



INTERPRETING WILL AT THE END OF LIFE

GUIDELINES TO GUARANTEE
THE RIGHTS TO LEGAL
CAPACITY AND DIGNIFIED
DEATH



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DescLAB | Laboratorio de Derechos Económicos, Sociales y Culturales

Bogotá – Colombia
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ISBN (Online):

978-958-52945-4-7

Design and edition:

PrácticamenteLechuga.

Photographs:

Cover: Aboodie Vesakaran, 2020.
Pages: Aboodie Vesakaran, 2020; Greg Rosenke, 2019; Possessed Photography, 2020.

This document was translated from Spanish using DeepL, proofread using Grammarly, and finally reviewed and corrected by the authors.

August 30, 2023

Cite as: Correa-Montoya, Lucas, Giraldo-Castaño, Monica y Jaramillo-Salazar, Camila (2023). *Interpreting will at the end of life. Guidelines to guarantee the rights to legal capacity and dignified death*. Bogotá: DescLAB. 39 p.

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TABLE OF CONTENTS

8 INTRODUCTION

9 METHODOLOGICAL ROUTE. HOW WAS THIS DOCUMENT ACHIEVED?

11 AUDIENCE. TO WHOM IS THIS DOCUMENT ADDRESSED?

12 FROM SURROGATE CONSENT TO THE BEST INTERPRETATION OF WILL AND PREFERENCES AT THE END OF LIFE. A PARADIGM SHIFT

12 **Mechanisms for the realization** of the right to die with dignity

14 **Consent** to the right to die with dignity

16 **The judicial struggle to enforce the will and preferences** of those who cannot express consent and did not do so in advance

19 **The paradigm shift:** from the subtraction of legal capacity to supported decision-making

21 SCOPE OF APPLICATION. IN WHICH CASES SHOULD THE PRINCIPLE OF THE BEST INTERPRETATION OF THE PERSON'S WILL AND PREFERENCES BE USED?

22 'GUIDELINES. HOW TO CARRY OUT THE BEST INTERPRETATION OF THE WILL AND PREFERENCES IN CASES OF A DIGNIFIED DEATH?

23 **Guideline 1.** Consent by the support network is given based on the best interpretation of the person's will and preferences

24 **Guideline 2.** The Committee in charge of studying the case shall evaluate the impossibility of manifesting the will and giving consent

25 **Guideline 3.** The support network is diverse and can be composed of people united by kinship, ties of closeness, and trust

26 **Guideline 4.** Address and rule out conflicts of interest to best interpret the person's will and preferences

28 **Guideline 5.** Verify that the person has been offered palliative care, with the available treatment options, and with the possibility of adjusting or refusing them

29 **Guideline 6.** The medical records and the narratives of the health care personnel can contribute to the best interpretation of the person's will and preferences

30 **Guideline 7.** The Committee in charge of studying the case shall comprehensively evaluate the suffering based on the person's life experience

31 **Guideline 8.** Build the person's life narrative with the best interpretation of the will and preferences through interviews with people in the support network

34 **Guideline 9.** Achieving the necessary consensus in the narrative by those who make up the support network

36 REFERENCES



ABBREVIATIONS AND ACRONYMS

ATE: Adequacy of Therapeutic Effort

MAS: Medically assisted suicide

MAiD: Medical Assistance in Dying

ICU: Intensive Care Unit

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INTRODUCTION

¹ More information about DescLAB at: <https://www.descslab.com/>

² More information about DMD at: <https://dmd.org.co/>

³ Colombian Constitutional Court. Decisions T-970 of 2014, T-721 of 2017, T-060 of 2020, C-233 of 2021 and T-164 of 2022.

To advance and deepen the right to die with dignity in Colombia, DescLAB | Laboratorio de Derechos Económicos, Sociales y Culturales¹ and Fundación Pro Derecho a Morir Dignamente (DMD Foundation)² have produced this document as a starting point for a necessary conversation: interpreting will and preferences at the end of life for those who cannot express consent.

In Colombia, the right to die with dignity is a multidimensional fundamental right that includes several mechanisms for its materialization. In our country, four mechanisms are available and completely legal to be chosen by each person according to their wishes and possibilities at the end of life: palliative care, adequacy of therapeutic effort (ATE), euthanasia, and medically assisted suicide (MAS)³.

Despite legal and regulatory advances around the right to a dignified death in Colombia, we know firsthand the barriers that hinder exercising such a right. Namely, we have witnessed the challenge of guaranteeing the right to legal capacity for people who cannot express consent when trying to access MAiD and do not have an advance directive.

⁴ Ministry of Health and Social Protection. Resolution 2665 of 2018 and Resolution 971 of 2021.

Currently, despite the Colombian Constitutional Court allowing third parties to provide support and make the best interpretation of the will and preferences of those who are unable to express their will, the regulation of the Ministry of Health and Social Protection⁴ prohibits this form of consent. In other words, the regulation goes against constitutional precedent.

After a year of work, this document brings together the results of the qualitative research and the contributions of different practitioners, which are aimed at giving substance to the principle of the best interpretation of the will and preferences of people in cases of access to dignified death.

Different practitioners, including lawyers, psychologists, and physicians, accepted the invitation to be part of the focus groups. Subsequently, they participated in the review of the draft of this document. The authors are grateful for their time, availability, and professionalism in contributing their knowledge to a social discussion. As previously mentioned, these guidelines respond to a felt need of many families and support networks, and therefore, it has always been essential that the result responds to a collective construction.

These guidelines have several objectives: first, to guide medical institutions when carrying out the process of making the best interpretation of will and preferences; second, to influence the regulations to be enacted by the Ministry of Health and Social Protection; third, to illustrate the content of the decisions of the judges and the Constitutional Court; and finally, to become safeguards to protect the right to die with dignity and to legal capacity.

This contribution occurs at the intersection of the right to die with dignity, the paradigmatic changes in legal capacity, and the provision of support for decision-making at the international and local levels. The best interpretation of the will and preferences of the person does not mean that the people in the support network can impose their beliefs or value system; on the contrary, it entails an exercise of providing formal support to exercise legal capacity and to define what the person who cannot express their will would have preferred.

From DescLAB and the DMD Foundation, as actors that seek to protect, expand, and deepen the rights of individuals and families at the end of life, this is a first step to continue advancing towards the full exercise of human rights.

METHODOLOGICAL ROUTE. HOW WAS THIS DOCUMENT ACHIEVED?

DMD Foundation and DescLAB have written this document of guidelines to gua-

rantee the rights to legal capacity and dignified death of persons unable to express their will in five phases.

In the first phase, we carried out a **methodological conceptualization** to outline a route and identify the preliminary objectives of constructing a document of guidelines for the interpretation of the will and preferences of people at the end of life. This conceptualization resulted in proposing three reality-based hypothetical cases to be solved in focus groups composed of medicine, psychology, and law practitioners. The team also elaborated a concise theoretical framework to set the discussion, its academic categories, and the most current and relevant debates.

