

# State Initiatives *in* End-of-Life Care

Issue 2, October 1998

Focus: Oregon

## Oregon Health Decisions: Lighting the Way to Common Ground



### INSIDE

- **Oregon Health Decisions:  
Lighting the Way to Common  
Ground**  
PAGE 2
- **OHD Contributions to End-of-Life  
Policy**  
PAGE 3
- **Policy Makers Assess OHD**  
PAGE 5
- **How OHD Engages Citizens in  
the Health Policy Process**  
PAGE 5
- **Community Meetings:  
Views from the Inside**  
PAGE 6
- **A Word of Encouragement to  
Other States**  
PAGE 8

## Oregon Health Decisions: Lighting the Way to Common Ground

“Oregon Health Decisions (OHD) is the interface between the remnants of democracy and technology,”

says Ralph Crawshaw, M.D., one of the founders of the small but influential grassroots organization. “You don’t want health care decisions made by bureaucratic fiat. The role of the expert is clear and necessary in describing what is possible, but cannot and should not be expected to present the broad values that inform a just democracy. People must decide for themselves.”

Helping citizens decide what their health care values are and transmitting those values to policy leaders willing and able to act on them is OHD’s mission.



*A citizen articulates his health care values in a recent Oregon Health Decisions community meeting.*

Since its emergence in 1983, OHD has been a significant player on Oregon’s rapidly evolving health care policy scene. OHD has been involved in a wide range of issues, including access, cost control, quality, fair allocation of resources, as well as end-of-life care. Students and leaders of Oregon’s end-of-life care reforms say that OHD’s work on publicizing advance directives and bringing citizen values to bear on health policy issues has been an indispensable part of the state’s collaborative reform movement, which has made a number of advances in taking better care of the terminally ill:

- expansive advance directive legislation
- the lowest rates of in-hospital death in the United States
- exceptional and growing hospice utilization rates
- aggressive comfort care and pain management policies
- comprehensive end-of-life care for most poor citizens through the Oregon Health Plan.

OHD’s role in change is all the more remarkable because it has stayed out of interest group advocacy, party politics, and lobbying. “OHD uses the partnership approach,” says Michael Garland, D.Sc.Rel., an OHD co-founder. “It doesn’t act as provocateur, or as a social critic—that’s the ‘Protest Model.’ We follow a rational model in our citizen deliberations and in front of policy makers.”

The following pages provide a summary of OHD’s end-of-life care policy milestones, examine the workings of its rational, partnership model, and offer several assessments by citizens and policy makers from the public and private sectors. ■

## OHD Contributions to End-of-Life Policy

### 1983–1985. Honoring Patient Dignity and Autonomy

To better understand public health care values, the Oregon Health Council, a policy advisory body appointed by the Governor, created Oregon Health Decisions as an outreach program to conduct community meetings throughout the state. The purpose of the meetings was to gather citizen views on a broad range of bioethical and allocation issues. In all, 5,000 Oregonians participated in some 300 meetings leading to a values and policy synthesis.

Protecting the dignity and autonomy of sick and dying patients emerged as a dominant value. Scores of participants told stories, says Garland, “of loved ones who died in confusion and indignity, with no control over their destinies, leaving a heritage of anger, fear, and guilt.” Public input suggested honoring the dignity and autonomy of dying patients would involve a number of major changes, not the least of which were better communication on the part of medical providers with their patients about their illness and treatment options, and a different way of viewing terminal illness: less as an enemy to be fought with futile, expensive technology, and more as a natural process to be dealt with compassionately.

The dialogues also made clear that Oregonians were not aware of the state’s living will statute which had been on the books since 1977.

A desire for much greater emphasis on disease prevention of all kinds, including the prevention of suffering for terminally ill patients, also emerged as a top priority.

And, setting the stage for later health care rationing debates (surrounding legislative action on the Oregon

Health Plan), citizen participants indicated their desire for universal access to an “adequate level of health care,” open and fair health care rationing decisions, and better control of spiraling health care costs.

OHD’s publication *Society Must Decide*, a report detailing the values surfaced in community meetings and subsequent recommendations from the health care parliament, was widely disseminated and gave OHD standing with the legislature and other key policy makers.

### 1984–1989, and 1993. Advance Directive Initiatives

Emboldened by the public’s unequivocal support for dignity and autonomy values and concerned about lack of public awareness about end-of-life rights and options, OHD began a series of initiatives that would ultimately result in major revisions to the state’s advance directive law, giving Oregon citizens more control over decisions at the end of life. OHD’s direct support of statutory amendments represents the organization’s only venture into advocacy in its 15-year history.

