not exhaustively. The law no. 219/2017 can be considered the culmination of a long legislative process and heated debates throughout Italian society on the issues of end-of-life and living wills. Concepts such as quality of life, patient autonomy and the right to accept or refuse any medical treatment are stated: controversial issues such as informed consent to medical treatment, pain therapy, prohibition of unreasonable therapeutic obstinacy, dignity at the end of life, advance care directives, refusal or suspension of life-sustaining treatments are now faced by the law 103.

Law no. 219/2017 guarantees the self-determination and dignity of the patient with primacy over any other choice of the physicians or the patient's family, pursuant to articles 2, 13 and 32 of the Italian Constitution and articles 1, 2 and 3 of the Charter of Fundamental Rights of the European Union. It means that a competent adult patient may exercise control over life-sustaining treatment choices not only at the present, by directly allowing or refusing care in the process of informed consent (Article 1), but also at a time of future inability to exercise the right to personal autonomy by writing advance care directives (Article 4) based on one's personal assessments, regardless of the reasons that justify the choices, including those of a religious nature<sup>104</sup>. By focusing the care pathway on informed consent and on the patient's will and freedom, deemed in its holistic dimension, i.e. also including his references,

<sup>&</sup>lt;sup>102</sup> Law of 22 December 2017, no. 219 ("Norme in materia di consenso informato e di disposizioni anticipate di trattamento"), published in the "Gazzetta Ufficiale" n. 12 of 16 January 2018.

<sup>&</sup>lt;sup>103</sup> For further details, see Mirzia Bianca, La legge 22 dicembre 2017, n. 219. Norme in materia di consenso informato e di disposizioni anticipate di trattamento. Prime note di commento, in Familia, 1, 2018, pp. 109-116; Ornella Spataro, La legge n. 219 del 2017 e la disciplina del fine-vita tra principi costituzionali e problemi aperti. Spunti di riflessione, in BioLaw Journal-Rivista di BioDiritto, 2, 2019, pp. 199-222; Marco Di Paolo, Federica Gori, Luigi Papi, Emanuela Turillazzi, A review and analysis of new Italian law 219/2017: 'provisions for informed consent and advance directives treatment', in BMC Medical Ethics, 20 (17), 2019, pp. 1-7.

Advance care directives are a legal document that specifies an individual's health-related wishes, draft in the event of any future inability to make informed decisions, attributing legally binding value to the care decisions expressed when he was still in full possession of his mental faculties, also based on his religious convictions. They may include directives on specific care treatments, but they may also cover a wider range of expressions of wishes in the medical field, in relation to a broader and more complex universe of personal principles and values that help shape a person's attitude towards choices in moral field. Article 4 of law no. 219/2017 establishes for each competent adult person the right of expressing his/her will regarding health treatments, as well as the consent or refusal to diagnostic tests, therapeutic choices and specific care treatments, in anticipation of any future impossibility of self-determination and after having acquired adequate medical information about the consequences of one's choices.

his personal beliefs, his values and his conception of the quality of life, the law no. 219/2017 marked a great change in the patient-physician relationship, because it allowed the transition to a new phase in which the patient's will becomes decisive. In this respect, three different principles are envisaged by the law: 1. the faculty to consent or refuse treatment: if the continuation of treatment is not in the interest of the patient, treatment can be suspended, allowing him to die peacefully; 2. the provision of a 'shared care planning'; 3. the recognition of the right for people to write advance care directives in the event of a possible future inability to make informed decisions.

It is important to underline that the Italian law no. 219/2017 does not introduce euthanasia, nor physician assisted suicide. Rather, it guarantees individuals the possibility of choosing whether to accept, refuse, maintain or suspend life-sustaining treatments, thus filling a "regulatory gap" which, over the years, had forced many terminally ill patients to choose to go abroad in order to avoid the compulsory prolongation of treatment imposed in Italy<sup>105</sup>.

## 12. A developing path. Prospects for increasing the legal protection of end-oflife choices in Italy

The Law n. 219/2017 was a first step, even a significant one, compared to the previous lack of a regulatory framework on the subject of end-of-life. It can be considered the first stage of a wider process aimed at clarifying the boundaries of a new "bio-law", based on the principle of individual selfdetermination with respect to a series of issues concerning the terminal stage of human life<sup>106</sup>. However, the debate is far from being resolved, and the regulatory framework on end-of-life is still in progress<sup>107</sup>.