In the second phase, members of DescLAB and the DMD Foundation convened and led three **focus groups** composed as follows:

- + Medical practitioners: Eight (8) practitioners from neurology, psychiatry, geriatrics, oncology, and palliative care attended. Over half of the practitioners have participated in committees for the right to die with dignity in Colombia.
- + Psychology practitioners: Six (6) practitioners from grief, life narrative, and end-of-life support fields attended. Half of the practitioners have participated in committees for the right to die with dignity in Colombia.
- + Legal practitioners: five (5) practitioners from fields such as family, property, medical, end-of-life, and human rights law attended.

In each focus group, we presented the case of a woman with Alzheimer's disease who did not sign an advance directive. Based on what she communicated prior to the knowledge of the medical condition and the deterioration of the health situation, her partner decided to request MAiD using the best interpretation of the person's will and preferences. Based on this hypothetical case, each of the participants had a turn to intervene and offer their concept and opinion regarding the tensions, difficulties, and concerns that emerge when dealing with surrogate consent and the best interpretation of the will and preferences of a woman who cannot directly express their will.

The team did not use the remaining two reality-based hypothetical cases developed in the first phase, so the focus groups' results would be consistent and comparable.

In the third phase, the **inputs were analyzed** through qualitative analysis software by DescLAB and DMD Foundation researchers. Each researcher categorized the information, and then the category tree was analyzed, discussed, and refined. The preliminary version of the guidelines document included a systematized categorization of the findings.

⁵ The Colombian Constitutional Court created such a legal duty through Decisions T-721 of 2017 (Justice: Antonio José Lizarazo Ocampo) and T-060 of 2020 (Justice: Alberto Rojas Ríos).

In the fourth phase, the team **shared the preliminary document** carried out by the two organizations with some of the participants in the focus groups, as well as with other experts in medicine, psychology, and law to learn their perceptions, recommendations, and suggestions; and thus integrate, as far as possible, their contributions to the final document. This phase, like the second phase, sought to consolidate the concerns of different stakeholders regarding surrogate consent and the best interpretation of the person's will and preferences.

In the fifth phase, the team of researchers **consolidated the final document** and carried out the editing, translation, publication, and dissemination process.

The struggle to recognize the right to die with dignity for people who need support in making decisions is a complex discussion with different bioethical and legal concerns. For this reason, the construction of this document had contributions from multiple actors and feedback from key practitioners in the field of dignified death in Colombia and Latin America.

AUDIENCE. TO WHOM IS THIS DOCUMENT ADDRESSED?

First, this guidelines document is addressed to the **Ministry of Health and Social Protection**. This public entity has the legal duty⁵ to regulate surrogate consent and allow support networks to make the best interpretation of the will and preferences of the person who cannot give consent to access the mechanisms of the right to die with dignity.

Second, it is addressed to the **Scientific-Interdisciplinary Committees for Dignified Dying**. These committees are the bodies that hear requests for Medical Assistance in Dying (MAiD) within the institutions providing health services and must know, observe, and directly apply the constitutional precedent on the right to die with dignity.

Third, it is addressed to **medical practitioners** who are directly involved in providing care for people, to those who provide information on the mechanisms offered by the right to die with dignity, offer therapeutic alternatives, and accompany people and their support networks in the process of illness and death.

Finally, it is addressed to the **Colombian Constitutional Court and judges**, judicial instances that hear daily cases in which the possibility of providing support for decision-making at the end of life is denied and, therefore, people are excluded from accessing the mechanisms provided by the right to die with dignity.

⁶ Colombian Constitutional Court, Decision C-239 of 1997 (Justice: Carlos Gaviria Díaz).

⁷ Correa-Montoya, Lucas and Jaramillo-Salazar, Camila (2022). A Slow Death #2. Data, barriers, and achievements on the right to die with dignity in Colombia. Bogota: DescLAB. p10.

⁸ See Decisions T-493 of 1993, C-233 of 2014, T-970 of 2014, T-132 of 2016, T-322 of 2017, T-423 of 2017, T-544 of 2017, T-721 of 2017, T-060 of 2020, C-233 of 2021, T-414 of 2021 and C-164 of 2022.

⁹ See Law 1733 of 2014, article 4 and Decision C-233 of 2014 (Justice: Alberto Rojas Ríos).

¹⁰ Pérez-Pérez, F.M. (2016). Adequacy of therapeutic effort, a strategy at the end of life. In: Revista Medicina de Familia SEMERGEN. Volume 41, number 8, 566 -574.

¹¹ Ibid.

FROM SURROGATE CONSENT TO THE BEST INTERPRETATION OF WILL AND PREFERENCES AT THE END OF LIFE. A PARADIGM SHIFT

In 1997, the Colombian Constitutional Court decriminalized euthanasia. Through Decision C-239 of 1997, the right to die with dignity emerged within constitutional precedent⁶ as the right that allows people to make autonomous decisions about the end of their life and death. It is a right “that allows the end of life and death to correspond to each person’s wishes and with their idea of dignity and autonomy. It entails that no one should be forced to live at the end of their life and die in conditions contrary to their will, amid pain, suffering, and uncertainty. It also includes the possibility of finding medical assistance to access a safe, accompanied, and protected death at the precise moment of one’s choice.”⁷

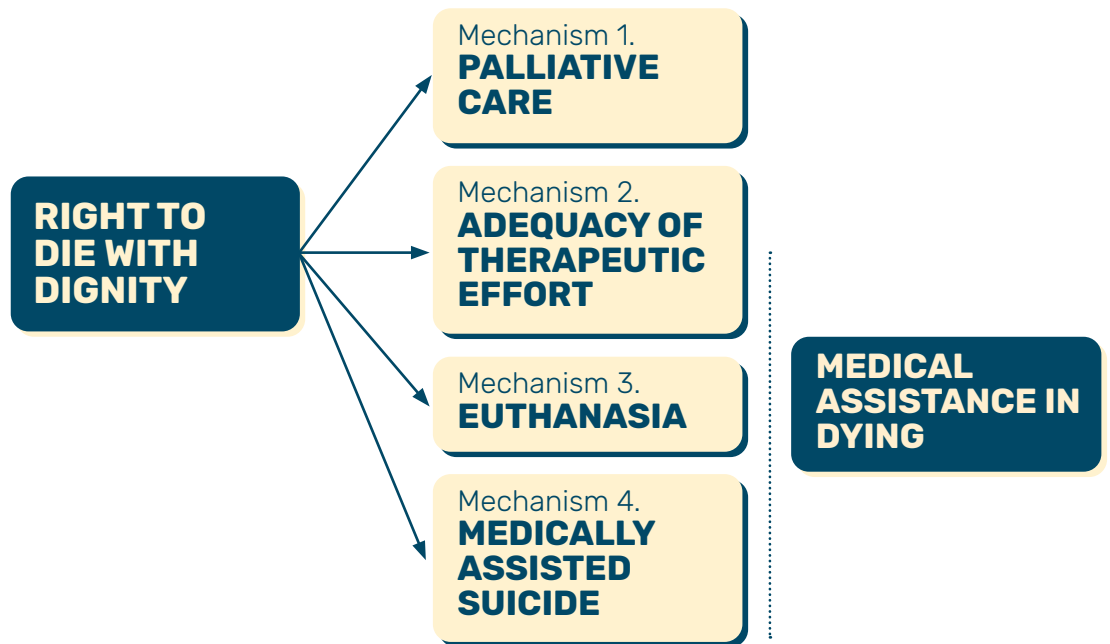
MECHANISMS FOR THE REALIZATION OF THE RIGHT TO DIE WITH DIGNITY

The Colombian Constitutional Court has accepted several mechanisms to realize this emerging human right⁸. The mechanisms for its materialization are, first, **access to palliative care**. Palliative care integrates a diverse set of medical and assistance services aimed at improving the quality of life of the person and their family through comprehensive treatment of pain, relief of suffering, and other symptoms, taking into account physical, emotional, social, and spiritual aspects⁹.

