

Bearing witness in life and death

by [Keith G. Meador](#)

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"On Our Own Terms: Moyers on Dying" (PBS)

In *Life is a Miracle* Wendell Berry says that in order to realize that life is an inexhaustible miracle, life must be lived within the thick particularities of "local land" and "local people." In the midst of such a way of life, dying can be acknowledged, even if it remains a painful mystery. Amid such a way of life, we can learn that living and dying are not ours to control. That same lack of control, whether in dying or living, also enables us to discover and embrace the fullness of life and death. When we trust others in community, we discover the significance of giving our lives to others, and ultimately to the Other. In such a giving, there are often miracles.

Our culture, however, tends to make such miracles unlikely. Dying in modern America is frequently messy, frustrating and debilitating—despite and because of medical advances. Many people seem to be less afraid of death than of dying alone, out of control, in intense pain, caught in a technological vise controlled by inattentive technicians.

Can we do better in helping people die well? Bill Moyers thinks so. In a four-part PBS series to be aired September 10-13, "On Our Own Terms: Moyers on Dying," Moyers provides several angles of vision on the end of life. He offers portraits of dying people and their families, hoping to show what "dying well" might look like in our time.

Moyers does not shy away from difficult issues. He focuses on how we can overcome the fear of dying and the denial of death in our culture. Can we really learn to live with dying? He also explores the emergence of "palliative care," highlighting the new attention given to pain management and a more wholistic focus on dying patients' physical, emotional and spiritual well-being. He confronts the debates over physician-assisted suicide and various efforts to control the circumstances of death. Finally, he attempts to address the systemic challenges to providing better care for dying persons and their families, looking in particular at a heroic hospice in

Birmingham, Alabama, that is devoted to caring for the working poor and the uninsured.

Many of the virtues of Moyers's work are apparent in this series: he displays a generosity of spirit, a willingness to tackle hard questions and an evenhanded consideration of debates, and he offers poignant portraits of individuals. He has a gift for focusing attention on a critical concern, inspiring conversation and reframing issues and debates. He clearly hopes that this series will stir congregations, community groups and others to discussion, engagement and action about how we die and care for those who are dying. A useful discussion guide and other resources are available on the Web site (www.pbs.org/onourownterms).

The first episode features an undertaker who is also a poet who tells us that we owe dying persons a commitment to "witness." He uses this term in a fairly generic sense, but it has a powerful resonance in a variety of settings: in a hospice program's commitment to telling stories about the person who just died; in a physician's insistence that we ought never to abandon those who are suffering or dying; in a nurse's emphasis on "sharing suffering" by being present with the dying; in the willingness of a hospice nurse to make regular home visits; and, perhaps most important, in the steadfast presence of families, and especially spouses, who bear witness to their love by giving consistent, dignified care and companionship. The examples of committed spouses are so moving that they might well be used with couples preparing for marriage.

The series conveys the hope that the palliative care movement will improve care at the end of life. In situations where there is strong family support and access to adequate health care, palliative care offers a significant opportunity for people to die "peacefully." Palliative care accepts the reality of terminal illness and lets the disease take its course, while making that course as comfortable and "humane" as possible. It both recognizes the limits of technology and draws on significant technological advances in pain management.

In many ways, an emphasis on palliative care is likely to reduce the controversy surrounding physician-assisted suicide. What most people fear, after all, is a death that comes after repeated aggressive interventions have left them helpless and dependent on technology. Indeed, the cases of physician-assisted suicide that Moyers follows in episode three make it clear that most people who contemplate this step are in no rush to end their lives. In the two highlighted instances of people

preparing to commit suicide, neither ended up doing so, and both eventually died without too much trauma. While the series carefully avoids taking sides in the debate, the examples suggest that, even in “ideal cases” in which the patients are mentally and physically capable, planning one’s own death adds a great deal of unnecessary mental strain to the dying process.

If an increased commitment to palliative care is the proposed solution, there are substantial barriers to the implementation of such treatment. “The system” is obliquely criticized in all four episodes, but palliative care continues to rest in the hands of the medical system. Only in episode four are the massive systemic problems of contemporary medicine faced. For example, Medicaid currently presents substantial financial disincentives to providing the sort of end-of-life care that the series praises, and even private insurance often will not cover home-care expenses, hospice programs, and the like. One doctor exclaims, “It’s easier to get a hip replacement than a nurse to visit you at home.”

As a result, many people are impoverished by exorbitant medical expenses, and sometimes family and friends are dragged along with them. In the worst cases there is no medical coverage at all, nor any close family or friends who can act as “primary caregivers.” Even Dr. Amos Bailey and his extraordinary team of caregivers at the Balm of Gilead Hospice in Birmingham, who provide the central focus of the final episode, find it hard to help the working poor and the uninsured die well. They must juggle treatment options based on financial considerations and try to alleviate long-felt family alienation.

