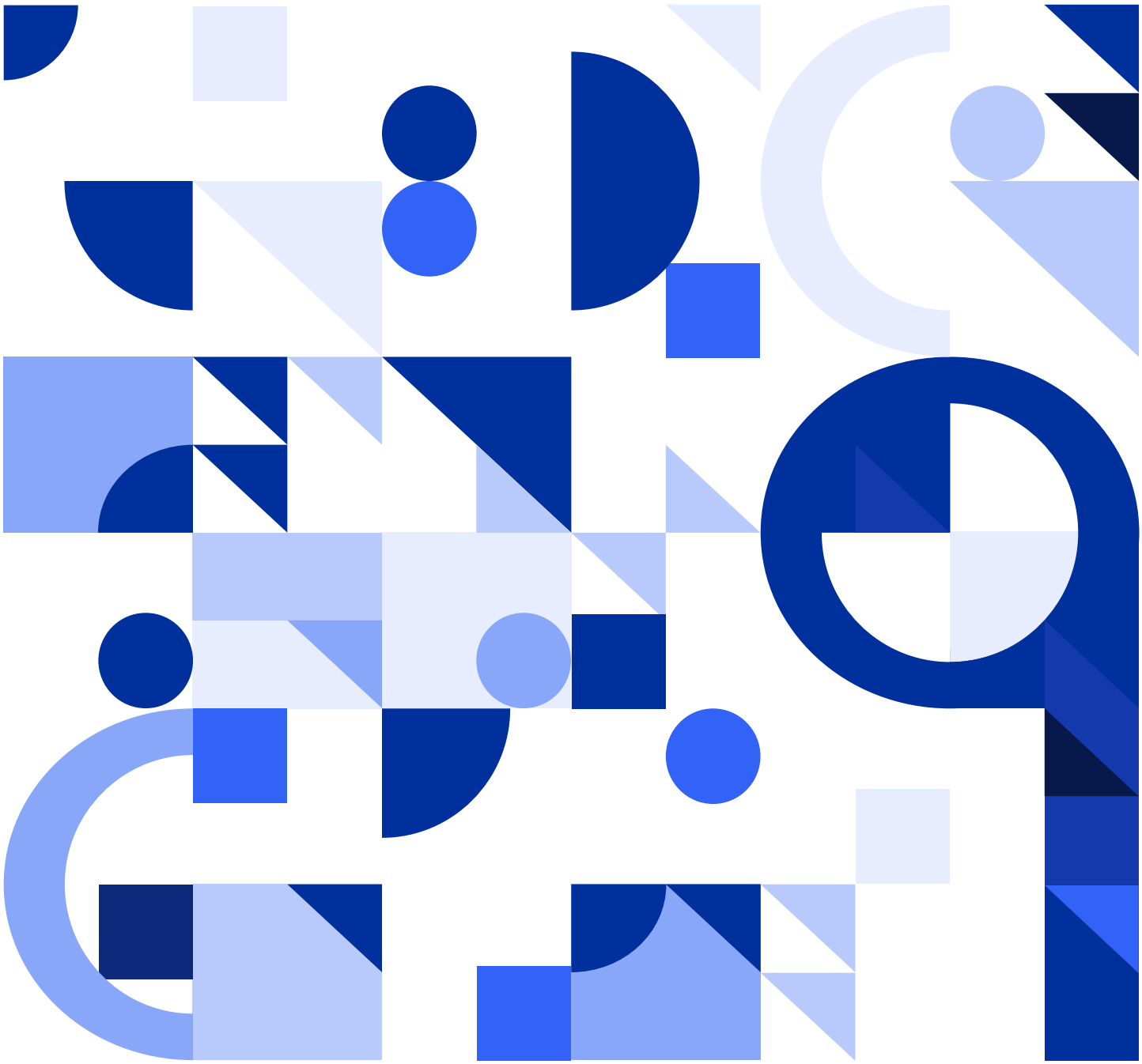
Monitor 09

DescLAB

MUCH MORE THAN EUTHANASIA:

The evolution and core of the emerging right to die with dignity in Colombia



LAB Monitor is DescLAB's series of publications that seeks to broaden and deepen the knowledge available on Social, Economic, and Cultural Rights and to support litigation, advocacy, and social mobilization strategies.

DescLAB is a B corporation under Colombian law that provides high-quality services, works in the public interest, and sets rights into action.

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ABBREVIATIONS AND ACRONYMS

Abbreviation	Meaning
ALS:	Amyotrophic lateral sclerosis
ATE:	Adecuacy of therapeutic effort
MAiD:	Medical assistance in dying
MAS:	Medically-assisted suicide
PAHO:	Pan American Health Organization
WHO:	World Health Organization

INTRO-
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Introduction

Introduction

Death is familiar and inseparable from the life experience of all human beings. Beliefs, fears, doubts, anxiety, anguish, and all kinds of positive and negative emotions are intertwined with it. For some people, it is better not to think about it; for others, it is a daily thought. Our attitudes toward the end of life and death vary according to our beliefs, the moment we are in, our health condition, and many other elements.

Life and its protection have been at the forefront of national and international legal protections throughout history, but we have been less concerned with its end. At **DescLAB**, we believe that what happens at the end of life, including the specific moment of death, is an issue that must be addressed through the lens of human rights. We believe that at this crucial moment, dignity, autonomy, and freedom must be guaranteed; that people must be protected from pain and suffering if these become incompatible with what a person considers to be a dignified life and with the kind of existence he may wish for themselves; and that society must act in solidarity when it comes to the end of life and death. That is why we are working to make the right to die a reality.

The essential core of the right to die with dignity entails that the end of life and death should be in accordance with each person's wishes and sense of dignity and autonomy and that no one should be forced to live or die in conditions contrary to their will and idea of a dignified life. This right also includes the possibility of obtaining medical assistance to have access to a **safe, supported, and protected death at the desired time.**

The right to die with dignity is multidimensional, and it includes several mechanisms for its realization, which provide different options for people to choose from according to their desires and possibilities. In the Colombian case, there are four legal mechanisms. First, **palliative care** integrates various medical and support services aimed at improving the quality of life of the person and their family, which includes the relief of suffering and other symptoms, and which must take into account not only physical but also psychopathological, emotional, social and spiritual aspects.[1]

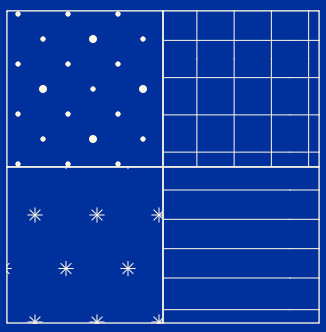
Second, the **adequacy of the therapeutic effort (ATE)** allows refusal, withholding, or withdrawal of procedures and treatments to be consistent with therapeutic proportionality and the person's autonomous decisions, even if such decisions indirectly result in death. This category includes decisions regarding life-sustaining measures such as mechanical ventilation and do-not-resuscitate orders.[2]

Third, **euthanasia** is the medical procedure by which a physician administers drugs in lethal doses to cause the person's death at the desired time at the person's request. Finally, **medically-assisted suicide (MAS)** is the assistance of a physician in providing drugs in lethal doses to cause their own death at the desired time and under medical supervision. The last two mechanisms come under the umbrella of **medical assistance in dying (MAiD)**, which is the assistance of a physician to end life at a specific time.

The right to die with dignity is an emerging human right. To make it a reality, we believe that several things are needed: first, to raise awareness of the right to die with dignity so that it can be effective on a larger scale; second, to provide simple and practical tools so that people can exercise this right; third, to guarantee and demand it directly from the Colombian healthcare system, if necessary with the intervention of judges; and fourth, to work with people and organizations, regionally and

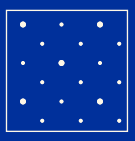
[1] Republic of Colombia (September 8, 2014). Law 1733 of 2014, art. 4; Constitutional Court of Colombia (2014). Decision C-233/14 (Justice Rapporteur: Alberto Rojas Ríos).

[2] See: (1) Pérez-Pérez, Fabio (2016). Adecuación del esfuerzo terapéutico, una estrategia al final de la vida *(Adequacy of the therapeutic effort, a strategy at the end of life).* Revista Medicina de Familia SEMERGEN. 41(8), 566 -574; (2) Ministry of Health and Social Protection (February 20, 2020). Resolution 229 of 2020, art. 5.1.1.1.1. (c) Adequacy of the therapeutic effort.



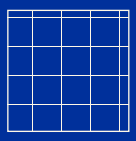
RIGHT TO DIE WITH DIGNITY

Making decisions in the end-of-life



Mechanism 1

PALLIATIVE CARE

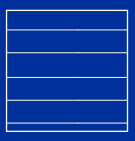


Mechanism 2

ADEQUACY OF THERAPEUTIC EFFORT

Mechanism 3

EUTHANASIA



Mechanism 4

MEDICALLY ASSITED SUICIDE

MEDICAL ASSISTANCE IN DYING

worldwide, using the case of the Colombian experience to advocate for the recognition and fulfillment of such a right.

Over the years, we have learned that the emergency room is the worst place to face end-of-life questions and make decisions about a dignified death. That is why, in 2017, we launched our strategy **#TakeControl.**[3] We knew that the right to die with dignity was an essential asset in Colombia's constitutional precedent and that there had been considerable legal progress but limited practical action. Therefore, we began to raise awareness about the right to die and educate people to remove its association with old age, aging, and illness. To this end, we decided to associate it with youth, adulthood, good health, and human rights.

It was not long until we realized that it was not enough to talk about death with dignity—we had to take action to help people learn about this right. In this sense, we recognize that there is an ethical dimension to the exercise of law and access to justice when we talk about dying with dignity: people need information and legal assistance in the most critical moments of their lives or those of their loved ones, and this means that they usually do not have the time or energy to invest in searching for lawyers or information, drafting legal documents and filing them. Legal knowledge must not be an obstacle; on the contrary, it must be quickly and widely available to those who need it.

For this reason, **DescLAB**, with limited time and human resources, created a set of ready-to-use, understandable, and easily adaptable handouts so that people could save time and effort to exercise their right to die with dignity. We also created and widely distributed a roadmap to clarify an otherwise confusing process scattered across multiple decisions.

Our strategic bet is not placed on medical emergencies but on social change. From the beginning, we have focused our efforts on bringing the issue of the right to die and its mechanisms to the dinner table; we are convinced that if it is addressed directly within families, if we know what those around us think about the end of life, and if we approach the issue of death in a simple, loving and everyday way, the exercise and guarantee of the right to die with dignity will be more accessible when it is needed.

Then came the time for impact litigation. Without looking for it, we began to receive complex cases from people who needed help and legal assistance at the end of their lives. At **DescLAB**, we have represented some cases that have allowed us to advance and consolidate the right to die with dignity in Colombia and Latin America.

As will be repeated throughout this publication, the right to die with dignity is an emerging human right, which means it is new and fragile. It is often attacked by the most conservative sectors who seek to misinform society. It is usually overshadowed by prejudices and preconceptions in families, the medical community, lawyers, and culture. In this sense, we make visible a series of obstacles and difficulties that judges face, hoping that this will strengthen the right to die with dignity.

From the beginning, we knew that activism and social mobilization around death and end-of-life decisions should be supported by strategies to generate practical knowledge to inform decision-making and monitor government actions. Therefore, since 2020, we have been producing information and knowledge about the right to die with dignity in Colombia and its legal developments,[4] collecting a considerable body of data that reflects access, gaps, and barriers.[5] In this regard, the present publication builds on previous publications, updating them and renewing some reflections.

[3] #TakeControl is DescLAB's digital strategy on death with dignity and can be accessed at https://www.desclab.com/tomaelcontrol.

[4] Correa-Montoya, Lucas (2020). Muerte digna en Colombia. Activismo judicial, cambio social y discusiones constitucionales sobre un derecho emergente (*Death with dignity in Colombia. Judicial activism, social change, and constitutional discussions on an emerging right).* DescLAB.

[5] See: (1) Correa-Montoya, Lucas and Jaramillo-Salazar, Camila (2021). De muerte lenta #1. Informe sobre las cifras y las barreras para ejercer el derecho a morir dignamente en Colombia (*Slow Death #1. Report on the data and barriers to exercise the right to die with dignity in Colombia).* DescLAB; (2) Correa-Montoya, Lucas and Jaramillo-Salazar, Camila (2022). De muerte lenta #2. Cifras, barreras y logros sobre el derecho a morir dignamente en Colombia *(Slow Death #2. Report on the data, barriers and achievements to exercise the right to die with dignity in Colombia).* DescLAB.

An emerging human right regarding death and longevity?

The Universal Declaration of Emerging Human Rights[6], a valuable document for international discussion that is not legally binding, establishes that all human beings, whether citizens or not of a particular state, have more rights than those recognized at any given moment in national or international legal systems. Identifying that human rights emerge in different ways, with non-state actors involved, and in response to various social demands, derives from understanding these universal and constitutional guarantees not as a static spatio-temporal appropriation,[7] but as an ethical catalog on which to transform the present and, in the words of Julios-Campuzano, as the foundations of a more hopeful future.[8]

The question of emerging human rights revolves around the search for new legal categories that entail a reinvention and reinterpretation of the values that inspire, represent, and materialize the United Nations Universal System for the Protection of Human Rights and all other regional human rights systems. It is also a question about the nature of human rights and its emancipatory, critical, and transformative dimensions.[9] This leads us to understand the catalog of rights as a finished result capable of adequately responding to all the needs, some old and some new, that we face daily. In this sense, it is an inquiry concerning the invisible needs of oppressed populations and the current social transformations that give rise to new challenges and, therefore, new rights. From this point of view, the problem of emerging human rights is connected with issues such as poverty, corruption, underdevelopment, climate change, nuclear and biological threats, technological innovations, migration and population displacement, discrimination, globalization and transnationalism, and the longevity of the population, among others.[10]

However, this emerging process involves something more comprehensive than the simple traditional mechanisms of rights creation. As the Declaration of Emerging Human Rights establishes, new rights emerge beyond

Photo by: Ron Szalata

[6] Institute of Human Rights of Catalonia (2009). Universal Declaration of Emerging Human Rights. IHRC.

[7] Julios- Campuzano, Alfonso de (2002). La globalización y la crisis paradigmática de los derechos humanos *(Globalization and the paradigmatic crisis of human rights).* Revista de Estudios Politicos, 116, 189-218.

[8] Ibid., p. 213.

[9] Ibid., p. 204.

[10] Institute of Human Rights of Catalonia, (2009). Universal Declaration of Emerging Human Rights. IHRC.

formalities. It goes beyond the debate monopolized by states in international human rights law since it acknowledges that other non-state actors, such as civil society and domestic actors, can catalyze this emergence.[11] Thus, the Declaration seeks to contribute to the well-being and formation of a new horizon of rights that may help guide social movements.[12]

The Declaration defines the right to die with dignity as the right not to prolong life artificially and to respect the person's will expressed in a living will or a similar document.[13] This is a rather timid and conservative approach, referring to the possibility of expressing one's will in advance but without indicating the content of such expressions, which are simultaneously at the center of the right to die with dignity. It only addresses the possibility of refusing or modifying medical interventions not to prolong life (ATE). Still, it does not directly mention practical medical assistance to end a person's life (MAiD) or access to palliative care.

Within the Inter-American Human Rights System, the recent Convention on the Rights of Older Persons[14] incorporates access to palliative care[15] within the right to health[16] and tangentially mentions the possibility of refusing, withholding, and withdrawing assistance measures within the framework of the right to life, without ever recognizing the right to die with dignity as an independent human right. Within the right to health of older people, the Convention establishes that palliative care should be included in the intersectoral health policies to be adopted but does not establish anything detailed about the mechanisms to die with dignity.

However, beyond the traditional right to health, which in this case is recognized for a traditionally invisible group such as older people, there is an emerging right for this same group and for the population in general: to provide free, informed, and unequivocal consent in the field of health.[17] This is not an entirely new right since its contents have been recognized within the framework of the right to health, autonomy, and physical integrity. Still, in this treaty, it emerges as an independent category. It refers to the right of older persons "to accept, refuse or voluntarily discontinue medical or surgical treatment [...] the older person may expressly state their advance wishes and instructions regarding health care interventions, including palliative care. In such cases, this advance directive may be expressed, modified, or extended at any time by the older person alone, through legally binding instruments, following national legislation."[18]

Finally, this Convention addresses death tangentially and links it to the right to life. Although there is no mention of the right to die with dignity, the treaty does refer to preserving dignity until the moment of death. It is from here that the obligation is derived that states take measures "so that public and private institutions offer the older person non-discriminatory access to comprehensive care, including palliative care, avoid isolation and appropriately manage problems related to the fear of death of the terminally ill, pain, and avoid unnecessary suffering and futile and useless interventions, in accordance with the right of the older person to express informed consent."[19]

The Convention on the Rights of Older Persons in the Interamerican System reflects the current state of affairs regarding the right to die with dignity on the continent, with few prospects for the future. It mentions palliative care within the right to health, addresses care in old age and respects the possibility of giving consent for ATE. However, it has yet to develop the most relevant and advanced mechanisms related to MAiD.

Similarly, the right to die with dignity does not exist in the Universal Declaration of Human Rights, an instrument of the Universal System that includes the right to life,[20] protects it in its private sphere from arbitrary

[11] Ibid., p. 42.

[12] Ibid., p. 40.

[13] Ibid., art.1(7).

[14] Organization of American States (2015). Inter-American Convention on the Protection of the Human Rights of Older Persons.

[15] Ibid., art. 2.

[16] Ibid., art. 19.

[17] Ibid., art. 11.

[18] Ibid.

[19] Ibid.

[20] General Assembly of the United Nations (1948). Universal Declaration of Human Rights, 217 A (III), art. 3.

The question of emerging human rights revolves around the search for new legal categories that entail a reinvention and reinterpretation of the values that inspire, represent, and materialize the human rights

interference,[21] and elaborates on the idea of the right to live with adequate levels of well-being,[22] without referring in any way to death. In the Interamerican System, the protection of the right to life follows the same pattern.[23]

The International Covenant on Civil and Political Rights also does not include any mention of the right to die with dignity. However, it does regulate the right to life with greater emphasis, particularly by prohibiting arbitrary deprivation of life and by referring in some detail to the death penalty.[24] This instrument does not mention the end of life or death as an issue upon which a person can make decisions.

Similarly, the International Covenant on Economic, Social, and Cultural Rights develops the right to an adequate standard of living[25] in which the conditions of existence are progressively improved. Food, clothing, and housing are relevant when addressing this right. However, there is no hint of the end of life or a dignified death as related concepts. In the Interamerican System, the Protocol of San Salvador incorporates the right to social security,[26] an idea related to guaranteeing a decent and dignified life, without linking it directly to the end of life or death.

Thus, core human rights treaties, both in the Universal and Inter-American systems, show little interest in addressing the end of life and death as a human rights issue, mainly because of the generalized idea that human rights should protect life as a biological reality and punish its violation or lack of protection by the states. **The idea of a dignified life is presented tangentially, more related to improving living conditions than to the type of life each person judges as valuable or to the end of life itself.**

In contrast to this brief international overview, Colombia's current status of the right to die with dignity constitutes a real advance in its emergence as a domestically recognized human right, whose core obligations and mechanisms will be detailed throughout this publication. It has gone through a process in which the central actor has been the judiciary, namely the Constitutional Court of Colombia. Through its activist and rights-creating work, it has led this process, usually on its own, with an absent legislative branch and an executive power that is often limited to complying with the judicial orders, usually not going forward, and frequently creating barriers and hindering the practical realization of this right.[27]

The emergence of the right to die with dignity reflects a process of social change in which regulatory evolution and the consolidation of new rights are only part of a much more complex and unfinished issue. But death is not a novel situation that justifies the emergence of a new right; **it is its intersection with the certainly current matter of longevity** that, together with advances in health technologies, has made it possible to ask questions about the kind of life we want to live and to make decisions regarding life and death, thus catalyzing the social transformation that justifies a new normative category.

Nowadays, we live longer lives and have access to better and more sophisticated health services that allow us to know more about our health conditions, opening the possibility of deciding not to extend our biological life and even choosing when and how to die. The emergence of the right to die with dignity allows us to reinterpret and challenge the well-established idea that life is a treasure or sacred gift that must always be lived to the fullest and that its termination must come from natural causes and not by an autonomous decision nor with the assistance of the health care system.

Now, the problem is not just having the possibility of receiving palliative care or deciding in advance and hoping that the end will come without much suffering; the real problem is that of making the principles of human dignity, autonomy, freedom, protection against torture, and solidarity a reality. These should not only have a place in the legal system: since social transformation

[21] Ibid., art. 12.

[22] Ibid., art. 25.

[23] Organization of American States (1969). American Convention on Human Rights, arts. 4 and 11.

[24] United Nations General Assembly (1966). International Covenant on Civil and Political Rights, art. 6.

[25] United Nations General Assembly (1966). International Covenant on Economic, Social and Cultural Rights, art. 11.

[26] Organization of American States (1999). Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, art. 9.

[27] The emergence of the right to die with dignity in Colombia will be discussed in detail in the following chapter.

must go beyond mere legality, it is necessary to make a place for such principles in the training of health professionals, in their relations with patients, and in the health care system, particularly in the clinics, because it is there where the right to die with dignity comes to life, either to present all the barriers and unimaginable obstacles or to offer a friendly, informed, supported, and expeditious service, necessary characteristics for protecting human rights at the end of life.

Taking control over one's end of life as a process of social change has both a personal and a familial side. It involves an intimate decision about death and a personal reflection on the past, present, and future, in which people must have sufficient information and the tools to anticipate the decisions to be made and to choose, according to their wishes, when necessary. It is also a family matter, which is why personal decisions should be brought to the dinner table, naturalized, normalized, demystified, and shared with the people closest to us since, in critical cases, they are the ones who will help us realize the right to die with dignity. When people have not previously reflected on their choices or when the family is not sufficiently informed, the guarantee of the right to die with dignity becomes difficult since emergencies and hasty decisions hardly catalyze the protection of this right.

Social change regarding a dignified death occurs within the framework of narratives in the life/death dyad. Decisions about dignified death are usually considered as something taking place in the face of illness, advanced age, and apparent proximity to death. This is a mistake because it makes people think that they have a long time to decide until it is too late to be able to do so. Therefore, end-of-life decisions should be considered within the realities of youth, adulthood, good health, or apparent distance from death: taking control and raising the issue at the dinner table is easier. In this sense, it is necessary to modify the place of this right within these narratives and position them in strategic scenarios to support the social transformations required for its materialization.

For decades, the right to die with dignity in Colombia was not the result of a planned strategy for social change but the result of a spontaneous, uncoordinated process in which the **judiciary,** and particularly the Colombian Constitutional Court, has played a dominant role. The **legislative branch,** despite multiple attempts to discuss a bill on the matter and numerous exhortations from judges to do so, has been unable to fulfill its task, and has remained anchored in anodyne discussions on biological life that paralyze its work. The **executive branch,** for its part, has been slow to act, and rather than being proactive and taking action in response to the emergence of the law, it has acted reactively and complied reluctantly with the judge's orders, making use of unjustified delays and creating un lawful barriers that violate rights. Finally, **civil society**—made up of a few organizations working on the issue and an equal number of medical schools and health institutions—has mobilized judicially in a limited way, often following the work of judges, which means that there has been no strategy to catalyze social change through judicial activism. Their role has been focused on education and raising awareness of the issue. With the arrival of **DescLAB** in 2017, this began to change, and impact litigation and the transformation of imaginaries in the media became more common.