Although the law has received a positive reception from many experts and scholars, as well as a large part of public opinion, some critical aspects have emerged, which continue to foster the scientific and legal debate.

<sup>&</sup>lt;sup>105</sup> In this regard, the case of DJ Fabo is striking, a competent terminal patient who chose to move to Switzerland to receive assisted suicide accompanied by the Italian politician Marco Cappato. The latter was subsequently convicted pursuant to article 580 of the Italian penal code, for having accompanied the suicide aspirant to Switzerland to carry out the assisted suicide there. The case was then referred to the Italian Constitutional Court, which ruled with decision no. 242 of 2019, admitting the possibility of access to assisted suicide under certain conditions. See below, § 12.

<sup>106</sup> See PIERLUIGI CONSORTI, Diritto e religione. Basi e prospettive, Laterza, Bari-Roma, p. 382 ff. On the concept of 'bio-law', see Fortunato Freni, La laicità nel biodiritto. Le questioni bioetiche nel nuovo incedere interculturale della giuridicità, Giuffrè, Milano, 2012.

<sup>&</sup>lt;sup>107</sup> See Vladimiro Zagrebelsky, Autodeterminazione in ordine alla fine della vita. La strada ancora da percorrere in Italia, in Notizie di Politeia: rivista di etica e scelte pubbliche, 38 (2022), 14, pp. 7-10.

Firstly, the Law n. 219/2017 does not provide for a conscience clause in favour of healthcare professionals<sup>108</sup>. According to the law, the clinician is obliged to enforce a decision to withdraw life-sustaining treatment freely taken by a competent adult patient (or his legal guardian) and then to let him die, if that is the patient's will. In other words, the physician must accept the patient's request even if it is contrary to his ethical or religious beliefs (Article 1, § 6), since the law does not provide for the right to refuse the administration of a medical service as an expression of conscientious objection (conscience-based refusals), not even on religious grounds<sup>109</sup>. A physician who provides life-sustaining treatment despite the refusal of a competent adult patient may be subject to criminal or civil liability.

Secondly, the law no. 219/2017 does not provide for a discipline on active euthanasia and assisted suicide. It means that they remain prohibited by Italian legislation both in the direct form, in which the physician actively helps patients to die by administering the substance that causes death (Article 579 of the penal code, murder of the consenting person), and in the indirect form, in which the agent prepares the euthanasia drug but death occurs as a consequence of the direct action of the patient wishful to put an end to his own life, who must self-administer the deadly substance prescribed for this purpose (Article 580 of the penal code, instigation and aid to suicide). Instead, forms of euthanasia so-called passive, or practiced in an omissive form, i.e. refraining from intervening to keep the suffering patient alive, are already considered criminally lawful, especially when the interruption of treatment has the purpose of avoiding the so-called "therapeutic obstinacy". However, there are many ambiguous cases in which it is not easy to distinguish whether it is euthanasia by action or omission, and which pose the problem of a possible inequality of

<sup>&</sup>lt;sup>108</sup> The primary reason for granting the right of conscientious objection to healthcare professionals is to enable them to maintain their moral integrity. See Mark R. Wicclair, *Conscientious Objection*, cit., pp. 87-108.

The doctor's exemption from professional obligations, in fact, is limited only to cases in which the patient intends to demand health treatments contrary to the law, professional ethics or good clinical-care practices. However, these are cases on which, in the case of a conflict between the doctor and the patient, the judge must decide: therefore, in the event of a ruling by the judge authorizing the suspension of life-prolonging treatment, the doctor must carry out this will, despite his contrary beliefs. See Davide Paris, Legge sul consenso informato e le DAT: è consentita l'obiezione di coscienza del medico?, in Biolaw Journal-Rivista di BioDiritto, 1, 2018, pp. 31-35; Caterina Gagliardi, La legge n. 219 del 22 dicembre 2017: obiezione di coscienza o autonomia professionale del medico?, in Il diritto di famiglia e delle persone, XLVIII, 3, 2019, pp. 1433-1443; Pamela Tozzo, Matteo Sanavio, Carola Salasnich, Luciana Caenazzo, Conscientious objection in Italian law n. 219/2017: a space for reflection still to be traced, in Biolaw Journal-Rivista di BioDiritto, 2, 2020, pp. 269-285; Claudia Bianca Ceffa, Obiezione di coscienza e scelte costituzionalmente vincolate nella disciplina sul "fine vita": indicazioni e suggestioni da una recente giurisprudenza costituzionale, in Nomos, 1, 2021, pp. 1-26.

treatment to the detriment of serious and suffering patients affected by pathologies that do not lead to per se to death as a result of the simple interruption of treatment.