Second, **the adequacy of therapeutic effort (ATE)** is defined by Pérez-Pérez as “the adjustment of treatments to the clinical situation of the patient. ATE should be considered in cases where there is a low possibility of response to treatments and entails assessing a change in the therapeutic strategy that involves withholding and withdrawing some treatment.”¹⁰ Pérez-Pérez questions the term “limitation of therapeutic effort” and notes that “it is not very appropriate, since the effort is not limited, but rather the therapeutic objectives change (moving towards other areas such as sedation, analgesia, psychological support, etc).”¹¹ There is a shift from the notion of limiting, in the sense of not doing, to adapting, for instance, adjusting to the therapeutic objectives and the will and preferences of the person receiving them.

The Colombian regulations define ATE as the possibility of “adjusting the treatments and care objectives to the clinical situation of the person, in cases where the person suffers from an advanced incurable, degenerative or irreversible disease or terminal illness when these do not comply with the principles of therapeutic proportionality, do not serve the best interest of the person, or do not represent a dignified life for them. ATE entails withholding or withdrawing activities, interventions, supplies, medications, devices, services, procedures, or

MECHANISMS OF THE RIGHT TO DIE WITH DIGNITY IN COLOMBIA



¹² Ministry of Health and Social Protection. Resolution 229 of 2020. Article 5.1.1.1.1. (c) Adequacy of Therapeutic Effort.

¹³ Sanchini V, Nardini C, Boniolo G. (2014). The withholding/withdrawing distinction in the end-of-life debate. In: *Multidisciplinary Respiratory Medicine*. March 11th; Volume 9, issue (1):13. Doi: 10.1186/2049-6958-9-13. PMID: 24618461; PMCID: PMC3978132.

treatments, where the continuity of these could generate harm and suffering, or be disproportionate to the therapeutic ends and means.”¹²

ATE can include medical acts related to withholding treatment, but it can also include medical acts related to action, such as withdrawing life-sustaining measures. As Sanchini, Nardini, and Boniolo point out, these decisions are often considered end-of-life and near-death. Bioethical debates have focused on medical intent and death causation in these situations. First, the medical purpose is not directly oriented to cause death but to avoid the imposition of professional judgment on the individual and to respect their duly informed decisions, even if it is clear that death will result from such omissions or actions. Secondly, the focus on causation has found a safe place to argue that the omissions or actions do not directly cause death but that the disease does so, and the decision to adjust the therapeutic effort only triggers the inevitable.¹³

In any case, discussions about intentions and causality in ATE are not black and white, and, in practice, some omissions and actions are closer to other mechanisms of the right to die with dignity, particularly MAiD. In the global context, discussions on ATE have sought to find a differentiated place to indicate what is legal and what is not, distinguishing some practices of ATE from MAiD (euthanasia and medically assisted suicide); this to enable a discussion on end-of-life decisions in medical-care settings regardless of what in a specific place may or may not be considered a crime. **The Colombian context, in which all possible mechanisms related to the right to die with dignity are legal, is**

¹⁴ Government of Canada - Province of British Columbia. Provincial Health Services Authority. Medical Assistance in Dying. The law in Canada has Changed.

¹⁵ See (1) Government of Canada - Province of British Columbia. Provincial Health Services Authority. Medical Assistance in Dying. The law in Canada has Changed, and (2) Goldberg R, Nissim R, An E, Hales S. (2021). Impact of medical assistance in dying (MAiD) on family caregivers. In: BMJ Support Palliative Care. March 11(1):107-114. DOI: 10.1136/bmj-spacare-2018-001686. Epub 2019 Mar 1. PMID: 30826737. .

¹⁶ Colombian Constitutional Court, Decision T-970 of 2014 (Justice: Luis Ernesto Vargas Silva).

¹⁷ Ibid.

¹⁸ Colombian Constitutional Court, Decision T-322 of 2017 (Justice: Aquiles Arrieta Gómez).

¹⁹ Colombian Constitutional Court, Decision T-970 of 2014 (Justice: Luis Ernesto Vargas Silva).

²⁰ Ibid.

²¹ Ibid.

²² Ibid.

²³ Ministry of Health and Social Protection. Resolution 229 of 2020. Articles 4.2.4.3, 4.5.1.1.

particularly fertile for this type of bioethical discussion and, instead of focusing on strictly differentiating ATE from MAiD to avoid talking about illegal or criminal conduct, we should find points of contact, closeness, and complementarity.

The third mechanism for accessing death with dignity is **Medical Assistance in Dying (MAiD)**, the process by which medical practitioners help a person who has requested it to end their life intentionally, safely, protected, and accompanied.¹⁴

MAiD can be exercised through **euthanasia**, where medical practitioners administer lethal doses of drugs, or through **medically assisted suicide (MAS)**, where medical practitioners give lethal doses of medications to the person, and the person administers such medications themselves, causing their death.¹⁵

CONSENT TO THE RIGHT TO DIE WITH DIGNITY

Throughout its jurisprudence on the right to die with dignity, the Colombian Constitutional Court has addressed the different characteristics of consent and how it can be expressed. In Decision T-970 of 2014, the Court indicated that consent must be free, informed, and unequivocal. **Free** “entails no pressure from third parties on the decision. What is decisive is that the motive for the decision is the patient’s genuine will to end the intense pain they are suffering.”¹⁶ **Informed** means that the person and their family have all the objective and necessary information to decide so that it is not hasty or biased,¹⁷ that the decision-maker is competent to understand the decision he is making and the irreversible effects that derive from it,¹⁸ and that it is not the product of altered or critical moments of consciousness.¹⁹ Finally, **unequivocal** means that the person’s clear decision leaves no room for doubt and is conscious and sustained over time.²⁰

