Abstract. In discussions of end-of-life care and what the often-used but often-misunderstood buzzword “accompaniment” means, the core of the issue has often been missed, leading to inappropriate responses by physicians, loved ones, and the dying persons themselves. Emphasis is often placed on the care of circumstances rather than the care of persons. In what follows, these issues are systematically addressed to show that when patients face physical death, a truly ethical response is authentic, loving accompaniment of them. This form of such accompaniment is explored. National Catholic Bioethics Quarterly 17.4 (Winter 2017): 649–660.

In the chaotic discourse that surrounds end-of-life care, questions of “What does it mean to care for a person at the end of their life?” and “What am I supposed to do for my loved one at this stage?” are often the most challenging to address. Yet they are often the most challenging precisely because they are often misunderstood or “misdiagnosed.” Even more difficult are the extreme cases in which a dying person or a member of the family concludes that it would be better to “end it all,” either in desire alone or by a request for physician-assisted suicide, which is increasingly available in the United States, Canada, and Europe.¹

¹ Physician-assisted suicide is currently legal in six US states (California, Colorado, Montana, Oregon, Vermont, and Washington) and Washington, DC, and in Canada, Switzerland, Netherlands, Belgium, Luxembourg, and Germany.
What does a response in these situations look like? What is one to do? In a comment about religion that is also pertinent in the realm of end-of-life care, G. K. Chesterton observed, “The trouble with our sages is not that they cannot see the answer; it is that they cannot even see the riddle.” Much confusion about end-of-life care stems from a misunderstanding of the “riddle” that is the human person and the challenges faced at journey’s end. It is for this reason that Julián Carrón concluded that, when trying to respond to any given situation, “We have to become even more aware of the nature of the challenge. Otherwise, we will try to plug the leaks, the circumstances, which will be useful for some time, but this will not be what truly changes things.”

What follows is an attempt to address the nature of the challenges faced by those at the end of life in a way that allows for a response on the part of medical practitioners, the loved ones of the dying, and dying persons themselves. An adequate response necessitates responding to the core of the issue. This core is often overlooked because of our frantic attempts to respond to the “leaks” or “circumstances” that constantly present themselves in the form of existential concerns, such as a perceived loss of dignity, autonomy and control, or the experience of suffering—circumstances that are often misunderstood because the core itself is not understood. Only when the core and the circumstances are understood does an authentic response begin to come to light and the accompaniment urged by Pope Francis begin to take a concrete form.

At the Core:

Fear and Anxiety in the Face of the Ultimate Questions

In the existential concerns of a person who is dying, what underlies everything else? What is the core that must be understood before we begin to make a response? Put bluntly, it is the fear and anxiety a person faces when confronted with the ultimate questions: questions that lie at the core of our being, that “constitute the stuff of which we are made,” questions such as, Who am I? Where did I come from? Why am I here? Why is there suffering? What comes after death? Such fear and anxiety are not specific to the dying process, but in the face of death, in our encounter with the looming reality of death, they are made all the more real to each individual person.

As theologian Luigi Giussani explains it, death “is the origin and the stimulus for all searching . . . because death is the most powerful and bold contradiction in the face of the unfathomability of the human question.” The issue is not the questions, but rather our inability to provide the answers, which is what leads to the fear

6. Ibid., 55.
and anxiety in the face of death. The Italian poet Giacomo Leopardi expresses this contradiction well when he writes,

Human Nature,
if you’re merely weak and worthless,
dust and shadow, why aspire so high?
But if you’re partly noble,
why are your best actions and intentions
so easily, by such unworthy causes,
both inspired and undone?  

It is not only our confrontation with our limitedness that causes this fear. It is true that a lack of answers is itself a cause of fear, but it is flight from the attempt to answer the questions at all that is both a new cause and completion of this fear, which could even be characterized as despair. St. Thomas Aquinas makes a useful distinction by positing that the confrontation with an evil that is difficult to avoid (e.g., death, limit) causes fear, while thinking that a good is unattainable when it is only difficult to attain (e.g., answers to questions) is what leads to anxiety or despair. In his Pulitzer Prize–winning book, The Denial of Death, Ernest Becker states it well: “The irony of man’s condition is that the deepest need is to be free of the anxiety of death and annihilation; but it is life itself which awakens it, and so we must shrink from being fully alive.” In other words, at the very core of our being exists a desire to be free from the anxiety that arises when we are confronted with these ultimate questions. Yet because death, which exacerbates these questions, has been reduced to a technical-biological reality, we “shrink from being fully alive”; we shrink throughout our lives, but especially at the end of life or when we witness the end of another’s life.