The “cutting-edge” caregiving at Balm of Gilead leaves open what it means to “die well.” Are there any resources, any narratives, into which we can place the stories of our living and our dying—a larger set of convictions to which we bear witness? The series largely brackets these deeper questions. When Moyers inquires about the death of his subjects, he seems to ask only if they died “peacefully.” Most seem to. “Dying on our own terms” is largely about “going quietly”—without the indignities of technology, without the horrors of extreme pain, and with the chance to “say goodbye” and be with those one loves most.

The place of death in the larger scheme of life remains a frustrating mystery even for the exemplars of the series. One of the dying people shown is a physician far too sensible and rational to become futilely angry at the cancer striking him. Nevertheless, he still struggles to make sense of his life now that it is ending. The

series comes dangerously close to embracing death at this point, with claims that death “gives life pizzazz” and is like “sugar.” The absence of a communal, shared narrative of death forces on this man and others a prolonged struggle, and for those without his knowledge, leisure time and community, there is precious little to cling to.

The burden of having to create such a narrative for oneself—to die “on our own terms”—forces most less-privileged people to die confused and bewildered, isolated from others, and trapped within the silence and evasion of death in the larger culture. Such underserved people encounter death as the ultimate betrayal of the culture’s endless promises for “full life.” The series’ focus on dying “on our own terms” fails to focus on the countless people who do not have the freedom, the family support or the financial means to dictate their own terms.

Is there another kind of witness to be offered? We were struck by the lack of overt involvement of religious communities in the care of the dying, judging from the evidence of this series. To be sure, the convictions of particular individuals surface throughout the series, and a chaplain is shown team-teaching a course for medical students with a physician. One primary caregiver in the series tearfully describes how she misses being able to attend religious services. But there is no mention of her community providing assistance with her home care of her dying husband.

The source of this limitation may lie not only with Moyers’s angle of vision, but with the churches and other faith communities. Perhaps they are not being present with dying people and their families. And perhaps faith communities are also failing to be public advocates for more faithful and just policies of care at the end of life.

How might Christians begin to rethink what it means to be the body of Christ in matters of life and death? Christians have traditionally embraced the vocation of caring for the sick and the dying. As historian Robert Wilken has pointed out, many Roman citizens would have characterized the early Christian communities as burial societies! Certainly the trend toward palliative care should be roundly endorsed by Christians and Christian health organizations. Religious communities should also invest in the powerful and faithful vision of such movements as parish nursing and hospice. After all, the team-oriented focus of hospice—in which doctors, nurses, chaplains and social workers join forces together in caring for dying persons and their families—draws its animating vision from the Christian tradition.

The Christian tradition offers resources for a compelling witness on issues of life and death. Indeed, the Christian narrative of God's presence in life, in death and in life beyond death offers a meaningful, coherent and truthful way for us to narrate the entirety of our life's living toward dying. Through our baptism into Christ's death and resurrection, our lives are no longer our own, but are hidden with God and lived in the power of Christ's grace and mercy. Death is neither something to fear nor something to embrace stoically. Though death remains the final and most awful manifestation of sin, no matter how we die, the Christian narrative of death and resurrection in Christ offers not simply the promise of an afterlife to remove death's sting, but participation in a cosmic mission of salvation. Salvation through Christ is the final defeat of the powers of destruction that imperil our lives and all human life. As St. Paul affirms, "It is not I who live, but Christ who lives in me." In the face of death, Christ goes on sustaining our lives and all life.

Being present to the dying, especially those whose lives seem to be without meaning—rather like the games played by also-rans at the end of a baseball season—is a witness to the genuine purpose of our lives: to abide with each other in faith, hope and love. By living with our own deaths present to us through baptism, we are better able to discern the false, fleeting treasures of the world and to devote our lives to a greater promise—not to a nation or corporation, but to the reconciliation of all things in God.

To its credit, Moyers's series offers poignant portraits and many helpful suggestions about ways in which our dying and the dying of those around us can be grace-filled. This process, however, should not begin only when the cancer diagnosis is offered. It ought to shape the entirety of life in community. We should begin to learn how to die not on medicine's terms, or our own terms, but on God's.

Of course, we are not called to dwell on death in some morbid way. Living in Christ frees us from the power of death over us, from the ways fear of death and avoidance of it control and limit our lives, our relationships and our actions. So much of our frantic living in this culture is precisely such an absurd embrace of death, of triviality, of nothingness, under the cloak of wealth and plenty. When we live life in such a way, death's sting is brutal. If we live differently, we will die differently, too. We will discover that life, and even death, is a miracle.