

A Palliative Care Chaplain’s Response to Medical Aid in Dying

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Abstract

In the past decade, the practice of Medical Aid in Dying has become increasingly widespread in the United States and around the world. As Orthodox Christians who profess that God is the ultimate author of life, we are called to develop a visionary response to the growing popularity of assisted death. This response must not only be a mere condemnation of the practice, but a vision that illuminates our views of life, death, suffering, and meaning.

In this paper, after first describing the overall legal and cultural landscape surrounding Medical Aid in Dying, I shall suggest a framework for reflection that touches upon three key concepts: autonomy, suffering, and the remembrance of death. Then, based on my own experience as a Palliative Care and Hospice chaplain, I shall discuss the potential spiritual gifts that arise both for those undergoing the process of dying and for those who care for the dying. I shall conclude by emphasizing what the Orthodox faith and tradition offer us to navigate the conclusion of our earthly life.

Introduction

At this time, Medical Aid for Dying is legal in ten US states and several countries around the world, including Canada.¹ Terminology varies by region and by one’s stance on the subject. It is sometimes called Physician Aid in Dying, Assisted Suicide, and Assisted Death. It is called “Death with Dignity” by the large, well-funded advocacy group Compassion and Choices.² Their publications on the subject have titles like, “Finish Strong;” they even have a theme song. For our purposes, I am using the term Medical Aid in Dying, or MAID, due to the increasing consensus in published medical literature.

MAID requirements vary by location; nonetheless, in all cases, one must be decisional and be an adult resident of a state in which it is legal. Candidates must have a terminal illness that leads to death within 6 months if the disease progresses as expected. They must be able to self-administer medication. They must consult with physicians, and there is a waiting period. Many patients are under the care of Hospice, though this is not a requirement.³ MAID is generally considered to be distinct from euthanasia, which is the act of bringing about the death of a person at his or her request. In euthanasia, someone other than the patient performs an act

¹ As of July 2023, MAID is legal in the states of California, Colorado, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington, as well as Washington D.C. Globally, it is legal in Australia, Austria, Belgium, Canada, Colombia, Germany, Italy, Luxembourg, Netherlands, New Zealand, Peru, Spain, and Switzerland. Source: “Legal status of physician medical aid in dying (MAID) and voluntary active euthanasia (VAE) in countries other than the United States, as of April 2023,” cited in *UpToDate*.

² “Compassion & Choices | End-of-Life Resources,” Compassion & Choices, accessed October 3, 2022, <<https://www.compassionandchoices.org/>>.

³ “Resources,” Death With Dignity, accessed November 1, 2022, <https://deathwithdignity.org/resources/>.

(e.g., administering a lethal injection) with the intent to end the patient's life.¹ Euthanasia is illegal throughout the United States.

Some religious denominations distinguish morally between euthanasia and MAID, and support MAID based on their understanding of autonomy and personal conscience. At this time, two major religious denominations, the United Church of Christ, and the Unitarian Universalist Association, have issued formal statements supporting the practice of Medical Aid in Dying, while distinguishing it from euthanasia, which they do not support.² However many are Orthodox Christian scholars, including Palliative.

Care physician, Dr. Daniel Hinshaw, feels that this distinction is not valid, because the writing of a lethal prescription and the administration of such lethal medication is not so morally distinct.³ In both cases, life is intentionally ended. In both cases, there remains an attitude that death should be within one's control and that the greatest good is to quickly alleviate the process of dying. As Orthodox Christians, we cannot endorse this individualistic view. Only with a prayerful and repentant orientation to God, based on both our understanding and partaking of the communal life in the Church, can we properly understand the meaning of life and death.

At this time, the Hospice and Palliative Nursing Association, the National Hospice and Palliative Care Organization, and the American Nurses Association are opposed to MAID.^{4,5,6} The American Academy of Hospice and Palliative Medicine takes a position of studied neutrality on the subject. They do note "concerns about a shift to include physician-assisted dying in routine medical practice, including palliative care" and argue that "such a change risks unintended long-range consequences that may not yet be discernable, including effects on the relationship between medicine and society, the patient and physician, and the perceived or actual integrity of the medical profession."⁷

¹ "Ezekiel J. Emanuel et al., "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe," *JAMA* 316, no. 1 (July 5, 2016): 79, <<https://doi.org/10.1001/jama.2016.8499>>.