7. “The inexhaustibility of the questions heightens the contradiction between the urgent need for an answer and our human limitations in searching for it.” Ibid., 48, original emphasis.
9. Thomas Aquinas, Summa theologiae I-II.43.1: “Accordingly, as to the matter in question, the object of fear is something reckoned as an evil to come, near at hand and difficult to avoid. Therefore that which can inflict such an evil is the efficient cause of the object of fear and, consequently, of fear itself. While that which renders a man so disposed that a thing is such an evil to him is a cause of fear and of its object, by way of material disposition. And thus it is that love causes fear: since it is through his loving a certain good, that whatever deprives a man of that good is an evil to him, and that consequently he fears it as an evil” (trans. Fathers of the English Dominican Province [London: Washbourne, 1920], 488).
11. Joseph Cardinal Ratzinger (Pope Benedict XVI) astutely observed that death has been reduced to the level of “technological activity” and, consequently, so too has human life. For “where it becomes too dangerous to accept death in a human way, being human has itself become too dangerous.” Ratzinger, Eschatology: Death and Eternal Life, 2nd ed., trans. Michael Waldstein, ed. Aidan Nichols (Washington, DC: Catholic University of America Press, 1988), 72.
Yet what of the argument that this is not the case? What of the people who have “lived life to the full”? Even in this case I would argue that one is not able to side-step this fear completely. Sheldon Vanauken, for example, writes of watching his wife, Davy, die. She is a woman who has lived a life to the full. Vanauken recounts that “Davy, too, was saying farewell to the wind, farewell to the wind and sky, watching it all go, fade away, die—and thanking God. And yet she was human, heartbreakingly human, and she did not want to die. . . . At all events, she did not, perhaps could not, conceal from me her human longing to live and her human fear of death.”

It is the human condition to experience fear in the face of these questions. Yet often we forget that we are made to live with these questions, not avoid or fear them. As theologian Gerald O’Collins observes, it is only in “the desire to establish and enjoy one’s own autonomy [that] brooding fears about health and death trap people in an anxious solitude.” And even though there is an “essential solitude,” a woundedness in our ability for relationship that we must all learn to accept, there remains the reality that this fear coupled with that solitude can turn self-destructive. In other words, our inability to cope with the thought of losing our autonomy or dignity, coupled with the reality of suffering or feeling like a burden to others, becomes the driving factor of our choices. It is to these existential concerns we must now turn.

The Presenting Symptoms and Circumstances

The core having been established—namely, the fear and anxiety that exist in the face of death, in the face of the inability to answer the ultimate questions, and the ensuing “anxious solitude” that develops—the presenting circumstances must also be understood before an authentic response can be made. First I will give examples of circumstances that are often thought to be of paramount importance but are not. Then I consider the symptoms and circumstances that are of importance.

The Problem with Appealing to a Loss of Dignity or Autonomy

A common concern among the dying, as well as the clinicians and family members who care for them, is the fear of losing one’s dignity. The concern is so great that over 75 percent of people who request PAS give it as a reason for this request. This concern for maintaining personal dignity would be pressing were it not for the lack of agreement on what kind of “dignity” is being discussed. For instance, at


14. Jean Vanier, *Community and Growth* (New York: Paulist Press, 1989), 329. “In each of our hearts, there is a wound—the wound of our own loneliness, which hurts at moments of setback and can be even more painful at the time of our death. Death is a passage which cannot be made in community. It had to be made completely alone.”


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the end of life, dignity is often associated with being in control of oneself and one’s bodily functions, or it is in some way related to how people perceive us.