The Italian Constitutional Court has recently dealt with this issue, legalizing assisted suicide in Italy under certain conditions<sup>110</sup>. With decision no. 242/2019, the Court declared that application of Article 580 of the Penal Code criminalizing assisted suicide is unconstitutional in the part in which it does not exclude the punishment of those who, in the ways provided for by law no. 219 of 2017 or with equivalent methods, facilitate the execution of the suicidal intention, formed in a free and autonomous way, of a person kept alive by life-sustaining treatments and suffering from an irreversible disease causing physical or physiological suffering deemed intolerable, but fully capable to adopt free and informed decisions, provided that these conditions and methods of execution have been verified by a public structure of the National Health Service, subject to the opinion of the territorially competent Ethics Committee<sup>111</sup>. According to the Court, based on current legislation, the suicide aspirant's decision to put an end to his life has binding effects on third parties. In addition, the Court noted that Law no. 219 of 2017 recognizes the citizen's

<sup>&</sup>lt;sup>110</sup> Cf. Constitutional Court, Decision 22 November 2019, no. 242. For an analysis of the decision see: Luciano Eusebi, Il suicidio assistito dopo Corte cost. n. 242/2019. A prima lettura, in Corti supreme e salute, 2, 2019, pp. 193-200; Antonio Ruggeri, La disciplina del suicidio assistito è "legge" (o, meglio, "sentenza-legge"), frutto di libera invenzione della Consulta. A margine di Corte cost. n. 242 del 2019, in Quaderni di diritto e politica ecclesiastica, 3, 2019, pp. 633-649; PAOLO CARETTI, La Corte costituzionale chiude il caso "Cappato" ma sottolinea ancora una volta l'esigenza di un intervento legislativo in materia di "fine vita", in Osservatorio sulle fonti, 1, 2020, 7, pp. 187-191; FABRIZIO TUROLDO, Aiding and Abetting Suicide: The Current Debate in Italy, in Cambridge Quarterly of Healthcare Ethics, 30(1), 2021, pp. 123-135. The decision resumes the observations and conclusions already formulated by the Constitutional Court with ordinance no. 207 of 2018, holding that the suicide aspirant must be a person affected by a pathology that is irreversible, the pathology must be the source of physical or psychological suffering that is intolerable, the person can be kept alive only through life support treatments, and the person remains able to adopt free and informed decisions. With regards to the ordinance no. 207 of 2018 see Angelo Licastro, Trattamenti sanitari, diritto all'autodeterminazione ed etiche di fine vita dopo l'ordinanza n. 207 del 2018 della Corte costituzionale, in Stato Chiese e pluralismo confessionale, Rivista telematica (https://www. statoechiese.it), n. 14, 2019, pp. 1-34; Federico Gustavo Pizzetti, L'ordinanza n. 207/2018 della Corte costituzionale: prime riflessioni su un "nuovo diritto" del paziente alla fine della vita, in Notizie di Politeia: rivista di etica e scelte pubbliche, 133, 2019, pp. 135-141; Mario Ricca, A Corpo Morto. Suicidio assistito e accudimento, o altrimenti che Essere ...a processo, in Diritti umani e diritti altrui. Per una semioetica della comunicazione globale, a cura di Susan Petrilli, Mimesis Edizioni, Milano-Udine, 2020, pp. 97-162.