² "To End Our Days," Pew Research Center's Religion & Public Life Project, May 30, 2020, accessed July 23, 2018, <<https://www.pewresearch.org/religion/2013/11/21/to-end-our-days/>>.

³ Daniel Hinshaw, "The Wounded Healer," interview by Sarah Byrne-Martelli, April 27, 2018, accessed February 7, 2023, https://www.ancientfaith.com/podcasts/woundedhealer/suffering_healing_and_physician_assisted_suicide_part_1.

⁴ "HPNA Value, Policy, and Position Statements," accessed February 1, 2023, <https://advancingexpertcare.org/position-statements/>.

⁵ National Hospice and Palliative Care Organization, "Medical Aid in Dying Resources," NHPCO, October 15, 2021, accessed October 23, 2022, <<https://www.nhpc.org/accordions/submission-outline-3-copy-3-copy-copy-2-2-copy-copy/>>.

⁶ "ANA Position Statement: The Nurse's Role When a Patient Requests Medical Aid in Dying | OJIN: The Online Journal of Issues in Nursing," accessed October 23, 2022, <<https://ojin.nursingworld.org/table-of-contents/volume-24-2019/number-3-september-2019/nurses-role-medical-aid-in-dying/>>.

⁷ American Academy of Hospice and Palliative Medicine, "Physician-Assisted Dying | AAHPM," accessed October 23, 2022, <<https://aahpm.org/positions/pad>>.

Notably, there are secular advocacy groups, such as “Not Dead Yet,” that oppose MAID on the grounds that it discriminates against the disabled. People with disabilities live on the front lines of a medical system that provides care for the disabled and dying. They argue that “although people with disabilities aren’t usually terminally ill, the terminally ill are almost always disabled.”⁸ People living with disabilities “object to being seen as expendable.”⁹ They remind us that disability is not worse than death. In light of these concerns, I believe we are called to consider Christ’s mandate to care for the needy. Christ admonishes us to love all who are suffering; as He tells us in the Gospel of Matthew, our very salvation depends on this. Surely, it follows that we must advocate for those who some might label as “expendable,” as noted above. All people are worthy to live.

MAID is often portrayed as the best means to a peaceful death. In 2014, the media widely covered the story of 29-year-old Brittany Maynard, who was living with terminal brain cancer and relocated to Oregon so she could access its “Death with Dignity Act.” Brittany stated, “My question is: Who has the right to tell me that I don’t deserve this choice? That I deserve to suffer for weeks or months in tremendous amounts of physical and emotional pain? Why should anyone have the right to make that choice for me?”¹⁰ MAID is depicted positively in the movie “How to Die in Oregon,” with a cancer patient named Cody.¹¹ There is a profound, quiet sadness embedded in the film. Every fiber of Cody’s being radiates fear and loss of control, though her words indicate otherwise. She stated: “[My death] will be tidy,” and that she “will not be humiliated” by the indignity of losing control.¹² Not knowing – but imagining – the type of pain Brittany and Cody faced should elicit our prayers and compassionate reflection.

Importantly, although intractable pain has been emphasized in the media as the primary reason for choosing MAID, an Oregon report citing the top five reasons for lethal prescriptions identified: “loss of autonomy” (92%), “less able to engage in activities” (90%), “loss of dignity” (79%), “loss of control of bodily functions” (48%) and “feelings of being a burden” (41%).¹³ The primary motivation for choosing MAID is not intractable pain or suffering, as commonly implied in public dialogue. Certainly, Brittany’s statements get to the heart of the question. What does the growing popularity of MAID say about our deepest human fears and hopes?

⁸ “Disability Rights Toolkit for Advocacy Against Legalization of Assisted Suicide,” Not Dead Yet, July 11, 2022, accessed October 23, 2022, <<https://notdeadyet.org/disability-rights-toolkit-for-advocacy-against-legalization-of-assisted-suicide>>.

