

*Joy and Suffering:
My Life with ALS*

by Martin J. D'Amore, MD

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Martin J. D'Amore was diagnosed with amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease) in 2010, at age forty-four. This short book, completed about one year before he died in 2015, details his journey during the course of his illness. At his death, he left behind his wife of twenty years and their three children.

D'Amore describes his book as a spiritual autobiography (ix). It exposes the good that came from a terribly debilitating disease, which gradually robbed him of all muscle control but left his cognition intact. He was determined "to show my family the value in someone who can do nothing for himself; who cannot be 'productive' in a worldly sense" (xi).

D'Amore admits that, before his illness, he focused on worldly success. He worked for eleven years as an interventional radiologist in suburban Charlotte, North Carolina, achieving the level of affluence he had dreamed of as a child in Oak Park, Illinois. However, peace and contentment eluded him. He struggled with the virtue of charity, his desire to take time off and help those less fortunate than himself, and materialism. "The allure of excess and indulgence was winning out" (16). He acknowledges that "it took ALS to get me to develop my soul" (103). This tragic and painful narrative of a young husband, father, and physician will resonate with the many people today who, though they indulge every worldly desire, mystifyingly ache for something more, something lasting. In fact, D'Amore has performed a profound and practical service not just for his family but for everyone who reads this remarkable book.

From his active pursuit of career and hobbies to his passive reception of care from others, D'Amore's spiritual journey sweeps the reader along from pervasive materialism to mature spirituality, from moral relativism

to a strong and abiding faith, and ultimately from self-centeredness to God-centeredness. Although written from a Catholic perspective, D'Amore's account will be a source of solace and great hope for anyone facing their own debilitating circumstances. ALS enabled D'Amore and his family "to see life as God does" (ix), and this new outlook both increased his faith and strengthened his self-respect, even as he slowly lost all the abilities that defined him as husband, father, physician, and friend. This lesson is vital in a culture that defines dignity in terms of what we do and have. The quality-of-life mentality is the source of the death-with-dignity movement, which espouses the view that people with debilitating conditions should have the right to choose to die rather than live. D'Amore exemplifies a radically and powerfully different perspective—choosing to live within a web of relationships with people who value the sick and disabled for who they are as human beings.

D'Amore's symptoms began in 2007 and, over the course of several years, he lost abilities that most people take for granted. He deteriorated rapidly after being diagnosed with ALS in 2010 and, in less than two years, was confined to a wheelchair.

Constantly more worried about his wife and children's sufferings than his own, D'Amore was determined to show that, with each ability lost, he gained new spiritual and social insights. For example, most ALS patients remain mentally alert and intellectually unchanged despite the inability to control their voluntary muscles. D'Amore was distressed by his physical helplessness until he recognized that, in a powerful way, it was "a blessing and I would not want it any other way" (33). He determined to "see life as God does" and use this opportunity to love, comfort, and prepare his family for his absence and their reunion in heaven (ix).

A good deal of the book addresses the meaning and purpose of suffering. As a Christian, D'Amore found meaning in Jesus Christ and strove to join his own hardships to those of his Savior. He found solace in the Mass, the sacraments, and the rosary. His journey was filled with great suffering and loss, yet he found happiness, joy, and peace. "It can be a wonderful thing, this suffering" (101). Although contemporary culture often depicts suffering as being without value, the author came to see that it is not evil per se but, rather, "paradoxically good" (101). Otherwise, how could it have accomplished such good in his life? D'Amore's theological insight echoes Pope St. John Paul II's 1984 apostolic letter, *Salvifici doloris*. "Suffering seems to belong to man's transcendence: it is one of those points in which man is in a certain sense 'destined' to go beyond himself, and he is called to this in a mysterious way" (I.2). Near the end of the book, having gone through this transformation, D'Amore writes, "Once we understand that suffering can bring happiness, even joy and inner peace, we can achieve great things for ourselves and others. . . . If only we approached suffering as it really is, an opportunity for improvement, ingenuity, and eternity. . . . Suffering brings us back to Christ" (101–102).

ALS patients face a difficult ethical dilemma when they lose the ability to breathe on their own. When this occurs, there is no longer any benefit in receiving oxygen through a face mask or tube. Before this happens, patients must decide whether to be connected to a ventilator by having a tube inserted into their windpipe. Although this will extend their lives, it prevents any further verbal communication.