The 1984–1985 community meetings led to OHD’s first policy initiative—legislative testimony supporting a surrogacy amendment to the existing advance directive law. Although the amendment never got out of commit-

tee, in 1989 a new power of attorney statute was adopted by the state legislature. In 1993, with the support of OHD, the Oregon Legislature created what is now one of the broadest advance directive laws in the country, combining both the living will provisions of the original statute with an expanded and clarified surrogacy provision. The revised statute also spelled out for the first time the elements of comfort care (including pain relief through medication), and provided for the withdrawal of tube-feeding and other forms of artificial life support.

Throughout the decade, OHD carried on a massive educational effort to empower citizens and advise them of their rights, using media campaigns, a speakers bureau, the continuing revision and dissemination of its consumer guide to Oregon’s advance directive law (*Making Health Care Decisions When You Can’t Speak For Yourself*), copies of which are still purchased by providers on behalf of their patients—as well as workshops on how to use advanced directive forms. Distribution of the forms to citizens entering hospitals and nursing homes or enrolling in HMO’s and group purchasing programs is now mandated by law.

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“OHD uses the partnership approach. It doesn’t act as a provocateur, or as a social critic—that’s the ‘Protest Model.’ We follow a rational model in our citizen deliberations and in front of policy makers.”

Michael Garland, D.Sc.Rel., Oregon Health Decisions Co-Founder



**OHD Contributions to End-of-Life Policy**  
*Continued*

The success of OHD’s advance directive initiatives is suggested in a 10-city comparison of advance care planning among nursing home residents, by Joan M. Teno, M.D., *et al.* The study measured the rate at which advance care directives like Do Not Resuscitate Orders (DNR) had been documented in patient records. In 1990—seven years after OHD’s advance directive efforts began—Portland, Oregon’s DNR rate of 69% was by far the highest of those studied, as shown in the figure below.

According to a study by Susan Tolle, M.D., *et al.*, Oregon’s DNR order rate had increased markedly by 1997—to an average of 91%—based on a sampling of 629 Oregon nursing home residents (*Journal of the American Geriatric Society*, 46:1-6, 1998).

Tolle attributes a large measure of Oregon’s high level of advanced care planning to OHD’s work: “It was cumulative. Gradually through public meetings and education, OHD helped Oregonians see that advance care planning was a good thing, and that they had a legal right to control their destinies. Now in 90–95% of the population there is this sense that—when there is a terminal illness—patients

and family members can call the shots about the use of ventilators, resuscitation, and ICU care.”

**1989–1991. Comfort Care and the Oregon Health Plan**

In 1989, the Oregon Health Services Commission, which is responsible for ranking services provided through the Oregon Health Plan, asked OHD to conduct a community meeting process to help build a consensus on values to guide development of the Oregon Health Plan. The Plan combines Medicaid reform and private insurance programs to reduce the number of uninsured citizens in Oregon. When deciding how much to budget for Medicaid, legislators use a prioritized list of health services which is the heart of the Plan.

As a result of the meetings, “community compassion,” including strong support for adequate pain relief, hospice care, all necessary equipment and ancillary services for the terminally ill, emerged as one of 13 values that would guide development of the Plan’s prioritized list. Citizens, however, did not place a high value on treatments that extended life when conditions were fatal and functionality could not be preserved.

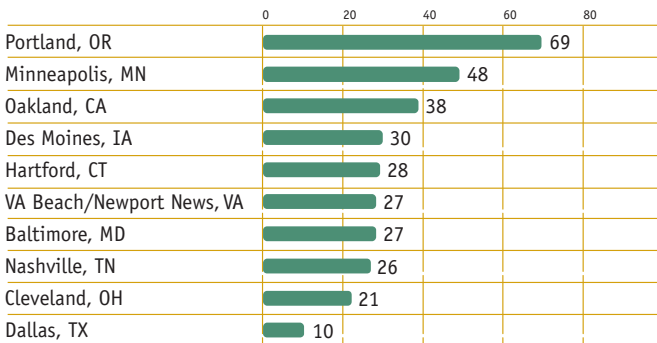
As of 1998, comprehensive comfort care for sick and dying Oregonians is the 263rd of 574 funded items—well up in the permanently untouchable range, says Commission Director Darren Coffman. Since its inception, some 400,000 additional citizens have been enrolled in the Plan, and the values discussions and debate preceding it are widely credited with creating a public recognition that comfort care is as crucial as health care at other times in life.