The figures of death with dignity

The approval of the right to die with dignity is high in Colombia. According to the latest results of *Colombia Opina* by *Invamer*,[28] 70.1% of people in the country agree with the possibility of accessing euthanasia in cases of physical and psychological suffering as a result of bodily injuries and serious and incurable diseases. The highest point of support was registered in August 2021 with 72.5%,[29] and the lowest in February 2022 with 68.5%.[30] Favorability ratings were higher in capital cities (74.9%) than in non-capital cities (64.4%).[31]

According to the results of the *Polimétrica* Survey[32] by *Cifras y Conceptos*, only 19% of the Colombian population want a total ban on euthanasia, while 38% are

[28] See: Invamer (2022). Colombia Opina number 13, June 2022.

[29] See: Invamer (2022). Colombia Opina number 11, April 2022.

[30] Ibid.

[31] Ibid.

[32] See: Cifras y Conceptos (2021). Polymetric Survey, September 2021.

in favor of full legalization, and 37% remain neutral on the issue.[33]

This high level of approval for euthanasia contrasts with the low levels of approval for other issues that generate similarly intense debate in Colombian society, namely same-sex marriage with 39.3% approval, same-sex adoption with 29.7% approval, and legalization of marijuana with 29.7% approval.[34]

The high level of acceptance of death with dignity in Colombia can be explained by the positive positioning of cases in the media, which in recent years has made it possible to bring people closer to the most intimate and complex decisions about the end of life and death.

Media exposure, intersecting with our own and our families' life experiences, has not only brought the issue of end-of-life decisions to the dinner table but also to the forefront of societal dialogue. This approach has been characterized by communicating positive messages and images of autonomy and dignity rather than negative notions of pity, pain, dependence, and deteriorating health. It has generated conversations about what we think and want for ourselves in these situations, making us all part of a larger movement.

From 2015, the year the Ministry of Health regulated euthanasia and its registration officially began, until December 31, 2023, the Colombian healthcare system has performed **692 euthanasia procedures**.[35]

These are only the official figures, which include cases performed according to regulations and within the healthcare system. Although the public healthcare system covers euthanasia and is free of charge, many people, professionals, and organizations continue to perform it privately. It is impossible to estimate how many of these procedures are carried out at home, with the help of families and physicians who charge for them, and where there is no control by specialized committees.

As of today, 2023 is the year with the highest number of euthanasia procedures carried out in Colombia. The number of euthanasias performed in the country last

[33] Ibid.

[34] See: Invamer (2022). Colombia Opina number 13, June 2022.

[35] Ministry of Health and Social Protection of Colombia (2024). Report of figures and data on dignified death (cutoff as of December 31, 2023). This is a response of May 23, 2024, obtained from a petition filed on February 14, 2023, a *tutela* action filed on March 11, 2024, and a motion for contempt requested on April 10, 2024.

Photo by: Liu

year was 271, with an average of 22.6 procedures per month.[36] Compared to 2015, when only four procedures were carried out, this is a high number.[37] **This means that the practice of euthanasia has multiplied by 67 in nine years**, a significant figure that shows that, over time, the issue remains well positioned in the media and in public opinion. It also underscores the importance of family conversations about the issue, as they play a crucial role in shared decision-making and fostering greater interest in making autonomous decisions about the end of their lives.

As of December 31, 2023, 366 men (52.9%) and 325 women (47.1%) exercised their right to die with dignity through euthanasia. In 2022, for the first time, a procedure was registered for a transgender person. No cases of intersex persons were registered.[38]

During the same period, the practice of euthanasia was concentrated in two places of Colombia (Antioquia and Bogotá, the capital of Colombia). In Antioquia, 294 cases were registered, representing 43.1% of the total, and in Bogotá, 285 cases were registered, representing 41.2%.[39] Together, these two regions account for 84.3% of the procedures carried out in the country.

Since 2017, euthanasia can be practiced on minors by order of the Constitutional Court through Decision T-544 of 2017 and according to the criteria established in Resolution 825 of 2018 of the Ministry of Health. Only two cases were registered on minors under 18 years old); the rest were practiced on adults.[40]

According to the most recent reports of the Ministry of Health, the average age of those who have requested euthanasia is 62.5 years old. Therefore, it is an action carried out on older people who are not of advanced age. Comparing this figure with the Colombian life expectancy, 77.5 years in 2023,[42] the average age of access to MAiD is 15 years lower.

In Colombia, cancer is the primary type of medical condition for which people request MAiD through euthanasia. Currently, 76% of the procedures (526 cases) were performed on people who had cancer as their primary diagnosis.[43] In contrast, only 24% (166 cases) were for non-cancer-related illnesses.[44]

Early end-of-life decision-making through advance directives remains low. As of December 31, 2023, of the 692 individuals who accessed MAiD through euthanasia, only 42.5% (294 persons) had completed an advance directive, while the remaining 57.5% (398 persons) had not done so.[45] Due to the absence of a comprehensive registry for advance directives and the failure to implement digital and interoperable medical records, we can only determine how many individuals have advance directives if they have already sought euthanasia.

Objectives and structure of this text

This publication has four objectives which are pursued in three chapters. First, it synthesizes and describes the emergence of the right to die with dignity in Colombia, analyzing how it was born, how it has evolved, and how it has been consolidated in recent decades, proposing a genealogy of the process that allows us to understand and communicate it. Second, it reflects on the law as an instrument of social change: it uses the path of the emergence and evolution of the right to die with dignity as a successful case—despite its difficulties and limitations. These two objectives are developed in the first chapter.

Third, the publication examines Colombia's current state of the right to die with dignity. It explains its legal nature and core obligations and discusses the mechanisms available to exercise it and the criteria that must be met to access them. The second chapter develops this objective.

Finally, in the conclusion of the text, it identifies the challenges that we will face in the future, not only in Colombia but also in Latin America, when it comes to the right to die with dignity, that is, the recognition, expansion, and deepening of the possibility of making free and autonomous decisions about the end of life.

[36] Ibid.
[37] Ibid.
[38] Ibid.
[39] Ibid.
[40] Ibid.
[41] Ibid.
[42] Pan American Health Organization (2023). Health in the Americas. Country Profile, Colombia.
[43] Ibid.
[44] Ibid.
[45] Ibid.

Chapter I

From the judicial authorities to the hospital.

The emergence of the right to die with dignity in Colombia

The emergence of the right to die with dignity in Colombia began in 1993. In 1991, the country had a new Constitution, and in 1992, a Constitutional Court and the *tutela* lawsuit[46]—both institutions created by the new Constitution. Without these two constitutional innovations, this process would not have begun or consolidated as it has been doing for three decades.

As Saffon-Sanín and García Villegas have described, both the constitutional text and the Court's early years were marked by a profound aspirational spirit.[47] This moment was characterized by the conviction that constitutional law could be a source of social change and that its contents were actual rights and not just political affirmations or programmatic desires that Congress and the government had to materialize over the years. This aspirational spirit has played a crucial role in the emergence and consolidation of the right to die with dignity, which continues 30 years later, filling it with energy for mobilization, advocacy, impact litigation, and the change of social imaginaries.

Characteristics of the emerging process of the right to die with dignity

The emergence of the right to die with dignity in Colombia has **five characteristics**. First, it has been **a process of social change led by the judicial authorities**, who have managed to create, position, and slowly develop a new constitutional right. It has also had a significant element of chance, in which cases scattered throughout the local judicial authorities, without a high-impact strategy, have reached the highest constitutional authority and found open and liberal judges capable of advancing it slowly but decisively.

The debate has not necessarily been peaceful. Within the Constitutional Court of Colombia, the emergence of the right to die with dignity has had to fight against the most conservative positions, which have been vehemently opposed.

This is a process of judicial activism in which judges have catalyzed social change in the face of the end of life and death. According to Rodríguez-Garavito and Rodríguez-Franco,[48] new rights have been recognized, others are being implemented, structural flaws are being transformed and corrected, and violations of constitutional rights are being repaired. At the same time, it mandates the creation of specific norms, policies, plans, and programs from the judicial branch that other branches of government must carry out. This role of the judiciary is very different from what is traditionally expected: resolving conflicts by interpreting the law–a reduced, limited, and predictable task–.

To date, 15 Constitutional Court decisions, 11 *tutela* decisions, and four constitutional review decisions have created, positioned, developed, broadened, and deepened the right to die with dignity in Colombia.

The second characteristic is that **it is a right created without the legislator's help**. Despite the orders given by the judiciary to legislate on this matter and the multiple attempts to discuss a bill addressing it, Congress still needs to fulfill its legislative configuration task. Legislators excuse themselves under the right to life and its inviolability in the Colombian legal system to deny the existence of the fundamental right to die with dignity, prevent its comprehensive legislation, and allow the barriers that hinder its realization to remain untackled. Frequently, the legislative debate suggests focusing on palliative care (strengthening and massifying it) rather than developing other in-depth mechanisms of such right.

Paradoxically, the absence of the legislative branch has been an excellent opportunity for the emergence of the right to die with dignity. Congress's inaction has meant that discussions on this right have not been hindered by the polarized debates of electoral politics, in which it could have run the risk of not emerging, not consolidating, or even disappearing. This entails a

[46] The *tutela* is an expeditious judicial mechanism created by the Political Constitution of 1991 that allows individuals to directly protect their fundamental rights in the face of threats and violations by the State and private parties in charge of providing public services.

[47] Saffon-Sanín, María Paula and García-Villegas, Mauricio (2011). Derechos sociales y activismo judicial. La dimensión fáctica del activismo judicial en derechos sociales en Colombia (*Social rights and judicial activism. The factual dimension of judicial activism in social rights in Colombia).* Revista Estudios Socio-Jurídicos, 13(1), p. 79.

[48] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South).* Buenos Aires, Siglo XXI Editores.

GENEALOGY OF THE RIGHT TO DIE WITH DIGNITY

- ▲ Decision
- ■ Resolution
- ★ Law
- ⦿ Bill

FIRST MOMENT 1
1993 - 1997

The unplanned emergence of the right to die with dignity

SECOND MOMENT 2
1997 - 2014

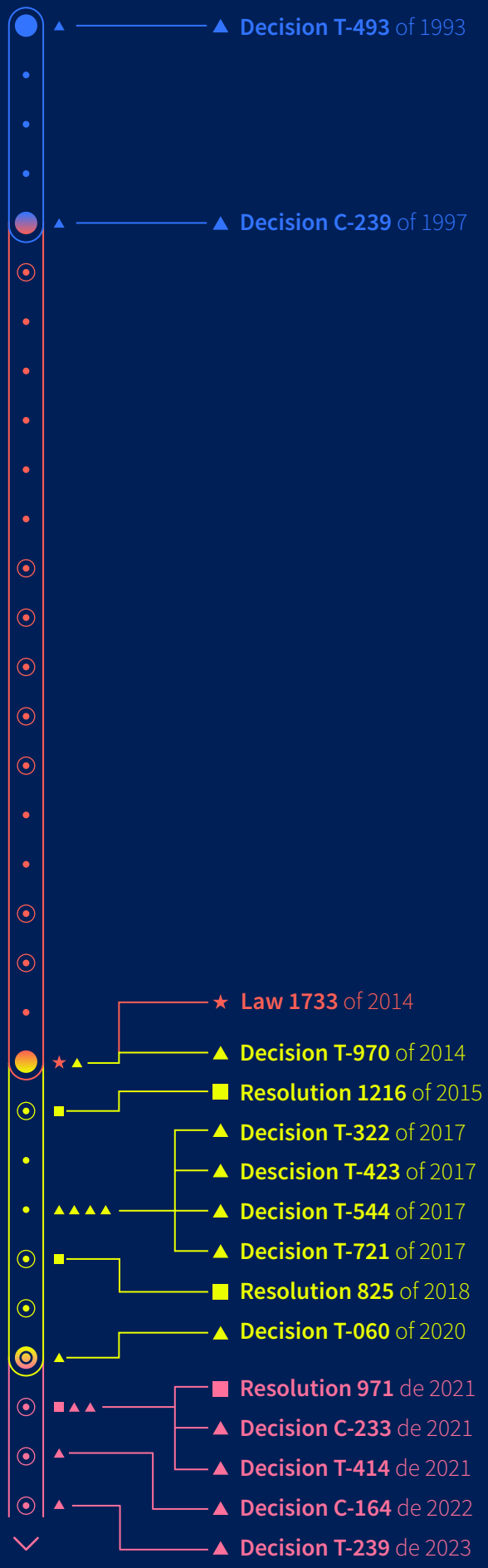
Judicial latency and legislative blockage

THIRD MOMENT 3
2014 - 2020

The fast-paced development and implementation

FOURTH MOMENT 4
2020 - PRESENT

Impact litigation to overcome barriers and expand the right to die with dignity



counter-majoritarian difficulty since the discussion has not taken place in democratic forums in which people are directly represented.

This difficulty is paradoxical since the acceptance rates of the right to die with dignity, particularly MAiD, are high, as already established in the introduction. The exercise of democracy is, therefore, precarious since elected representatives do not comply with court orders, do not carry out their work of public discussion on people's rights, and are not aligned with public opinion or the preferences of the majority. Democratic representation is, therefore, prey to conservative minority interests masquerading as the majority.

To this day, the only contribution of the legislative branch has been a general palliative care law[49] that offers some valuable definitions but needs more effective provisions to massively increase its supply and improve access, timeliness, and quality to such mechanisms of the right to die.

Since 1998 and to date, Congress has attempted on 19 occasions to debate and approve a bill on the right to die with dignity. Generally, the bills did not have a debate or did not pass the first of the four required debates. Rarely have bills have had more than two debates.

The third characteristic is that **the right has been created with the timid action of the executive**. The executive branch has yet to play an active role regarding the right to die with dignity. Its part has been reactive and subsidiary to fulfilling judicial orders to realize it.

Up to now, the responsibility for regulating the process and procedures related to this right has fallen on the Ministry of Health, which has carried it out slowly, incompletely, and frequently, creating unnecessary barriers that are inconsistent with the mandates of the constitutional precedent on the matter. At the same time, this Ministry and the National Superintendence of Health (the entity in charge of overseeing and supervising the provision of health services in Colombia) have been distracted from playing a leading role in monitoring the health care system and transforming the daily practices that materialize or hinder the effective enjoyment of the Colombian people's right to die with dignity. Six Ministry resolutions and a Superintendence guideline constitute the regulations available on the matter.

The fourth characteristic is that **this right has been created without a strategic social movement**. Social organizations, scientific societies, and universities have often been absent in the emergence of the right and the social mobilization and innovation needed to catalyze judicial activism. The social movement has been distant from what Saffon-Sanín and García-Villegas call the "broader political strategy aimed at social transformation through the materialization of social rights."[50] For decades, there has been a lack of a vibrant, creative, and coordinated social movement on this issue that would provide social, political, and legal support for the social transformation that underlies the legal one.

Organizations and social actors have focused on educational and awareness-raising efforts regarding the right to die with dignity. Changing attitudes and beliefs about the end of life and death and using advance directives are among their priorities. This critical task needs to be completed and more effectively embedded in the provision of health services.

The emergency process has not strengthened these social organizations, nor has it fostered the creation of a social movement or strategic and long-lasting alliances. In Colombia, in the judicial discussions on the right to die with dignity, a couple of organizations are dedicated to the subject, some medical and law schools of certain universities, and associations of health professionals and patients that present their technical concepts to the Constitutional Court when required.

Despite some academic debates, publications, and educational courses, these spaces are reactive and activated by significant legal developments, like new decisions of the Constitutional Court or regulations of the Ministry of Health. Academic and scientific discussions could be more fruitful, permanent, and sustained over time.

Finally, the fifth characteristic is that **it is a right appropriated by citizens thanks to the media**, which has

[49] Republic of Colombia (September 8, 2014). Law 1733 of 2014.

[50] Saffon-Sanín, María Paula and García-Villegas, Mauricio (2011). Derechos sociales y activismo judicial. La dimensión fáctica del activismo judicial en derechos sociales en Colombia *(Social rights and judicial activism. The factual dimension of judicial activism in social rights in Colombia).* Revista Estudios Socio-Jurídicos, 13(1), p. 85.

created awareness and empowerment about the right to die with dignity and end-of-life decisions.

Along with the judicial developments achieved by the Constitutional Court in the last three decades, journalists and the media have carried out their informative and opinion-forming work responsibly and effectively to generate recognition and empathy within Colombian society when it comes to the right to die, giving voice and face to real people who have shared their cases and intimate struggles, many of them painful, all courageous and determined.

Given Colombia's privileged position, these local cases have been widely disseminated in the Americas and worldwide. Journalists and the media have massively covered landmark judicial decisions made by the judges, reporting the figures and the evolution of access to the procedure and highlighting individuals' barriers and difficulties. Thus, by giving social actors visibility and lobbying capacity, they have strengthened the advocacy actions of social actors.

Thanks to the positive and massive communication of the legal and social advances of the right to die with dignity in Colombia, the issue enjoys broad approval and support from citizens. The media have effectively contributed to creating individual, family, and collective knowledge through all these actions. This is not a small contribution because, thanks to this public communication process, people have been able to know their rights and when they can realize them. They have been able to see themselves reflected in the life stories of others, to ask themselves what they would want if they were in the same situation, to see how family and friends support such decisions, and to have conversations at the dinner table about their wishes at the end of life.

Over 30 years, the process has gone through four moments. **First**, the constitutional discussion on the right to die with dignity emerged within the constitutional precedent. **Second**, it experienced a judicial latency and a legislative blockage, in which, despite its nominal existence, it was not guaranteed, or at least not legally, within the health care system. **Third**, the right to die with dignity experienced rapid development and implementation, which meant that the right went beyond its nominal existence and opened the way for its full implementation. For the first time, it was taken seriously and invoked repeatedly, records of requests and procedures were kept, and new barriers and challenges arose within the healthcare system. **Finally**, its emerging process and impact litigation have begun implementing intentional actions to monitor and overcome obstacles.

The following sections describe each of these moments, presenting and analyzing the main decisions and relevant normative sources and detailing the legislature's attempts to debate and pass a law.

First moment: the unplanned emergence of the right to die with dignity (1993-1997)

The highest courts began legal discussions on the right to die with dignity in 1993. This first moment lasted about four years, and the only relevant actor was the judiciary, which issued two decisions on the matter.

The beginning of the process presents several paradoxes. First, even though Colombia is one of the most advanced countries in the world regarding MAiD, and namely euthanasia, the public and legal discussion did not begin there, but with ATE, specifically with the refusing, withholding, and withdrawing of medical treatments to treat cancer. Second, although the discussions are centralized in the most privileged circles, the first decision of the Constitutional Court was born from an anonymous case of a peasant woman in rural Colombia who did not belong to those elites.

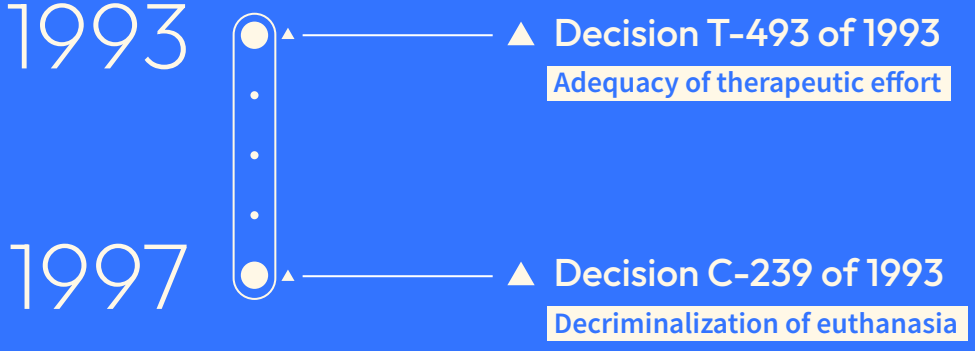
Decision T-493 of 1993[51] launched the judicial debate on the right to die with dignityh. It was a case of one of the mechanisms of the right to die, the adequacy of therapeutic effort. In this decision, the Constitutional Court of Colombia reviewed a *tutela* lawsuit that arose from the petition of her brother and the ombudsperson to order a woman to undergo the medical treatments against cancer that, according to the physicians treating her, were necessary to preserve her life. In the plaintiffs'

[51] Constitutional Court of Colombia (1993). Decision T-493/93 (Justice Rapporteur: Antonio Barrera Carbonell).

1

FIRST MOMENT
1993 - 1997

The unplanned emergence of the right to die with dignity



▲ Decision
■ Resolution
★ Law
⦿ Bill

opinion, due to her illiteracy and the alleged subjugation to her husband, the woman had decided to interrupt such treatments to treat the breast cancer, and, therefore, her right to life was in danger.

Given these arguments, the first judge decided that the judicial procedure was justified. To protect the woman's health and life, he ordered the husband to make available all the means necessary for her to have access to the health service from which the woman had withdrawn.

When the lawsuit reached the Constitutional Court, the Justices ordered an in-depth examination of the evidence. They found that both the woman's and her husband's evidence suggested that the refusal of treatment had been voluntary and without the pressure alleged by the plaintiffs. The woman stated that she had not continued with the therapies because it was uncomfortable for her to travel to the place where they were performed and because she was convinced that it would be God –according to her religious beliefs– who would decide on the future of her health.

Based on the above, the Court presented two main arguments when adopting the decision that triggered the discussion on the right to die with dignity in Colombia. On the one hand, it considered that the right to autonomy enshrined in Article 16 of the Constitution was violated. To this extent, it was established that if a person decides not to undergo medical treatment due to personal convictions, neither the State nor any private individuals can demand an obligation contrary to their own will. Otherwise, it would be privileging a worldview that allows institutions and third parties to impose their decisions over the autonomy and freedom of a person. At the same time, the Court ruled that violating the right to autonomy included violating the right to personal and family privacy enshrined in Article 15 of the Constitution. Interference in such a personal and private sphere and conduct undermines the freedom and privacy to which everyone is entitled. By attempting to force the woman to undergo specific treatments that she voluntarily refused, other parties unlawfully interfered with her privacy.

With this first case, the Court began to define the framework for decisions on dying with dignity without directly mentioning the existence of a specific fundamental right. This judicial conclusion addressed the possibility of refusing, withholding, or withdrawing medical treatment, even if this decision leads to death, without directly provoking it. The Court identified the matter as a constitutional issue relating to freedom, autonomy, and privacy, and for the first time, these issues were being addressed at the judicial level.

Three and a half years later, in **Decision C-239 of 1997**,[52] the right to die with dignity emerged in the Colombian judicial precedent. In this decision, the Constitutional Court analyzed a claim of unconstitutionality filed by a citizen against the crime of mercy killing, included in the Criminal Code.[53] The plaintiff claimed that the crime of mercy killing should not be subject to a lesser penalty than other crimes against life. From a conservative point of view, by imposing a lesser punishment for such a crime, the plaintiff argued that the legislative branch had disregarded constitutional rights and protections, including the right to life. His initial claim was that the crime of mercy killing should be declared unconstitutional, that it should be excluded from the legal system, and that such act should be punished with a higher penalty. However, the result was contrary to what was planned.

The plaintiff did not intend to catalyze a discussion on death with dignity, much less did he want the Court to go a step further and create a ground in which there would be no criminal consequence for mercy killing and, in this way, euthanasia would be decriminalized. For this reason, the emergence of the right to die with dignity is described as unplanned since it did not respond to a carefully designed strategy to achieve planned objectives but instead arose from a citizen's initiative to attack the Criminal Code, an initiative that found a place in the Court and that led to the emergence of the right in the Colombian constitutional orbit.

In Decision C-239 of 1997, unlike the previous and most of the successive decisions on the right to die with dignity, the Court did not discuss a specific case in which a constitutional right had been violated but instead carried out an abstract analysis of its constitutionality.[54] In Colombia, any citizen can challenge a legal norm

[52] Constitutional Court of Colombia (1997). Decision C-239/97 (Justice Rapporteur: Carlos Gaviria Díaz).