Daniel Sulmasy would argue that there are three different categories of dignity: attributed, intrinsic, and inflorescent. Intrinsic dignity is “the kind of dignity people have simply because they are members of the human family”; it is not based on “biological, psychological, social, economic, or political conditions, [or] the views of other persons, [or] any particular set of talents, skills, or powers.” This dignity cannot be lost.

Attributed dignity is most often what people mean by “dignity.” It refers to the dignity we assign to others or ourselves based on a created set of values (e.g., skills, power, knowledge) “Control” is a common value used at the end of life when evaluating the dignity attributed to a person. Thus, the “loss of control” is easily felt or regarded as a loss of dignity. As Sulmasy argues, however, loss of this control is only the “loss of the dignity we attribute to other persons” or to ourselves.

Inflorescent dignity (from the noun inflorescence, referring to the blossoming of a flower) refers to the dignity attached to human flourishing, that is, to being able to live “lives that are consistent with and expressive of the intrinsic dignity of the human” and with “some objective conception of human excellence.” This category of dignity is important, for it seems that it is precisely what is being lost in the dying process. Since, for example, bodily integrity and autonomy are a part of human excellence (even if they are not the best of human excellences), the loss of these elements would indeed be a loss of one’s inflorescent dignity.

It is significant to note, though, that both attributed and inflorescent dignity are “logically and linguistically dependent upon the intrinsic sense of the word.” Thus, even though the concern about loss of dignity should not be taken lightly, appeals to a loss of attributed or inflorescent dignity, though serious concerns, are not of paramount importance, since even assigning these categories of dignity to a person “requires that one first pick the individual out as a member of a natural kind that is intrinsically worthy of the appellation, dignity.”

The other side of this coin is the concept of autonomy. When taken to its extreme in the “radical autonomy case”—the case in which we should have the right to choose everything, even when we die—it is “the core of the contemporary

21. Ibid., 941.
22. Ibid.
right-to-die claim.” According to the statistics of those who requested PAS, “loss of autonomy” is cited most frequently as their desire for it. In other words, the person dying wishes “to avoid death as something which happens to me.” It is true that in dying we lose our perceived autonomy. Arguably, though, the desire for autonomy itself is rooted in “a deep-seated unease with the passivity of the dying process—with the helplessness of the patient.” Put another way, those who make the argument for PAS from autonomy are not really arguing that they should be able to die as they see fit, but rather that they should be able “to avoid dying,” to avoid this experience altogether.

What Is Really Important: Agent-Narrative Suffering and a Loss of Dignity

If neither dignity nor autonomy is really at issue, what is? Of the circumstances that need be addressed, the first is that of suffering, though of a particular kind. In many debates, suffering is often equated with physical pain. Yet as Sulmasy notes, pain is “fundamentally a biological phenomenon,” while suffering is “an experience that makes explicit a person’s actual finitude.” After all, “not all pain causes suffering . . . and not all suffering is caused by pain.” Suffering, true human suffering, though it includes physical pain, is not reducible to it. At this juncture, the concept of agent-narrative suffering, as put forth by Lynn Jansen and Sulmasy, is helpful.

Jansen and Sulmasy distinguish between two types of suffering: neurocognitive and agent-narrative. Neurocognitive suffering “has a direct causal relationship to the patient’s underlying disturbance in physiological, neurochemical, or mechanical