⁹ Ibid.

¹⁰ Brittany Maynard, “My Right to Death with Dignity at 29,” CNN, November 3, 2014, accessed February 4, 2023, <<https://edition.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/index.html>>.

¹¹ *How to Die in Oregon*, directed by Peter Richardson (Clearcut Productions, 2011).

¹² Ibid.

¹³ “Oregon Health Authority: Oregon’s Death with Dignity Act: State of Oregon,” Oregon Health Authority, accessed February 4, 2023, <<https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>>.

The Orthodox theologian Vigen Guroian notes, “Death is becoming the ultimate concern of all those who lack the mediation of the sacred and transcendent in their lives, religious and non-religious people alike. Such people tend to fall into slavery either to a stultifying and debilitating dread of death or to the comforting illusion that life is for the living and death is for the dying.”¹⁴ Instead of getting stuck in this dualism, we must articulate a response to MAID through our compassionate and visionary understanding of Christ’s life and death. We must not leave our argument against MAID there, with a forbidding “no.” We run the risk of alienating those who are ambivalent and shutting down potential dialogue. We must examine *why* it is so appealing and *what* deep existential questions lead someone to it, in order to craft our responses accordingly. As noted earlier, I believe there are three core concepts that might inform an initial response to MAID: 1) autonomy, 2) suffering, and 3) the remembrance of death. This is only a beginning formulation, and my hope is that we will continue to have dialogue within the Orthodox Christian community.

Autonomy

Autonomy is one of the four basic principles of biomedical ethics, the other three being justice, non-maleficence, and beneficence.¹⁵ Autonomy in medicine emphasizes allowing patients to make their own decisions and facilitates the conditions within which decisional patients have self-determination. In health care decisions, our respect for the autonomy of the patient implies that the patient has the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act. This principle is the basis for the practice of “informed consent” in the physician/patient relationship.¹⁶

Autonomy is a deeply valued principle, and peer-reviewed medical literature demonstrates that autonomy is a primary driver of decisions in favor of MAID. For example, a 2017 paper in the *New England Journal of Medicine*, summarizing the recent implementation of MAID by the University of Toronto Health System, stated that “loss of autonomy” was the primary reason for a patient’s request to have MAID.¹⁷ The second and third reasons cited were the “wish to avoid burdening others” and the “intolerability of not being able to enjoy one’s life.”¹⁸ Notably, as with the study in Oregon cited earlier, few patients cited “inadequate control

¹⁴ Vigen Guroian, *Life’s Living toward Dying: A Theological and Medical-Ethical Study* (Eerdmans, 1996), 40.

¹⁵ Beauchamp T, Childress J. *Principles of Biomedical Ethics*, 7th Edition. New York: Oxford University Press, 2013.

¹⁶ Jonsen A, Siegler M, Winslade W. *Ethics*, 7th Edition. New York: McGraw-Hill Medical, 2010.

¹⁷ Madeline Li et al., “Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada,” ed. Debra Malina, *New England Journal of Medicine* 376, no. 21 (May 25, 2017): 2082–88, <<https://doi.org/10.1056/nejmms1700606>>.

¹⁸ *Ibid.*

of pain or other symptoms,” which, again, is often over-emphasized in the justification for MAID.¹⁹

Related to the concept of autonomy, we must also consider the emotional and spiritual experiences of a patient's family members. The family members of a person choosing MAID may experience profound conflict, confusion, and complicated grief. Additionally, even though the patient may technically act as the decision-maker for MAID, there is variation in the medical protocols utilized. The evidence suggests that medical clinicians administer the medication when needed. In other words, even though the patient is ostensibly the center of the MAID decision, their clinical providers and family members are still deeply involved in facilitating the process of death.²⁰

As an Orthodox Christian Palliative Care Chaplain who has served for 20 years in multifaith hospital and home Hospice settings, where complex medical decision-making is part of daily life, I witness patients and families struggling deeply with their autonomy and sense of self-determination. Who is in charge? Is it God? The patient, the family, the doctors? A perception of a lack of autonomy can create a deep sense of instability, fear, and panic. This underlying panic in the face of distressing illness causes patients to question what is in their control. Pursuing MAID has become one way for patients to feel they are in control.