[53] "Mercy killing. Whoever kills another for mercy, to put an end to intense suffering resulting from bodily injury or serious and incurable illness shall be sentenced to imprisonment for six months to three years". Republic of Colombia (1980). Decree 100 of 1980, art. 326.

[54] See: (1) Republic of Colombia (1991). Political Constitution of Colombia; (2) Republic of Colombia (1992). Decree 2067 of 1991.

that, in their opinion, violates the Constitution. On this occasion, the Court declared the crime of mercy killing constitutional but created a ground for the exclusion of criminal liability. It issued a decision indicating that there would be no criminal liability when the following criteria were met: the person was duly diagnosed with a terminal illness;[55] experienced physical or psychological suffering incompatible with their idea of dignity, expressed free consent, and a medical practitioner performed the procedure.

In this decision, the Court mentioned for the first time the right to die with dignity in close relation to the right to live with dignity: "The fundamental right to live in a dignified manner entails the right to die with dignity."[56] It then went on to give it content. In this sense, it recognized that different approaches to life exist; some understand it as a sacred gift over which people have a restricted margin of decision, and others assume it as something valuable but not absolute, intimately related to autonomy and the personal life project.

The Court's analysis was based on recognizing human dignity as a supreme value that radiates other fundamental rights, including autonomy as its highest expression. In this sense, the right to life as a valuable but not sacred good entails that a person can decide whether to continue living when suffering is incompatible with one's idea of dignity.

In line with the above, the Court has determined the approach to be taken regarding cases involving dignified death in the future: a pluralistic perspective, with legal issues strictly distinguished from religious ones. People should be able to view life as sacred without imposing their values on others, as there is no constitutional obligation to maintain a biological existence. This clarification was crucial for the emergence of the right to die with dignity, as it resolved the tensions of the first decisions dealing with the case, mainly C-239 of 1997, and settled the debate between law and religious beliefs.

As Rodríguez-Garavito and Rodríguez-Franco point out, this is the effect of restructuring the framework in which certain judicial decisions define and establish the parameters within which similar situations are decided, or public problems are understood and materialized.[57] Therefore, the court has avoided being swayed by religious morality and the idea of life's sanctity being dictated by vague majorities, in allowing individuals to make specific end-of-life decisions within the framework of constitutional law and human rights.

In this same decision, the Court tangentially considered the relationship between the right to die with dignity and the principle of solidarity to highlight the non-criminal nature of the action of one who helps another to die when the established criteria are met. It also addressed the relationship between the right to die with dignity and protection against torture and ill-treatment and established that preventing a person from having access to the medical assistance necessary to end their life and thereby put an end to the suffering that afflicts them is equivalent to cruel, inhuman, and degrading treatment.

In addition to the above, the Court stated that the State has the duty to care for and protect life but that this duty is not absolute. On the contrary, there are limits to doing so, and there must be harmony between the goods and values protected by the Constitution. Thus, it declared that the protection of life is compatible with free and autonomous decisions related to the end of life and death. This powerful idea opened the door to creating the emerging right to die with dignity.

In 1997, the Court decriminalized mercy killing and, in doing so, allowed the legal practice of euthanasia when the strict criteria previously indicated were met. Regarding the actions of the person causing death, it is considered that physicians should be the ones called to do so because they are the ones who can provide the necessary information and the knowledge to ensure that the conditions are safe. Therefore, the action is

[55] In 2021, through Decision C-233/21, the Constitutional Court eliminated the terminal illness criterion and declared it sufficient to have a serious and incurable illness.

[56] Constitutional Court of Colombia (1997). Decision C-239/97 (Justice Rapporteur: Carlos Gaviria Díaz).

[57] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South).* Buenos Aires, Siglo XXI Editores, p. 26.

lawful since it is an act of solidarity in which a professional provides medical assistance to cause death to a person who has given free, informed, and unequivocal consent and suffers from a terminal illness.

Decision C-239 of 1997 is a landmark ruling:[58] a powerful statement that starts the legal, judicial, and social discussion and, at the same time, restructures the frame of reference and aims to catalyze the production of regulations on the right to die with dignity. Under the new grounds created, the criteria for exercising the right to die with dignity via euthanasia arise. The right is addressed intensely,[59] since it is in this decision that its core obligations and mechanisms are defined and specified. This decision also has the effect of restructuring the framework[60] under which the right to die with dignity will be understood and applied in the future, that is, an understanding that the right to life is not absolute and must be used in line with the rights to human dignity, autonomy, and protection against torture. Likewise, this decision attempted to generate an effect of normative production by urging Congress, for the first time, so that, within the framework of its functions and by constitutional principles, it would regulate dignified death via euthanasia.

Decision C-239 of 1997 was not free of discussion or controversy. Three of the nine justices who made up the Court expressed their dissenting opinion[61] and recorded their arguments within the decision. In the first place, the dissenting justices disagreed with the interpretation of the right to life and how the Court resolved the tension between this right and the emerging right to die with dignity. In the second place, they argued that the Court had supplanted the work of legislators by going beyond the general and abstract judgment of constitutionality and creating a new ground for excluding criminal liability for a crime.

This decision is a breakthrough in Colombia's emergence of the right to die with dignity. Thanks to this decision, the judicial authorities began the creation of judicial precedent naming the right, linking it to other constitutional rights, and establishing specific criteria for its exercise. This entailed an enormous symbolic effect[62] in the emerging process of the right since it positioned the discussion on death with dignity as a human rights issue and favored the transformation of social narratives and public opinion on euthanasia. However, its practical and direct impact[63] was much more limited, and it was not until 2014 that the right to die with dignity became operational and accessible within the healthcare system.


Photo by: Lisa Barker

[58] López-Medina, Diego (2012). El derecho de los jueces. Obligatoriedad del precedente constitucional, análisis de sentencias y líneas jurisprudenciales y teoría del derecho judicial *(The law of judges. Mandatory nature of constitutional precedent, analysis of judgments and jurisprudential lines and theory of judicial law).* Bogota, Legis and Universidad de los Andes.

[59] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South).* Buenos Aires, Siglo XXI Editores. p. 27.

[60] Ibid., p. 45.

[61] The justices who issued a dissenting opinion were José Gregorio Hernández, Vladimiro Naranjo Mesa, and Hernando Herrera Vergara.

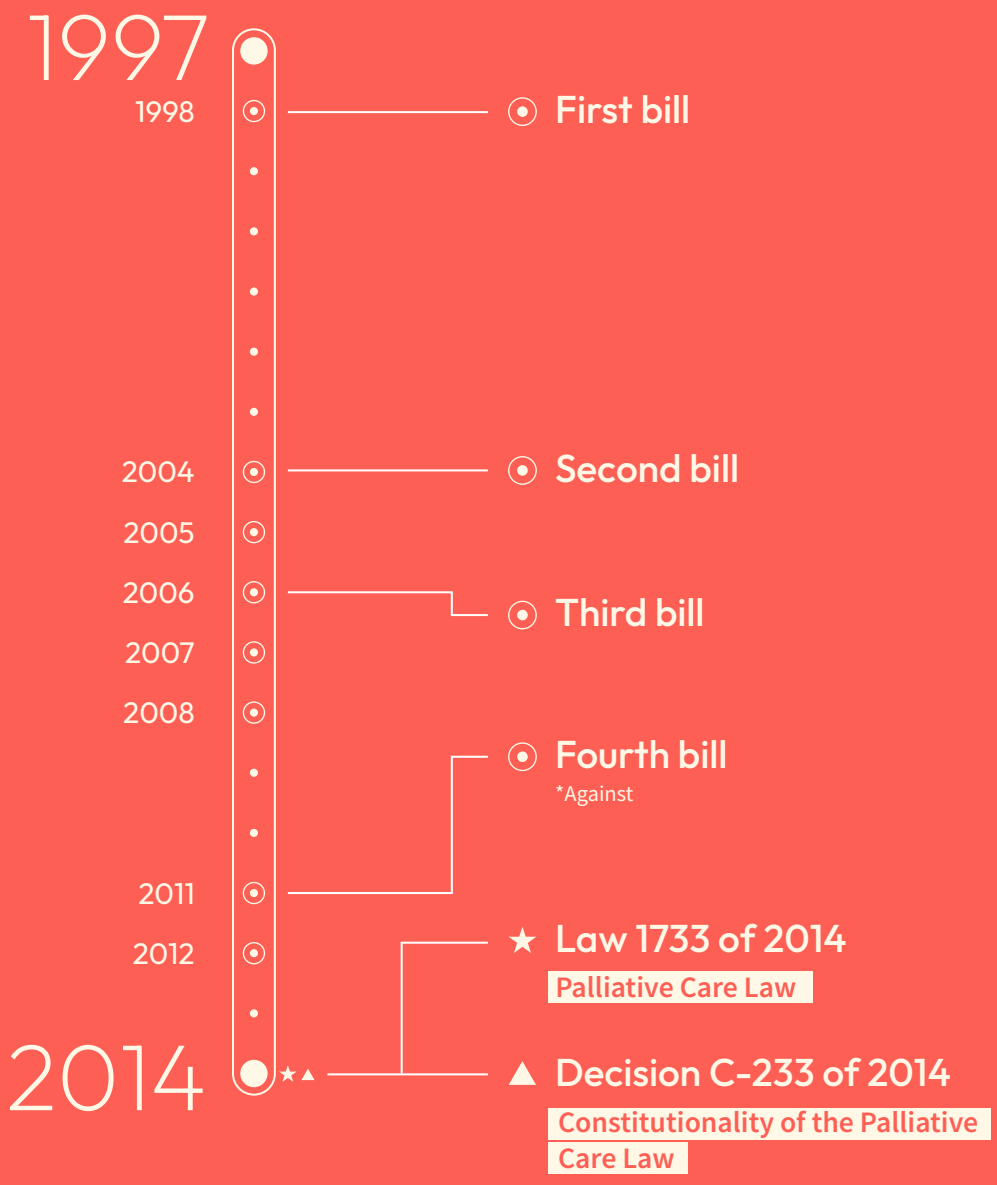
[62] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South).* Buenos Aires, Siglo XXI Editores. p. 38.

[63] Ibid., p. 38.

2

SECOND MOMENT
1997 - 2014

Judicial latency and legislative blockage



- ▲ Decision
- ■ Resolution
- ★ Law
- ⊙ 4 bills presented 9 times

As can be seen, the public and legal debate on dignified death was unplanned at the time and did not have an impact litigation strategy behind its emergence.[64] Social organizations did not actively mobilize to bring cases on dignified death before the judges or the Constitutional Court and did not design any strategy to position the issue before public opinion—nevertheless, the two judicial decisions described above catalyzed the existence of this new right.

Second moment: judicial latency and legislative blockage (1997-2014)

The second moment regarding the emergence and consolidation of the right to die with dignity in Colombia lasted from May 1997 to December 2014. It was characterized by judicial latency and legislative blockage. The Congress discussed four bills on dignified death on nine occasions without success. However, a palliative care law that did not address the right to die with dignity was adopted, and a judical decision upheld the constitutionality of the law.

In Decision C-239 of 1997, the question of implementing euthanasia was not addressed or resolved. Physicians were placed in a difficult position: they had to verify the criteria set by the Court and could provide adequate assistance in dying; however, nothing shielded them from possible criminal prosecution, in which they had to prove that the procedure had indeed complied with the Court's criteria. This made euthanasia cumbersome within the Colombian healthcare system.

The enormous public, media, academic, and political commotion generated by this decision did not translate into more people requesting euthanasia procedures, nor did it result in people seeking protection in cases where they were denied the procedure within the healthcare system. The emergence of the fundamental right to die with dignity in the highest judicial authorities remained anchored in the legal, medical, and media elites. The creation of the right was not reflected in citizens' awareness of it, nor in the practical and qualified knowledge to make it effective in a public, inclusive, and transparent way within the healthcare system. Through the testimonies of people and their struggles and the intervention of journalists and the media, it took seventeen years to raise awareness and knowledge in Colombian society.

Of course, euthanasia was carried out, as it had been for decades before the Constitutional Court decriminalized it. However, euthanasia was performed privately and with negative social, ethical, and legal implications, an issue that remains unresolved in many cases. Private procedures were only available to those who could afford them and had sufficient social networks to reach the professionals and institutions providing such services. This did not guarantee democratic access to justice but created a service reserved for those who could find and pay for it.

Private practice involves many ethical and legal risks. Since there is only one person to verify that the criteria are met, and that person is usually the one performing the procedure, there is no third-party oversight or review. The procedure is not public; it is not recorded and does not appear in the person's medical records, which is risky for those in a vulnerable situation who do not have the opportunity to express their wishes, opening the way for relatives to act against their will.

After the first moment of the right's emergence and creation, physicians and clinics had no defined role, insurance companies had no concrete obligations, and healthcare institutions were not legally obliged to provide the service. In this way, both the emerging right to die with dignity and the materialization of euthanasia remained inactive in medical and legal practices.

In light of the Constitutional Court's order, it was expected that Congress would legislate on the right through a complete and detailed law that would solve the practical challenges and create the concrete steps to make it effective, but this has yet to happen. As mentioned above, the legislature has been largely absent from the process. The few Congress members who have led the drafting and discussion of bills have only encountered blockages and obstacles in their attempts to achieve a broad, democratic, and practical debate to regulate this right in depth.

[64] Correa-Montoya, Lucas (2008). Litigio de alto impacto. Estrategias alternativas de ejercer el Derecho *(High impact litigation. Alternative strategies for practicing law).* Revista de Derecho, 30, 247-267.

Between 1997 and 2014, Congress had the opportunity to discuss **four bills presented nine times**. Only one has attempted to legislate against the fundamental right to die with dignity. The others sought to develop legislation in line with the Court's developments.

The first bill was presented to the Senate in 1998 by Germán Vargas Lleras from the Colombian Liberal Party. Unfortunately, it was rejected in less than a year due to a lack of debate. Subsequently, in 2004, a second bill was presented, this time by Senator Carlos Gaviria Díaz, who had been the Reporting Justice for Decision C-239 of 1997 and who had been elected to Congress in 2002 by a left-wing party called the *Frente Social y Político* (Social and Political Front). This proposal was also dismissed without debate.

In 2006, the third bill was introduced by Senator Armando Benedetti Villaneda of the *Partido de Unidad Nacional* (National Unity Party). This initiative went much further, seeking to regulate not only euthanasia—as the Constitutional Court had urged Congress to do in 1997—but also MAS and to establish mechanisms for evaluating and controlling procedures through the creation of a national commission. Between 2006 and 2014, the Senator presented this project five times. In 2008 and 2012, it was approved in the first debate. In 2008, the bill reached the Senate plenary and was rejected; on the other three occasions (2006, 2007, and 2014), it was dismissed without any debate.

In 2011, the first and only bill introduced sought to eliminate the right to die with dignity. It was introduced by Senator Carlos Alberto Zuluaga Díaz of the Colombian Conservative Party and members of other parties, including Senator Benedetti's National Unity Party. It was debated in the Senate committee and rejected on October 11, 2011.

During this second moment, the legislature only managed to debate and adopt **Law 1733 of 2014**[65], which refers to access to palliative care for people with terminal illnesses or chronic, degenerative, and irreversible diseases that significantly impact life quality. The law focused on the right to palliative care without mentioning the right to die with dignity.

Article 4 of the Law defines palliative care as "appropriate care for the patient with a terminal, chronic, degenerative, and irreversible illness where the control of pain and other symptoms requires, in addition to medical, social, and spiritual support, psychological and family support during illness and bereavement. Palliative care aims to achieve the best possible quality of life for the patient and family. **Palliative medicine affirms life and considers dying as a normal process. The physician will use the methods and medications at their disposal or reach if there is the hope of alleviating or curing the disease**."[66] As can be seen, the approach to such care is conservative and does not define it as part of the right to die with dignity.

This law is also timid regarding ATE. The same Article states that "[...] the physician will use the methods and medications at his disposal or reach, as long as there is hope of alleviating or curing the disease. When there is a diagnosis of brain death, it is not his [the physician's] obligation to maintain the functioning of other organs or devices by artificial means if the patient is not eligible to donate organs."[67] Thus, ATE is mentioned tangentially, subordinated to palliative care in moments of brain death, and is not recognized as a mechanism of the right to die with dignity.

Although it did not attempt to regulate the right to die with dignity, this law provided some valuable definitions that will help make it a reality in the years to come: terminally ill person and chronic, degenerative, and irreversible disease with a high impact on the quality of life. In addition to the above, it recognized some legal rights: the right to receive palliative care and information—for both the patients[68] and their families[69]—, the right to have access to a second opinion,[70] and the right to include children and adolescents in the right to receive palliative care.[71]

[65] Republic of Colombia (September 8, 2014). Law 1733 of 2014, art. 5 (1).

[66] Ibid., art. 4.

[67] Ibid., art. 4.

[68] Ibid., art. 5 (2).

[69] Ibid., art. 5 (2) and (7).

[70] Ibid., art. 5 (3).

[71] Ibid., art. 5 (6).

Despite its limitations, the right to express one's will in advance is one of the most important innovations of this law.[72] Civil society has promoted this decision for decades by signing documents such as living wills and advance directives. Even though these were made in a free and autonomous way, their content, formalization, and binding conditions for the healthcare system still needed to be legally defined. The law did not indicate that these documents could or could not be used to express one's will regarding euthanasia. In this regard, as will be discussed in more detail below, the Ministry of Health regulated the matter in detail in the following years through Resolutions 1051 of 2016 [73] and 2665 of 2018.[74]

Finally, Law 1733 of 2014 created the obligation for the healthcare system to have a comprehensive network of palliative care service providers and required the Ministry of Health to monitor it. Since the President vetoed it,[75] the content of this law was then analyzed by the Constitutional Court in **Decision C-233 of 2014**.[76] The bill was sent back to Congress and to the Court for consideration. In its decision, the Court reiterated its precedent on the right to palliative care and its relationship to the right to health and human dignity, stating that palliative care does not seek to hasten, directly cause, or postpone death and is, therefore, different from MAiD.

The Court analyzed advance directives to express the patient's will, considering only the possibility of refusing, withholding, or withdrawing treatment. In this sense, the Court avoided studying advance directives in relation to MAiD. The Court interpreted advance directives as an expression of the patient's will, considering only the possibility of refusing, withholding, or withdrawing treatments. In this sense, the Court avoided analyzing advance directives in relation to the right to die with dignity. It explicitly stated that these documents could not be used to make "anticipated termination of life" or MAiD decisions. This position changed in the future when advance directives made it possible to consent to the right to die with dignity, including not only palliative care and AET but also MAiD. Ultimately, the Court declared that the law did not address the right to die with dignity and was not subject to the statutory reserve. Therefore, the President declared it constitutional[77] and signed it into law.

The right to die with dignity underwent no significant legal or practical developments during this second moment. The symbolic effects of Decision C-239 of 1997 remained in the discussion of elite circles, lawyers, health professionals, and journalists but did not reach the citizens. Some legislators repeatedly tried to regulate the right and to address an entirely new mechanism—medically-assisted suicide—but their attempts were unsuccessful. Citizens and organizations did not mobilize to request the process before the Colombian healthcare system to strengthen the emergence and creation of the right. There were 17 years of judicial delay and legislative blockage.

Third moment: the fast-paced development and implementation (2014 - 2020)

As of 2014, the right to die with dignity emerged from judicial latency and was developed broadly and deeply, thanks to the various cases that reached the judges and were reviewed by the Constitutional Court. In these cases, people requested unregulated procedures and, as a result, encountered obstacles within the healthcare system, forcing them to use judicial mechanisms to resolve the violations of rights they faced.

As a result, the Colombian Constitutional Court established rules to make the right to die with dignity effective for both adults and minors; it required the creation of a mechanism to register procedures; it monitored and followed up on government actions; it elaborated on the criteria of psychological suffering; it allowed third parties to best interpret the will and preferences of those who could not give their consent; and it ordered some symbolic reparations. The executive power, through the Ministry of Health, was then obliged to regulate the

[72] Ibid., art. 5 (4).

[73] Ministry of Health and Social Protection of Colombia (April 1, 2016). Resolution 1051 of 2016. Repealed by Resolution 2665 of 2018.

[74] Ministry of Health and Social Protection of Colombia (June 25, 2018). Resolution 2665 of 2018.

[75] Republic of Colombia (1991). Political Constitution of Colombia, art. 167.

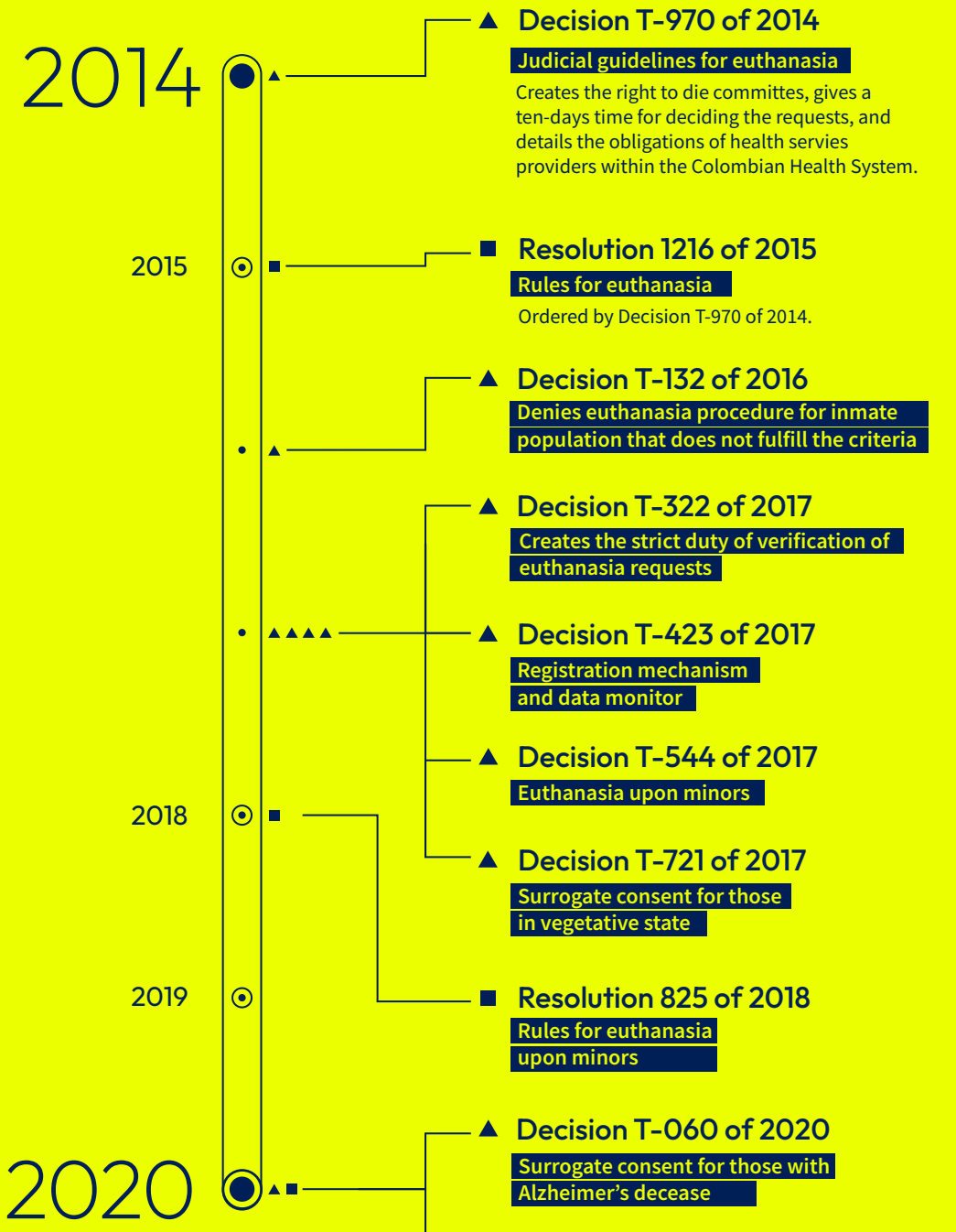
[76] Constitutional Court of Colombia (2014). Decision C-233 /14 (Justice Rapporteur: Alberto Rojas Ríos).