<sup>111</sup> Cf. Considerations of law § 2.3. Article 580 of the Italian penal code punishes assisting in the commission of a suicide or reinforcing the suicidal intent in someone else, as opposed to instigating the suicide, and provides that any conduct aimed at executing the suicide that does not affect the deliberative process of the suicide aspirant is punishable by five to twelve years' imprisonment, without distinction between the assistance and instigation.

right to reject or interrupt health treatment<sup>112</sup>. Therefore, if a fully capable terminally ill person chooses to put an end to his own life and assistance to other people constitutes the only way out to escape, in respect of his own conception of personal dignity, the maintenance of an artificial life no longer desired and which he has the right to refuse<sup>113</sup>, the absolute prohibition of assisting suicide ends up unjustifiably and unreasonably limiting the patient's freedom of self-determination in the choice of therapies, including those aimed at the end of suffering (deriving from the articles 2, 13 and 32, second paragraph, of the Italian Constitution), imposing a single mode of death<sup>114</sup>.

It should be noted that decision no. 242 of 2019 does not establish a "right to die". The Constitutional Court, in fact, clearly excludes that from the right to life, implicitly recognized by Article 2 of the Italian Constitution and expressly by Article 13 of the Constitution, the right to renounce life can arise, and therefore a real right to death<sup>115</sup>.

In 2019, a request for a referendum aimed at the partial abrogation of Article 579 of the Italian penal code (murder of the consenting person) had reached the necessary quorum<sup>116</sup>. The objective of the referendum was to decriminalize active euthanasia: the doctor would be allowed to administer a euthanasia drug (i.e., one that causes death) to the patient who requested it. Therefore, in the event of a positive outcome of the referendum, active euthanasia would have been permitted in the forms envisaged by the law no. 219/2017, provided that the requisites indicated by the Constitutional Court in decision no. 242/2019, while it would have been punished if the crime had been committed against an incompetent person or a person whose consent had been extorted with violence, threats or against a minor under the age of eighteen. However, in February 2020 the Italian Constitutional Court declared the referendum inadmissible, establishing that it would have exceeded the limits reasonably set by the Constitutional Court with the sentence n. 242/2019, liberalizing all forms of homicide of the consenting<sup>117</sup>.

<sup>112</sup> Considerations of law § 2.3.

<sup>113</sup> Ibidem.

<sup>114</sup> Ibidem.

<sup>115</sup> *Ibidem*. According to the Court, the current legislation (laws n. 38 of 2010 and n. 219 of 2017) – on the basis of which the doctor can, with the patient's consent, resort to continuous deep palliative sedation in association with pain therapy, to deal with refractory pain health treatments – does not allow the doctor to make direct treatments available to the patient who is in the conditions described above, not to eliminate his suffering, but to determine his death (*ibidem*.).

<sup>&</sup>lt;sup>116</sup> Article 579 of the Italian penal code establishes that whoever causes the death of a man, with his consent, is punished with imprisonment from six to fifteen years.

<sup>&</sup>lt;sup>117</sup> Constitutional Court, Decision 15 February 2022, no. 50. For further details, see Antonio

As a result, the question of a possible decriminalization of euthanasia and assisted suicide in Italy remains far from resolved. To overcome the current regulatory gap, a law aimed at fully implementing the availability of the right to life in the terminal stage of human life would be needed, which should detail the rules on the possibility of access to medically assisted death (the methods of formalizing consent, the preventive assessment of its legitimacy, the subjects who can access the practice of euthanasia, the legitimate interests to be protected) and the public guarantee procedures to be observed, on which an agreement should be found in Parliament<sup>118</sup>. However, the political stalemate surrounding agreement on an assisted dying law persists even after the practice has been partially accepted by the Constitutional Court. A bill (no. 2553, called "Provisions on medically assisted voluntary death") was approved by the Chamber of Deputies on 10 March 2022, and sent to the Senate of the Republic for the necessary approval<sup>119</sup>. Interestingly, the proposal included a conscience clause for healthcare professionals. In this regard, it is undeniable that the future legislative framework should explicitly guarantee healthcare professionals the right to conscientious objection. In fact, contestation in the name of religion very clearly falls within a secular framework of guaranteeing civil rights, given that some professional obligations can legitimately be considered incompatible with religious precepts and obligations. Therefore, no physician should be required to administer a lethal injection or assess a patient's eligibility if he has a