We as Christians have a different perception of what it means to be in control; we profess that God is the author of our lives. Yes, we can discern and control many things. We have free will to choose or reject God's love. Many of us can choose where we spend our dying days, who we spend them with, and to define what “quality of life” means for us. We may seek relevant information for informed consent and appropriate decision-making, and act on that information. But we are not in control of when we are born or when we die. God's love, dynamically engaged with our free will, leads us to a life transformed by prayer and faith. We look to Scripture, we receive Communion, and we seek counsel from our clergy.

Yes, we are individuals, but our humanity is found in the larger body of Christ. Our truest selves are found when we live in communion, with one another. The end of life is the time in which we most need to trust God. God's love – not our self-centered autonomy, as defined by popular culture – and our faithful exercise of free will dynamically lead to a life that is ever-transforming in prayer and discernment.

Suffering

As noted earlier, MAID is often portrayed as the best and quickest way to avoid suffering. However, as Orthodox Christians, we have a nuanced understanding of suffering,

¹⁹ Ibid.

²⁰ Max Zworth, Carol Saleh, Ian Ball, Gaelen Kalles, Anatoli Chkarokoubo, Mike Kekewich, Paul Q. Miller, Marianne Dees, Andrea Frolic, and Simon Oczkowski. Provision of medical assistance in dying: a scoping review. *BMJ Open* 2020; 10:e036054. <doi: 10.1136/bmjopen-2019-036054>.

recognizing that suffering is part of this earthly life and always has the potential to be transformed by God. Metropolitan Methodios has said:

The Church has always rejected inflicted and unnecessary voluntary suffering and pain as immoral; but at the same time, the Church also has perceived in suffering a positive value that often goes unrecognized in the logic of the world in which we live, a world characterized by secularism, materialism, and individualism...the 'good death' recognized in Orthodox ethics is that death in which the human person accepts the end of his or her life in the spirit of moral and spiritual purity, in hope and trust in God, and as a member of His kingdom.²¹

Clinicians who serve in Palliative Care and Hospice know that a peaceful death is not always easy, especially in the case of metastatic disease or intractable symptoms. However, we view the needs of our terminally ill patients through the lens of "Total Pain," a concept credited to Cicely Saunders, the founder of the Hospice movement.²² Total pain has physical, psychological, social, and spiritual components. It involves creative and dedicated care from an interprofessional team of specialists: physicians, nurses, social workers, and chaplains. In order to benefit from the care philosophy of total pain, patients and their providers must be honest about hopes and fears and to admit when curative medicine has reached its limits. The Hospice philosophy never hastens death but seeks to focus on comfort and alleviating distressing symptoms such as pain, dyspnea, or shortness of breath, in collaboration with the Hospice team of caregivers, including clergy and chaplains. It is clear that we need ongoing community education on Palliative Care and Hospice so that we can more comfortably elect this type of care as soon as it is medically appropriate.

In liturgy, we pray for a "Christian ending to our lives: painless, blameless, and peaceful." Our tradition has always understood that no one needs or wants a painful, drawn-out, shameful, solitary end of life. We do not encourage end-of-life suffering for its own sake. Instead, we view suffering through the lens of our Lord as an example of love for all people. Yes, approaching death can be scary, confusing, and heartbreaking. Even Christ Himself grieved and cried at the death of His friend Lazarus. Christ, showing His human vulnerability, said in the garden, "Father, if thou art willing, remove this cup from me; nevertheless not my will, but thine, be done."²³ He cried out to His Father in Heaven from the cross.

We also note that St. Mark the Ascetic said, "The mercy of God is hidden in sufferings, not of our choice, and if we accept such sufferings patiently, they bring us to repentance and

²¹ Greek Orthodox Metropolis of Boston, "Letter from Metropolitan Methodios about PAE | Greek Orthodox Metropolis of Boston," accessed July 23, 2018, <https://boston.goarch.org/about_us/chancellor/discussion_physician_assisted_suicide/letter_from_metropolitan_pas.html>.