[77] Ibid.

3

THIRD MOMENT
2014 - 2020

The fast-paced development and implementation



▲ **Decision T-970 of 2014**
Judicial guidelines for euthanasia
Creates the right to die committes, gives a ten-days time for deciding the requests, and details the obligations of health servies providers within the Colombian Health System.

■ **Resolution 1216 of 2015**
Rules for euthanasia
Ordered by Decision T-970 of 2014.

▲ **Decision T-132 of 2016**
Denies euthanasia procedure for inmate population that does not fulfill the criteria

▲ **Decision T-322 of 2017**
Creates the strict duty of verification of euthanasia requests

▲ **Decision T-423 of 2017**
Registration mechanism and data monitor

▲ **Decision T-544 of 2017**
Euthanasia upon minors

▲ **Decision T-721 of 2017**
Surrogate consent for those in vegetative state

■ **Resolution 825 of 2018**
Rules for euthanasia upon minors

▲ **Decision T-060 of 2020**
Surrogate consent for those with Alzheimer's decease

■ **Resolution 229 of 2020**
The bill of rights and duties of patients must include information on the right to die

▲ Decision
■ Resolution
★ Law
⊙ 3 bills presented 7 times

matter following these judicial advances and to provide clear rules for the actors of the healthcare system to act and guarantee the right to die with dignity.

During this period, the media brought to light the cases and struggles of people who made autonomous decisions about the end of their lives and who encountered obstacles and difficulties in exercising their right to die with dignity. By reporting on these cases, they contributed to the positioning and positive transformation of the debate on a subject as difficult to communicate as death. For its part, the legislative branch debated several bills to regulate the issue but failed in adopting legislation on the matter.

This is the most prolific moment in legal production: seven decisions,[78] three bills debated seven times in Congress, and five resolutions issued by the Ministry of Health[79] make up the legal progress made on this issue.

After the landmark Decision C-239 of 1997, we identify Decision T-970 of 2014[80] as a second milestone that marked a new moment in Colombia's emergence of the right to die with dignity. In this decision, the Constitutional Court analyzed the case of a woman who had been living with colon cancer for five years until her health and quality of life deteriorated significantly. At first, she agreed to palliative care, but then she refused some medical procedures. Finally, she asked for MAiD through euthanasia. Her physician refused because he considered it "a homicide to which he could not consent."[81]

The insurance company within the Colombian healthcare system denied the request for the procedure because, although Decision C-239 of 1997 decriminalized mercy killing, neither Congress nor the Ministry of Health had regulated the matter. The insurance company also argued that it could not force practitioners to act against their conscience and beliefs.

In the lower court, the judge agreed with the insurance company and denied any violation. He stated that the matter had not been expressly regulated by Congress or the Ministry of Health. Therefore, the applicable norm was Article 11 of the Constitution, which establishes the inviolability of the right to life.[82]

The Constitutional Court selected the case for review. This was the first time that the Court had the opportunity to address the obstacles faced by individuals trying to exercise their right to die with dignity through euthanasia due to the lack of specific regulations on MAiD caused by the legislative deadlock that has existed since 1997. The result was Decision T-970 of 2014.

With this decision, the Colombian constitutional case law moved from the conceptual and theoretical advances achieved through Decision C-239 of 1997 to operationalizing the law and its actual application within the Colombian healthcare system.

This decision made several contributions that marked the onset of rapid development of the right to die with dignity in Colombia. First, it reaffirmed it as a fundamental right in the Constitution. Although briefly addressed in Decision C-239 of 1997, the Court finally resolved the matter in Decision T-970 of 2014. This decision gave rise to the fundamental right to die with dignity: a complex, autonomous, directly enforceable right that does not require legislative intervention and can be enforced judicially through the *tutela* lawsuit.

With this decision, the Constitutional Court established that the right to die with dignity emerged in 1997 and consolidated as a fundamental right in 2014. Three elements were used to characterize it as fundamental: The direct and essential relationship of a dignified death to human dignity, the existence of a legal consensus on the scope and content of the right, and the translation of dying with dignity into a subjective right in which the actors are identified, and the relationships and obligations imposed are clear.

Thus, the Court concluded the conceptual discussion by stating:

> The right to die with dignity is an autonomous right, independent [of] but related to [the right to] life and other rights. It is impossible to consider a dignified death

[78] See: Colombian Constitutional Court, Decisions T-970/14; T-132/16; T-322/17; T-423/17; T-544/17; T-721/17; and T-060/20.

[79] See: Resolutions 1216 of 2015 (repealed); 1051 of 2016 (repealed); 2665 of 2018; 825 of 2018; and 229 of 2020.

[80] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[81] Ibid.

[82] "The right to life is inviolable. There shall be no death penalty." Republic of Colombia (1991). Political Constitution of Colombia, art. 11.

> as [part] of the right to autonomy, nor is it possible to understand it as a part of the right to life. It is simply a complex and autonomous fundamental right that has all the characteristics and attributes of the other constitutional guarantees of its category.[83]

In this decision, the Court also tangentially addressed the different mechanisms for realizing the right to die with dignity: access to palliative care, ATE, and MAiD through euthanasia. However, it did not attempt to conceptualize the right beyond this.

As a second contribution, the Court pointed to the different ways and moments people can consent to the right to die with dignity. Building on what it had established in Decision C-239 of 1997, it specified that consent must be free, informed, and unequivocal:

> Free means that there is no third-party pressure to decide. The determining element is that the motive for the decision must be the patient's genuine desire to end the intense pain he is suffering. Furthermore, consent must be informed, which means that professionals must provide the patient and family with all objective and necessary information so that no hasty decisions are made when a human life is at stake. Finally, consent must be unambiguous. A decision such as the one made here is, in principle, intended to protect the patient's life and his own will; therefore, this criterion seeks to ensure that the patient's decision to cause his death is consistent and lasting, that it is not the product of critical or depressive episodes.[84]

In addition to these characteristics, the Court addressed the moments in which consent can be expressed. It can be given in advance, before being aware of the illness that has triggered the decision to access the mechanisms provided by the right to die with dignity, or after being aware of it.[85] It also stated that consent can be informal, for example, when it is expressed verbally, in daily conversations, by any means, or formal, when it is recorded in writing, audio, or video if it meets the minimum conditions established by the regulations on advance directives.[86]

[83] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[84] Ibid.

[85] Ibid.

[86] Ibid.

Photo by: Muhammad Zaqy Al Fattah

Likewise, consent may be expressed directly by the person deciding their own life and death or in a surrogate manner:[87]

> When the person suffering from a terminal illness cannot express their consent, [i]n such cases, and to not prolong their suffering, the patient's family may substitute consent by providing support through the principle of the best interpretation of their will and preferences. In these cases, the same procedure established in the previous paragraph is followed, but the Interdisciplinary Committee must be more rigorous in fulfilling the criteria.[88]

Third, the Constitutional Court addressed the lack of protection of the rights of individuals in the absence of legislation on the right to die with dignity. The legislative latency and the fact that Congress had debated several bills without concrete results had become an obstacle to access, and this case was an opportunity to make it visible and correct it. Based on its previous precedents, in particular Decision C-139 of 1996, the Court established that the Constitution has direct normative effects, application, and validity, has immediate legal consequences, and does not depend on a subordinate norm, whether legislative or regulatory. At the same time, it recognized that the work of the legislature is essential in the protection of fundamental rights, but since the Constitution is a superior norm, its legal content has a direct impact on the lives of individuals and the rights to which they are entitled.[89]

The Court did not limit itself to stating that the absence of legislation should not be an obstacle but went further and ordered the Ministry of Health to issue a regulation for the Colombian healthcare system that would follow the guidelines established in the decision. It also ordered the creation of a medical protocol that would serve as a reference for the procedures to be followed to guarantee the right to die with dignity through euthanasia.[90] In this sense, it dictated the general criteria to be observed by the healthcare system. First, it referred to the prevalence of the patient's autonomy, which requires that service providers to analyze the cases always taking into account the patient's will, which can only be disputed in very particular situations.[91] Second, celerity and timeliness imply that the right to die with dignity cannot be delayed since this would mean imposing an excessive burden on the person requesting it. At the same time, it requires that the process of receiving, evaluating, and deciding on requests be agile, prompt, and without excessive bureaucracy, which prevents the patient from effectively exercising the right.[92] Third, the criterion of impartiality was formulated, which refers to the fact that physicians must be neutral in carrying out the procedures necessary to realize the right to die with dignity. Whether ethical, moral, or religious, their positions cannot lead to denying this right and its mechanisms. Likewise, in cases where the physician asserts such convictions, they cannot be forced to carry out euthanasia procedures but must designate another professional to perform them.[93]

In addition to establishing general criteria, the Court went a step further and ordered the creation of a three-member body within clinics, hospitals, and institutions that provide health services to receive, evaluate, and decide on requests for MAiD through euthanasia. The Constitutional Court called these bodies "right-to-die committees," and according to the Court's decision, they are composed of:

> A group of interdisciplinary experts who will perform various functions in cases where the right to die with dignity is requested. Among other tasks to be determined by the Ministry, the Committee will have to provide psychological, medical, and social assistance to the patient's family so that the decision does not negatively impact the family or the patient's situation. This assistance cannot be formal or sporadic but must be constant during the phases of decision and execution of the procedure, aimed at the practical realization of the right. In addition, this Committee must supervise the entire process, respecting the terms of this decision and the impartiality of those involved in the process. Likewise, in the event of the discovery of any irregularity, it shall suspend the procedure and bring to the attention of the competent authorities the possible commission of a misdemeanor or a crime.[94]

[87] Curently, substitution must be understood in the context of full recognition of the legal capacity of individuals and their right to receive assistance in exercising it. Therefore, the support network does not substitute or replace consent but instead provides formal assistance in making the best interpretation of the will and preferences of the person who, for whatever reason, cannot express their will at a given time. See: Correa Montoya, Lucas, Giraldo Castaño, Mónica and Jaramillo Salazar, Camila (2023). Interpreting the will at the end of life. Guidelines to guarantee the rights to legal capacity and dignified death. DescLAB.

[88] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[89] Ibid.

[90] Ibid.

[91] Ibid.

[92] Ibid.

[93] Ibid.

[94] Ibid.

At the same time, it established precise procedures and deadlines to be followed. In this sense, the Court set forth the obligation of physicians to receive requests for MAiD and to convene the Committee that must exist in the institution so that it can begin its process,[95] subject to an expeditious deadline of ten days. The three-member body must evaluate and decide on the request within this period.[96]

Within this framework, the leading role of physicians and clinics in access to the right to die with dignity has been recognized since they are "the main obligated parties regarding the application of procedures aimed at giving effect to the patient's will to exercise his or her right to die with dignity." [97] However, this does not mean their obligations are unlimited, or they can be forced to act against their conscience. The decision protects their right to conscientious objection and sets conditions and obligations so that the possible exercise of this right does not become an obstacle to the right to die with dignity.

To this end, the Court stated that

> The personal convictions of the physicians responsible for carrying out the procedure, which may be contrary to the performance of that duty, cannot constitute an obstacle to the patient's exercise of fundamental rights. In this case, within twenty-four (24) hours of the physician's written explanation of the reasons why the performance of the procedure is contrary to his personal convictions, another physician must be assigned to perform the procedure.[98]

In addition, a reporting and documentation requirement for euthanasia has been introduced. The Committees must submit a comprehensive report detailing all aspects of the procedure to the Ministry of Health. This measure is intended to enable the Ministry to oversee the practice thoroughly.

As detailed by Rodríguez-Garavito and Rodríguez-Franco, Decision T-970 of 2014 had a decisive unblocking effect that managed to break an inertia characterized by the poor knowledge of the population and the lack of public and legal mobilization of social organizations. The decision also unblocked the legislature and resolved the absence of clear rules to carry out MAiD through euthanasia and guarantee the right to die with dignity.[99]

Four months after Decision T-970 of 2014, the Ministry of Health, through Resolution 1216 of 2015,[100] regulated euthanasia by establishing the conformity of Committees and their rules of procedure.[101] Clinics' and health insurance companies' responsibilities were indicated,[102] the different stages of the process of guaranteeing euthanasia were detailed,[103] and institutional conscientious objection was prohibited, as established by the Court.

With this resolution, the public policy production effect of judicial activism materialized,[104] thanks to the creation of specific regulations applicable to this right. This norm at the regulatory level would become a practical guide for the healthcare system and the implementation of the right to die with dignity.

In Decision T-132 of 2016,[105] the Court reviewed a case in which the right to health, the special constitutional protection of inmates, and the right to die with dignity intersected. In this case, it analyzed the situation of a 49-year-old man detained in prison who suffered from several non-terminal illnesses and, in the face of numerous obstacles to timely access to health services, medicines, and surgical procedures, decided to request MAiD. Both the lower and appellate courts denied the request because the plaintiff did not have a terminal illness and did not meet any of the criteria for the realization of this right. This case allowed the Constitutional

[95] Ibid.

[96] Ibid.

[97] Ibid.

[98] Ibid.

[99] At the time of this document's publication, Colombia did not have a law on dignified death or medical assistance in dying, but its absence has been replaced by a rich and solid constitutional jurisprudence and some regulatory norms issued by the Ministry of Health.

[100] Ministry of Health and Social Protection of Colombia (April 20, 2015). Resolution 1216 of 2015. Currently, the above resolution has been repealed and replaced by Resolution 971 of 2021.

[101] Ibid., art. 7.

[102] Ibid., art. 12, 13c and 14.

[103] Ibid., art. 15 et seq.

[104] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South)*. Buenos Aires, Siglo XXI Editores. p. 44.

[105] Constitutional Court of Colombia (2016). Decision T-132/16 (Justice Rapporteur: Luis Ernesto Vargas Silva).

Court to reaffirm the strict criteria for access to MAiD through euthanasia. It also strengthened the constitutional precedent that such requests cannot be a way out to solve other types of problems or difficulties faced by individuals.

With Decision T-322 of 2017,[106] the Court reviewed a case in which the right to health, the right to care, and the elderly as rights holders converged with the right to die with dignity. In this judgment, the Court analyzed the complaint of a 90-year-old man who verbally requested euthanasia to a clinic and to his physicians. He did not have a terminal illness but argued that he was alone and had no one to give him the help or care he needed; he could not walk well and was close to using a wheelchair. He then went to court and filed an oral *tutela* lawsuit, ultimately denied.

This judicial decision created the strict duty of verification that the *tutela* judge has when faced with cases related to the right to die with dignity:

> The *tutela* judge has a strict duty to verify the facts in the *tutela* action, claiming the right to die with dignity. The decision to die with dignity is independent of a person's love for life and occurs when the person suffering from a terminal illness renounces an existence without dignity without implying a disregard for life. In these cases, the *tutela* judge is obliged to guarantee the right to life and human dignity, which means that the judge acts with the conviction that the right to life is the basis for guaranteeing other rights. For this reason, the constitutional judge must ascertain the factual context of each case, as well as the capacity of the person to express their will, especially in the case of a request as radical as the practice of euthanasia.[107]

This strict duty of verification should lead the judge to know and delve deeper into the social reality of each case,[108] to verify that the request for MAiD does not originate from the violation of other rights, nor is it a product of situations that judicial authority can resolve or help to resolve.

In Decision T-423 of 2017,[109] the Court analyzed the case of a 24-year-old woman with terminal cancer who, after receiving the prescribed treatments that proved ineffective and caused side effects that prevented her from performing daily activities, had stopped chemotherapy. With the support of her mother, she directly and explicitly asked both the physician and the clinic to guarantee her right to die with dignity through euthanasia. The physician did not respond to her request, and the clinic refused the procedure because, in the absence of an oncologist, it was impossible to convene the right-to-die Committee necessary to evaluate and decide the case, as required by Resolution 1216 of 2015 of the Ministry of Health.

The lower court protected the woman's right to die with dignity and ordered, among other things, that the healthcare system prepare everything necessary to convene the Committee to evaluate the woman's case and carry out the procedure. Since the woman was in an intermediate town where the hospital network did not meet the necessary standards or qualifications, the insurance company had to arrange for her transfer to another city where appropriate medical services were available.

The transfer occurred, but the receiving hospital was uninformed of the purpose of the transfer, and there were delays with the woman's medical records. The obstacles and barriers created an emotional and physical burden for the woman and her family because the administrative staff had no clear way to guarantee her right to die with dignity. In the end, the procedure was full of doubts and irregularities, and instead of euthanasia, a 12-hour terminal sedation was performed.[110]

In this judicial decision, the Constitutional Court identified the right to die with dignity as an autonomous and complex fundamental right established in Decision T-970 of 2014. At the same time, it was an opportunity to review the severe administrative barriers that persisted—and still do—despite the rules and guidelines previously defined in the jurisprudence and regulations in force.

The Court verified that although Decision T-970 of 2014 and Resolution 1216 of 2015 had created the obligation for the Committees to report the procedures performed to the Ministry of Health, it was impossible to monitor a

[106] Constitutional Court of Colombia (2017). Decision T-322/17 (Justice Rapporteur: Aquiles Arrieta Gómez).

[107] Ibid.

[108] Ibid.

[109] Constitutional Court of Colombia (2017). Decision T-423/17 (Justice Rapporteur: Iván Humberto Escrucería Mayolo).

[110] Ibid.

request from the moment a person made it. Therefore, it ordered the Ministry of Health to create an effective registration mechanism to have data and monitor the situation from when it was requested and not only when performed. The Ministry did not fulfill the order immediately; it was necessary to carry out a judicial pressure process to achieve it in 2021—four years later.

The Court also ordered the National Superintendence of Health to ensure that healthcare providers have the infrastructure and appropriate personnel to carry out the euthanasia procedure and to monitor the correct implementation of the right to die with dignity. Four years later, this order led to the adoption of a directive by the same authority.

The Court again urged Congress to pass a law regarding the need for legislative regulation and imposed a two-year deadline, which expired without being met.

Finally, the Court ordered a public act of acknowledgemente and reparation, apologizing to the woman's family in the presence of the local hospital directors that caused the violation, the insurance company, and the Ministry of Health.

Through Decision T-544 of 2017,[111] the Court analyzed the case of a child with an intellectual disability and communication difficulties, whose health condition was complex and delicate. He and his family faced challenges in accessing services within the healthcare system. As a consequence of his serious health condition, his parents applied for MAiD. Without a response, they turned to the courts to protect their son's constitutional rights.

With this case, the Court clarified that in its jurisprudence, there was no age limit to guarantee the right to die with dignity and that when Resolution 1216 of 2015 regulated the procedure for access to a dignified death through euthanasia only for adults, it disregarded the fundamental rights of a group that enjoys special constitutional protection: children and adolescents.[112] The Court recognized that it was unacceptable that, while adults are not required to continue their vital existence in cases of illness and suffering, children and adolescents are subject to an unlimited obligation to live.[113]

[111] Constitutional Court of Colombia (2017). Decision T-544/17 (Justice Rapporteur: Gloria Stella Ortiz Delgado).

[112] Ibid.

[113] Ibid.

Photo by: Catrin Johnson

At the time of the decision, the child had already died, having agreed to palliative care for a short period and having been sedated to avoid pain and suffering. Thus, the Court ordered the Ministry of Health to regulate the procedure of euthanasia for children and adolescents and to issue a specific protocol to guide the actors of the healthcare system.

In this decision, the Constitutional Court recognized that the healthcare system and the Committees that decide on requests must act more strictly when dealing with this protected population. The verification of consent must be rigorous. The Committee must consult the child's will and consider the child's maturity and development level. In addition, parental consent must be obtained, and if proxy consent is used, the Committee members must be more strict than they are in adult cases.

For its part, the Court has gone further in urging Congress to regulate the matter. In contrast to previous rulings in which it had urged Congress to do so, in this case, it decided to order the Ministry of Health to present a bill on the subject, using the legislative initiative granted to it by the Constitution.[114] Years later, the Ministry of Health would introduce a bill to comply with this court order, but without any intention of having it debated and approved.

In Decision T-544 of 2017, the opposition within the Court became visible. In the dissenting opinion, Justice Pardo Schlesinger argued her position on three aspects.[115] First, the discussion of the coexistence of the right to life and the right to die with dignity, where she argued that

> In a certain sense, the simultaneous recognition of the right to life and the right to perform or authorize acts directly contrary to life seems logically impossible or at least incongruent with the criterion of taking rights seriously. To recognize at the same time the right to life and the legitimacy of actions directly contrary to life is as absurd as recognizing the right to property and to theft or the right to a good name and to insult.[116]

Second, about the consideration of the dignity of life, the dissenting judge argued that life as a biological fact cannot cease to be dignified since this dignity derives from the fact of having it:

> The founding ruling of the line we are following today seems to be based on the assumption that there are conditions in which life is no longer dignified. This affirmation is incompatible with the Social State of Law model if it is understood to mean that life, in itself, has ceased to be dignified. In fact, life is not a simple operation among many but consists of the very being of the living. To lose life for a person is to lose his own being.[117]

Finally, Justice Pardo Schlesinger referred to the discussion on conscientious objection, in particular of the clinics–a controversial topic for the conservative judges:

> Decision T-970 of 2014 made euthanasia an absolute obligation for all clinics. Resolution 1216 of 2015 imposed the obligation to have nonobjecting medical personnel without considering the situation of the institutions that provide health services in the light of a religious, ethical ideology, which is covered by paragraph a) of Article 14 of Law 133 of 1994, statutory legislation for the development of Article 19 of the Political Constitution. I consider that it was not legally necessary to impose this restriction on the right to establish institutions for the provision of health services oriented to religious [and] ethical ideals.[118]

To date, Resolution 971 of 2021 still prohibits institutional conscientious objection. Only the physician assigned to carry out MAiD by euthanasia can invoke it. Health and administrative professionals involved in the request and the procedure cannot declare themselves as conscientious objectors, nor can health professionals who provide information or assistance in accessing services related to death with dignity.

The Ministry of Health complied with the order to regulate euthanasia in children and adolescents in Resolution 825 of 2018, in which it established that decision-making in medical settings must meet the ability to communicate the decision, understanding, reasoning, and judgment. However, if it is not possible to

[114] Republic of Colombia (1991). Political Constitution of Colombia, art. 154.

[115] See: Dissenting opinion of vote of Cristina Pardo Schlesinger to Decision T-544/17 (Justice Rapporteur: Gloria Stella Ortiz Delgado).

[116] Ibid.

[117] Ibid.

[118] Ibid.

understand or communicate the decision due to a disability or the progression of the disease, the healthcare system must provide reasonable assistance and accommodations to enable the voluntary, free, informed, and unambiguous expression of the decision.[119]

This situation poses a central problem: in practice, the possibility of access to MAiD through euthanasia is limited for people who, like the child in the case dealt with in Decision T-544 of 2017, due to their intellectual development and communication difficulties, cannot understand or express the free, informed and unequivocal will to end their own life. This creates a tension between a personal decision and the possible provision of assistance to give consent, a situation in which eugenic decisions or those based on caregiver fatigue should be avoided.