25. Ratzinger, Eschatology, 71, original emphasis.
27. Ibid.
28. Sulmasy, Rebirth of the Clinic, 61, 63.
29. Ibid., 62, 63. In Salvifici doloris, Pope John Paul II notes, “Insofar as the words ‘suffering’ and ‘pain’ can, up to a certain degree, be used as synonyms, physical suffering is present when ‘the body is hurting’ in some way, whereas moral suffering is ‘pain of the soul’. In fact, it is a question of pain of a spiritual nature, and not only of the ‘psychological’ dimension of pain which accompanies both moral and physical suffering. The vastness and the many forms of moral suffering are certainly no less in number than the forms of physical suffering” (n. 5, original emphasis).
30. “In the context of the medical care of conscious, competent, adult human being, suffering can be understood as a meaning a person assigns to his or her own experience of bodily finitude through sickness and pain. Ultimately, the meaning of all suffering is death. Suffering is a premonition of the ultimate dissolution of one’s own person. Sickness and pain are the foretaste of death, which threatens to surrender the integrity of the embodied person. Behind every twinge of pain, beneath every wave of nausea, and within every drop of blood, the shadow of death is lurking.” Sulmasy, Rebirth of the Clinic, 63, original emphasis.
function or integrity.” Such suffering does not result from the patient’s belief about his condition. Rather, it is something diagnosable. For example, there is a difference between a patient who feels depressed because of a chemical imbalance in the brain and a patient who feels depressed because of, say, the gravity of his diagnosis. While the former is an example of neurocognitive suffering that can be treated with medication, the latter is agent-narrative suffering and cannot be treated with medication. Agent-narrative suffering “results from damage to the agency and narrative interests of patients.” This suffering is belief-dependent, bearing, at most, an indirect relationship to the patient’s underlying medical condition. The depression of a patient who has received a grave diagnosis may be due not to a chemical imbalance but to his damaged sense of agency and his sense of loss about how he thought his life would play out. These are two different kinds of suffering, and they call for different responses. It is a mistake for a doctor to try to treat agent-narrative suffering by the use of medication, since medication cannot relieve it. Yet PAS, for example, attempts to use medicine in precisely this manner: to relieve agent-narrative suffering with a lethal dose of barbiturates. It is agent-narrative suffering that interests us here.

Agent-narrative suffering persists at the end of life even when neurocognitive suffering has been practically eliminated through medication, because agent-narrative suffering pervades the human condition, most explicitly in the face of death. Jansen and Sulmasy argue, however, that this pervasiveness need not result in utter helplessness and despair on the part of the one experiencing it. For even though “there is ample reason to believe … that agent-narrative suffering is pervasive at the end of life. … There is also good reason to believe that in many cases agent-narrative suffering can be treated in a way that restores the patient to a condition of psychosocial well-being.”

A person who feels that his dignity has been lost is experiencing such suffering. In a system in which death has become a purely technological problem to be handled by the appropriate institutions, the greatest danger is the felt loss of dignity, the experience of being reduced to a technological-biological issue to be solved. On the basis of his clinical experience with dying patients, Sulmasy asserts that “what must be preserved and yet is always in danger of being lost in health care is the complex nexus between dignity, vulnerability, and the personhood of the patient.” In this nexus, the dignity of the person is the easiest for us to fail to recognize.

32. Examples are anxiety disorder, DSM-IV diagnosable depression, psychosis, chest pain, phantom limb pain, insomnia, bone pain, hallucinations, and seizures.
34. Ibid., 322. Examples are fear, loneliness, angst, pitifulness, disgust, sadness, worthlessness, anger, and loss of independence.
35. Ibid., 330.
36. Ratzinger, Eschatology, 70.
37. Sulmasy, Rebirth of the Clinic, 25.
The Experience of the Loss of Dignity

What matters, then, is the feeling of dying patients that their dignity has been lost. Although they are, objectively, still in complete possession of their intrinsic dignity, as discussed above, their subjective feeling of loss leaves them increasingly vulnerable. As William Breitbart observes, it is at this stage that, in extreme cases, patients request PAS, primarily “because they feel they have lost all meaning, dignity and purpose in life.” However, when the patient becomes vulnerable in this way, death is not the only remedy. The suffering caused by this vulnerability can be alleviated, to some degree, by external social support: from health care workers, family members, and friends. By reaching out to that person and constantly affirming their intrinsic dignity, value, and worth, we better equip them, even in this vulnerable state, to endure the challenges with which they are faced.

What Does “Accompaniment” Look Like?

Given the core of the issue and a better understanding of the presenting circumstances and symptoms, we can explore a response of authentic “accompaniment.” In order to alleviate agent-narrative suffering stemming from the fear and anxiety of facing the ultimate questions, we should accompany those who are dying in such a way that they are able to maintain a sense of their dignity and value even in a fragile and weakened state. Such accompaniment should be offered by health care providers (especially physicians), family members, and loved ones. Even the dying person has a role to play.