²² David Clark, "Total pain, disciplinary power and the body in the work of Cicely Saunders." 1958–1967, *Social Science & Medicine*, Volume 49, Issue 6, 1999, Pages 727-736, ISSN 0277-9536, <doi.org/10.1016/S0277-9536(99)00098-2>.

²³ Luke 22:42.

deliver us from everlasting punishment.”²⁴ Yes, dying is not free from grief or fear. But nevertheless, we may join Christ in praying that God’s will be done.

The Remembrance of Death

As Christians, we seek to practice the “remembrance of death,” which is a constant, prayerful contemplation of our lives and eventual deaths. It is not morbid or negative, though it may involve tears and grief. This remembrance is Step Six in the Ladder of Divine Ascent of St. John Climacus.²⁵ It evokes St. Paul: “I die daily.”²⁶ This remembrance engenders courage, hope, and repentance in the face of frailty. It leads to the “peace that surpasses understanding” – a state where we are governed not by fear, but by reassurance of God’s love.²⁷ It also exhorts us to view medical interventions not as the perfect solution to illness, but as a way to facilitate comfort while seeking to deepen our connection with God. As Fr. Joseph Woodill has written, with reference to St. John’s ladder:

What sort of medicine would people climbing a ladder to God want to develop? We would want medicine to be a craft that comforts, heals, and relieves pain. We would not want a medicine that prompts us to neglect living the sort of life that would allow us to face death with peace.”²⁸

A practice such as MAID runs counter to the joyful, humble remembrance of death. Its implementation sidesteps the very necessary contemplation of the mystery and wonder of death, seeking instead to manage death and claim it as being within our control.

Notably, the remembrance of death is woven throughout the liturgy. Our liturgical practices teach us how to navigate the end of life, and we can take these practices out into the world to care for loved ones. Our liturgical life shows us how to dwell in life’s complexities: joy, wonder, shame, fear, and doubt. How can we be joyful when keeping vigil at the cross on Holy Friday? Because we know that Christ has trampled down death by death. How can a death be anything other than devastating? By connecting it to our understanding of the fellowship of saints, as we pray: “May their memory be eternal.” What if we are overwhelmed with fear, anger, and sadness? We join our voices with the Theotokos in the Lamentations service on Holy Friday.

²⁴ G. Palmer, Philip Sherrard, and Kallistos Ware, *The Philokalia, Volume 4: The Complete Text; Compiled by St. Nikodimos of the Holy Mountain & St. Markarios of Corinth*, 64071st ed. (Farrar, Straus and Giroux, 1999), 139.

²⁵ John Climacus, trans. Colm Luibheid, and Norman Russell, *John Climacus: The Ladder of Divine Ascent* (Classics of Western Spirituality), 1st Edition (Mahwah, NJ: Paulist Press, 1982).

²⁶ 1 Cor 15:31.

²⁷ Phil 4:7.

²⁸ “The Hub - Euthanasia, Physician-Assisted Suicide, and the Pursuit of Death with Dignity,” Orthodox Church in America, accessed July 23, 2018, <<https://www.oca.org/the-hub/the-church-on-current-issues/euthanasia-physician-assisted-suicide-and-the-pursuit-of-death-with-dignity>>.

What do we do when we are impatient and distracted and struggling? We stand in Church and pray. When we connect the remembrance of death to the joyful sorrow of liturgy, it becomes life-giving. When this remembrance of death is woven into everyday life, we have no need to seek a “cure” such as MAID, for we frame death within the sacramental life of repentance and humble participation in the life of the Church.

Deepening Faith: Accompanying the Dying

Those who care for the dying know it can be a healing and illuminating process for those who witness it. Therefore, a holistic Christian perspective means that we do not shy away from sickness and death. We show up at the bedside. We weep with those who weep. We experience real examples of how people die, and through this, we may see how peaceful death can be within reach.