Resolution 825 of 2018 introduced an age limit for implementing MAiD, detailing how children and adolescents understand death. In this sense, it indicated that it is not possible to perform the procedure on a person under 12 years of age unless a sufficient level of maturity and development is established at a close age.[120] However, although it is possible to evaluate each specific case, some populations are excluded altogether: newborns or neonates; children in early childhood; those with altered states of consciousness; and those with intellectual disabilities or psychiatric disorders that limit the ability to understand, reason, and make reflective judgments.[121]

In Decision T-721 of 2017,[122] the Court analyzed the case of a woman in Bogota who had been diagnosed with epilepsy since childhood and was now in a permanent vegetative state. As a result of the situation, it was not possible to determine the pain or suffering the woman was experiencing, as she was unable to communicate. The family based their interpretation of her pain and suffering on the changes in her breathing and the state of dependence she was in.

In addition to euthanasia, the family had also submitted a request for AET, which was neither processed nor responded to, and the healthcare system directly denied their request for palliative care. In the context of multiple obstacles and irregularities in the application of Resolution 1216 of 2015, the woman died of natural causes without undergoing the procedure requested by her family.

The woman was declared legally incompetent,[123] and her legal representatives asked the healthcare system for MAiD. When they did not receive a response, they went to court. The lower court ruled in favor of the family, finding that both the insurance company and the clinic had violated the law by failing to comply with the provisions of Resolution 1216 of 2015. This was mainly because the clinic stated that it had convened the Committee, but its decision was recorded in the minutes and was confidential.

The appellate court overturned the decision and agreed with the clinic, arguing that there was a response from the Committee and that, although the contents were confidential, the decision was to refuse the procedure because it did not comply with Resolution 1216 of 2015 provisions. The Committee pointed out that the woman did not have a terminal illness and that there was no record of an advance directive, much less any evidence of the woman's decision—not that of her representatives or her family—to consent to euthanasia.

With the ruling, the Court defined the fundamental right to die with dignity as "a set of capacities which enable a person to exercise autonomy and control over the process of death."[124] It also addressed and developed the multidimensionality of the right, indicating that access to palliative care, the possibility of ATE, and euthanasia are part of it.[125]

In light of Decision T-970 of 2014, the Court analyzed the issue of surrogate consent—the ruling that recognized this figure. It concluded that by requiring the existence of an advance directive, the regulation of Resolution 1216 of 2015 had violated the right to die with dignity. Again, it pointed out that a prior written statement was

[119] Ministry of Health and Social Protection of Colombia (March 9, 2018). Resolution 825 of 2018, art. 2 (2.2).

[120] Ibid., art. 2 (2.3).

[121] Ibid., art. 3.

[122] Constitutional Court of Colombia (2017). Decision T-721/17 (Justice Rapporteur: Antonio José Lizarazo Ocampo).

[123] In Colombia, Law 1996 of 2019 eliminated the judicial interdiction to which some persons with disabilities were subjected.

[124] Constitutional Court of Colombia (2017). Decision T-721/17 (Justice Rapporteur: Antonio José Lizarazo Ocampo).

[125] Ibid.

not necessary for the person to be assisted in deciding because to require it would limit the exercise of the right of those who could not make the decision or had not done so while their health condition still allowed them to do so.

At the time of the decision, the Court issued two landmark rulings: it ordered the Ministry of Health to amend Resolution 1216 of 2015 on consent and to regulate how ATE can be requested (for example, refusal and withholding of assistance measures) and the timeframe for responding to that request. Finally, it again urged Congress to legislate on the matter. To date, the Ministry still needs to implement these three orders.

Following Decision T-423 of 2017, Resolution 229 of 2020[126] of the Ministry of Health ordered insurance companies and clinics to issue a letter of rights and obligations containing relevant elements on the right to die with dignity. Among its minimum contents, the Court established that it should include general information that would give an account of the existence of this right.[127]

Furthermore, the Court addressed the right to be promptly informed by the physician of the existence of a duly motivated conscientious objection in cases involving euthanasia. In these cases, physicians with such objections must write in advance to the medical institution so that a non-objecting professional can effectively manage the immediate care.[128]

The Resolution in question included a specific chapter on the right to die with dignity that addressed, among other operational issues, some applicable medical definitions, the obligation to publicize and communicate the procedures established to receive, evaluate, and decide on requests for euthanasia of adults and minors, and the obligation to inform about the possibility of advance consent.

In the last case of this moment, Decision T-060 of 2020,[129] the Court dealt with the case of a 97-year-old woman who was diagnosed with several serious illnesses, including Alzheimer's and schizophrenia. Her daughter requested the euthanasia procedure for her mother but was required to present the advance directive. This was impossible because the document did not exist, and the woman's health did not allow her to express it, as required by constitutional jurisprudence and the Ministry of Health regulations. In addition, despite the seriousness of her medical diagnosis, physicians did not consider her condition as terminal. For this reason, the clinic refused the procedure, as did the two judicial authorities who heard the case.

When the case reached the Court, a moderate follow-up process was developed.[130] Thus, it requested a specific report from the executive branch on compliance with the orders issued in previous decisions. Specifically, it asked the Ministry of Health about the order issued in Decision T-721 of 2017, which required it to amend Resolution 1216 of 2015 regarding surrogate consent. Thus, the Court warned: "The lack of regulation by the Ministry of Health and Social Protection regarding the conditions for the viability of surrogate consent in relation to the right to die with dignity may constitute a threat to the guarantee of this fundamental right, contrary to the dignity of patients and their families."[131]

Therefore, it insisted on the Ministry's obligation to regulate surrogate consent in two cases: when the person is in a situation of legal incapacity or under circumstances that prevent them from expressing their will and when they lack an advance directive. Finally, the Court reiterated its call for Congress to legislate.

Despite the above, in the third moment of development and implementation of the right to die with dignity, Congress failed in its regulatory work. Between 2015 and 2020, Congress had the opportunity to discuss three bills presented seven times. There were no attempts to regulate against the fundamental right to die with dignity, nor against the constitutional precedent achieved so far; they all sought to develop legislation following the progress achieved judicially until then.

[126] Ministry of Health and Social Protection of Colombia (February 20, 2020). Resolution 229 of 2020.

[127] Ibid., art. 4, num. 4.1.11.

[128] Ibid., art. 4, num. 4.2.3.4.

[129] Constitutional Court of Colombia (2020). Decision T-060/20 (Justice Rapporteur: Alberto Rojas Ríos).

[130] Rodríguez-Garavito, César and Rodríguez-Franco, Diana (2015). El Juicio a la Exclusión. El impacto de los tribunales sobre los derechos sociales en el sur global *(The trial of exclusion. The impact of courts on social rights in the Global South).* Buenos Aires, Siglo XXI Editores. p. 28.

[131] Constitutional Court of Colombia (2020). Decision T-060/20 (Justice Rapporteur: Alberto Rojas Ríos).

The first bill of this third moment was presented to the Senate of the Republic in 2015 by Armando Benedetti Villaneda of the National Unity Party. Congress did not debate the bill, and it was filed. It was presented a second time in 2018 and met the same fate.

In 2019, two more bills were presented. Senator Armando Benedetti of the National Unity Party presented the first, but Congress dismissed it without debate as in previous years. Juan Fernando Reyes Kuri of the Liberal Party presented the second in the House of Representatives, the first time such a bill was presented in that body.

In 2020, three bills were introduced: one in the Senate by Armando Benedetti Villaneda, which was dismissed without debate; one in the House of Representatives, again by Juan Fernando Reyes Kuri, who managed to be approved in the first debate, but did not have a second debate and was filed; and finally, the initiative bill of the Ministry of Health, ordered by the Constitutional Court in Decision T-544 of 2017, which did not have a debate and was finally dismissed.

During 2014-2020, significant progress was made in normative production. This period saw the consolidation of the right to die with dignity as a fundamental, autonomous, and multidimensional right. It also marked the full recognition of the three mechanisms for exercising this right: palliative care, adequacy of therapeutic efforts, and euthanasia. The Constitutional Court established firm judicial guidelines for its realization, and the Ministry of Health tailored the procedure regulation to accommodate adults and minors. In addition, the Court identified and eliminated general obstacles to access to this right and ordered the legislative branch to take the necessary measures.

Fourth moment: impact litigation to overcome barriers and expand the right to die with dignity (2021-present)

Since 2020, civil society has been working to push for legal progress on specific issues. Despite the rapid development and implementation achieved between 2014 and 2020, barriers to exercising the right to die with dignity remain. Until then, the actors of a nascent social movement had not succeeded in generating the legal changes necessary to guarantee this right widely and without legal or administrative barriers. They had yet to mobilize to ensure that the executive power, through the Ministry of Health, complied with the judicial landmark decisions. In this sense, this current evolutionary moment is characterized by the fact that, for the first time, it includes impact litigation processes that are intended to generate progress towards profound transformations regarding the right to die with dignity, building on the precedent of previous judges and exerting pressure to go further in structural issues that have not yet been resolved.

The first result of this pressure from the judicial authorities was **Resolution 971 of 2021**.[132] In 2017, the Constitutional Court ordered the Ministry of Health to amend Resolution 1216 of 2015 and create an effective registration mechanism that would allow cases of MAiD through euthanasia to be recorded from the moment the procedure is requested and not only when performed. The Court ordered this regulatory adjustment within 30 days of the decision, but the Ministry of Health took four years to implement it.

Thanks to the judicial pressure exerted by **DescLAB**, the Ministry of Health adopted Resolution 971 of 2021, and implementing such a mechanism became a reality. As a result, the registry was strengthened, and the system for reporting euthanasia requests and the reporting obligations of clinics were created.[133] This has led to a significant change in the figures and knowledge available on access to the right to die with dignity; it has also made it possible to understand how the procedures are distributed throughout the country, the geographical disparities, the gender distribution, the average age, difference by type of disease, among other relevant data.[134]

In addition to the registration system and the clarification of the duties and obligations of the healthcare system, Resolution 971 brought other innovations and

[132] Ministry of Health and Social Protection of Colombia (July 1, 2021). Resolution 971 of 2021.

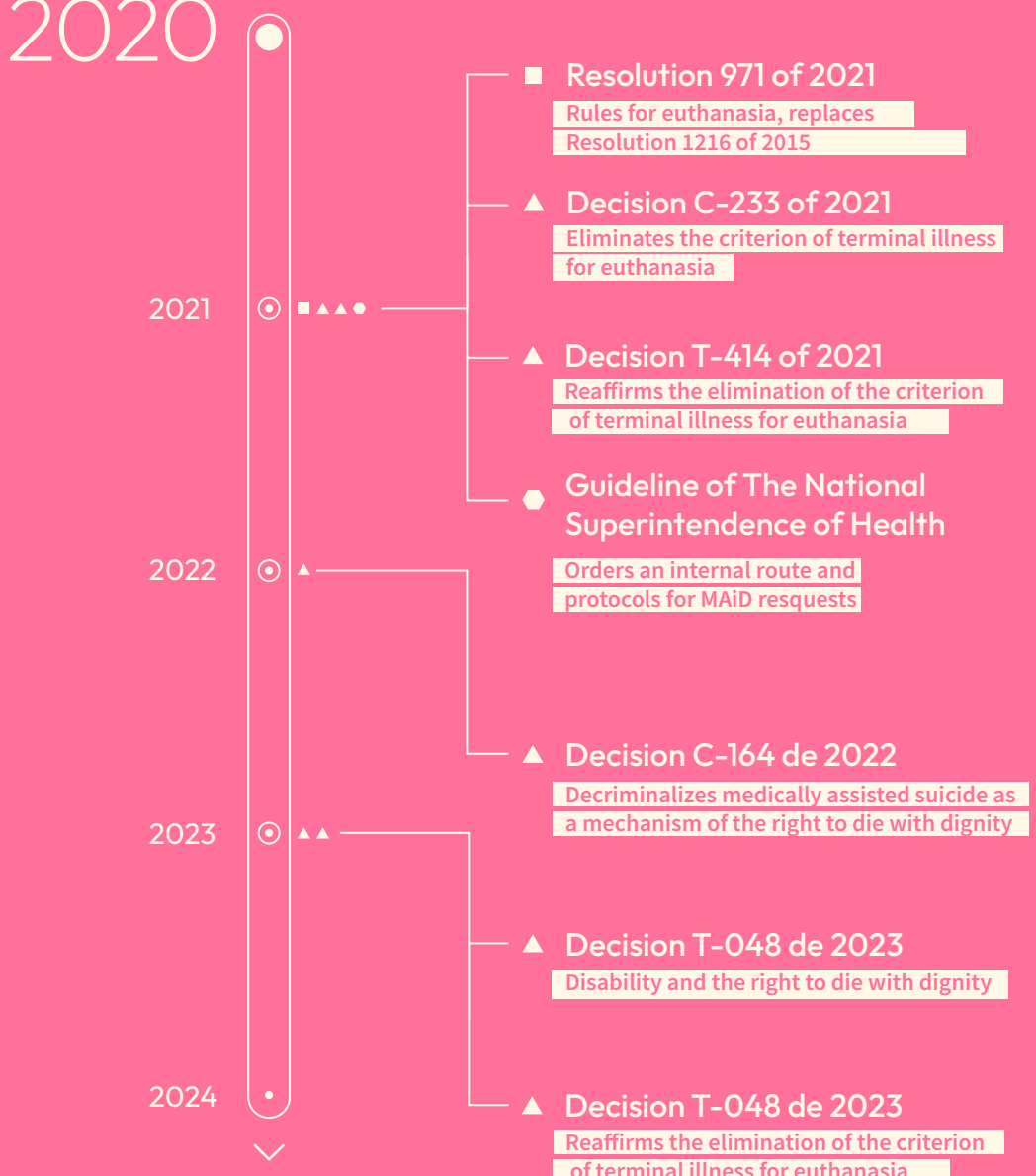
[133] To learn more about DescLAB's achievement, see "Registration of euthanasia requests: The Triumph of DescLAB at the Ministry of Health" at https://www.desclab.com/post/registro.

[134] See: (1) Correa Montoya, Lucas and Jaramillo Salazar, Camila (2021). De muerte lenta #1. Informe sobre las cifras y las barreras para ejercer el derecho a morir dignamente en Colombia *(Slow Death #1. Report on the data and barriers to exercise the right to die with dignity in Colombia).* DescLAB; (2) Correa Montoya, Lucas and Jaramillo Salazar, Camila (2022). De muerte lenta #2. Cifras, barreras y logros sobre el derecho a morir dignamente en Colombia *(Slow Death #2. Report on the data, barriers and achievements to exercise the right to die with dignity in Colombia).* DescLAB.

4

FOURTH MOMENT
2020 - PRESENT

Impact litigation to overcome barriers and expand the right to die with dignity



barriers. Contrary to Resolution 1216 of 2015, the Ministry eliminated the obstacle of the treating physician as the gateway to the procedure. Thanks to this new resolution, all physicians in Colombia are responsible for receiving the requests, making an initial analysis, and activating the Committee in charge of deciding whether to authorize the procedure. It does not matter who the physician is, whether the person is hospitalized, or whether the physician's specialty is related to the health condition motivating the request: All can and must receive and then process verbal or written requests.

In turn, **Resolution 971 limited the possibility for foreigners not domiciled in Colombia to access euthanasia**. Foreigners can only access MAiD if they have been residents of the country for one year before the request. This regulation is constitutionally problematic because it restricts the protection of constitutional rights to foreigners by requiring them to have a more extended period of residence.

The Resolution also **allows for a second Committee**, composed of different professionals, to be requested if the first Committee refuses to authorize the procedure. This change gives more room for action within the healthcare system to protect the right to die with dignity before cases go to Court.

Finally, regarding the medical conditions for which it is possible to request euthanasia, Resolution 971 of 2021 requires only the presence of a clinical condition at the end of life. This category includes incurable advanced illness, terminal illness, and agony. The three clinical conditions mentioned in the regulation have a near-fatal prognosis of medium-term, six months, and days or hours, respectively.

As a second result of this moment, and as the third milestone of the overall process, the Constitutional Court, in its **Decision C-233 of 2021**,[135] eliminated the barrier of terminal illness as a requirement for access to euthanasia. As we have presented, since 1997, this judicial authority had established as a criterion that the applicant's illness must be in a terminal state, with the understanding that death was foreseeable in a short time. Subsequently, through technical documents, the Ministry of Health indicated that in Colombia, to have a terminal illness, the prognosis of life must be less than six months.[136]

After 24 years, the Constitutional Court again analyzed the constitutionality of the crime of mercy killing. The plaintiffs argued that the article of the Criminal Code violated the right not to be subjected to cruel, inhuman, and degrading treatment, the right to autonomy, and the right to human dignity. In turn, they argued that *res judicata* had not been established, mainly because, although the material content of the crime of mercy killing remained the same, the amount of the penalty established in the new Criminal Code adopted in 2000 had increased, resulting in a change in the legal effect of such conduct.[137] In addition, they stated that there was a different legal context since not only were the norms contained in other laws, but there was also an advance in the regulations—both in Colombia and the world—and in the decisions of the Court on the matter.

It was clear that the plaintiffs were seeking social change by asking the Court to conduct an abstract analysis of constitutionality.[138] In contrast to what happened in 1997, this litigation strategy sought to expand the grounds for exclusion from criminal liability and to remove the terminal illness criteria from the judicial precedent. Most *amicus curiae* from legal and medical experts supported the premise, pointing out that the terminal illness criteria violated constitutional rights. Interventions from government agencies opposed the lawsuit. Both the Ministry of Justice and the Ministry of Health argued that the terminal illness criterion and the current regulation protected the person's right to life and the physician's legal certainty.

Thanks to this decision, the Court modified the constitutional precedent on terminal illness to adopt a new extension for the practice of euthanasia. It held that the crime of mercy killing is not perpetrated when the conduct: "(i)

[135] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

[136] Ministry of Health and Social Protection of Colombia (2015). Protocol for the Application of the Euthanasia Procedure in Colombia 2015. University of Antioquia, the National University of Colombia and the Meditech Foundation.

[137] "Mercy killing. Amended by art. 14 of Law 890 of 2004, as of January 1, 2005. Whoever kills another person for mercy to put an end to intense suffering due to bodily injury or serious and incurable illness shall be punished with imprisonment from sixteen (16) to fifty-four (54) months.

[138] See: (1) Republic of Colombia (1991). Political Constitution of Colombia; (2) Republic of Colombia (1992). Decree 2067 of 1991.

is performed by a physician, (ii) is performed with the free and informed consent, before or after diagnosis, of the passive subject of the act, and provided that (iii) the patient suffers severe physical or psychological suffering as a result of bodily injury or serious and incurable disease."[139] Thus, it is no longer necessary to have a terminal illness, but only a serious illness that is also incurable.

In analyzing its constitutionality, the Court, after defining the issue of *res judicata* and reviewing all the constitutional precedents on dignified death, argued that the requirement of terminal illness was an obstacle to the exercise of the right to die with dignity, mainly because it restricted human dignity in its various facets: on the one hand, it violated the right to die with dignity, autonomy and self-determination; on the other hand, it ignored the protection of physical and moral integrity and the right to be protected from torture and maltreatment.

In this sense, if Decision C-239 of 1997 marked a milestone by establishing that there is no obligation to live and its configuration beyond mere biological subsistence, Decision C-233 of 2021 represented a breakthrough by consolidating autonomy and self-determination as the pillars of the decision of MAiD, beyond the proximity or remoteness of death.

The Court stated that it is clear that the Constitution does not privilege any particular model of life, but it does protect the autonomy to choose how and under what conditions a person decides to die, mainly when the person's state of health leads to "physical or moral degradation"[140] or exposes them, in a prolonged and indefinite manner, to a state of health that the person considers cruel and incompatible with their idea of dignity, given their assessment of pain and suffering.[141]

Although the diagnosis of a serious and incurable illness is still required, for the first time, the physicians-patient relationship finds a relative balance. By eliminating the criterion of terminal illness, it is the will and consent of the person that prevails over the proximity of death to realize the right to die with dignity through euthanasia. This judicial decision marks the transition from a decision-making model that prioritized the medical assessment of patients' near-death prognosis to one of autonomy, in which patients themselves assess the impact of serious and incurable health conditions on their quality of life.

The criterion of terminal illness became a power of attorney for the healthcare system; that is why people with oncological diagnoses were the ones who had access to almost all euthanasia procedures until 2021.[142] In the process of medical determination of the terminal state of an illness, autonomy was subordinated to the apparently scientific decision of medicine to determine whether the person would die in the next six months, as enshrined in the protocol adopted by the Ministry of Health.[143]

The Court held that the requirement of a near-fatal prognosis of a specific time is disproportionate and unreasonable and restricts the self-determination of individuals:

> Given that the criminal offense of mercy killing requires, from its legislative configuration, a series of extreme health conditions, as well as an experience of intense suffering, which ensure that the benefits of a dignified death are directed only to persons whose conditions currently have no medical answers other than the attempt to manage severe pain [...], in the Chamber's view, the additional criterion of a prognosis of near-death (or terminal illness) does not contribute to maximizing autonomy and self-determination and may instead impose the continuation of the prognosis of death in the terminal phase of the illness.[144]

In this sense, if the person already has a serious and incurable illness that is a source of pain and suffering that the person considers incompatible with their idea of a dignified life, they should be able to determine when and how to end their life. This choice goes beyond limiting or refusing treatment and allowing the disease to progress to a terminal state; on the contrary, it involves

[139] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

[140] Ibid.

[141] Ibid.

[142] Correa-Montoya, Lucas and Jaramillo-Salazar, Camila (2021). De muerte lenta #1. Informe sobre las cifras y las barreras para ejercer el derecho a morir dignamente en Colombia *(Slow Death #1. Report on the data and barriers to exercise the right to die with dignity in Colombia).* DescLAB.

[143] Ministry of Health and Social Protection of Colombia (2015). Protocol for the Application of the Euthanasia Procedure in Colombia 2015. University of Antioquia, the National University of Colombia and the Meditech Foundation, 2015, p. 13.

[144] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

"the possibility of determining when a state of health is incompatible with the characteristics that make life worth living and when the pain becomes unbearable."[145] The Court also referred to this aspect when it stated that "the criterion that the person must, in addition to suffering from a serious and incurable illness, have a prognosis of imminent death is disproportionate since it prevents persons suffering from the above illnesses from exercising their self-determination and choosing how to end their life."[146]

Decision C-233 of 2021 reaffirmed that life goes beyond mere subsistence and is not a sacred value or an absolute principle in a secular and pluralistic society. Therefore, from the perspective of human dignity, forcing a person to live and not providing assistance to do so not only violates their autonomy but also constitutes cruel, inhuman, and degrading treatment.