**1994. Voter Advisory Meetings on Physician-Assisted Suicide**

Concerned about the polarized, inflammatory debate preceding Oregon’s first vote on physician-assisted suicide, OHD teamed up with the Oregon Hospice Association to sponsor simultaneous statewide meetings to give some 400 voters in 17 sites a neutral, safe, and open forum in which to create an inventory of Oregonians’ values on the issue. The meetings represented the first time OHD had gone to voters (the principal policy audience for the ballot measure) and the first time it had used EdNet teleconferencing technology with two-way video and audio. After the meeting OHD developed a voter advisory guidesheet to help other citizens assess their values and beliefs on assisted suicide, together with a summary report titled *Request for Physician-Assisted Suicide: How Will You Vote?*

**Rate of Do Not Resuscitate Orders in 10 Cities, 1990**

Measures DNR order documentation rate among all nursing home residents (2,175) in 270 long-term care facilities in 10 cities.



Results are weighted for sampling design of study.  
Source: Adapted from a study by Joan M. Teno, M.D., *et al.*, *Journal of the American Geriatric Society*, 45:939-944, 1997

*“Gradually through public meetings and education, OHD helped Oregonians see that...they had a legal right to control their destinies.”*

Susan Tolle, M.D., director of the Center for Ethics in Health Care

## Policy Makers Assess OHD



**Bob DiPrete**  
Director, Oregon Health Council

“OHD community meetings are not academic; they result in change. They

provide real reflections of community values and preferences that act as reminders to policy makers.”

### Paige Sipes-Metzler, D.P.A.

Former Executive Director of the Oregon Health Services Commission (during the Oregon Health Plan development years) now Chair of the OHD Board

“Policy makers are often limited by narrow mandates: ‘Fund mammography for women.’



When they are guided by the kind of broad values information OHD provides—‘Maintain women’s health’—they can think out of the box and might vote five allocations instead of one.”

### John Santa, M.D.

Medical Director, HealthFirst Medical Group, Former Corporate Medical Director, Oregon Blue Cross

“There is a problem with our current model: buyers and sellers are separated. Insurers want to keep employers happy because they are the formal customers; employers are price driven. Insurers like Blue



Cross regard OHD as a unique vehicle to gauge public attitudes about reform issues.”

## How OHD Engages Citizens in the Health Policy Process

### Identifying Goals and Methods

Clarifying the goal of citizen involvement in informing a particular policy direction is critical to structuring each project. OHD projects typically seek to achieve one or more of these goals: extracting values, building community around issues, and educating citizens. OHD uses different methods to reach these goals, often combining techniques to gain richer, more credible results. (See figure below.)

### From Values to Policy: A Typical OHD Project Process

Larger projects typically have four distinct phases. They begin in the real world of politics where emerging policy information needs are identified, usually in collaboration with major state policy makers. Action then moves to the community setting where OHD’s large network of organizations and contacts is activated, and the signature community meeting process is launched (with or without other methods). Once OHD principals have gathered and synthesized community values, they resume intensive consultation with their primary policy audience—which OHD calls

“the policy receptor site”—as it seeks to use the values information to define health policy solutions. The following section sets forth the major steps of this four-phase process.

### Phase I: Timely Identification of a Clear Policy Connection

Political timeliness is a feature of OHD projects. Leaders pick issues early enough to help citizens define their core values before positions have hardened and policy solutions have been formed.

OHD’s skill at identifying policy audiences ready and willing to act on citizen values is also well known and widely praised. Longstanding relationships with policy leaders has been fundamental to OHD’s success.

“We try to maintain longstanding relationships with Governor John Kitzhaber, the Oregon Health Commission, the Health Services Commission, the Health Resources Commission, the Oregon Medical Assistance Program, the Insurance Pool Governing Board, and the Office for Oregon Health Plan Policy &

Research. Those are both personal and institutional relationships,” says Garland. OHD leaders also regularly attend health commission meetings and monitor legislative policy debates.

*Continues*

Oregon Health Decisions Goals and Techniques

Techniques	Goals		
	Educate About Issues	Extract Information	Build Community
Community Meetings	■	■	■
Town Hall Meetings	■	■	■
Parliaments		■	
Focus Groups		■	
Media Campaigns	■		■
Interactive Video Conference	■	■	
Informational Videos	■		
Randomized Surveys		■	
Surveys at Meetings	■	■	
Speakers Bureau	■		
Issue Workshops	■		
Publications	■		

Source: Adapted from *Community Responsibility for Health Policy: Tools, Structures, and Financing* (August 1995) by Michael Garland

## Community Meetings: Views From Inside



**Bob Coe, Community Meeting Participant**

“Some of the nuances of health care I hadn’t thought about, but as we discussed things, the comments of others helped me see things in a different way.”