Ruggeri, Autodeterminazione versus vita, a proposito della disciplina penale dell'omicidio del consenziente e della giusta sottrazione ad abrogazione popolare parziale (traendo spunto da Corte cost. n. 50 del 2022), in Dirittifondamentali.it, Rivista on-line, 1, 2022, pp. 464-485; Andrea Pugiotto, Eutanasia referendaria. Dall'ammissibilità del quesito all'incostituzionalità dei suoi effetti: metodo e merito nella sent. n. 50/2022, in Rivista AIC, 2, 2022, pp. 83-100; Fabio Cembrani, Mariano Cingolani, Piergiorgio Fedell, L'autonomia decisionale della persona nelle situazioni di vulnerabilità, di debolezza e di razionalità limitata: iniziali riflessioni a margine della sentenza n. 50 del 15 febbraio 2022 della Corte costituzionale, in Stato, Chiese e pluralismo confessionale, Rivista telematica (https://www. statoechiese.it), 8, 2022, pp. 1-17. For some doubts on the admissibility and scope of the referendum, see Nicola Colaianni, Ammissibile? Alcuni dubbi sul referendum fine vita, in Stato, Chiese e pluralismo confessionale, Rivista telematica (https://www.statoechiese.it), 22, 2021, pp. 37-46; GIOVANNA RAZZANO, Le incognite del referendum c.d. sull'eutanasia: fra denominazione del quesito, contenuto costituzionalmente vincolato e contesto storico, in Consultaonline, 3, 2021, 8 dicembre 2021, pp. 973-983; GIULIANO BALBI, L'omicidio del consenziente. Alcune riflessioni sul quesito referendario, in www.sistemapenale.it, 11 febbraio 2022, pp. 1-10.

<sup>118</sup> See Stefano Canestrari, I tormenti del corpo e le ferite dell'anima: la richiesta di assistenza a morire e l'aiuto al suicidio, in www.dirittopenalecontemporaneo.it, 14 marzo 2019, pp. 1-21; Chia-RA TAMBURINI, Per non morire di inerzia: piste di riflessione per una legge italiana su alcuni aspetti del fine vita, in Biolaw Journal-Rivista di BioDiritto, 3, 2020, pp. 261-270; Alessandra Camaiani, "Il fine non giustifica i mezzi": la Corte costituzionale frena gli entusiasmi referendari sul fine vita, ma salva l'ordinamento da un grave vuoto sanzionatorio, in Consulta online, 2, 2022, pp. 631-646.

<sup>119</sup> See Antonio Ruggeri, Oscurità e carenze della progettazione legislativa in tema di morte medicalmente assistita (prime notazioni), in Consultaonline, 31 marzo 2022, pp. 407-414.

conscience-based reason not to do so<sup>120</sup>. Nevertheless, the early closure of the legislature in the summer of 2022 has made the future of this legislative proposal very uncertain. At present, its translation into law appears to be confined to an indefinite time horizon. Indeed, in the legislature that has just begun, there does not seem to be a political parliamentary majority in favour of amending Articles 579 and 580 of the penal code.

## 13. The influence of Catholic Church on the current Italian legislation on end-of-life

The influence of religion on the law-making process in the field of bioethics reveals a great diversity of situations depending on the different religious traditions, both on the landscape of actors and their methodologies and, above all, on authorities producing the norms<sup>121</sup>. As regards the Italian situation, the question is: to what extent can it be said that the current Italian regulatory framework on the end-of-life issues is conditioned by religions and above all by the Catholic Church? Whether and what influence of the religious groups' views on end-of-life issues can be found in law no. 219/2017, in the decisions of the Constitutional Court, and finally in the current phase of evolution of the regulatory framework? Is the power of the Catholic Church in Italy still so strong on ethical issues (and, among these, on end-of-life issues)? Or can we say that Italy has embarked on the path of greater secularization of its legislation, according to the notion of "laicità" (i.e. secularism) provided by the Constitutional Court back in 1989?

It is not easy to answer these questions. Certainly, the Catholic Church and other widespread religions in Italy have made a strong opposition, expressing their dissent and obstruction, toward the law no. 219, and, currently, toward

<sup>120</sup> In this regard, the recent position of the Abrahamic monotheistic religions seems acceptable, emphasizing that "No health care provider should be coerced or pressured to either directly or indirectly assist in the deliberate and intentional death of a patient through assisted suicide or any form of euthanasia, especially when it is against the religious beliefs of the provider. It has been well accepted throughout the generations that conscientious objection to acts that conflict with a person's ethical values should be respected. This also remains valid even if such acts have been accepted by the local legal system, or by certain groups of citizens. Moral objections regarding issues of life and death certainly fall into the category of conscientious objection that should be universally respected". See Position Paper of the Abrahamic Monotheistic Religions on Matters Concerning the End of Life, cit., p. 8. Obviously, the eventual recognition of a conscience clause for the healthcare professional would require adjustments to guarantee the right of patients to receive care as in the end of life.