From the outset, the Court explicitly stated that human dignity, as a value, a principle, and a right that permeates the Colombian legal system, includes a dimension of a life free from humiliation and the protection of physical and moral integrity. The Constitution expresses this dimension in the prohibition of ill-treatment as a fundamental right that the State is obliged to protect.[147] About this obligation, the Court stated that "although the actions of the authorities do not constitute the direct source of their suffering, the fact is that the possibility of putting an end to it, in appropriate conditions, is often left in the hands of the health system and the authorities that define what is criminally prohibited."[148]

Regarding the criterion of terminal illness, the Court also noted that based on Decision C-239 of 1997, which stated that people are not obliged to live a life of pain and suffering "in order to defend a model of life such as that of the martyr, who faces any suffering before its sacred value,"[149] it is not clear why those who have serious and incurable illnesses with an uncertain life prognosis should do so. In this sense, it pointed out that "if a person cannot be obliged to suffer intensely for a short time (near death), it is not justified that they should be obliged to endure it for a much longer or, in any case, uncertain time (lack of prognosis of near death)."[150]

Throughout the decision, the Court reiterated the reasons why the criterion of terminality is an obstacle to accessing the right to die with dignity, as well as imposing conditions that the person "considers unworthy and incompatible with their idea of a dignified life."[151] On this point, there is a reflection based on the rule established in Decision T-970 of 2014, which emphasizes the importance of the subjective dimension over pain and suffering in any discussion between the person and the healthcare system since "regardless of the means to understand the phenomenon of pain and suffering, they are first and foremost a subjective experience of the person."[152]

In this decision, the Court went further, stating that suffering is experienced not only because of the illness but also because of the whole dynamic of being ill without the certainty of a life prognosis:

> The suffering derived from the disease is also related to the burdens imposed on the patient by diagnoses and treatments; the uncertainty of the outcome deepens it; it is materialized in family relationships; and it has a profound relationship with time since the anticipation of future pain or death can increase or decrease the intensity of suffering.[153]

Therefore, if the person suffers from a serious and incurable illness, it is not justifiable that they can choose to end their life only when they are declared to be terminally ill, even if this results in greater suffering for an indeterminate time. In this sense, although palliative care is available, the Court reaffirmed that it cannot be a condition for a person to receive it to access other mechanisms of the right to die with dignity.

[145] Ibid.

[146] Ibid.

[147] "No one shall be subjected to forced disappearance, torture, or cruel, inhuman, or degrading treatment or punishment." Republic of Colombia (1991). Political Constitution of Colombia, art. 12.

[148] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

[149] Ibid.

[150] Ibid.

[151] Ibid.

[152] Ibid.

[153] Ibid.

In addition to the judicial decisions previously analyzed, the third result of the pressure exerted by the judicial authorities is the case of **Yolanda Chaparro**,[154] a woman with amyotrophic lateral sclerosis (ALS), who was required to have a certain degree of deterioration in her health condition to have access to euthanasia, thus meeting the criteria of terminal illness—mandatory at the time. In 2020, the Colombian healthcare system told her that she must wait until her health condition deteriorated severely to exercise her right: that she must find herself unable to breathe, eat, walk, or perform activities autonomously for her illness to be considered terminal, the very condition she wanted to avoid.

This impact litigation resulted in **Decision T-414 of 2021**,[155] which confirmed and strengthened the new judicial precedent: the criterion of terminal illness cannot be mandatory for any person who decides to apply for MAiD, and it is sufficient to have a serious and incurable illness.

Fourth, at the end of 2021, the National Superintendence of Health issued an updated **guideline**[156] addressed to insurance companies, clinics, and health professionals, with instructions to verify the implementation of the regulation on the right to die with dignity. In doing so, it ordered the healthcare system to create an **internal route** to receive, manage, and coordinate their actions with requests related to MAiD. In addition, it instructed these companies to **register** with the Superintendency the location of their network of clinics that provide services related to MAiD through euthanasia and to implement the right-to-die Committee and an internal protocol for receiving, evaluating, and deciding on MAiD requests.

[154] Learn more about #YolandaTomaElControl litigation strategy at www.desclab.com/yolanda.

[155] Constitutional Court of Colombia (2021). Decision T-414/21 (Justice Rapporteur: Cristina Pardo Schlesinger).

[156] National Superintendence of Health. (2021). External guideline 20211700000006-5 September 17, 2021.

Photo by: Daniel Jams

Once the Court decided to eliminate the criterion of terminal illness for access to euthanasia, we at **DescLAB** believed that it was time for Colombia to become one of the countries in the world with more advanced guarantees and possibilities for realizing the right to die with dignity. In 2020, we launched the impact litigation strategy to challenge the constitutionality of the crime of assisting suicide.[157] The goal was to ensure that the State did not prosecute the physician when the person met the same criteria as the required in euthanasia. **DescLAB** achieved this objective with a decision that marks a fourth milestone: Decision C-164 of 2022.[158]

Through this impact litigation strategy, we sought the decriminalization of medically-assisted suicide (MAS) and the recognition of a new mechanism to realize the right to die with dignity. **DescLAB** argued before the Constitutional Court that Congress had exceeded its freedom of legal configuration by criminalizing MAS and that by punishing it criminally, it had violated and restricted constitutional rights such as the right to die with dignity and the constitutional protection of human dignity. Moreover, we argued that it had unconstitutionally restricted the protection of personal autonomy and limited the constitutional principle of solidarity. In this decision, as in Decisions C-239 of 1997 and C-233 of 2021, the Court conducted an abstract analysis of the constitutionality of a norm—it analyzed the crime of inciting and assisting suicide in the Colombian Criminal Code—.

Once again, most of the *amicus curiae* supported the claims presented by DescLAB. Both medical and legal experts supported the case, arguing that it was constitutionally inadmissible for MAS to be considered a crime while euthanasia was legal. As in the case of Decision C-233 of 2021, both the Inspector General and the Ministries of Health and Justice requested that the decision be declared constitutional on the grounds, among others, that there was already a mechanism for exercising the right to die with dignity and that it was not necessary to extend it to others.

Decision C-164 of 2022 declared the conditional constitutionality of the crime of assisting suicide on the understanding that the act will not be penalized if a physician performs it with free, informed, and full consent and the person suffers severe physical or mental suffering as a result of bodily injury or serious and incurable illness. In addition to declaring the crime unconstitutional, it ruled that "medically-assisted suicide is one of the existing mechanisms of special assistance in dying as a recognized form of the right to die with dignity."[159]

The Court's arguments for decriminalizing assisting suicide began from the perspective of medical action, explaining how and why this crime violated the limits of the State's punitive power. In this regard, the Court pointed out that the criminalization of such assistance was "a manifestly inadequate measure to protect life, especially if it is understood that life is a legal good at the disposal of its owner and inseparably linked to dignity. Therefore, it can only be concluded that the legislator has violated the constitutional principle of necessity by not providing for criminal sanctions as a last resort."[160] At the same time, in response to the question of harmfulness, it stated that "when a third party, following medical criteria and ethics, facilitates the materialization of the will of the person who decides to end its life, it does not commit a harmful and therefore unlawful interference."[161]

The Court also found that criminalizing this conduct was disproportionate in light of previous decisions decriminalizing mercy killing:

> Despite this gradation in which mercy killing would be considered more serious than assisted suicide, the fact is that when mercy killing is practiced under certain objective and subjective conditions, euthanasia is configured. No criminal response is given because it is a constitutionally valid practice. On the other hand, when the same objective and subjective conditions are present in the case of MAS, a criminal response is given. This creates a disparity in the legal treatment of the two procedures that is not proportional. Thus, while in certain analogous subjective and objective circumstances, the criminal justice system refrains from intervening against the physician who executes and causes a death, it is mobilized to prosecute and punish the physician who, in the same circumstances, helps a person who commits suicide, violating the principle of proportionality in criminal matters.

[157] Republic of Colombia (July 24, 2000). Law 599 of 2000, art. 107, paragraph 2, which states: "When the aiding or abetting is intended to put an end to intense suffering resulting from physical injury or serious and incurable illness, a prison sentence of sixteen (16) to thirty-six (36) months shall be imposed."

[158] Constitutional Court of Colombia (2022). Decision C-164/22 (Justice Rapporteur: Antonio José Lizarazo Ocampo).

[159] Ibid.

[160] Ibid.

[161] Ibid.

> What is more, such a criminal response is disproportionate if one considers that the contribution of the helper is accessory because it depends on the principal act of the offender. In contrast, the contribution of the one who achieves the result himself is greater. The logical and constitutionally valid consequence is that there is greater reason to consider that MAS should not be treated as a crime and instead to recognize that it allows greater protection of the fundamental rights of human dignity, dignified life, dignified death, and autonomy.[162]

In ruling that Congress had exceeded the limits of the State's punitive power by prosecuting and punishing the conduct of a physician who assisted a person who met the same criteria, the Court emphasized the need for a professional with medical and technical knowledge to assist in the process. In this sense, the role of the physician in the process of MAS is not only to facilitate a means but also to provide support, as much as humanly possible, to maintain dignity until the last moment of life.

In the second part of the argument on the decriminalization of MAS, the Court referred to the rights that may be violated for those who have given consent and have a serious and incurable illness that causes unbearable physical or psychological pain. Thus, in line with decisions C-239 of 1997 and C-233 of 2021, it stated that the imposition of a penalty on a physician who assists a person to end their life violates human dignity, the right to live with dignity and autonomy. This is mainly because when such decisions are restricted, human dignity is suppressed in its dimension of autonomy, and life becomes a matter of mere biological subsistence. In this sense, given the existence of full consent, the physician's action should not be prosecuted.

On this point, the Court emphasized the autonomy and control over the end of life protected by MAS, stating that:

> The materialization of autonomy and human dignity is even greater since it is the patient who self-administers the prescribed medication to achieve the result and maintains control over the causal process of their death, which euthanasia does not presuppose to the same degree. Whoever chooses MAS instead of euthanasia is no more or less than claiming agency to end their suffering, preferring not to "delegate" such an important event to a third party.[163]

Finally, the Court considered whether the criminalization of MAS violated the principle of social solidarity. This decision's reflection on the solidarity of health professionals in the exercise of the right to die with dignity is unique in constitutional precedent. Although it had made some references to solidarity—in the analysis of the medical act in the decriminalization of euthanasia—the Court had not referred to MAS as an explicit act of solidarity by the physician towards the person who is trying to put an end to suffering. In this sense, it remarked:

> Pain suffered by a patient in extreme conditions directly involves the physician, who is the one who can alleviate such pain and help the patient to materialize the decision—already made—to put an end to it. Physicians can act ethically and according to the highest principles of morality when motivated by altruistic purposes such as solidarity and respect for the patient facing suffering perceived as contrary to their idea of dignity. In the case of MAS, it is clear that the principle of solidarity guides the physicians since the purpose of their action is to end the suffering of others and to realize the patient's will.[164]

Even if it is an act of solidarity, the Court clarified that there is no obligation to assist if it goes against the physician's conscience. In line with other judicial precedents, the rule that physicians are not obliged to assist a person in dying if it goes against their beliefs is reaffirmed and fully protected.

In **Decision T-048 of 2023**,[165] the Constitutional Court analyzed a case concerning capacity, consent, and euthanasia. It was a case about the denial of MAiD by a right-to-die Committee to a man with sclerosis who was declared legally incompetent due to mental disability. The Committee did not authorize the euthanasia procedure because it doubted his mental capacity and competence to decide to die due to the interdiction measure. The lower court, in turn, requested that the interdiction[166] be revised and converted to a judicial decision of supported decision-making.

[162] Ibid.

[163] Ibid.

[164] Ibid.

[165] Constitutional Court of Colombia (2023). Decision T-048/23 (Justice Rapporteur: Diana Fajardo Rivera).

[166] Interdiction is the judicial decision of legal incompetence in the Colombian legal system.

Decision C-164 of 2022 was a strategic litigation strategy led by DescLAB in which we sought the decriminalization of assisting suicide and the recognition of a new mechanism for realizing the right to die with dignity: medically-assisted suicide

The man and his daughter claimed judicial protection of his right to die with dignity and legal capacity. However, both the lower court and the Court of Appeal declared that the claim was inadmissible because the plaintiff's legal capacity had not been verified under the provisions of Law 1996 of 2019.[167] Nevertheless, the psychiatric evaluation indicated that the applicant had the mental capacity to make decisions and that the judge in the lower court had personally interrogated him. In this scenario, he reaffirmed his will and stated he was conscious of the choice. Still, the lower and appellate courts insisted on an interdiction review judgment and a judicial decision of supported decision-making.

The legal issue raised by the Constitutional Court was whether the Committee had violated the right to die with dignity of a person with disabilities whose capacity and competence to decide on the end of his life was in doubt because he had been declared legally incompetent by a court decision that had not been reviewed, but who, on the other hand, had a medical opinion that he was mentally competent to make decisions.

To resolve this issue, the Court summarized the precedents related to the right to die with dignity. As for consent, it reaffirmed that the decision as to how long an existence is compatible with the idea of a dignified life rests with the person, and their will must prevail. Apart from the fact that consent must be free, informed, and unequivocal, it stated that "it presupposes the capacity of the person to understand the state of health and choices at the end of life, as well as the responsible exercise of the profession by the treating physicians, both to inform of the procedures to be performed and to verify the maturity of the judgment and will"[168] and that "the assessment of the validity of the consent must be analyzed according to the situation of each person."[169]

The Court then referred to the precedent on the autonomy of persons with disabilities in making decisions related to medical procedures. In addition to describing the legal transformation of the exercise of the rights of persons with disabilities and its impact on the Colombian legal system, it explained the difference between legal capacity and autonomy in health-related decision-making and how the latter depends on the nature of the health intervention and the degree of autonomy required of the person to give consent.[170]

According to General Comment No. 1 of the Committee on the Convention on the Rights of Persons with Disabilities[171] and Law 1996 of 2019—which introduced the incorporation of supported decision-making paradigm for persons with disabilities to exercise their legal capacity without barriers and with support—, the figure of interdiction was eliminated and the Court established that "the review of the decision has the sole purpose of assessing the need for support, but not to preserve in time the figure (or the logic) of interdiction, since this is an institution opposed to the paradigm of international human rights law on capacity."[172]

In light of this, the Court found that the man who requested the euthanasia procedure met the criteria to exercise his right to die with dignity through euthanasia. In addition to being duly diagnosed with a serious and incurable illness and experiencing pain and suffering due to this health condition. Regarding his consent, the Court argued that it:

> Is (i) free, in that the request to die with dignity was made directly by him, without any interference, pressure, or influence from third parties, and is clearly based on his living conditions; (ii) informed, in that he has explained that he knows what his illness is, how it affects his body, and his unlikely prognosis for recovery; and (iii) unequivocal, since he has expressed his decision on several occasions, that is, to the physician in charge of palliative care, to his psychiatrist, to his neurologist, and to the judge of first instance, in which he has consistently reaffirmed his will and desire to put an end to a life which, in his opinion, is incompatible with what he expects, wants, and considers worthy.[173]

The rule presented in this decision concerns the relationship between the right to die with dignity, consent, and legal capacity. In this regard, the Court stated that:

[167] Law 1996 of 2019 abolished judicial interdiction in Colombia and established that the judicial system must review all cases of persons subject to this measure of legal capacity restriction.

[168] Constitutional Court of Colombia (2023). Decision T-048/23 (Justice Rapporteur: Diana Fajardo Rivera).

[169] Ibid.

[170] Ibid.

[171] Committee on the Convention on the Rights of Persons with Disabilities (2014). General Comment No. 1, Article 12: Equal recognition before the law.

[172] Constitutional Court of Colombia (2023). Decision T-048/23 (Justice Rapporteur: Diana Fajardo Rivera).

[173] Ibid.

> In expressing his consent to end his life, the person who wishes to exercise his right must demonstrate the "capacity to understand the situation" or, in other words, "sufficient intellectual capacity to make decisions." But it does not require his "recognition of legal capacity." This is shown not only by the words used by the Court in this regard but also by some of the constitutional criteria indicated to the legislator to be taken into account when regulating, [...] namely the rigorous verification, by competent persons, of the actual situation of the patient, as well as of the "maturity" and "soundness" of the judgment.[174]

In this sense, the Court ruled that the interdiction review is not required for decisions related to medical procedures and reiterated that it is not necessary to prove the legal capacity of persons with disabilities when the Committees evaluate consent. Therefore, the requirement of another judicial procedure—such as the review of the interdiction to decide on the assistance in the decision-making process—not only violates the right to die with dignity and autonomy of the person but also subjects them to cruel, inhuman, and degrading treatment.

In addition to resolving the issue of legal capacity and the right to die with dignity, Decision T-048 of 2023 established a new rule in cases of dignified death: **the clause of normative preference in favor of constitutional precedent**. Based on one of the arguments of Decision C-233 of 2021, in which healthcare providers were required to apply the current regulations if they did not contradict constitutional precedent, the Court insisted on this guarantee in the MAiD process. The judiciary and the operators of the health system must be "fully aware of the constitutional jurisprudence and apply the administrative regulation, always verifying that it does not become an obstacle to access to the fundamental right to die with dignity."[175] In this way, the fundamental rights of the petitioners will be protected from the consequences of the lack of updating of the administrative regulations of the Ministry of Health and the contradictions that have yet to be corrected by the Ministry.

Finally, **DescLAB** provided legal representation to **Martha Sepulveda**,[176] a woman with ALS who, like Yolanda Chaparro, was not terminally ill. In this case, we

Photo by: Arno Senoner

[174] Ibid.

[175] Ibid.

[176] Learn more about #MarthaTomaElControl litigation strategy at www.desclab.com/martha

requested the procedure before the healthcare system, which the Clinic authorized without significant difficulties or obstacles. However, 36 hours before the euthanasia procedure was to take place, the Clinic canceled the procedure and irregularly changed its legal arguments. Initially, the Clinic had stated that, although she did not have a terminal illness, she met all the criteria established by the Colombian legal system; subsequently, the provider canceled the scheduled procedure, claiming that Martha did not have a terminal illness and that this criterion was still enforceable, which is another example of the kind of obstacles and irregularities that take place every day and that, in most cases, end in impunity.

Although Martha Sepulveda had accessed to euthanasia at the beginning of 2022, the Constitutional Court resolved her legal case with **Decision T-239 of 2023**.[177] This decision confirmed the rule established by Decision C-233 of 2021, which eliminated the criterion of terminal illness for access to MAiD.

From the facts of the case, the Court verified that the rules in force at the regulatory level, in particular Resolution 971 of 2021, contradicted the constitutional precedent by continuing to require the criterion mentioned above and developed the duty to update the subordinate norms to bring them in line with jurisprudential advances. At the same time, it reaffirmed the clause of normative preference in favor of the constitutional precedent, from which derives the duty of the entities of the healthcare system to know and directly apply such precedent to avoid the creation of obstructions and the violation of constitutionally protected rights.

Throughout this fourth moment of emergence and consolidation of the right to die with dignity, the legislative branch has continued its passive work. However, Congress urgently needs to fulfill its regulatory role in this matter. Between 2021 and this document's publication date, Congress has had the opportunity to discuss **two bills presented on four occasions**. There were no attempts to regulate against the fundamental right to die with dignity, nor against the constitutional precedent achieved to date; they all sought to develop legislation by building on the progress achieved judicially.

The first bill of this fourth moment was introduced in the Senate in 2021 by Senator Armando Benedetti Villaneda of the National Unity Party, and the Senate committee approved it in the initial discussion; the bill had a second debate and was then withdrawn in plenary. The second bill was introduced in the House of Representatives by Juan Carlos Lozada Vargas of the Colombian Liberal Party. It was approved in the first debate in the House of Representatives; however, it did not reach a second debate in plenary and was, therefore, filed. The same bill was presented to the Senate in 2023 by Humberto de la Calle Lombana.

* * *

Over the past thirty-one years, we have witnessed the emergence, expansion, and deepening of the right to die with dignity. What began as scattered cases of anonymous individuals has evolved into strategically planned cases aimed at social change. This strategic planning, coupled with the creation, development, expansion, and deepening of the right to die with dignity by the judiciary, as evidenced by the **fifteen decisions** issued during the period analyzed, instills confidence in the significant progress made in this crucial area and optimism for the future.

Since 1998, the legislative branch has debated **seven bills on the right to die with dignity on 19 occasions**. Additionally, there have been periods when up to three other bills have been introduced. Despite these discussions, the role of the legislature in this matter and the demands of the judiciary to regulate it have not yet been fulfilled.

The executive branch has adopted a cautious stance on the right to die with dignity, aligning itself with the judicial progress on this matter. In impact litigation cases presented to the Constitutional Court, the Ministry of Health and the Ministry of Justice have expressed opposition, advising the Court against broadening or intensifying the right to die with dignity. During this period, the executive branch released **six resolutions and one guideline**, most of which were enacted with delay as per court orders.

[177] Constitutional Court of Colombia (2023). Decision T-239/23 (Justice Rapporteur: Jorge Enrique Ibáñez Najar).

Unfortunately, the most significant legal obstacles to the effective guarantee of the right to die with dignity are found in the regulations of the Ministry of Health. This authority has used its regulatory power to establish norms and impose obstacles and unconstitutional criteria contradicting legal precedents. At the same time, the Ministry has refused for years to comply with some of the landmark decisions issued by the Constitutional Court, forcing people to try to overcome obstacles and the social movement to seek judicial intervention several times to enforce previously issued orders that should be complied with promptly and in good faith.

The media, for its part, has been a strategic ally of the social movement and the right to die with dignity. Through their positive coverage of real cases, they have not only promoted legal and regulatory changes but also put pressure on public officials. Their work has empowered the public, strengthening positive imaginaries and narratives in Colombian public opinion, focusing not on illness, deterioration, or grief but on messages of autonomy, dignity, courage, and struggles at the end of life. The media's role in shaping public opinion on this issue cannot be overstated. As a result, death with dignity has one of the highest favorability indexes in public opinion, giving hope for a more compassionate future.

In this process, we have gone from a nascent social movement with few relevant actors and minimal impact actions to an evolving movement that is beginning to act in a coordinated way, forming a network, building common agendas, and working strategically for several years to bring about social change. This inspiring evolution of the movement, which carries out impact litigation strategies to create social change, monitors government actions and failures to act, advocates before the authorities, and strengthens positive narratives in the media, is a testament to the progress made in the fight for the right to die with dignity.

Chapter II

What are we talking about when we talk about the right to die with dignity?

Reflections on the essential core of a fundamental right

After describing the emerging process and the positioning of the right to die with dignity within the Colombian legal system, the second chapter will develop its current legal status. To achieve this, we will discuss its legal nature, the different mechanisms it offers citizens to make autonomous decisions about the end of life and death, and the legal criteria that must be met to access MAiD.

The right to die with dignity in Colombia is a fundamental right that allows people to make autonomous decisions about their end of life and death, including access to medical assistance to cause death at a given moment. It is an independent and autonomous right that is closely related to other rights protected in the Colombian legal system, such as human dignity, the right to autonomy, the right to live a life protected from torture and ill-treatment, and the constitutional principle of social solidarity.

The right to die with dignity in Colombia is not a one-dimensional concept. It is a multidimensional right, offering Colombians the freedom to exercise it through several mechanisms: palliative care, adequacy of therapeutic effort (ATE), and medical assistance in dying (MAiD). The latter includes euthanasia and medically-assisted suicide, which both constitutional precedents and regulatory norms have extensively addressed. These mechanisms are not mutually exclusive; on the contrary, they complement each other to provide individuals with the broadest possible range of choices in their end-of-life decisions. Several criteria must be met to access MAiD, including having a duly diagnosed serious and incurable illness, experiencing physical or psychological suffering incompatible with the concept of dignity, giving free, informed, and unequivocal consent, and being assisted by a physician.

A fundamental right of immediate application that can be judicially protected

According to judicial precedent, the right to die with dignity is an autonomous fundamental right independent of other rights. Consequently, it is not dependent on the right to life or an element of autonomy. It has its existence, which derives from the constitutional principle of human dignity, which, like all rights, is closely related to others without depending on them. Moreover, it is a multidimensional and complex right; it is a guarantee to which all persons in Colombia are entitled, but whose applicability depends on specific and restrictive circumstances that must be verified beforehand to avoid committing a crime.[178]

> For this Court, there is no doubt that the right to die with dignity is a fundamental right. And this is so for several reasons. In its reasoning, the Court has pointed out that a fundamental right seeks to guarantee human dignity. For a right to be considered fundamental, it must be closely linked to dignity as a value, a principle, and a right within our constitutional order. Decision C-239 of 1997 considers that its primary purpose is to allow life to consist not only in the vital subsistence of a person but goes far beyond that. These additional aspects belong to a subject endowed with dignity, who, as a moral agent, can carry out its life project. When this does not happen, people do not live with dignity. Even more so when they suffer from an illness that causes intense suffering to the patient. In such cases, who, if not the people themselves, should decide what the future of their lives should be? Why force people to live against their will when they have the right to decide over their own lives?[179]

Second, there is a consensus on the right's existence based on the two previous decisions on the matter and the instructions given to the legislature to regulate it. Finally, it is considered a fundamental right because it is a guarantee that can be translated into a subjective right in which the active and passive actors and the core obligations are clear.