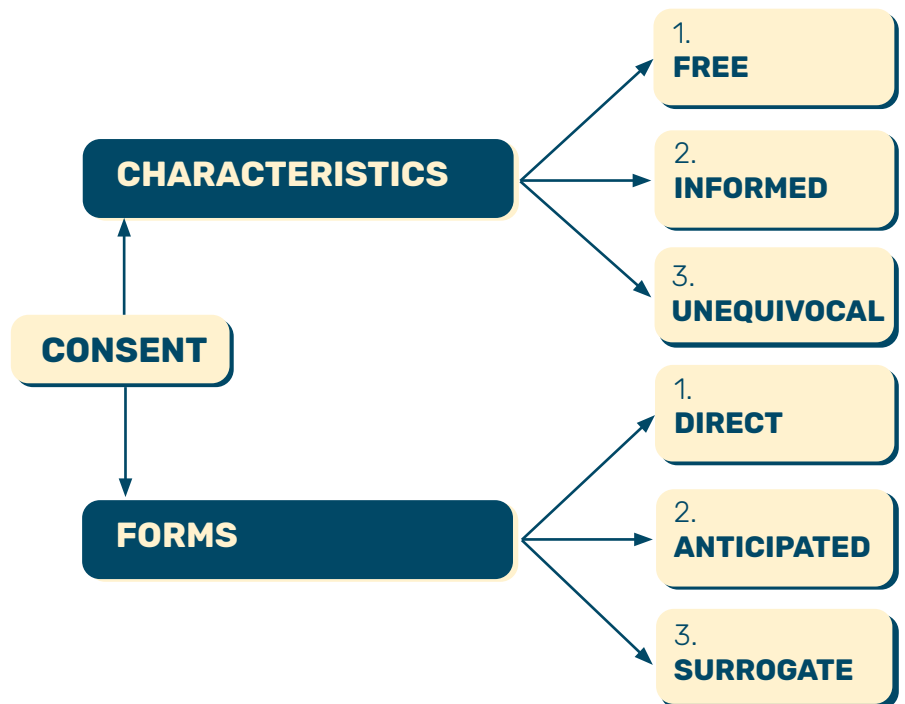
Consent can be expressed in multiple ways in compliance with the previous characteristics. First, it can be **direct**²¹ when it is provided by the same person who will exercise the right through any of its mechanisms when, at a given moment, they met the requirements established by the current regulations. For example, a cancer patient rejects the treatments offered and requests MAiD.

Second, consent can be **anticipated**²² when given by the same person who will exercise the right through any of its mechanisms without necessarily having a particular diagnosis and expecting their wishes to be respected. In this case, people in Colombia have the right to sign an advance directive in which, in full use of their faculties, in a free, conscious, and informed manner, they declare their will, for example, to refuse treatment or to agree to MAiD²³.

²⁴ Ibid.

Third, as the Constitutional Court has indicated, consent can be **a surrogate**²⁴; this means the possibility that consent to access the right to a dignified death and its different mechanisms can be provided by third parties, mainly when the person has not expressed their will through an advance directive and is in a state of health that prevents them from expressing their consent through any possible means.

CHARACTERISTICS AND FORMS OF CONSENT FOR REALIZING THE RIGHT TO DIE WITH DIGNITY IN COLOMBIA





THE JUDICIAL STRUGGLE TO ENFORCE THE WILL AND PREFERENCES OF THOSE WHO CANNOT EXPRESS CONSENT AND DID NOT DO SO IN ADVANCE

The possibility of third parties substituting consent for access to the mechanisms of the right to die with dignity, particularly for access to MAiD, has generated extensive legal and bioethical debates in Colombia. On the one hand, judicial authorities have acknowledged it and ordered its application; on the other hand, the Ministry of Health and Social Protection hinders it and makes its use impossible. In recent years, this struggle has taken place under the umbrella of recognizing legal capacity for persons with disabilities and the paradigm shift that implies moving from the subtraction of capacity to the provision of support for decision-making.

In **Resolution 1216 of 2015 (now repealed)**, through which the Ministry of Health and Social Protection complied with the orders given by the Constitutional Court through Decision T-970 of 2014, surrogate consent was regulated in the following terms:

In the event that the person of legal age is legally incompetent or under the existence of circumstances that prevent them from expressing their will, such request may be submitted by those who are entitled to give surrogate consent, **provided that the patient's will has been previously ex-**

²⁵ Ministry of Health and Social Protection, Resolution 1216 of 2015, art. 15.

²⁶ See Correa-Montoya, Lucas, (2020). A Dignified Death in Colombia. Judicial activism, social change, and constitutional discussions on an emerging right. Bogotá: DescLAB. 70 p.

²⁷ Colombian Constitutional Court, Decision T-721 of 2017 (Justice: Antonio José Lizarazo Ocampo).

²⁸ In Colombia, Law 1996 of 2019 eliminated the judicial interdiction to which some persons with disabilities were subjected through the provisions of the Civil Code and Law 1306 of 2009.

pressed through an advance directive or living will and requiring, on the part of the relatives, that such will is on the records.²⁵

In an unconstitutional action, the Ministry's regulation, by requiring people to have previously filled out an advance directives document, annulled in practice the possibility of third parties to express surrogate consent in favor of those who were unable to do so, to support them and to make the best interpretation of their will and preferences. Such disregard of the constitutional precedent has set the basis for subsequent judicial discussions.

According to the analysis of the jurisprudential evolution of the right to die with dignity in Colombia,²⁶ through **Decision T-721 of 2017**,²⁷ The Colombian Constitutional Court analyzed the case of a woman with a disability derived from epilepsy diagnosed in childhood and who was in a vegetative state. As a product of her situation, it was impossible to establish, neither technically nor medically, the pain faced by the woman, given that communication was nonexistent. The family related their interpretation of the pain and suffering based on the changes in her breathing and the condition of dependence in which she found herself. The woman died naturally, without undergoing the procedure requested by her family in the context of multiple obstacles and irregularities in applying current regulations on the right to die with dignity.

At the time, the woman was declared incompetent,²⁸ and her legal representatives requested the health system to perform the euthanasia procedure. When they did not receive a response, they went to court. The first instance judge ruled in favor of the family, finding that the health system had violated the right to die with dignity by not complying with the provisions of the regulations in force at the time, mainly because, in the defense, the hospital indicated that it had convened the committee and that its decision was in the records, but such were confidential. The second instance overturned the decision and agreed with the health institutions, establishing that there was indeed a response, although confidential, but indicated that there was no advance directive, much less any proof of the woman's decision, not that of her family, to agree to MAiD.

When the case reached, the Constitutional Court analyzed the issue of surrogate consent in light of **Decision T-970 of 2014**, which detailed this form of expressing consent. The Decision concluded that requiring an advance directive to be able to surrogate consent nullified the right to die with dignity of those who, like the woman in the case, cannot make such a decision.

In Decision T-721 of 2017, the Court made a structural ruling and ordered the Ministry of Health and Social Protection to adapt the regulation on surrogate consent. Namely, it demanded that it was unnecessary to have an advance directive for the support network to manifest the will in place of the person. To date, this order has yet to be complied with.

²⁹ Colombian Constitutional Court, Decision T-060 of 2020 (Justice: Alberto Rojas Ríos).

³⁰ Ibid.

³¹ Ministry of Health and Social Protection, Resolution 971 of 2021, article 11.

Subsequently, through **Decision T-060 of 2020**,²⁹ The Constitutional Court addressed the case of a 97-year-old woman with various serious diseases, including Alzheimer's disease and schizophrenia, whose daughter had requested the euthanasia procedure for her. In the process, she was required to provide an advance directive so that the surrogate consent could be given, but this was not possible since this document did not exist and the woman's state of health did not allow her to express it. For this reason, the health service providers denied the request made by the daughter, as did the two judicial instances that heard the case.

Upon reviewing the case, the Constitutional Court requested a specific report from the Ministry of Health and Social Protection on compliance with the orders issued in a previous judicial decision, which required it to modify the current regulations related to surrogate consent. The Court verified that the order had not been complied with, and the barrier created by the Ministry of Health and Social Protection persisted.