While trying to convey his own thoughts about this decision, D'Amore uses problematic language that, strictly speaking, is not written in clearest bioethical terms. For example, when speaking generally about the benefits and burdens of treatment, he determines that he would probably accept a tracheostomy and ventilator. However, his fear of developing the locked-in state, whereby he would have no ability to communicate, including the loss of eye movement, led him to write, "I will have

advance directives to end my physical life" (71). Perhaps it was an oversight or a poor choice of words by someone who was not an expert in moral theology or Catholic bioethics. Based on evidence throughout the book of the author's faithful spiritual journey, it is not hard to accept this as a possible error in phrasing.

From a Catholic perspective, an ALS patient may choose to stop ventilator support when such treatment becomes extraordinary or burdensome, as long as his intention is not to hasten his own death.¹ This point is often lost on supporters of assisted suicide, who hope to demonstrate that the withdrawal of therapy constitutes euthanasia. The author clearly states, "I don't want to be euthanized" (69). Throughout the discussion, D'Amore correctly refers to making decisions on the basis of their benefits and burdens. Costs, burdens, and other factors that affect the patients and others may make continuing life-sustaining treatment morally optional. In cases like D'Amore's, the primary intention is to stop burdensome treatments; death is foreseeable but not intended. There is a concern, however, that D'Amore has not made this distinction clear enough for some readers, and his example could influence others to make unethical or immoral decisions. The author, it seems, is not advocating intended death. In fact, he completes this section by stating, "I do not worry, though. The Holy Spirit will guide me" (71).

This brief spiritual biography is a tour de force, the kind of personal narrative that awakens readers to the value of suffering. The author describes how he was "heavily burdened with attachments, pride and haste" (96). He, like many others on their path to beatitude, learned to turn off worldly "noise and . . . emotions, and [listen] to God's word, [which] lights my path" (107). D'Amore's experience is universal, and his struggle with ALS deepened his faith, hope, and charity, enabling him to shoulder his cross and be an example to others. In the process, he discovered that our essence is not defined by things outside of ourselves, such as our job, home, or bank account. Rather, it is defined interiorly by a desire to be united with Christ and to love others generously. D'Amore's suffering delivered him into the bosom of

Jesus Christ. Despite all that ALS took from him, he gained much more. D'Amore ends his narrative with this lesson: "Life has been unfair to me: unfairly good" (108).

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1. See US Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, DC: USCCB, 2009), dir. 57: "A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community."

***Bioethics and the Human Goods:
An Introduction to Natural Law Bioethics***
by Alfonso Gómez-Lobo with John Keown

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This short but tightly written text has a very clear goal of introducing the reader "to the foundations of natural law theory in relation to bioethics, and to the application of that theory to some of the key issues at the beginning and end of life" (xi). Alfonso Gómez-Lobo considers the book a sister to his earlier work, *Morality and the Human Goods: An Introduction to Natural Law Ethics*, which he suggests could "profitably be read before this one," (xi) since it offers a more complete introduction to natural law ethics.

The book is well written and offers a different, much-needed voice in contemporary bioethical discussions that, too often, are overly fond of principlism and utilitarianism. While the text does not cover all of the many important topics of bioethics, it does accomplish at least two important objectives: it gives a solid introduction to natural law theory, and it demonstrates the theory's applicability by applying it to a few important beginning-of-life and end-of-life issues.

Perhaps one of the most important things a reader needs to know about this book is that it was written largely by the late Alfonso Gómez-Lobo, Ryan Professor of Metaphysics and Moral Philosophy at Georgetown University. Gómez-Lobo died in 2011 and left the manuscript unpublished

and the project, though largely complete, still unfinished. John Keown, who holds the Rose F. Kennedy Chair in Christian Ethics at the Kennedy Institute of Ethics at Georgetown, assumed the responsibility of bringing the project to completion. His intention was to finish it "in the way [Gómez-Lobo] indicated in his response to the referees' reports that he intended to finish it and, where he left no indication, to finish it in the way I think he would have finished it or at least would not have objected to it being finished." Keown also acknowledges that he made a number of relatively minor changes and amended the work to take account of developments since the original manuscript was written. Nevertheless, he states emphatically that he "neither added nor subtracted anything fundamental," so that the finished text "remains largely the work of Gómez-Lobo," although Keown acknowledges having written about a third of the book. Thus, it might be best for the reader to think of this as a joint effort, especially since it is impossible to know definitively which parts are Gómez-Lobo's and which are Keown's (ix).

In addition to providing an alternative to consequentialism, utilitarianism, and principlism, *Bioethics and the Human Goods* offers an insight into what Gómez-Lobo