Since the landmark 2014 decision (Decision T-970), all subsequent decisions have referred to the right to die with dignity as a fundamental right. As the previous chapter recounts, the Court has deepened its protection and broadened its contours with each case it has specifically addressed.

The recognition of the right to die with dignity as a fundamental right is a significant achievement. It means that protecting autonomous decisions about the end

[178] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[179] Ibid.

of life and death, including the possibility of accessing MAiD at a given moment, is of the same importance and relevance as the rights that the Constitution considers essential, such as life, freedom, and autonomy.

The status of a fundamental right means it enjoys all the judicial protections available to constitutional rights in Colombia, such as the *tutela*, an expeditious judicial remedy without excessive legal formalities that allows people to claim their rights against acts and omissions of public and private entities that violate or threaten them. The nature of a fundamental right has permitted and encouraged the strategic use of the *tutela* and the intervention of constitutional judges to expand and deepen the right to die with dignity, remove barriers, and monitor the actions and omissions of the Colombian healthcare system.

The recognition of the right to die with dignity as a fundamental right has significant implications for its judicial protection. Its implementation and guarantee do not require regulation by other public authorities, especially the legislative branch. This means that it has immediate effect and application, allowing people to claim it directly within the Colombian healthcare system without any specific legislation.

However, as indicated in the previous chapter, the struggle for a specific regulation remains. The Court has urged Congress to comprehensively legislate on this right in order to establish clear standards for its exercise, recognizing that the absence of such rules constitutes an obstacle. However, in the absence of congressional action, the Court has chosen to set the guidelines and order the specific regulation by the Ministry of Health to ensure that the Constitution and constitutional precedent maintain their effectiveness and application.

One right, four mechanisms for exercising it

Oftentimes the right to die with dignity is understood soley as the possibility to access the euthanasia procedure. However, it is important to understand that the right to die with dignity is multidimensional. It provides several mechanisms and options for individuals to decide on the end of their life and death.[180] These mutually compatible mechanisms include access to palliative care, adequacy of the therapeutic effort (ATE), and medical assistance in dying (MAiD), which includes euthanasia and medically-assisted suicide (MAS).

Constitutional precedent has established that these mechanisms

> Must enhance the dignity and capacity for self-determination of all persons on the verge of death. For this reason, a person cannot be required to exhaust one mechanism before accessing another or accept treatment that is considered disproportionate. Nevertheless, it is up to the patient to determine the course of action best suited to the state of health, vital interests, and concept of a dignified life.[181]

The first component is access to palliative care, which encompasses a range of medical and support services designed to enhance the well-being of the patient and their family. It focuses on comprehensive pain management and relief of suffering and other symptoms while acknowledging the psychological, physical, emotional, social, and spiritual aspects. As palliative care comprises medical interventions, patients have the right to decline it. Moreover, choosing palliative care does not preclude patients from later pursuing the other options available under the right to die with dignity.[182]

The second is adequacy of therapeutic effort (AET)[183], also known as limitation of therapeutic effort or readjustment of care. Pérez-Pérez defines it as "the adaptation of treatments to the patient's clinical situation. AET should be considered in cases where there is a low likelihood of a response to treatment and involves the evaluation of a change in therapeutic strategy involving the withdrawal or non-initiation of a treatment."[184] The same author questions the notion of limiting the therapeutic effort, noting that "it is not very appropriate, since the effort is not limited, but rather the therapeutic objectives change (moving to other areas such as sedation,

[180] See: (1) Constitutional Court of Colombia, Decision T-721/17 (Justice Rapporteur: Antonio José Lizarazo Ocampo); (2) Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

[181] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

[182] Republic of Colombia (September 8, 2014). Law 1733 of 2014, art 4.

[183] Correa-Montoya, Lucas, Giraldo-Castaño, Mónica and Jaramillo-Salazar, Camila (2023). Interpreting the will at the end of life. Guidelines to guarantee the rights to legal capacity and dignified death. DescLAB.

[184] Pérez-Pérez, Fabio (2016). Adecuación del esfuerzo terapéutico, una estrategia al final de la vida *(Adequacy of the therapeutic effort, a strategy at the end of life). Revista Medicina de Familia* SEMERGEN. 41(8), 566 -574.

analgesia, psychological support, etc.)."[185] There is a shift from the notion of limiting, in the sense of not doing, to adapting; for example, adapting these goals to the will and preferences of the person receiving them.

The Colombian regulations define ATE as the possibility of

> Adjusting the treatments and objectives of care to the person's clinical situation in cases where the person suffers. ATE involves the refusal, withholding, and withdrawal of activities, interventions, inputs, medicines, equipment, services, procedures, or treatments when their continuation could generate harm and suffering or be disproportionate to the therapeutic objectives and means.[186]

ATE can include medical actions related to withholding or omitting treatment, as well as actions such as withdrawing life support. Sanchini, Nardini, and Boniolo (2014) noted that these decisions are often framed in the context of end-of-life and near-death situations. Bioethical debates have focused on the question of medical intentions and the causality of death in such decisions. In this context, it is essential to note that such intentions are not directly aimed at causing death but rather at avoiding the imposition of professional judgment on the person, preventing therapeutic overuse, and respecting the person's informed choices, even when those choices result in death. In this way, the focus on causality has found a safe place to argue that omissions or actions do not directly cause death, but rather the illness experienced by the person, so that the decision to adjust the therapeutic effort only triggers the inevitable.[187]

In any case, discussions about intentions and causality in ATE are not black and white. In practice, some actions and omissions are closer to other mechanisms of the right to die with dignity, namely MAiD. In the global context, it is helpful to find a nuanced place to indicate what is legal and what is not, distinguishing some practices of ATE from MAiD in order to enable a discussion about end-of-life decisions in medical care settings, regardless of what may or may not be considered a crime in a particular country.

For its part, all possible mechanisms related to the right to die with dignity are legal, making it a particularly fertile ground for this bioethical discussion. Instead of emphasizing a strict differentiation between ATE and MAiD, the focus should be finding points of contact, proximity, and complementarity without discussing illegal or criminal acts.

Under the umbrella of MAiD, we find two mechanisms to materialize the right to die with dignity. These provide **safe, supported, and protected medical assistance to cause death at a given time and in accordance with a person's wishes.**

The first of these mechanisms is euthanasia, a medical procedure in which a physician directly causes the death of a person who meets the legal criteria. The Constitutional Court decriminalized it in Decision C-239 of 1997, but Congress has not regulated it to date. The Ministry of Health, following the orders of the Constitutional Court, has regulated it for adults by Resolution 971 of 2021 and minors by Resolution 825 of 2018.

The other mechanism is MAS, a procedure in which a physician provides the means—medication and instructions—for a person who meets the legal criteria to cause their death in a safe, supported, and protected manner. The Constitutional Court decriminalized MAS in Decision C-164 of 2022, but neither Congress nor the Ministry of Health have regulated the matter.

The first chapter explained that the mechanisms for exercising the right to die with dignity did not emerge uniformly but gradually and at different pace. The discussion and process of the right's emergence began in 1993 with a case on ATE. Later, in 1997, the Constitutional Court decriminalized euthanasia. Subsequently, between 2014 and 2020, the Court included palliative care under the umbrella of the right to die with dignity. Finally, in 2022, it decriminalized MAS.

The multidimensionality of the right to die with dignity implies that dignity and autonomy are guaranteed at the end of life. The existence of various mechanisms seeks to ensure that life, in its last moments, corresponds to the wishes and choices of people so that they are not forced to live against what they consider as dignified for

[185] Ibid.

[186] Ministry of Health and Social Protection of Colombia (February 20, 2020). Resolution 229 of 2020, art. 5.1.1.1.1. (c) Adequacy of the therapeutic effort.

[187] Sanchini Virginia, Nardini Cecilia, Boniolo Giovanni (2014). The withholding/withdrawing distinction in the end-of-life debate. *Multidisciplinary Respiratory Medicine,* 9(1), p.13. DOI: 10.1186/2049-6958-9-13.

their existence in a context of pain and suffering close to torture and cruel, inhuman and degrading treatment.

Criteria for exercising the right to die with dignity

The right to die with dignity is the subject of a detailed regulation in Colombia. As established by constitutional precedent and the current rules of the Ministry of Health, strict criteria must be met to access its mechanisms, specifically euthanasia or MAS.

In Decision C-239 of 1997, the Colombian Constitutional Court set forth four criteria for access to euthanasia. As described in the previous chapter, these criteria have since evolved to eliminate barriers and ensure their application by analogy with other mechanisms of the right to die with dignity.

First criterion: expression of free, informed, and unequivocal consent

The exercise of the right to die with dignity is a profound decision, one in which each person evaluates their life conditions, considering their unique and deeply personal concept of dignity. Since it is an irreversible decision, the termination of life must be based on the person's consent, given the paramount protection of life in the Colombian legal system. However, it is not a simple expression of will. Throughout the evolution of the fundamental right to die with dignity, constitutional decidions have defined strict characteristics that must be met, the moments in which it can take place, and the possibility of supporting people who cannot decide for themselves.

From the beginning of the emergence of this right, in Decision C-239 of 1997, the four characteristics that consent must meet in order to be considered sufficient and valid for access to euthanasia were enshrined. According to the Constitutional Court,

> The consent of the passive subject must be free, unequivocal, and expressed by a person capable of understanding the situation in which they are placed. In other words, consent implies that the person has serious and reliable information about the illness, the therapeutic options, and the prognosis and has sufficient intellectual capacity to make the decision.[188]

[188] Constitutional Court of Colombia (1997). Decision C-239/97 (Justice Rapporteur: Carlos Gaviria Díaz).

Photo by: Christina Victoria Craft

Subsequently, Decision T-970 of 2014 detailed the meaning of each of these characteristics. Free consent "means that there is no pressure from third parties on the decision. It is crucial that the motive for the decision is the patient's genuine will to end the intense pain they are suffering."[189] It must be a decision that is rigorously verified by the healthcare system,[190] in order to prevent requests for access to the right to die with dignity from being the result of situations of poverty, lack of care, and healthcare, among other social elements that could be resolved by other means.

Consent must also be informed, which means that the person and the family must have all the objective and necessary information to make a choice that is not hasty or biased[191] due to the impact of a problematic situation or lack of information about available treatments and their likelihood of success. Whoever makes the decision must also be able to understand its implications and the irreversible effects that will result from it to ensure that it is not the result of altered, critical, psychotic, or depressive moments of consciousness.[192] Finally, consent must be unequivocal; the decision must be unambiguous, leave no room for doubt, and be conscious and intentional over time.[193]

Constitutional precedent has also recognized that consent manifestation may occur at different times. While the medical diagnosis may catalyze the decision to consent, this may not work in all cases. Illness or health condition, for example, in an emergency or accident, does not allow enough time or deteriorates more or less rapidly the quality of life and the ability and competence to make a free, informed, and unequivocal decision on the different mechanisms to exercise the right to die with dignity.

For this reason, consent may also be given before or in anticipation of knowing the diagnosis or being unable to express one's will due to deteriorating health and quality of life. As the right to die with dignity has emerged, civil society has developed documents and tools that allow people to express their will in advance. Various organizations have documents known as living wills or advance directives that provide simple information on the criteria to be met, the options available, and formats that include the specific decisions and the persons designated to carry them out at the appropriate time.

Advance directives were tangentially addressed by Law 1733 of 2014[194] and then regulated by Resolution 1051 of 2016,[195] which initially referred only to advance decisions on ATE and did not directly consider the possibility of advance decisions on MAiD. However, such documents began to be used in cases of euthanasia to the extent that the regulation did not prohibit it, and therefore, they were utilized by analogy. In addition to the above, this regulation established the minimum content of the advance directive and how it should be formalized before a public notary.[196] This restriction meant that its formalization before witnesses or by means other than in writing was impractical for decision-making.

In 2018, the Ministry of Health updated the regulation with Resolution 2665 of 2018, which–once again–did not explicitly mention the possibility of using this type of document in MAiD cases, although Resolution 1216 of 2015 had established that they were valid to give consent in these cases.[197] Despite this error, the resolution corrected two main aspects: first, it expanded the possibilities of formalization so that the document could be signed and formalized before a notary, witnesses, or a physician. Second, it allowed it to be made in audio and video.

In addition, precedent has established that consent may be formal or informal, formal being understood as written and informal as oral.[198] The regulations, as already mentioned, have tried to provide different options and mechanisms to express one's will in a valid and anticipated form, with more or less criteria, trying to achieve a balance between the formality required by the type

[189] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[190] Constitutional Court of Colombia (2017). Decision T-322/17 (Justice Rapporteur: Aquiles Arrieta Gómez).

[191] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[192] Constitutional Court of Colombia (2017). Decision T-322/17 (MP: Aquiles Arrieta Gómez).

[193] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

[194] Republic of Colombia (September 8, 2014). Law 1733 of 2014, art. 5(4).

[195] Ministry of Health and Social Protection of Colombia (April 1, 2016). Resolution 1051 of 2016, art. 4.

[196] Ibid., art. 6, para. 6.

[197] Ministry of Health and Social Protection of Colombia (April 20, 2015). Resolution 1216 of 2015, art. 15.

[198] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

of decision to be made and the necessary flexibility so that at the time of deciding the person finds the fewest obstacles that prevent the guarantee of the right to die with dignity.

Finally, the precedent, starting with Decision T-970 of 2014, established that consent could also be surrogate. This exceptional option occurs "when the person suffering from a terminal illness is incapable of giving consent. In such cases, and in the interest of not prolonging their suffering, the family may provide their consent by proxy. In these cases, the same procedure is followed as in the previous paragraph, but the Interdisciplinary Committee must be more rigorous in following the criteria."[199] In the process of the emergence of the right to die with dignity, the figure of surrogate consent has met with all kinds of opposition and great concern, mainly when it refers to MAiD.

Resolution 1216 of 2015, which regulates the procedures and responsibilities of the healthcare system concerning MAiD, merges the concepts of surrogate consent and prior consent by establishing that:

> If the person of legal age is incapacitated or some circumstances prevent the expression of the will, such a request may be made by those who are entitled to give surrogate consent, subject to the condition that the patient's will has previously been expressed in an advance directive or living will and that the relatives are also required to leave a written record of such will.[200]

Two Constitutional Court decisions, T-721 of 2017 and T-060 of 2020, addressed the issue of surrogate consent in end-of-life decisions following a merger. It was found that the right to die with dignity for individuals unable to give their consent was compromised due to the elimination of the surrogate consent provision. Since 2017, the Court has ordered the Ministry of Health to regulate the matter, but this still needs to be accomplished.

Due to legal advances in the right to equal recognition before the law and legal capacity, the concept of surrogate consent currently needs to be revised. Globally and in Colombia, it is necessary to make a transition from the substitute decision-making paradigm on legal capacity to that of supported decision-making.[201] This paradigm shift[202] means that all people, including those with disabilities, in a coma, vegetative or minimally conscious state, with cognitive impairment, dementia, among others, are recognized as capable of making decisions and need different types of support to do so.

These supports vary in depth and depend on each person's specific needs at any given time. The consequence of this change is that it is not possible to speak of surrogate consent since all people, regardless of their state of health, are considered to have legal capacity, which cannot be taken away or substituted; on the contrary, they have the support to make decisions and exercise this capacity.

However, the fact that the law recognizes the legal capacity of all persons does not mean that they are always in an actual position to make decisions and, when it comes to accessing the right to die with dignity, to give their consent in a free, informed, and unequivocal manner. The United Nations Committee on the Rights of Persons with Disabilities has stated that "if, despite considerable efforts, it is not possible to ascertain a person's preferences, the determination of best interests should be replaced by the best interpretation of the person's will and preferences."[203]

Traditionally, the application of the best interest of the person meant that, in the most complex cases, those assisting the person had to think and decide based on what was considered objectively good or desirable for the person, regardless of whether the

[199] Ibid.

[200] Ministry of Health and Social Protection of Colombia (April 20, 2015). Resolution 1216 of 2015, art. 15.

[201] See: (1) United Nations General Assembly (2007). Convention on the Rights of Persons with Disabilities, art. 12; Committee on the Rights of Persons with Disabilities (2014). (2) General Comment No. 1, art. 12: Equal recognition before the law; Republic of Colombia. (August 26, 2019). Law 1996 of 2019.

[202] See: (1) Bach, Michael and Kerzner, Lana (2010). A New Paradigm for Protecting Autonomy and The Right to Legal Capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice. Commissioned and submitted to The Law Commission of Ontario; (2) Dinerstein, Robert D. (2012). Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making. *Human Rights Brief,* 19(2), 8-12; (3) Quinn, Gerard. (2010). Personhood & Legal Capacity. Perspectives on the Paradigm Shift of Article 12 CRPD. *HPOD Conference, Harvard Law School.*

[203] Committee on the Rights of Persons with Disabilities (2014). General Comment No. 1, Article 12: Equal recognition before the law.

person would have chosen, preferred or not.[204] It was an objective principle aimed at guaranteeing the rights of the individual. As a result of applying the principle of the person's best interests, for example, in emergencies, physicians used all the means of assistance since the preservation of life and health was a higher interest that should always prevail.

The United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 on legal capacity require a shift from the principle of best interests to the principle of the best interpretation of the person's will and preferences. This type of high-intensity support should be used in exceptional cases where the person is incapable of communicating and cannot express their will and preferences by any means or in any way. This means that third parties in the support network, based on their knowledge of the person, personal values, principles, beliefs, past decisions, life-long conversations, and other elements of interpretation and judgment, indicate in a reasonable and supported way what the person would have decided in this situation if the person had been able to give direct consent.

Using the principle of the best interpretation of the person's will and preferences is not a way to substitute consent. Skowron understands this exercise as both a process and an outcome.[205] In the first case,[206] whoever makes the best interpretation of the person's will and preferences does not decide for the person or impose their will or preferences on the person. On the contrary, by interpreting what they would have chosen for themselves, they provide the most profound possible support to interpret, know, and respect their wishes.

In the second case,[207] allowing the use of this principle does not automatically mean that the person will have access to the mechanisms of the right to die with dignity, in particular MAiD, but that the support network will be allowed to make the best interpretation of the person's will and preferences. That is, the network will provide support, and on that basis, it will be determined whether that would have been the person's will, whether they would have refused, or whether the network does not have sufficient elements to make that best interpretation.

The principle of the best interpretation of the will and preferences makes it possible for a person unable to express their will to have their support network protect the values, beliefs, and principles that make up their biographical life: the life that goes beyond biological existence, the one full of projects, goals, objectives, relationships, satisfactions, the life that the person considers to be meaningful and dignified, the one that the person wanted to live and wished to live.

The constitutional precedent on MAiD has profoundly developed the criterion of free, informed, and unequivocal consent; in practice, however, its characteristics and modalities have been extended to the other available mechanisms of the right to die with dignity, such as palliative care and ATE.

Second criterion: diagnosis of serious and incurable illness

The second criterion for exercising the right to die with dignity is that the person, whether an adult or a minor, has a duly diagnosed illness that is serious and incurable. In Decision C-233 of 2021, the Constitutional Court delved this requirement for cases related to MAiD. First, the person must have a particular pathological condition that a physician has duly diagnosed; there must be no doubt about the situation that affects them. Second, the illness must be incurable; it cannot be eliminated or reversed with the available health knowledge, technology, and resources. Finally, the illness must be serious; its impact on the person must be detrimental to their well-being.[208] At the center of the condition of serious illness is the quality of life: when the person who experiences it believes that its effects are detrimental to the way of life, to the quality of life, and the life project, regardless of whether death is foreseeable in the short, medium, or long term.

[204] Donnelly, M. (2016). Best interests in the mental capacity act: time to say goodbye. *Medical Law Review,* 24(3), 318-332.

[205] Skowron, Paul (2019). Giving substance to 'the best interpretation of will and preferences.' *International Journal of Law and Psychiatry,* 62, 125-134.

[206] Ibid.

[207] Ibid.

[208] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

In decisions C-233 of 2021, T-414 of 2021, and T-239 of 2023, the Constitutional Court ruled that it was no longer necessary to have a terminal illness in order to apply for MAiD. The Court reasoned that the previous criterion, in force since 1997, had impeded access to the right to die with dignity. The 1997 legal reasoning was based on the idea that individuals facing a terminal illness understand that medical treatment cannot provide a cure, and therefore, they are not choosing between death and many years of life but rather between dying under conditions of their choice or enduring prolonged suffering that they consider unworthy.[209]

Law 1733 of 2014 introduced the definition of terminally ill, which Resolutions 1216 of 2015,[210] 825 of 2018, and 971 of 2021 reiterated. This law defined the term as:

> Anyone who has a serious disease or pathological condition that has been accurately diagnosed by an expert physician, which is progressive and irreversible, with a prognosis of near death or in a relatively short time, which is not susceptible to a curative treatment of proven efficacy that allows modification of the prognosis of near death; or when the therapeutic means used for curative purposes have ceased to be effective.[211]

Neither the constitutional precedent nor Law 1733 of 2014 nor the regulations of the Ministry of Health specified what it meant to have a fatal prognosis in the near future or a short period. It was the Protocol for the Application of the Euthanasia Procedure in Colombia—an official document without the value of a legal norm—which indicated that "near" was understood as a maximum of six months and which defined the standardized tests recommended to determine the situation of terminal illness.[212]

In its decisions C-233 of 2021 and T-414 of 2021, the Constitutional Court affirmed that it is not necessary to wait until death is imminent or the state of health has deteriorated to make death foreseeable in a short time. In doing so, it recognized that forcing a person to have a terminal illness violates the right to die with dignity, the right to a dignified life, and the right to autonomy and poses a risk for ill-treatment. This criterion extends equally to access to palliative care and ATE. However, it has generated less legal and bioethical discussion and tension than its application to MAiD.

Third criterion: to experience physical or psychological suffering incompatible with one's idea of dignity

It is not enough to have a serious and incurable illness; it is also necessary that such a condition causes intense suffering, whether physical or psychological, which the person considers incompatible with their idea of dignity. The Court has recognized, since Decision C-239 of 1997, that this element is purely subjective, that it touches the most intimate sphere, and that, even if there are scientific or technical tools to determine or qualify pain, it is the person who is best able to judge whether or not the pain and suffering are compatible with their idea of dignity.

Decision T-970 of 2014 underscores the autonomy of the individual in medical matters:

> Even if it can be medically established that an illness causes great pain (objective aspect), limiting this certainty to a medical concept contradicts the idea of autonomy and freedom of persons. No one but the patients themselves knows something is causing them such suffering that it is incompatible with their idea of dignity. Pain can be understood from many medical perspectives, and the lack of medical consensus may violate patients' rights. Although the physician's role in these procedures is indispensable, it is not absolute. Thus, the patient's will determines how undignified the suffering caused is, coupled with the medical examinations. Doctors cannot oppose the patient's will if it is clear, objectively and subjectively. The autonomy of the patient prevails.[213]

The Court went on to elaborate:

> The issues raised in this case demonstrate the close relationship between the right to die with dignity and human dignity. In the opinion of this Chamber, the right to die with dignity entails the possibility of making a reasoned and informed choice in which the person may choose to

[209] Constitutional Court of Colombia (1997). Decision C-239/97 (Justice Rapporteur: Carlos Gaviria Díaz).

