



From the Forums -

Citizens in
National Issues Forums
Deliberate about:

At Death's Door

What Are the Choices?

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Introduction

Since the National Issues Forums (NIF) issue book, *At Death's Door: What Are the Choices?* was published in 1997, forums have been convened around the country to give citizens an opportunity to deliberate about the question of “How society should care for people who are suffering and near death.”

This report explores, through the eyes and ears of 15 moderators and convenors, some of what happened during those forums.

The focus in this report is not only on what was said during the forums, but on who talked about the issue, why they talked about it, and how they talked about it, in terms of what matters to them personally about this issue.

The intent is to provide useful, and perhaps provocative, information for past and future moderators, convenors, Public Policy Institute (PPI) faculty, journalists, officeholders, and health care professionals. It may also be helpful to anyone who is interested in this issue in particular, or in the sometimes-unpredictable directions that public talk can take in the yeasty environment of NIF deliberative discussions.

What's the Issue?

Death is a fact of life. It is a natural part of the life process. The end of human life comes in many ways — from sudden and untimely, to slowly and with great pain and suffering. Any type of death leaves friends and family members grieving. But for the person who is dying, and for everyone who faces an unknown type of death someday, the concern is about how much pain, suffering, and loss of autonomy it is necessary to endure.

Today's incredible advances in medical technology and medication can not only miraculously prolong life but also in many cases prolong death, often in its most painful and debilitating stages. The combination of medical advances and aggressive intervention has changed the dying process for many people into “a gauntlet of high-tech care, unwanted treatments, severe pain, and depression.”

The problem of people who suffer a prolonged and painful dying process became a controversial public topic for Americans about 100 years ago when discussion of physician-assisted suicide entered the public realm by way of publications and discussions among professionals and officeholders. It became an

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issue as individuals and groups voiced arguments for and against physician-assisted suicide — sometimes rooted in strongly held religious beliefs. Attempts to legislate a resolution to this issue have only added fuel to the fire.

The NIF issue book, *At Death's Door: What Are the Choices?* provided people with a framework to encourage deliberative discussion of the issue of prolonged, painful death, and physician-assisted suicide. The framework takes people through consideration of three different choices, or perspectives, regarding the issue.

Choice 1:

Let Patients Die With Dignity advocates physician-assisted suicide as a humane way of death that is already practiced in secret. Advocates of this choice believe that legalization would help prevent errors and abuses and make it equally accessible to people who truly need it.

Choice 2:

Improve Care for the Dying focuses on relieving the suffering during the dying process by ensuring adequate pain relief and by giving the dying person more control over what kind of medical care and treatments they get or do not get.

Choice 3:

Above All, Sustain Life promotes a commitment to preserving and sustaining life and condemns the use of advances in medicine to shorten life as an abuse that would undermine society and medicine.

The issue book, *At Death's Door*, was produced by Public Agenda and the National Issues Forums Institute and published by Kendall/Hunt Publishing Company in 1997. The issue framework in the book has been used in a variety of settings and for a variety of purposes including community forums, schools, and adult literacy programs. This report describes the forums where it has been used to give citizens an opportunity to deliberate about the issue using this framework.

The Forums

The forums were held in a variety of settings such as colleges, universities, libraries, churches, in meeting rooms and conference halls, and at the monthly banquet of a philosophical society.

Motivations for convening the forums included: to respond to high levels of general interest in the issue in the community, to provide adult education in churches, to use as a forum experience, as part of a PPI curriculum, to follow up on interest generated in the issue during a PPI, at the request of hospice and other health care workers, to enrich a conference on death and dying, as research for part of a doctoral dissertation, to provide programming for a group that meets to discuss issues, and because of an impending voter referendum on legalizing physician-assisted suicide in Oregon.

Forums were held on weekdays, weeknights, Saturdays, and Sundays. Some were an hour long, some three-hours long and some were a series of three one-hour sessions. Attendance ranged from less than a dozen people to more than 100. Participants included high school students, college students, professors, doctors, nurses, clergy, and various community members.

People came to the forums in response to pamphlets, newspaper articles, promotion by churches or organizations, letters, and personal invitations.

A couple of forums included a speaker of some kind; such as a medical ethicist or a professor. But most of the forums featured only the participants themselves, sitting in U-shaped seating arrangements, circles, or semicircles. Whether there was a speaker or not, people at the forums came to talk about how society should deal with people who are terminally ill. And at every forum their talk started with their own stories.

Why People Came to the Forums and How They Talked

Most (perhaps even all) of the people who came to the forums did so because the issue was personally relevant to them in some way. They expressed through their stories the ways in which they found this to be their own issue. Some had had recent experiences with a dying family member. Many had had similar experiences that were not recent but still fresh in their memories. As one moderator said, “People are closely, emotionally involved — personally involved, some got teary. Just telling their stories was a very realistic experience for them, it was often still a very raw personal issue.”