The Court, in this second case, warned that "the lack of regulation by the Ministry of Health and Social Protection regarding the conditions for the viability of surrogate consent in the scope of the right to die with dignity -regarding which this Corporation had already issued an order in Decision T-721 of 2017- may constitute a threat to the guarantee of said fundamental right, contrary to the dignity of patients and their families."³⁰ Therefore, the Court reiterated the obligation of the Ministry of Health and Social Protection to regulate surrogate consent in two events: first, when the person is in a situation of legal incapacity or under the existence of circumstances that prevent them from expressing their will and; second when there is a lack of a formal document of advance directives.

Despite the two decisions, the structural orders continue to be unfulfilled by the Ministry of Health and Social Protection. On July 1, 2021, the new **Resolution 971 of 2021** was issued. This regulatory norm repealed Resolution 1216 of 2015. Although it was an opportunity to comply with the structural Court orders on surrogate consent, the Ministry decided to continue with the non-compliance and prohibit it again.

Currently, Resolution 971 of 2021, when referring to non-compliance with the minimum conditions for processing the MAiD request before the committee, establishes that the committee will not be activated "when the request is through a third party in the absence of an advance directive."³¹ In other words, given the current regulation provided by the Ministry of Health and Social Protection, a third person can only request the procedure for another person who cannot express consent when they have an advance directive; this goes against the orders issued in Decisions T-721 of 2017 and T-060 of 2020.

³² See (1) United Nations, General Assembly (2007). Convention on the Rights of Persons with Disabilities (A/RES/61/106). Art. 12. (2) Committee on the Rights of Persons with Disabilities (2014). General Comment No. 1, Article 12: Equal recognition before the law. (CRPD/C/GC/1, May 19, 2014). (3) Republic of Colombia, Law 1996 of 2019.

³³ 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, no. 2 (2012): 8-12. (3) Quinn, Gerard. (2010). "Personhood & Legal Capacity. Perspectives on the Paradigm Shift of article 12 CRPD." HPOD Conference, Harvard Law School, 20 February.

³⁴ Committee on the Rights of Persons with Disabilities (2014). General Comment No. 1, Article 12: Equal recognition before the law. (CRPD/C/GC/1, May 19, 2014), ¶ 21.

³⁵ Donnelly, M. (2016). Best interests in the mental capacity act: time to say goodbye. *Medical Law Review*, 24(3), 318-332.

³⁶ Skowron, Paul (2019). Giving substance to 'the best interpretation of will and preferences'. En: *International Journal of Law and Psychiatry* 62 (2019) 125-134.

THE PARADIGM SHIFT: FROM THE SUBTRACTION OF LEGAL CAPACITY TO SUPPORTED DECISION-MAKING

Due to the legal advances related to the right to equal recognition before the law and legal capacity, the concept of surrogate consent needs to be revised. Currently, globally and in Colombia, we must transition from the subtraction of legal capacity to supported decision-making.³²

This paradigm shift³³ entails that all people, including those with disabilities, those in a coma, vegetative state, or in a state of minimal consciousness, with neurodegenerative diseases, among other situations, are recognized as people capable of making decisions and are entitled to different kinds of support in the decision-making process.

Such support varies in intensity and depends on each person's particular needs at a given moment. It follows from this change that it is not possible to talk of surrogate consent when it comes to access to the right to die with dignity because, regardless of the person's state of health, all persons are considered legally competent and are entitled to support in making decisions.

However, the fact that legal norms recognize the legal capacity of all persons does not imply that all persons are always in a position to make decisions and express consent in a free, informed, and unequivocal manner. The United Nations Committee on the Rights of Persons with Disabilities established that: "when, despite considerable effort, it is not possible to determine the preferences of a person, the best interest determination should be replaced by the best interpretation of the person's will and preferences."³⁴

Traditionally, using the principle of the person's best interests meant that, in the most complex cases, those assisting the person had to think and decide based on what was considered suitable or desirable for a person, regardless of whether the person would have chosen or preferred it.³⁵ It seemed to be an objective principle in which the rights of individuals were guaranteed. As a result of applying the criterion of the person's best interests, in cases of emergency, medical practitioners deployed all possible assistance measures given that preserving life, integrity, and health was considered to be in the person's best interests.

The United Nations Convention on the Rights of Persons with Disabilities and General Comment Number 1 on Legal Capacity required to stop using the best interest principle and provide support using the principle of the best interpretation of the person's will and preferences. Skowron³⁶ understands this interpretation exercise in two senses: as a **process** and an **outcome** that supports decision-making and does not replace the person's will.

³⁷ Ibid.

³⁸ Ibid.

The best interpretation of the will and preferences is a type of high-intensity support that should be used exceptionally when the person is not, in fact, able to communicate, and it is in absolute impossibility to express their will and preferences by any means or modes available. In other words, direct communication should always be attempted, facilitating and promoting the person's expression of will.

However, such direct communication may not be possible in all cases, and the possibility of making decisions and accessing support cannot disappear, as this would violate the right to legal capacity and a form of discrimination. Therefore, in these exceptional cases, the people in the support network, for example, those linked by ties of kinship, trust, or closeness, can intervene to provide support in decision-making and the exercise of legal capacity.

To make the best interpretation of the person's will entails that third parties in the support network, based on their knowledge of the person, their values, principles, beliefs, previous decisions, and conversations held throughout life; that is, based on their life history, among other elements of interpretation and judgment, indicate in a reasonable and supported manner, what the person would have decided in this situation if they could express their consent directly.

Using the principle of the best interpretation of the person's will and preferences is not a surrogate for the person's consent. As a process,³⁷ when performing the best interpretation of will and preferences a third person does not decide for the person and does not impose their own will and preferences. On the contrary, when interpreting what the person would have decided for themselves, they provide support of the most profound kind available so that the person's wishes are known and respected.

As a result,³⁸ allowing this principle does not automatically mean that the person can access the mechanisms of the right to die with dignity. On the contrary, the support network will be allowed to interpret the person's will and preferences to provide support. As a result of this exercise, it will be established, first, if this would have been the person's will; second, if, on the contrary, the person would have refused; and third, if the support network does not have sufficient elements to carry out this best interpretation.

Practicing the principle of the best interpretation of will and preferences allows people who find themselves unable to express their will and preferences that their support network can provide them with profound support to assert the values, beliefs, and principles that make up their biographical life that is, the life that goes beyond biological existence, the life that is full of projects, goals, objectives, relationships, satisfaction, the life that the person considered full of meaning and dignity, the life that person wanted and wished to live.

SCOPE OF APPLICATION. IN WHICH CASES SHOULD THE PRINCIPLE OF THE BEST INTERPRETATION OF THE PERSON'S WILL AND PREFERENCES BE USED?

The Scientific-Interdisciplinary Committee for Dignified Dying should use the principle of the best interpretation of the person's will and preferences when seeking access to the mechanisms of the right to die with dignity, particularly MAiD, through euthanasia in the following situations.

First: The person has a serious and incurable disease following Decision C-233 of 2021, that is, when they have a duly diagnosed pathological condition that causes negative impacts on the quality of life and personal well-being, that prevents the person from carrying out autonomously their life project and that the scientific knowledge and technologies cannot cure it.

Second: Every attempt has been made to obtain the person's direct consent, which has been unsuccessful.