[210] Ministry of Health and Social Protection of Colombia (April 20, 2015). Resolution 1216 of 2015, art. 2.

[211] Republic of Colombia (September 8, 2014). Law 1733 of 2014, art. 2.

[212] Ministry of Health and Social Protection of Colombia (2015). Protocol for the Application of the Euthanasia Procedure in Colombia, 2015. University of Antioquia, the National University of Colombia and the Meditech Foundation, 2015, p.13.

[213] Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

Operationalizing the principle of the best interpretation of the will and preferences allows the support network to provide support to assert the values, beliefs, and principles that make up the biographical life of the person who cannot express their will at a given moment

> end a life of intense suffering and pain. It allows [them] to withhold or withdraw torturous treatments that do not improve [their] health but only undermine their dignity. Each person knows what is best for [them], and the State should not adopt paternalistic positions that disproportionately interfere with such decisions.[214]

Recent decisions have faced the tension between this personal decision and the intervention of third parties in assessing pain or suffering. This situation is also related to the criterion of consent described above. In decisions T-544 of 2017, T-721 of 2017, and T-060 of 2020, the Colombian Constitutional Court faced situations in which other persons assessed suffering and the idea of a dignified life; in the first two cases, the parents, in the last, a daughter. In the 2020 case, due to the situation of health and disability, it was not possible to confront the person to obtain her position. In fact, during the period before the deterioration caused by the serious and incurable illness, the woman had not given any light or hint of a prior decision. Hence, when her illness overcame her, the doubt remained regarding her assessment of the intolerable suffering.

The assessment of suffering as incompatible with one's idea of dignity can be achieved when the person is unable to express their will or make the assessment themselves, thanks to the best interpretation of the will and preferences made by other people united by kinship, trust, and closeness and who provide support in the decision-making process. Based on previous assessments, opinions, choices, and priorities, the support network can better interpret whether the person would have chosen a dignified death or, on the contrary, would have opposed it.

At the same time, neither the constitutional precedent nor the regulations derived from it have determined the type of pain that must be experienced since it is sufficient that the person experiencing it evaluates it as intense, unbearable, and incompatible with the idea of a dignified life. Therefore, this criterion applies to any pain or suffering experienced and is not limited to physical pain or suffering.

The intervention of the Colombian College of Psychologists in Decision T-322 of 2017 was particularly revealing, given the importance of taking into account the facet of psychological pain that can result from a terminal illness: "Pain and suffering do not refer exclusively to the physical deterioration or damage to a person's health, as they also include the psychological suffering associated with advanced age, the loss of physical autonomy, the perception of psychological abandonment or loss of dignity, which leads to a deterioration in the quality of life of the person experiencing it."[215]

In Decision T-423 of 2017, the Court noted that the right to die with dignity through euthanasia "applies not only to the suffering of physical pain but by analogy to all those events which, because of an illness, affect the health and physical or mental integrity of the person."[216] In recent cases involving neurodegenerative diseases, the Court has had the opportunity to address the intersection between the pain and physical deterioration that people experience, together with the psychological suffering that comes with knowing that this deterioration will continue and deepen, significantly affecting autonomy, independence, freedom, and human dignity.

The Constitutional Court, in its Decision C-233 of 2021, had the opportunity to reflect in more depth and detail on the criterion of experiencing pain and suffering incompatible with the very idea of dignity, recognizing that there are different theoretical currents to understand pain, suffering, and their nature. The first approaches it as an object of sensitive perception in some part of the body, which means that "pain has spatiotemporal conditions and degrees of intensity found in some areas or parts of the body. Pain is thus understood in terms of physical characteristics or conditions that have caused damage or trauma to the body's tissues"[217] so that it can be described, quantified, evaluated, and compared.

The second approach affirms that "each person has a unique and privileged epistemological access to pain, or, in other words, that each person has the epistemic authority to claim that [they are] afflicted by pain. The

[214] Ibid.

[215] See: Intervention of the Colombian College of Psychologists in Decision T-322 of 2017 (Justice Rapporteur: Aquiles Arrieta Gómez).

[216] Constitutional Court of Colombia (2017). Decision T-423/17 (Justice Rapporteur: Iván Humberto Escrucería Mayolo).

[217] Constitutional Court of Colombia (2021). Decision C-233/21 (Justice Rapporteur: Diana Fajardo Rivera).

feeling of pain is therefore private, intimate, and personal to the extent that the one who suffers it, and not another, is the one who can directly know and evaluate it."[218] In line with previous decisions, the Court emphasized the subjective nature of this criterion and warned that the imposition of objective criteria on pain and suffering creates risks and possible violations of constitutional rights:

> Denying or questioning the existence or the extent of suffering or pain not only means annulling or degrading the patient's experience but also, since it is per se impossible for the other person to know it directly, entails a violation of the autonomy and dignity of the person who suffers it. Consequently, the imposition of someone else's criterion for the extent of pain, the questioning of how it is or is not manifest, or the demand for certainty about its state go beyond the understanding of someone else's subjective experience.[219]

This decision also ruled on mental or psychological suffering, recognizing multiple manifestations that go beyond the physical:

> Suffering as an emotional state projected from an extreme medical condition [...] is not exhausted in physical pain but is cast in a mental dimension. Suffering derived from the condition is also associated with the burdens imposed on the patient by diagnoses and treatments; the uncertainty of the outcome deepens it; it is materialized in family relationships; and it has a profound connection with time since the anticipation of future pain or death can exacerbate or alleviate the intensity of suffering.[220]

Returning to what the Court established in Decision T-970 of 2014, Decision C-233 of 2021 summarized the rules regarding this criterion. First, the subjective dimension of pain and suffering takes precedence in any discussion or disagreement between the patient, the physicians, and the healthcare system; irrespective of the means used to understand the phenomenon of pain and suffering, they are primarily a subjective experience of the person.[221] Secondly, technical and scientific tools enable an understanding of pain and suffering from a medical point of view and contribute to access to the right to die with dignity since they promote a dialogue between physician and patient to transmit and communicate information about the location and sensation of pain intensity.

From the beginning of the protection and development of the right to die with dignity, the Colombian constitutional precedent has been correct to treat pain and suffering not only from the physical dimension but also from the psychological dimension on an equal scale. At the same time, it has been correct to give precedence to subjective elements in the personal assessment of suffering, allowing people to decide when the situation they face is incompatible with their concept of human dignity rather than to medical evaluations.

This recognition of the personal and subjective elements of human suffering has avoided undue generalizations related to particular medical conditions, which can easily lead to the abstract assumption that a specific illness or way of life is not worth living. Fortunately, these bioethical and eugenic risks have not materialized yet in the Colombian context because each person, in their situation, has the right to evaluate whether the way they live is compatible with their idea of dignity. This also means that people in similar situations make different assessments: some decide to continue living while others choose to end their lives, and the legal system protects them both.

Fourth criterion: assistance must be provided by a physician

The right to die with dignity is a fundamental right that allows people to make autonomous decisions about the end of life and death. These choices must allow for a safe, supported, and protected death; therefore, medical procedures and specific health services must be assisted and provided by health professionals within the health system, not by family members or persons without knowledge and experience, nor in an unsafe manner or clandestine setting. Since 1997, the Constitutional Court has established that such professionals should carry out euthanasia since they have the training, knowledge, and experience to communicate with the person, explain the procedure and its risks, and finally perform it.[222]

[218] Ibid.
[219] Ibid.
[220] Ibid.
[221] Ibid.

[222] See: (1) Constitutional Court of Colombia (1997). Decision C-239/97 (Justice Rapporteur: Carlos Gaviria Díaz); (2) Constitutional Court of Colombia (2014). Decision T-970/14 (Justice Rapporteur: Luis Ernesto Vargas Silva).

This criterion was created in the context of the decriminalization of mercy killing, which led to the recognition of euthanasia as part of the right to die with dignity. It was essential to identify who could carry out the procedure without any prosecution and who would be committing a crime by carrying out the same actions. Thus, it is not only a question of knowledge and experience but also of protection and safeguards to prevent anyone from practicing MAiD because this would mean a lack of protection of the right to life.

Subsequently, in Decision C-164 of 2022, by which the Constitutional Court decriminalized MAS, the criterion was reaffirmed and detailed in a manner analogous to what the Court had done in 1997. First, it recognized that

> The physician-patient relationship is not of an authoritarian or paternalistic type, involving a vertical scheme, but rather a relationship of trust based on the principles of scientific competence of the physician and informed consent of the patient. Thus, the physician is in the best position to provide the patient with all the necessary information so that the patient, in the exercise of autonomy, can decide on the procedure to be undergone without in any way imposing the will of the physician on that of the patient.[223]

Second, regarding the physician's expertise, the Court stated the following:

> The position in which the physician finds itself justifies that it is itself that may provide suicide assistance in the terms described here. Indeed, it must be recognized that constitutionally valid suicide assistance is that which guarantees human dignity. It is not enough for someone to help another to die, but this must be done under the most humane conditions possible. In this process, assistance cannot be understood as the simple facilitation of a means to achieve the result but as the use of technical knowledge to ensure that the patient's dignity is preserved until the last moment. The physician has the pharmacological and pathophysiological knowledge to provide the best possible assistance.[224]

Therefore, physicians are the only individuals qualified by the Colombian legal system to assist and carry out the procedures that implement the MAiD mechanisms of the right to die with dignity established by the law.

Judicial precedent has developed this criterion so that MAiD cases clarify who is not subject to criminal sanctions and who may be.

* * *

In Colombia, the right to die with dignity is an evolving fundamental right. There is increased awareness among people about their end-of-life options. Many request assistance from the healthcare system and face challenges they seek to resolve through judicial review. Conservative social groups are attempting to undermine this right by questioning its fundamental nature, obstructing its progress, and spreading misinformation. Looking ahead, judges and the Constitutional Court will continue to play a crucial role in safeguarding human rights at the end of life, just as they have in the past.

Photo by: Guilherme Stecanella

[223] Constitutional Court of Colombia (2022). Decision C-164/22 (Justice Rapporteur: Antonio José Lizarazo Ocampo).

[224] Ibid.

Chapter III

Conclusions.

What is the future of the right to die with dignity in Colombia?

As an emerging right, the right to die with dignity owes its existence to a group of anonymous individuals whose individual and solitary struggles slowly reached their goal. These were cases without prominent lawyers and without the support of social organizations that would have argued their cases before the highest courts or the media. These struggles found liberal judges who, with their knowledge and position, played a crucial role in creating a fundamental right based on constitutional interpretation and embedding it in the orbit of other constitutionally protected rights.

Thirty-one years have passed since the first judicial decision on free and autonomous choices about illness, end of life, and death. Despite this, the reality for those seeking to die with dignity is still fraught with obstacles. Urgent advocacy is needed to remove these barriers and ensure timely and protected access to this right and the procedures that make it possible.

Although the legal scenario could be better and the efforts of the different actors need to be prolonged, the progress made in Colombia guaranteeing the right to die with dignity is unique in the region. In this sense, it is necessary to continue identifying the barriers that prevent access to the right to die with dignity and its mechanisms, the challenges posed by the healthcare system, and possible solutions so that more and more people in Colombia can make informed, free and autonomous decisions regarding the end of life. *The Slow Death*[225] report series describes the barriers identified by DescLAB and provides an annual quantitative and qualitative analysis, which we will explain below.

First barrier: Lack of availability and focus on palliative care. In addition to difficulties of availability, this type of care is often provided from religious or ideological perspectives that deny or obstruct access to other mechanisms that guarantee the right to die with dignity. Usually, the approach to ATE and MAiD in palliative care is seen as incompatible with or contrary to this area of practice. In other cases, access to palliative care is imposed as a prerequisite or prior step to requesting MAiD. Unconstitutionally and illegally, health professionals and clinics are forcing applicants to receive palliative care to evaluate their applications before the right-to-die Committees.

DescLAB's belief in completely guaranteeing the right to die with dignity is a guiding principle of our advocacy work. It's not enough to have access to MAiD or palliative care alone. Both should be available to those who need them as part of the same right. Each mechanism of the right to die with dignity should coexist, respecting the wishes and beliefs of those exercising their rights at the end of life.

Second barrier: Lack of regulation of the adequacy of the therapeutic effort (ATE). Despite court orders, there is still a need to regulate the practice of ATE, particularly concerning the refusal, withholding, and withdrawal of life-sustaining treatment in the case of persons who cannot make decisions or who have not previously done so. The lack of regulation of ATE—the absence of clear rules for knowing who can make decisions and who is in charge of authorizing the procedures—violates the rights of those who seek to exercise their right to die with dignity through this mechanism.

When third parties must make the best interpretation of a person's will and preferences, there are no clear rules to guide the actions of the support network, health professionals, and the Colombian healthcare system. For some people, the answer is *lex artis*, that is, the accepted practices within the medical profession, but this is not sufficient and often leads to violations of rights because it carries the risk of making the person's wishes invisible, of preventing the support network from making the best interpretation of the will and preferences, and of leaving the decision on what is considered compatible with the idea of dignity and autonomy only to the medical practitioner.

Currently, it is not possible to know how people and their support network can and should access ATE, what procedure to follow, how to request it, how to make the best interpretation of the will and preferences, and who is called to make decisions that can—directly or indirectly—cause a person's death. Since 2017, the Constitutional Court has ordered the Ministry of Health to

[225] See: (1) Correa- Montoya, Lucas and Jaramillo-Salazar, Camila (2021). De muerte lenta #1. Informe sobre las cifras y las barreras para ejercer el derecho a morir dignamente en Colombia *(Slow Death #1. Report on the data and barriers to exercise the right to die with dignity in Colombia).* DescLAB; (2) Correa-Montoya, Lucas and Jaramillo-Salazar, Camila (2022). De muerte lenta #2. Cifras, barreras y logros sobre el derecho a morir dignamente en Colombia (*Slow Death #2. Report on the data, barriers and achievements to exercise the right to die with dignity in Colombia).* DescLAB.

regulate the matter, a court order that, five years later, has yet to be fulfilled.

In parallel with the lack of regulation, health professionals and providers often require that individuals exhaust all possible and available treatments before allowing them access to MAiD. These treatments are offered not as therapeutic alternatives that the person can refuse but as mandatory steps to receive and evaluate MAiD requests. This imposition takes place as an act of power by health professionals over people and their families, where they illegally and unconstitutionally transform therapeutic options into obligations.

Third barrier: Lack of regulation of medically-assisted suicide. To date, there is still no regulation on MAS. In May 2022, the Constitutional Court decriminalized it, declaring it part of the right to die with dignity in Colombia. Under the same criteria as for euthanasia, a physician cannot be prosecuted for assisting a person to die. However, it is necessary to regulate MAS and, through this regulation, to materialize it as a service within the Colombian healthcare system.

In a scenario similar to the decriminalization of euthanasia before 2015, MAS is not considered a crime. Nevertheless, it is not a regulated practice for clinics within the healthcare system. In this sense, although the assistance provided by physicians is not criminalized, the procedure has yet to become effective in practice. This means that once it is requested, people will only encounter obstacles, and the actors of the healthcare system will refuse to receive and evaluate the requests and carry out the procedure.

However, the current panorama of MAS is much more positive than it was for euthanasia decades ago. After nine years of regulation of this mechanism, there is a whole history of experience with euthanasia that can be used to perform MAS legally. Likewise, as reiterated throughout this publication, acceptance and barriers to MAiD are decreasing.

Fourth barrier: Persistence of the terminal illness barrier in regulation. With regard to euthanasia, there is still a long way to go in several aspects of the regulation. With the elimination of the terminal illness barrier, the door has been opened for other types of illnesses considered serious and incurable to be evaluated by the committees on death with dignity within the healthcare system. However, access to euthanasia for serious and incurable illnesses continues to be prohibited by Resolution 971 of 2021, a regulation that still requires a terminal illness or severe advanced illness to access MAiD through euthanasia.

Although the Constitutional Court ordered the Ministry of Health to make the regulatory adjustments, the entity has refused to amend the resolution. This inconsistency between the Court's rulings and the regulatory standards needs to be resolved, as in some cases, clinics are acting in bad faith to impose barriers on individuals. To overcome this, the Ministry has to update the regulations in line with judicial progress.

Fifth barrier: Obstacles for people with mental illnesses. In addition to neurodegenerative and cardiac diseases, mental illness has become one of the reasons for requesting euthanasia in Colombia. To date, only one person has accessed euthanasia with a mental illness, specifically major depression, and there is still no consensus on how to assess the seriousness and incurability of this type of diagnosis.

The stigma of mental illness and psychological pain are issues that are just emerging from the perspective of the right to die with dignity. DescLAB represents people with mental disorders and illnesses in the process of exercising their right to die with dignity. There are several tensions—some deeper than for other types of illnesses—within the criteria that need to be assessed for mental illness at the time of requesting MAiD that have yet to be resolved. On the one hand, there is tension about the consent and will of people diagnosed with mental illness because while they may be able to give consent, this is not always possible. This situation raises questions about

their capacity and competence, particularly for those with certain chronic disorders or who are in crisis.

On the other hand, there are tensions about the seriousness of the illness and its persistence. As we have seen, the severity of the condition depends on the impact it has on the individual's life project, but measuring this impact in medicine is a task that varies from one practitioner to another. At the same time, the persistence of the illness is confronted with the resistance to treatment and the autonomy of each person about the best course of the illness and the treatment they want. Thus, mental illness—as a serious and incurable disease—remains in limbo when physicians evaluate requests for MAiD.

Sixth barrier: Unconstitutional exclusion of foreigners. As mentioned above, foreigners who do not reside in Colombia are still excluded from access to MAiD. Although the Colombian Constitution grants them the same protection of their rights as Colombian citizens, barring explicit exceptions to guarantee public order, the current regulation on the right to die with dignity requires foreigners who wish to apply for MAiD to prove that they have been living in the country for more than one year. This exclusion is an unconstitutional and illegitimate obstacle imposed by the Ministry of Health that does not protect public order but creates unjustified differences among the country's residents based on their nationality and place of domicile.

Seventh barrier: Exclusion of the support network to best interpret the will and preferences of those who cannot manifest consent. Those who cannot express their will and have not filled out an advance directive are excluded from access to MAiD. This happens because the support network—with the elimination of surrogate consent by the Ministry of Health—is prevented from making the best interpretation of the person's will and preferences.

The support network exists to provide formal and informal assistance in decision-making. In cases where the person cannot give consent, the network is entitled to make the best interpretation of the person's will and preferences. However, this network—which knows what the person would have wanted—is prevented from doing its job, providing support, giving consent, and requesting MAiD. This applies, for example, to people in a persistent vegetative state or with a form of dementia such as Alzheimer's disease.

Photo by: Mehdi Sepehri

As an international principle of legal capacity that is fully applicable in Colombia, the best interpretation of will and preferences is the way to regulate consent and overcome this barrier. This form of consent applies to the support network of people who once expressed their desire to have access to MAiD and who did not record this decision in an advance directive; to people who, on different occasions, were able to communicate that, if they were in a specific state, they preferred not to live in that way and wanted to be helped to die, among other situations. It is clear, then, that it is not a question of the support network imposing its will on the person who is incapable of giving consent, nor that such a network can decide without limits who lives and who does not, but rather that those who know the person best can help them make decisions and give the best interpretation so that their will is fulfilled[226].

Eighth barrier: Unconstitutional use of conscientious objection. Finally, there is the unconstitutional use of conscientious objection by physicians and hospitals. This objection arises from one of the prerogatives of freedom of conscience —the capacity of individuals to act or refrain from performing an act based on their convictions, beliefs, or way of perceiving the world—according to which no one is forced to act against their conscience. On the basis of this legitimate right and prerogative, some physicians and clinics use this right unconstitutionally and illegally to deliberately obstruct the exercise of the right to die with dignity.

In terms of conscientious objection in cases related to the right to die with dignity, the Colombian Constitutional Court has established that the physicians involved in the procedure may object based on personal convictions without this becoming an obstacle to fulfilling the rights of the perston. In Resolution 971 of 2021, the Ministry of Health established that there should be non-objecting professionals in the Committee and that it should be guaranteed that whoever performs the procedure should also be a non-objecting physician. At the same time, it clarified that the medical institutions could not claim institutional conscientious objection.

In this sense, physicians who claim a deep belief or conviction against performing the procedure can only invoke conscientious objection. In practice, however, some of them refuse to receive and evaluate requests or provide objective information about people's options regarding the end of their lives and the right to die with dignity, using their beliefs as a cover for violating the rights of others and fulfilling their professional duties.

Some clinics also claim institutional conscientious objection on the basis that they, as a corporation, profess a particular religious belief. Often, the fact that religious orders own these facilities or that their directors profess a faith or belief system is used to refuse to receive, evaluate, process, or perform the requests on the right to die. Some have created the fiction that clinics and hospitals are instruments for advancing certain religious beliefs. To this end, they seek to impede the exercise of fundamental rights rather than being vehicles for providing health services.

* * *

Colombia is today the only country in the Global South that fully and decisively protects the right to die with dignity. Together with some countries, such as the Netherlands, Belgium, Luxembourg, Germany, Spain, Australia, and Canada, it occupies a privileged place in the global conversations and struggles on this issue.

Three decades after the first case on this right reached the Constitutional Court of Colombia, this process has begun to be deliberate and strategic. Thus, our goal should be a self-determined death so that people can think of themselves as finite beings, plan, anticipate, and choose the end of their lives, and make completely autonomous decisions in which the intervention of third parties is to inform and assist.

We are moving toward an entirely self-determined death, where scientific knowledge is at the service of people seeking a safe, supported, and protected death. We fight to ensure that people, their lives, and their ideas of dignity are not subordinated to the beliefs of others.

[226] Correa-Montoya, Lucas, Giraldo-Castaño, Mónica and Jaramillo-Salazar, Camila (2023). Interpreting the will at the end of life. Guidelines to guarantee the rights to legal capacity and dignified death. DescLAB.

[227] El País. (August 3, 2022). Deputies unify the two bills that seek to legalize euthanasia.

Despite being the most advanced country on the continent, we are not alone. In the last few years, we have seen the issue move forward in the region. In Uruguay, there are two bills on MAiD, whose social and legislative discussion began in 2021 and will continue throughout 2024.[227] In Argentina, there are three bills whose discussion has generated enormous attention.[228] Chile's draft political constitution included an article on death with dignity, and although the people rejected it, it marks a path towards constitutionalizing the discussion in the region.[229] Finally, there have been cases in Perú[230] and Ecuador[231]–where euthanasia was decriminalized–that have opened the doors to significant conversations.

Advancing the right to die with dignity requires a framework of social mobilization that can build a common agenda to expand and deepen this right and its mechanisms and to monitor its proper implementation. **DescLAB** is here to lead this new social movement, generate high-level knowledge, propose difficult conversations, and develop high-impact actions. **We are a voice, not an echo.**

[228] La Nación (August 28, 2022). Derecho a la muerte digna: los proyectos de ley que reavivan el debate sobre eutanasia.

[229] Republic of Chile (2022). Proposed Political Constitution of the Republic of Chile.

[230] See: (1) Cable News Network (CNN) (July 27, 2022). Peruvian judiciary gives the green light to Ana Estrada's euthanasia request; (2) El País (May 5, 2024). Maria Benito, the patient who fought against the health system to die with dignity in Peru, dies.

[231] The Associated Press (AP News). (February 7, 2024). Ecuador's high court decriminalizes euthanasia, following a lawsuit by a terminally ill patient.

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