Other participants expressed it to be a personal issue for themselves as they considered what the end of their own lives might be like and what choices they might want to have at that time.

In forum groups that included college and even high school-aged participants, moderators found that young people expressed a surprisingly strong personal connection with the issue. Younger participants often told stories about Grandma or Grandpa, and watching them go through the dying process. And these young people were well aware

that the family had been faced with some very difficult choices during that time. Some young people also recounted stories of friends and fellow students who had been in car accidents and related the circumstances surrounding an untimely dying process.

The effect that this intense personal connection to the issue had on the deliberation process at the beginning of the forums was to very quickly set a tone of seriousness and ownership of the issue. Unlike other issues that may be interesting to talk about or that affect others (such as welfare or alcohol) absolutely everyone eventually faces death.

Moderators often struggled to describe what they saw as an almost contradictory phenomenon during the beginning of these forums — that although the conversation, especially during the personal stories, was emotional, serious, and often intense, participants also expressed relief in being able to talk about this issue and to consider choices. One moderator said, “People seemed to enjoy the chance to talk.” Many people were eager to talk, but some were very quiet, at least at first. One moderator found his request for personal stories met by a long silence. Then the stories poured out and the challenge was to move the talk to consideration of the choices.

Similarly, moderators described the tone of the conversation by the end of the forums to be an odd mix of seriousness and optimism. Comments included: “There was a certain buzz in the room, on the somber side, but it was an enthusiastic somber.” “There was a certain kind of excitement that ‘we can talk about it, we can deal with it’.” “Many left energized and enthused, upbeat, relieved, many made almost a pledge to be more vigilant about this regarding legislation.” “They saw a dilemma before them, the end of the forum was not emotional, but it was unsettling.” “People were generally pretty optimistic and energized.” “People were more confident, more enlightened. There was a mild exhilaration that we could talk about this and go some places that a lot of others hadn’t gone before and not be threatened about it.”

For forum participants in Oregon, consideration of the issue had a broader immediate relevance since the forums were being held prior to a voter referendum on legalization of physician-assisted suicide. For many of them the issue was not only personal but also a consideration of the dilemma of reconciling personal values with the desire for society to impose some controls.

Unlike the many people who recounted how rarely the opportunity to discuss death, dying, and physician-assisted suicide ever came up, the participants in the Oregon forums were frequently involved in talk about the issue since it had become a hot public controversy in the state. But like other forum participants in forums around the country, Oregonians were also looking for a different way to talk about the issue.

What Deliberation Did

So many participants had emotional personal stories to tell that it would be easy to lose sight of the fact that many also came to the forums with strongly held positions regarding this issue. Some positions related to, among other things, personal experiences, lack of personal experiences, or deeply held religious values and teachings.

There was very little mention by moderators of talk during the forums about facts, fig-

ures or “what the experts say.” The recounting of personal stories was the centerpiece of these forums. People did express positions on the issue, but moderators frequently saw a change in response to the stories. One moderator said, “People became more open in their talking and thinking — in response to the personal stories — this happens after people test each other. We took special care to lay out the ground rules so that the emotion wouldn’t carry them away from the issue.”

People who came to the forums with strongly held positions usually didn’t change their positions by the end of the forum. But moderators spoke of a “softening” and an “opening” toward others as they listened. Some participants said that the forum had helped them to clarify their position, while others held onto their position but expressed new understanding of others’ views in light of the stories of their personal experiences.

Many participants displayed great empathy after hearing the personal stories. With this issue, unlike some other issues, people seem to be easily able to imagine themselves in someone else’s situation.

The structure of the forums and of deliberation seemed to allow people to relax enough to truly listen to each other. One moderator said, “Several people came up to me afterward. They said they hadn’t been sure what would happen, that it was a sensitive topic. But they said that they had felt safe in the discussion environment and knew they could express themselves and not be judged.”

This ease of relating to (if not agreeing with) others tended to put forum participants into some mentally tough situations. As one moderator put it, “The challenge that the forum presented was to wrestle with others’ viewpoints as they held those up to their own values.”

Moderators saw participants increasingly questioning each other as forums progressed. They referred to positions that didn’t change but “expanded” as people deliberated. In a group of academics, the conversation “started out as an intellectual discussion but became more personal.” Another moderator said, “Their own personal positions didn’t change, but in almost every case, they got a different view of the complexity and a different view of others’ beliefs.”

One moderator reflected on how deliberation on an issue like this takes on different characteristics because of regional culture. He said, “Here (in the South) we have a ‘culture of politeness’ that makes it both easier and harder to deliberate. On the surface it appears to be going well, but it can make it harder for people to express their feelings. The moderator has to read the group and use the tools of probing as the opportunities arise.”