Third: The person cannot express their will and preferences directly due to health issues. For example, but not exhaustively, being in a coma, vegetative state, in a state of minimal consciousness, neurodegenerative diseases, among other circumstances.

Fourth: The person has not previously expressed their consent through an advance directive.

Fifth: To have a support network composed of family members or persons of trust who are in a position to make the best interpretation of the person's will and preferences regarding the right to die with dignity.

Sixth: A request for access to the right to die with dignity has been made by a support network member.

The principle of the best interpretation of the person's will and preferences cannot be used to access medically assisted suicide since this mechanism of MAiD requires for its application the direct possibility of the person to express consent and to carry out the action of ending their own life.³⁹



GUIDELINES. HOW TO CARRY OUT THE BEST INTERPRETATION OF THE WILL AND PREFERENCES IN CASES OF A DIGNIFIED DEATH?

As a result of the methodological route traced and followed, this document systematizes **nine technical guidelines** that will guarantee the right to a dignified death, to legal capacity and make operational the principle of the best interpretation of persons' will and preferences.

These guidelines address the following matters: (1) the significance of making the best interpretation of the person's will and preferences; (2) the need to assess the impossibility of giving consent of those for whom MAid is requested; (3) the composition of the support network; (4) addressing and ruling out conflicts of interest; (5) verifying that the health system has offered palliative care and the adequacy of the therapeutic effort ; (6) the role that both the medical records and previous conversations with care practitioners can play in the process; (7) the assessment of suffering in terms of the person's life experience; (8) constructing the life narrative and the best interpretation of the will and preferences through interviews with the support network and; (9) the necessary consensus in the interpretation of the will and preferences.

Each guideline has a brief explanation and practical recommendations. The scope is to communicate the priority behind each guideline and to guide the

work of the practitioners who will operate them. This is an open-ended process and document; through its use and the reflection of the people involved, it will be possible to make adjustments and add valuable information.



GUIDELINE 1. CONSENT BY THE SUPPORT NETWORK IS GIVEN BASED ON THE BEST INTERPRETATION OF THE PERSON'S WILL AND PREFERENCES

All individuals have the right to access support in making decisions, including those with more complex health conditions who cannot express their consent directly. In these cases, the person's support network is called upon to do the best interpretation of will and preferences of the person who cannot express their consent and did not do it in advance. Support network members are responsible for analyzing and reflecting on the person's decision in such a situation and the reasons that would lead them to make such a decision.

The support network should evaluate who the person is, what values and principles guide their life, what their beliefs are, what decisions they made in the past, and what they have said about illness and death before being in such a situation. In making this assessment, each person in the support network will define whether the person would agree to exercise the right to die with dignity through any of its mechanisms, including MAiD, and the reasons for this interpretation.

Making the best interpretation of the person's will and preferences does not mean the people within the support network can impose their beliefs and value system. It does not mean that what they believe is "best" or "good" for the person in such a situation or what they would do if they were in those circumstances will be the best interpretation of will and preferences. On the contrary, making the best interpretation of the person's will and preferences entails an exercise of participation through empathy to define what the person who is unable to express their will would have preferred, even if that decision is contrary to what members of the support network personally believe or wish for themselves.



Practical recommendations:

Verify whether there is an advance directive in which the person has expressed their will before being unable to express consent.

+ Ask whether the person in such a health situation could talk and decide what they would say, what they would choose, and why they would do it.

+ Identify what previous and related decisions were made, for example, to reject procedures, if they wanted their life to be artificially extended or if they were opposed to it, what their position was regarding the mechanisms of the right to

die with dignity, whether they agreed or disagreed, what reactions were caused by cases on the media regarding a dignified death, what responses were caused by the illness processes of people close to them, among others.

+ Verify that the people in the support network interpret the will and preferences of those who cannot express their choices instead of telling their beliefs or wishes.



GUIDELINE 2. THE COMMITTEE IN CHARGE OF STUDYING THE CASE SHALL EVALUATE THE IMPOSSIBILITY OF MANIFESTING THE WILL AND GIVING CONSENT

In Colombia, all persons are entitled to the legal capacity to make decisions. After Law 1996 of 2019 was enacted, there are no legally incompetent people, and additionally, people have the right to be provided with the support they need to exercise such right to legal capacity.

In extreme and exceptional cases, people may find it impossible to express their decisions, either because their state of health does not allow them to do so or because they cannot give their consent in a free, informed, and unequivocal manner at a given moment. Some examples are people in a coma, in a vegetative state, people in a state of minimal consciousness, people with Alzheimer's disease, or with advanced dementia who are conscious but completely disoriented in time and space, among other situations.

Even in these extreme cases, people are considered fully capable and have the right to be provided with support to make decisions. The support that is used and required in these types of cases is one of the most profound type; that is, the people who are part of the support network make the best interpretation of the will and preferences and, therefore, the decision that is made is the one that the person would reasonably have, made if they could have made it.

Before allowing third parties to make the best interpretation of the will and preferences, it must be verified that the person cannot express their will directly by any means available. It should be confirmed that the people in the support network are not imposing their will or silencing their voices.



Practical recommendations:

+ Acknowledge the person as capable of making decisions and provide the support they require in the decision-making process.

+ Verify that the interested party is, in fact, unable to express their will directly by any means or in any way.

+ **Ensure** that there is no undue interference by third parties; the person should always be interviewed directly, regardless of their health situation and even if there is no answer.



GUIDELINE 3. THE SUPPORT NETWORK IS DIVERSE AND CAN BE COMPOSED OF PEOPLE UNITED BY KINSHIP, TIES OF CLOSENESS, AND TRUST

When carrying out the best interpretation of person's will and preferences, it must be verified and guaranteed that those who carry out the interpretation belong to the support network of the person who will have access to the mechanisms of the right to die with dignity and who cannot express their consent directly. The support network corresponds to the persons linked to through ties of kinship or closeness, knowledge, and trust.

The family should not automatically be considered part of the support network. It is essential to explore and characterize the relationships of closeness, trust, and knowledge with the person to determine whether or not they are in a position to interpret best the will and preferences of the person, who should be at the center of the conversation and decisions.

The support network does not refer only to persons legally related by kinship nor to persons accompanying the person in hospital settings as caregivers. In some cases, persons legally related by kinship may not be included in the support network; for instance, there may be a legally presumed link, but this does not necessarily or automatically translate into an actual relation of closeness, knowledge, and trust.

The Scientific-Interdisciplinary Committee for Dignified Dying must identify the persons who are part of the support network of the person who will access the right and who cannot express their will. This identification should be made through an individual conversation with those who carry out the request, with those who provide caring services for the person, and with those linked by kinship. Based on this identification, a map of relationships should be drawn up in which the person who will access the right and cannot express their consent is at the center, and the identified persons are around them.

This map should be used to characterize the links that unite the person with each person identified within the support network. These ties should reflect daily closeness, trusting relationships for certain aspects of life, particularly those related to health and end-of-life decisions, and in-depth knowledge of the person, their wishes, preferences, values, beliefs, and previous choices.

Once the map of relationships and links has been identified, the closest and most trusted people should comprise the support network to make the best interpretation of will and preferences. As far as possible, this network should include a plural number of people who are not too numerous to allow a consensus to be reached but not so small as to lack controls and safeguards. The support network should be informed of its role and responsibilities.