See Christian Byk, Religions, Bioethics and Biolaw, cit., p. 306.

any hypothesis of legalization of assisted suicide and euthanasia<sup>122</sup>. However, after years of absolute immobility of the Italian legislator on end-of-life issues, a new approach is now evident, more consistent with the ideological postulates and with the positions of a secular state<sup>123</sup>. The power of religion (of the Catholic Church *in primis*) is still evident, even if less than in the past. Behind the legislative inertia, which reflects a more general difficulty of the Italian Parliament in regulating ethical issues, the "undeclared and unmentionable" fear of many political parties of offending Catholics citizens and losing votes clearly emerges.

Nonetheless, at the level of civil society something has changed: citizens, often Catholics too, are more aware and able to distance themselves from the official teachings of the Catholic Church, perceiving in the regulation of euthanasia or assisted suicide an "extra right" for citizens, not an obligation to which anyone indiscriminately submits. A secular ethical pluralism seems to be slowly making its way, even in the context of a traditionally Catholic country where the majority of citizens still maintain more or less close ties with the Catholic Church and its teachings. In this perspective, Law no. 219/2017 can be considered the apex of a more general tendency of ethical and juridical culture in Italy to place the freedom of choice at the end of life within the fundamental freedoms that belong to the constitutional tradition.

## 14. Conclusive remarks

Some concluding remarks can be made based on the general trends described above. Legislative decisions on the end of life are inevitably difficult because they have to regulate scientifically controversial issues, for which individual opinions attributable to ethical, moral and religious principles are often decisive, both when the law provides nothing, and when the law takes a position by regulating one or more concrete issues.

Religions are among the supporters of an unconditional right to life. For

<sup>122</sup> Clear evidence, for instance, can be found in the grave concern that was expressed by the Italian bishops in the extraordinary session of 17 August 2021 due to the signature collection for the referendum which aims to decriminalize the consented murder, effectively opening to euthanasia in Italy. According to the Italian bishops, anyone who finds himself in conditions of extreme suffering must be helped to manage pain, to overcome distress and despair, not to eliminate his own life. Choosing death is the failure of the human, the victory of an individualistic and nihilistic anthropological conception in which neither hope nor interpersonal relationships find more space. See https://www. avvenire.it/chiesa/pagine/fine-vita-grave-inquietudine-per-la-raccolta-di-firme-per-il-referendum.

<sup>&</sup>lt;sup>123</sup> See Francesco Alicino, Diritto alla salute e fattore religioso nello spazio giuridico europeo. Alla ricerca di un laico e sostenibile pluralismo etico, in federalismi.it, 3, 2020, pp. 1-30.

this reason, they are committed to countering the visions that affirm the idea that every man is the lord of his own life, that he is free to choose how and when to turn it off, and, therefore, that physical suffering can be ended through legalized suicide (i.e., euthanasia).

In this regard, it should be noted that today the advancement of medical care allows for artificially delaying the end of life, even for very long periods of time. Above all, it allows to lengthen the condition of the terminally ill, which is a "hybrid" condition, that is without life and without death. From this point of view, some scholars argue that euthanasia leads to a sort of natural law, far from the artifice of technology<sup>124</sup>. The individual is given the opportunity to live his life as long it is considered such, leaving life "at the right time". However, the idea that human beings are free to decide when life should be considered "over" inevitably generates doubts and perplexities, not only from a religious perspective. Moreover, it raises questions about the acceptability of a request for euthanasia and assisted suicide not only due to incurable diseases or terrible pains (i.e., as a last-resort option for a very small number of terminally ill patients), but also in cases of "healthy people" with problems of a different nature (for example, caused by depression, financial failure, sentimental disappointment, momentary psychic fragility, etc.), who are simply "tired of living". It means that a terminal illness is no longer a prerequisite for euthanasia or assisted suicide, as already happened or considered in some jurisdictions (for example, in the Netherlands). Thus, there is a danger of an ad libitum extension of the freedom to dispose of human life, which is clearly highlighted by most religions, but also by many secular scholars<sup>125</sup>.