Another moderator observed that having strong voices expressing opposite ends of the issue spectrum promoted effective deliberation by throwing the choices into greater relief. The moderator felt that this is especially helpful if the strong opposing views are expressed early in the forum. She said, “Having two strong views of the ends of the spectrum, in conjunction with the framework, helped everyone else (and those holding the strong views) see the middle in contrast to the extremes. This allowed people to have the privilege to consider other ways of looking at the issue and to consider other choices.”

These forums brought together people with personal experiences with and often, posi-

tions on the issue. Many left the forums with the same positions but an expanded way of thinking about the issue and about others. Part of their expanded thinking as a result of considering the issue face-to-face with others was in viewing the issue as not just a personal matter, which it most certainly is, but also, at the same time, as a social issue.

Viewing the issue of dying and physician-assisted suicide as simultaneously a personal, and a social issue, had the effect of bringing a number of dilemmas to the surface. Deliberation of the three choices is what helped people to identify, if not resolve, the nature of the dilemmas.

What People Struggled With — and Why

People not only cherish the lives of family and friends, but they also hold deep beliefs about the sanctity and value of the lives of all humans — even total strangers. They know that this is both a personal and a societal issue.

In these forums, over and over again, people expressed a very strong desire to retain control over decisions about their own lives and the lives of family members. But they also know, from either personal experience, or from the experiences related to them by others, that the dying process is sometimes a time of great need for help and support. To meet those needs, individuals and their families often turn to other parts of society; health care, government, and sometimes the legal profession.

People in these forums struggled with the desire to retain autonomy over their own decisions while worrying about the abuses that might happen without some government regulation. They want government to be a watchdog against abuses, but don't want government to get too involved with telling doctors what they can and can't do. Some worried, for example, that legalizing physician-assisted suicide may actually open the door to making it impossible for physicians to ease a person's discomfort or honor their wishes about the end of their life. They worry that introducing a lot of regulations may take autonomy for decision making away from the doctor and patient.

One moderator said, "Generally they saw this as a terribly personal decision. They didn't see a role for big government." But, as another said, "I sensed that they were truly beginning to recognize that their choice impacted someone, or could impact someone else, and they needed to wrestle with that." A third said, "There were some deeply perplexed thoughts about what would be right for an entire community in terms of setting policy direction."

In some forums there was a coming-to-grips with viewing this issue as both personal and societal. A moderator summed it up for his forum, "There was a recognition that it is a family issue, but that government will impact family decisions with the public policy that it creates. Thus, we have to deal with it. Even the policy of local hospitals will impact these personal decisions. They were beginning to realize they might have to get involved in civic activity."

Another major area of struggle was regarding strongly held values about the sanctity of life but also about the quality of life. A desire to alleviate suffering during the dying process, and to the greatest extent possible, was practically a universal theme in these

forums. But since the reality is that not all suffering can be relieved, it left people torn between a desire to prolong the life of a loved one but also to minimize their suffering by whatever means they could. What came out of this struggle was often a strong sense that whenever possible, the dying person's wishes must be honored.

Retaining personal control and decision making for one's life was a strong theme in these forums. People want other things, too, safeguards and laws from the government, pain relief and sometimes life-prolonging treatments from doctors. But they draw the line at giving up control over their lives in order to get those things. As one forum participant said, "If I have to give a physician control of my life to get superlative care, I am not willing to trade off control, even for superlative care."

What People Left the Forums With

More often than not, and perhaps unexpectedly, people left the forums with — in a word — optimism.

Many had finally found a place where people were willing to talk, and listen to them, about this most personal and perplexing issue. Although every situation at the end of a person's life is unique, it is at the same time, and in many ways, a common experience that we all share. The opportunity to share the consideration of public policy that we may all have to live and die with, gave people a sense of the strength that community can bring, even to this most difficult and sensitive issue.

The Interviews

Between 10/20/99 and 11/23/99, 15 moderators and convenors were interviewed by telephone about *At Death's Door* forums. They were:

Sue Binder	Charleston, West Virginia
Judy Burridge	Corvallis, Oregon
Joyce Buttermore	Panama City, Florida
Mona Connolly	Hilliard, Ohio
Sadie Flucas	Naperville, Illinois
Bob Frey	Charleston, West Virginia
Ann Hinsdale-Knisel	Adrian, Michigan
Matt Hayes	Louisville, Kentucky
Don Littrell	Columbia, Missouri
Sue Mortensen	Naperville, Illinois
Pat Russell	Kent, Ohio
Paul Sunderland	Portland, Oregon
Diana Wayand	Tallmadge, Ohio
Ann Wolford	Blacksburg, Virginia
Virginia York	Panama City, Florida