Practical recommendations:

+ Address all relationships of closeness, knowledge, and trust that the person has in their life, not only relationships derived from kinship. These may be non-legally formalized permanent partners and companions, close friends, co-workers, and neighbors.

+ Chart the relationships of the people in the support network to get a picture of who is closer and who is not.

+ Form a plural support network to facilitate decision-making; to this end, the people who make up the network must be fully identified and be able to be contacted.

+ Inform the people in the support network about what is expected of their work and clarify the responsibilities that derive from it.



GUIDELINE 4. ADDRESS AND RULE OUT CONFLICTS OF INTEREST TO BEST INTERPRET THE PERSON'S WILL AND PREFERENCES

To correctly interpret the person's will and preferences, those in the support network should not be motivated by conflicts of interest in the decision they interpret or in the outcome.

A conflict of interest is a situation in which a person in the support network may find themselves in which the primary interest of interpreting the person's will and preferences is unduly influenced by a secondary interest, which may be financial, family, personal, or otherwise.

Approaching and ruling out possible conflicts of interest among the people in the support network must be done with special care, given that they may be the person's relatives, acquaintances, and financial dependents. This situation may result in a secondary interest in several ways that do not necessarily translate into a conflict of interest that prevents the person in the support network from making the best interpretation of the person's will and preferences. On the one hand, the person's death may benefit the support network person because it

makes them an heir or relieves them of caregiving or financial responsibilities. On the other hand, keeping the person alive may benefit the person financially dependent on their income, who lives with them, and who, upon death, could see their situation significantly altered.

The existence of these secondary interests does not imply that a conflict of interest automatically leads to excluding the person from making the best interpretation of the will and preferences. The people in the support network must acknowledge this secondary interest and verify that it does not lead to a biased interpretation of the will. Special care must be taken when excluding someone close to the person because this can lead to the exclusion of significant people from the support network – even the exclusion of all people in the support network – making it impossible to provide support through the best interpretation of the will and preferences.

In any case, when the existence of secondary interests and the risk of influencing the primary interest is verified, the person should be excluded from being part of the support network and from making the best interpretation. Then, the process must continue with other members of the support network.



Practical recommendations:

- + Acknowledge** the possible existence of a secondary interest in the people in the support network, help them, and accompany them so they can identify themselves.
- + Identify** the possible undue influences that such secondary interest may generate in the person in the support network and in making the best interpretation of will and preferences.
- + Create** a space to communicate the ethical and legal responsibilities of the individual in making the best interpretation and the duty to prevent the secondary interest from influencing the primary interest unduly.
- + Exclude** from the support network individuals who, after addressing the conflict of interest, allow the secondary interest to influence the primary interest unduly.
- + Seek** other potential support network members and include them in the process, or continue with the remaining ones.



GUIDELINE 5. VERIFY THAT THE PERSON HAS BEEN OFFERED PALLIATIVE CARE, WITH THE AVAILABLE TREATMENT OPTIONS, AND WITH THE POSSIBILITY OF ADJUSTING OR REFUSING THEM

As in the request and processing of MAiD for persons who express consent directly, the committee must verify that palliative care and the available treatments have been offered in cases where the support network makes the best interpretation of will and preferences.

The right to die with dignity is a multidimensional right that can be exercised through various mechanisms, and, in all cases, the decision to MAiD cannot be motivated by a lack of access to the health system. In this sense, palliative care must be offered and available as a mechanism of access to death with dignity. It is also necessary to verify that the person has been provided with other possible treatments or procedures to improve their quality of life.

In addition to the above offers, it should be verified that the person and their support network have been offered the possibility of adjusting the therapeutic effort, for instance, refusing, withholding, or withdrawing medications, procedures, and even life support measures.

Providing access to palliative care and other reasonable treatment alternatives does not mean these must be mandatory to access MAiD. The right to die with dignity does not entail that all its mechanisms and the services provided by each one must always be used.

Thus, verifying that the health system has been available to the person is a way to ensure that the motivation that leads the support network to best interpret the person's will and preferences is not the absence of palliative care or the lack of health services.



Practical recommendations:

+ Ask if the health system can offer additional services that might change the person's mind if they could express their will.

+ Identify whether the person has participated in an institutional or home-based palliative care program.

+ Identify whether there are other procedures or treatments that, if offered, could change the person's decision if they could express their wishes.

+ Identify whether there is the possibility of adjusting the therapeutic effort by withholding or withdrawing medications, procedures, and even life support measures, which could change the person's opinion.

+ **Ask** the support network if it would like to opt for any palliative care measures or adequacy of therapeutic effort prior to requesting MAiD because this is what the person would have preferred.



GUIDELINE 6. THE MEDICAL RECORDS AND THE NARRATIVES OF THE HEALTH CARE PERSONNEL CAN CONTRIBUTE TO THE BEST INTERPRETATION OF THE PERSON'S WILL AND PREFERENCES

In applying the principle of the best interpretation of the person's will and preferences, it is advisable to verify the medical records and their relationship with the health care personnel. Health practitioners (physicians, psychologists, therapists, among others) who have cared for the person may have inquired about the person's preferences for care in critical, serious, or end-of-life situations; there may also be a spontaneous manifestation by the person in the medical records.

The support network can initially indicate whether the person has kept or documented their medical records. If this is not the case, the practitioners and institutions where the person was attended should be identified to request the medical records and verify if any manifestation regarding the person's end-of-life wishes was recorded in the last five years.

At this point, we do not seek to understand the personal position of the health practitioners consulted but only to gain access to what is in the medical records regarding the person's will. Likewise, to understand, through interviews with the practitioners, in what context the recording of the will took place. Lacking such background information cannot hinder proceeding with the support network's best interpretation of the person's will and preferences.

If no reference to will and types of care is found in the medical record, the best interpretation of the person's will and preferences must be constructed solely through the support network.



Practical recommendations:

+ **Identify** the health practitioners who have cared for the person.

+ **Review** medical records based on key concepts or words such as: "advance will," "advance directive," "Death with dignity," and "refusal of treatment," among others.

+ **Check** with the support network whether what is recorded in the medical record corresponds to the person's life experience.



GUIDELINE 7. THE COMMITTEE IN CHARGE OF STUDYING THE CASE SHALL COMPREHENSIVELY EVALUATE THE SUFFERING BASED ON THE PERSON'S LIFE EXPERIENCE

Pain and suffering, as part of human existence and a person's life course, have a high component of subjectivity. What for one person is intense pain or suffering incompatible with their idea of dignity may not be so for another. Therefore, despite the existence of technical scales to assess the impact of certain health conditions on the body, the mind, and life project, defining with certainty how much one suffers will always be an exercise in which the individual's experience must be privileged.

The suffering experienced by a person unable to express their will must be assessed comprehensibly, considering the person's life course. Namely, suffering must be interpreted based on what the person would think about their situation and whether they would want to be in it. It must be interpreted if the condition they find themselves in allows them to develop their biographical life, their freedom, dignity, and autonomy.