Response of Doctors

Doctors can accompany those at life’s end in three ways: having a “restorative” goal in mind for the one dying (i.e., not merely pain control), providing holistic care by engaging in an authentic relationship with their patient, and never giving in to a request for PAS.

First, doctors should endeavor to provide more than pain control, and restore the patient in whatever capacity is possible. Even when a patient is in the terminal stages of an illness, the doctor retains the moral obligation to give “attention to restoration of all the intrapersonal and extrapersonal relationships that can still be addressed”; to help the person seek restoration of their relationships to others and self. This attention never comes in the form of inappropriate medical prescriptions. Yet because doctors often perceive such patients as incapable of restoration, “they [often] conclude that the only issue before them is how to make the patient as comfortable as possible in the dying process.” However, the morally superior course of action would be to assist the person in confronting the important existential questions that arise, the

40. Ibid., 127.
ultimate questions.\textsuperscript{42} Jansen and Sulmasy have argued that “as patients approach death, they confront many important questions; and it is important that they address these questions in a manner that is consistent with their character and considered values. To do this, they need to be in a state of psychosocial health. It follows that even patients who are close to death have important interests in being restored (to the extent possible) to a state of psychological health.”\textsuperscript{43}

It is these questions to which Giussani refers, as pointed out above.\textsuperscript{44} Because illness is not only a bodily event but also a spiritual one, more than medicine is required. Doctors possess a lofty calling, often not realized or even perceived, to see their work as having not merely a technological-biological nature but also an intensely spiritual one. Ultimately, doctors must come to see both themselves and their patients as more than just biological machines to be fixed, their profession as more than that of biological mechanics: “To heal a person, one must first be a person. We are all spiritual beings. Health care is a spiritual discipline.”\textsuperscript{45}

Second, doctors have a moral obligation to accompany the dying person by providing holistic care, engaging in an authentic relationship with their patients. As the human person is “intrinsically spiritual”\textsuperscript{46} and the end of life is a time when the “spiritual” questions are as much at issue as physical concerns, if not more so, doctors must engage in a holistic approach to healing that involves “attention to psychological, social, and spiritual disturbances.”\textsuperscript{47} As I have argued throughout this paper, the human person is not of a purely technological or biological nature. Thus, treating the person as a mere technological-biological problem to be solved and forgetting our intrinsically spiritual nature (e.g., our need for relationship) is a reductionist understanding of the care physicians are called to provide. For example, doctors should never be “too busy” to spend time simply conversing with dying patients and their families.

Finally, a doctor must never give in to a request for PAS. Treating a condition that is not caused biologically (e.g., agent-narrative suffering) with a lethal dose of...
barbiturates is nonsensical, because it is not a response to the problem and not a treatment but a total cessation of life. Hence “to honor this request [for PAS] would be to violate a fundamental norm of medicine.” Given that agent-narrative suffering really does exist, and given the doctor’s obligation not only to relieve suffering but also to restore the patient to psychosocial health, Jansen and Sulmasy argue that the clinician also must not honor a patient’s request for opioids or lethal doses of barbiturates in an attempt to “treat” agent-narrative suffering. The clinician should never assume that a patient is incapable of being restored to psychosocial health or that the patient has no interest in restoration, because the patient will always retain his need and desire to confront the important questions. Thus, as Jansen and Sulmasy conclude, “Physicians should not participate in medically inappropriate interventions, even when their patients request them to do so.” Doctors have a responsibility to provide more than mere pain control; they have an obligation to work toward the restoration of the patient as far as possible.

Response of Loved Ones

The family members and loved ones of the dying person also have a central role to play, arguably the most important of all. Their role, like that of doctors, is also one of accompaniment, albeit of a different nature. In this case, true loving accompaniment dictates a total giving of oneself to the other person, in such a way that a coexistence of persons results. The bond of love between these two persons, then, would result in the ability to participate in the same experiences. In the case of a dying person, while two people cannot be the subject of the bodily suffering or the agent-narrative suffering, both could still enter the same overarching experience. That is the consequence of love.