Finding a balance between the contemporary and somewhat conflicting needs for the protection of the right to life and the right to respect for private life and individual self-determination in therapeutic matters will certainly be one of the challenges facing State legislators in Western societies<sup>126</sup>. Looking to the future, as advances in technology and medical practice expand our ability to prolong life, it will be essential that lawmakers find legal solutions to end-of-life issues, without leaving this matter unregulated. Whatever these solutions

<sup>&</sup>lt;sup>124</sup> See Craig Paterson, *Assisted Suicide and Euthanasia: A Natural Law Ethics Approach*, Routledge, New York-London, 2008.

<sup>125</sup> See Daniel P. Sulmasy, John M. Travaline, Louise A. Mitchell, E. Wesley Ely, Non-faith-based arguments against physician-assisted suicide and euthanasia, in The Linacre quarterly, 83 (3), 2016, pp. 246-257; Josè Pereira, Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls, cit., pp. 38-45; Giovanni Fiandaca, Le questioni di fine-vita tra filosofia e diritto, in Notizie di Politeia: rivista di etica e scelte pubbliche, 140, 2020, pp. 126-132.

<sup>&</sup>lt;sup>126</sup> See LORENZO D'AVACK, Consenso informato e scelte di fine vita: riflessioni etiche e giuridiche, Giappichelli, Torino, 2020.

are, they must primarily be aimed at legalizing an approach to end-of-life situations that avoids futile therapeutic measures and supports therapeutic effort limitation and proportionality based on palliative care<sup>127</sup>. From this point of view, although each State may have conflicting systems to regulate assistance to the dying on the basis of its own traditions and ideological options, including those of a religious nature, it will be important for national legislators to also consider the implications of faith teachings for the ongoing debate and any future implementation of legal solutions on end-of-life situations, promoting "a reciprocal understanding and synergies of different approaches between the monotheistic religious traditions and secular ethics concerning beliefs, values, and practices relevant to the dying patient" 128. In fact, religion and spirituality can offer not only a supportive role in end-of-life and palliative care of patients, but also a key contribution to a possible rapprochement between secular ethics and religious ethics capable of guaranteeing resources to address the major areas of concern regarding the end of life that remain unresolved today<sup>129</sup>. This cooperation is even more important if we consider the multi-ethnic, multicultural, and multi-religious evolution of Western societies, especially in Europe. To date, States are no longer culturally and religiously homogeneous entities, but an increasingly diversified population has emerged within them. In this respect, the last few decades have led to a multicultural and multi-ethnic patient population, with their own beliefs and needs with respect to healthcare treatments and, particularly, end-of-life situations. Therefore, providing culturally competent end-of-life care presents a challenge for nation States today and in the future, particularly in countries with increasing religious diversity and a high concentration of ethnic or religious minorities<sup>130</sup>.

<sup>&</sup>lt;sup>127</sup> In this respect, see RICHARD HUXTABLE, Euthanasia, ethics and the law: from conflict to compromise, Routledge Cavendish, Abingdon, 2007; Dominic Wilkinson, Euthanasia, in David Edmonds (ed.), Ethics and the contemporary world, Routledge, London-New York, 2019, pp. 277-290; TANIA BORTOLU, Fine vita tra biodiritto e "bio-equity". Modelli a confronto, in Comparazione e diritto civile, 2, 2021, pp. 523-558.

Position Paper of the Abrahamic Monotheistic Religions on Matters Concerning the End of Life, p. 5. In this regard see also NAOMI R. CAHN, AMY ZIETTLOW, Religion and End-of-life Decisionmaking, cit., p. 1736.

<sup>129</sup> See Michael McCarthy et Al., There's No Harm in Talking: Re-Establishing the Relationship Between Theological and Secular Bioethics, cit., pp. 5-13.

<sup>130</sup> See Ivo Quaranta, Mario Ricca, Malati fuori luogo, R. Cortina, Milano, 2012; Giancarlo Anello, Multiculturalità, "diritti" e differenziazioni giuridiche: il caso dei trattamenti sanitari, in Stato, Chiese e pluralismo confessionale, Rivista telematica (www.statoechiese.it), 16, 2013, pp. 1-15.