The evaluation carried out by the group of practitioners should include both what the person expressed verbally at some point to the people in their support network, as well as what the person valued in their everyday life, what characterized their biographical life, and what filled them with dignity, freedom, and autonomy. It is essential to acknowledge that biographical life is not only altered, and even lost, in situations of physical pain but also has to do with the inability to lead an autonomous life, with the possibility of making decisions or with the impossibility of recovering physical and mental faculties that were enjoyed in the past and that are considered part of the personal idea of a dignified life.

Likewise, it must be verified that the experience of suffering taken into account is that of the person and not that of their support network. Although the support network may experience pain due to the person's health condition, exhaustion, and burnout in caregiving, the pain or suffering of third parties should not be the reason for requesting MAiD.

People who are not conscious or have some form of dementia might not experience physical pain, and some practitioners might argue that there is no suffering. However, even though physical pain and suffering cannot be proven, the assessment will allow the support network to interpret best the person's will and preferences regarding what they would have wanted in that situation.



Practical recommendations:

+ Assess suffering in a comprehensive manner based on the biographical life and life experience of the person.

+ Verify how the person has adapted to changes in their health, autonomy, and modifications derived from the aging process to avoid stereotyped ideas about capacity, autonomy, and youth.

+ Inquire about what the person valued and enjoyed when they were able to express their will and contrast it with the situation in which they find themselves today.

+ Verify whether the person would consider the current physical or mental pain or suffering incompatible with their idea of dignity.



GUIDELINE 8. BUILD THE PERSON'S LIFE NARRATIVE WITH THE BEST INTERPRETATION OF THE WILL AND PREFERENCES THROUGH INTERVIEWS WITH PEOPLE IN THE SUPPORT NETWORK

After identifying the support network, the person's life narrative should be constructed based on semi-structured interviews with the different support network members.

The interviews are aimed at delving into the values, beliefs, and preferences that guide a person's life. In this way, it will be possible to identify how the person made decisions, their perception of both biographical and biological life, and personal beliefs about life, illness, and death, among others.

Interviews must be conducted by mental health practitioners (psychology or psychiatry) who have no conflicts of interest with the family or the person and have not expressed conscientious objection to the right to die with dignity.

It is recommended that the interviews be conducted individually and not in groups to guarantee impartiality in the narratives. Having a minimum of three interviews and a maximum of five is also recommended. Once the interviews have been completed, the person in charge of the process should prepare a report with two parts:

- 1.** Identification of the support network and relationship map.
- 2.** Narrative of the person's life:
 - a.** Biography.
 - b.** Spiritual and religious beliefs.
 - c.** Posture towards health and disease.
 - d.** Stance towards the end of life.
 - e.** Position on the right to die with dignity and its mechanisms.
 - f.** Possible conflicts of interest on the part of the support network.



Practical recommendations:

Interview at least three adults from the support network and no more than five. Eventually, there may be single persons without large support networks where these minimums may be excessive and should be waived.

+ **Conduct** the interviews individually so there is no interference in the narratives with other support network members.

+ **Search** for people in the support network who are not part of the MAiD request to include them in making the best interpretation of will and preferences.

+ **Verify** that the people in the support network identified through the interview were considered from the beginning. If new people emerge, including them in the process is necessary.

+ **Carry out** the individual interviews taking into consideration the following areas:

The questions should be formulated in an open-ended manner, ensuring that they do not generate bias or induce any answer. The suggested questions can be used as a guide but can be complemented by the interviewer based on the particular analysis of the case.



Type of link:

- + What is the type of relationship you have with the person? (family, work, friendship, health provider).
- + For how long have they known one another?
- + What is the frequency of contact?
- + In what spaces or activities have both shared a common ground?
- + What are their bonds of closeness, knowledge, and trust?



Support network:

- + Who does the person trust? Who are the people close to them? Which of them are family members?
- + Who are the best people to make the best interpretation of the will on the options provided by the right to die with dignity?



Biography of the person whose will and preferences are interpreted:

- + How is the family composed?
- + What did they do for a living?
- + What was day-to-day life like before the deterioration of the health condition?
- + What are their priorities in life, what do they value most, what makes them happy?
- + What did they do in their free time before the deterioration in their quality of life?
- + What are their long-term goals or dreams?



Religious, spiritual, and value stance:

- + Is there a significant religious belief, spiritual practice, or value system in their life?
- + Did they consider decisions about the right to die with dignity compatible with their religious beliefs or spiritual practices?



Posture towards health and disease:

- + Did they ever have a personal or third-party illness situation that confronted them with death (for instance, COVID-19, cancer, coma, ICU hospitalization, etc.)? If yes, what reflections and comments did they make about it?
- + Did they once reflect and comment on the advanced illness situation of others close to them? What kind of reflections and comments did arise?
- + How they behaved when sick, did they like to be attended to and cared for, and allowed help with day-to-day activities.



End-of-life beliefs:

- + Did they speak once about death and the end of life? What were their thoughts about their death?
- + Did they speak once about their old age?
- + Did they speak once about palliative care?
- + Did they speak once of the adequacy of therapeutic effort? For instance, the possibility of refusing and adjusting treatments
- + Did they speak about MAiD, euthanasia, or medically assisted suicide?
- + Did they speak about what kind of care they wanted to receive in the event of serious illness or end of life?



Advance directives:

- + Were they aware of the existence of the advance directives, and if so, why did they not complete them?



Conflicts of interest:

- + Who are the primary caregivers?
- + How and by whom the financial expenses are covered?
- + Who supports the person's financial decisions?
- + Are there any advance directives on other topics?



GUIDELINE 9. ACHIEVING THE NECESSARY CONSENSUS IN THE NARRATIVE BY THOSE WHO MAKE UP THE SUPPORT NETWORK

For a correct implementation of the principle of the best interpretation of the person's will and preferences, once the interviews with the support network have been carried out, it must be verified that there is consensus. The versions of the values, beliefs, and decisions made in the past by the person must be aligned; for instance, there must be concordance in what the support network members say about the person's will and preferences.

The inputs obtained in the interviews should lead to the same conclusion about the person's decision. Regardless of whether the narratives and references are different, a person's profile should be identified, and the verbalization of what the person would have decided should be consistent. Likewise, all persons interviewed from the support network must conclude that the person receiving support in decision-making would indeed choose to access the right to die with dignity.

Consensus among the members of the support network must be total. If one in the support network provides information that does not agree with the other

narratives, this should prevent them from accessing MAiD. It is crucial to verify that the lack of consensus in any support network member is based on the actual interpretation of the person's will rather than on the personal assessment made by the third person or on a conflict of interest.

In case of a lack of consensus that makes it impossible to reasonably establish the best interpretation of the person's will and preferences, it is possible to reapply for the procedure, for which it is vital to assess the new information available and to survey the same people from the previous application, together with other additional people from the support network and to contrast with the interpretations of the will and preferences previously elaborated.



Practical recommendations:

+ Identify why the support network cannot reach a consensus on the narratives.

+ Verify that the lack of consensus in the narratives by the support network does not derive from a conflict of interest, the imposition of a third party's opinion, or an erroneous application of the principle of the best interpretation of the will.

+ Record the lack of consensus and the diverse narratives of the support network.

+ Suspend MAiD application when there is no consensus on the narratives by the support network.

+ Indicate that it is possible to reapply for MAiD in the future.

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