An example of this true loving accompaniment can be found in A Severe Mercy, the memoir by Vanauken mentioned earlier. When his wife, Davy, was diagnosed with a terminal illness, Vanauken explicitly committed himself to this self-giving accompaniment: “An iron resolution built up in me, perhaps the most powerful and unswerving of all my life, that in the months ahead I would do all and be all for her; I would sustain her and hold her up with my love. All I was came into focus in my fierce and almost terrible will to do this, to let nothing impede me from doing this.” What Vanauken did was to suffer alongside Davy, even to the point of entering into Davy’s fear of death itself. In so doing, he experienced what he knew as the “substituted love” of Charles Williams: “In Charles William’s Descent Into Hell he sets forth his Doctrine of Substituted Love: carrying one another’s burden is not just a figure of speech or something meaningful only in terms of physical burdens like a trunk. Davy’s burden was not death but the fear of death. . . . I then entered into the

49. Ibid.
51. Vanauken, Severe Mercy, 158.
fear, her fear, with all my heart and mind and imagination, felt it, carried it along with my own fear, which was also real but other. And her burden grew lighter.”

This is true loving accompaniment. It involves entering into the life of others through a true and authentic gift of self, so as not only to be a firsthand witness to their suffering but to truly experience it beside them, to face the questions with them. The descriptions of accompaniment by Vanauken and of substituted love by Williams get to the heart of the matter: the person who loves someone who is dying must enter into the very experience of the other and not merely observe it. This is accompaniment, to enter into the ethos of another person’s suffering.

Response by the Person Who Is Dying

On the part of the individual who is dying, one could term their proper response to the process of dying as “witness.” The effect of the dying person being a witness to others cannot be underestimated. Vanauken describes the effect of his own wife’s witness: “It is simply true, without exaggeration, to say that she was a tower of strength to everyone—nurses, doctors, ministers no less than friends—all drew strength from her cheerful, brave, deeply loving spirit. Love shone forth from her; and love not only begets love, it transmits strength. . . . [The hospital] said that Davy had done more for them, for their nurses and other patients, then they had ever been able to do for her.”

The witness of Davy’s strength to continue to engage in life and not abandon herself to the depression of death gave all those around her the strength to carry out their task of accompaniment. In other words, Davy, though truly experiencing the fear and anxiety that death produce, clearly did not flee from confronting these questions but faced them boldly. Even though she could not provide the perfect answer, she was not forced to live in fear and anxiety. It is a witness such as this that benefits not only the person dying but all those who surround them. Such an attitude can transform a very negative response to pain and death to an attitude of love. In effect, a good witness on the part of the dying person can allow those who observe that witness to take their accompaniment all the more seriously.

In addition, the dying person is learning from the experience, absorbing the education it offers. Although in Christian theology the endurance of suffering is often discussed in terms of its redemptive quality, suffering also serves an educative function. Giussani argues that this is the case “because sacrifice [suffering] keeps us from harboring the illusion that life on earth must last indefinitely; it keeps us from confusing the pilgrim’s poor path with the luminous eternal happiness of our homeland.” In other words, suffering teaches the dying person, as well as those who accompany him, that physical life is not our final goal, it is not the end.

52. Ibid., 165, original emphasis.
53. Ibid., 164.
A Call for Loving Accompaniment

Francis’s exhortation to the Pontifical Academy for Life in 2015 remains true today: “The objective of palliative care is to alleviate suffering in the final stages of illness and at the same time to ensure the patient appropriate human accompaniment.”55 Yet as has been shown, the suffering most in need of alleviation is not necessarily physiological in nature, and the appropriate human accompaniment must be aimed at restoring each person and so enabling them to address the ultimate questions. We enter this search alongside those who are dying, truly entering the search with them, whatever it may entail. This is the path of loving accompaniment: not consenting to the easy way or the path of least resistance, but being with them as they engage the questions at the core of their humanity, entering that questioning with them. This is no easy task, and it is not one that is easily understood by many. However, it is the one that leads away from a disintegrated mass of partial answers and instead to the greatest fulfillment, satisfaction, and peace. As the poet Cesare Pavese so beautifully writes, “What man seeks in his pleasures is that they should be infinite, and no one would ever give up hope of attaining that infinity.”56