Great literature teaches us how to be with the dying. Stories such as “The Death of Ivan Ilyich” demonstrate how confusing, yet joyful and peaceful the end of life can be. Ivan Ilyich is painfully isolated in his dying. His isolation is “in his knowing, the remembrance of his coming death: He tried to get back into the former current of thoughts that had once screened the thought of death from him.”²⁹ Insane falsities in his interactions with others force him inward. Ivan’s physical pain is interwoven with existential and spiritual pain. His inner and outer worlds cause profound suffering, as does the realization that he may have wasted his life: “It occurred to him that what had appeared perfectly impossible before, namely that he had not spent his life as he should have done, might, after all, be true.”³⁰ He receives Communion at the suggestion of others, and it provides a brief respite. He experiences profound pain as he is dying. And yet ultimately, we are told that Ivan experiences the Light of Christ, and this brings him peace.

We can learn from examples like this. We can practice accompanying the dying, not like Ivan’s family did as they dodged the truth and avoided his pain, or as Job’s friends did as they encouraged him to curse God, but as honest and compassionate Christians. We may see that when a person starts the active dying process, they have life-giving visions of beloved people or places. As a clinician, I have witnessed dozens of experiences like this. I recall my patient Vera who saw “orbs of light” and remarked that she’d had a lovely visit with her (deceased) mother that morning. I have seen people sit up in bed with a joyful look on their faces or ask for a “ticket for the train.” My patients have looked at me, their faces shining with light, saying, “I’m ready and I’m not afraid.”

At the end of life, the passions often come to the forefront with greater intensity, especially in terms of relationships with others, so it is important to remain connected to

²⁹ Leo Tolstoy, Richard Pevear, and Larissa Volokhonsky, “*The Death of Ivan Ilyich and Other Stories*.” First Vintage edition. (London: Vintage Classics, 2010), 17.

³⁰ *Ibid*, 20.

the sacramental life of the church and to our clergy. Our perception of meaning, values, and relationships may intensify and develop greater clarity, both for better and for worse. To witness this bravely teaches us all how we should live our lives – not in anxiety and fear, but with repentance and wisdom. Being with the dying offers us powerful experiences that we may then carry into our own life choices.

Conclusion

How can we help those who are suffering at the end of life? How can we reshape our collective vision of illness into a time of reflection and growth, in the face of something as daunting as death? How can we spiritually bolster ourselves in a way that does not resort to assisted death? We must deepen our faith, both reaching inward with our own spiritual work and reaching outward to care for the dying with the compassionate boldness that Christ has given us. We seek counsel with our priests. We educate ourselves about the real reasons people seek MAID – isolation, loneliness, despair – and seek to address those deeper causes. We practice living in a manner that facilitates our interconnectedness; we remind our sick loved ones that they are not a burden but members of our beloved family. We become more knowledgeable about the appropriate, comprehensive medical options at the end of life, including Palliative Care and Hospice.

Death is not a failure or a battle that we lose. It is not an escape from this awful material world. Instead, it is a joyful union with the God who gave us His image from the beginning. It is not something to outwit control or hasten. Death is not a lack of healing or a failure of living. Death is “not disappearance, but revelation.”³¹ As Orthodox Christians, we believe death is conquered not by human means or medical means, but by Christ. All is revealed and healed through the person of Christ. Healing may occur even as bodily sickness continues; we can die healed, meeting Christ at the cross, the transformative place in which He tramples down death by death and we find life in Him.

We have many “tools” to facilitate this: prayer, sacramental life, liturgy, community, service, and caring for others. If we utilize the spiritual tools we are given, the option of MAID pales in comparison to a prayerful, brave, repentant, and joyful dying process. A life lived fully within a finite horizon may have a “trivial character in contrast to a life lived in recognition of God.”³² Our faith asks us to engage “the significance of death and the nature of the truth. As to the latter, Orthodoxy reminds the world of Who this Truth is.”³³ This truth is the person of Christ, and when we see this truth, we may live and die with hope.

³¹ John Behr, “*Becoming Human: Meditations on Christian Anthropology in Word and Image*.” 8.2.2013 (Crestwood, NJ: St Vladimirs Seminary Press, 2013), 4.

³² “Care at the End of Life: What Orthodox Christianity Has to Teach | Antiochian Orthodox Christian Archdiocese,” accessed July 23, 2018, <<http://ww1.antiochian.org/node/21291>>.

³³ Ibid.