**Merrily McCabe, Community Meeting Participant**

“First the group was divided, but we talked through that and came to a consensus. We didn’t get there by strong-arming but by rational discussion.”



**John Hofer, Community Meeting Facilitator**

“Participants develop their thoughts to a higher degree of clarity and start to see new dimensions to a problem. They also see how complex these health care issues are—how there will be trade-offs rather than a perfect solution.”

### How OHD Engages Citizens in the Health Policy Process

*Continued*

Once the policy connection has been made, OHD gets a “handshake agreement” from policy leaders to honor the values identified in the community dialogue process. A subcommittee is then appointed to work with OHD staff. Together they identify policy information needs, determine the goals and methods to be used in engaging citizens in the policy process, and begin to think about what form the resulting values report will take. OHD also secures funding for the project during this phase.

#### Phase II: Activating the Community Resource Network

OHD maintains and tries constantly to expand a network of community organizations and interested individuals. While in early citizen deliberation processes, it “called a party” and invited people to come, now it seeks the support of local community leaders and taps into their constituencies. In part this strategy is pragmatic: it saves time and resources, and it has broadened participant demographics. OHD also wants to stimulate local democracy by motivating and empowering what Crawshaw calls “enclaves with a feeling of community; we want to leave something behind in a society that’s cynical and alienated.”

During this activation period, OHD is also training a cadre of volunteer community meeting facilitators. The training reflects OHD’s insistence on facilitator neutrality and active listening skills. Marge Ginsburg, Executive Director of Sacramento Healthcare Decisions, uses the OHD facilitator model and finds it both challenging and profound: “You’re not there to teach them anything, and this is so hard to realize. You are there as ears. Instead of telling, you ask, ‘Why is

that important to you?’ You want their values. This doesn’t come naturally. But, once you give up the ‘educator role,’ it is so liberating.”

#### Phase III: Gathering and Synthesizing Citizen Values—the Three-Act Community Meeting

The community meeting process—OHD’s hallmark—is designed to be standardized, simple, useful in short time frames (about two hours), and replicable by volunteers. By all accounts it is also highly effective in surfacing values that can be converted into policy guidance. (See citizen and policy leaders assessments on pages 5 and 6.)

##### Act One: Announcing Purposes

**1.** A convener (C) begins by announcing the subject of the meeting and the identified policy audience: “Folks, you are here today because the Health Services Commission wants your input on values about health care. The Commission is developing priorities and wants your values to guide this process. Tonight we will consider the question, ‘What makes health care important to you?’”

**2.** Two handouts are distributed, one to collect information about the group’s demographics, the other containing scenarios intended to trigger small group discussion.

##### Act Two: Surfacing Values

**1.** Small group discussions of the scenarios begin with a simple question by the Table Leader (TL): “What do you think should have happened to the woman on the ventilator?” Facilitators call this the “vote” or judgment call and explain that values are best identified by presenting participants with a choice that creates some conflict and struggle.



*Oregonians exchange values and beliefs at a recent OHD community meeting. Participants and facilitators say the opportunity to listen to other citizens is the most important ingredient in the community meeting process.*

#### Phase IV: Advising the Primary Policy Audience

OHD leadership stays in touch with the policy audience during the citizen deliberation process; after it concludes, policy consultation intensifies. The summary report is disseminated to citizen participants and others, and presented formally to the policy audience.

OHD reports typically synthesize citizen values into what Garland calls “pilot’s checklists” for policy leaders to consider as they construct the policy solution. These value checklists address specific policy questions determined in advance, and in effect become the goal and specifications for policy change. OHD principals also offer anecdotal and contextual information from the meetings, and tease out possible policy implications but refrain from advocating particular policy solutions.

OHD’s report, *Common Purpose in Health Policy*, provides an good example of the checklist approach. In answer to one of the overriding policy questions—will people object to the use of practice guidelines to implement the Oregon Health Plan?—the report offered this guidance:

“No, but participants emphasized their concern that special attention should be paid to basic human values of respect and quality in the way guidelines are developed and implemented.”

*Continues*

2. The TL then asks participants to explain their choices: “Why do you think the woman should have been taken off the ventilator?” The TL also encourages people to talk about their hopes and fears and tell stories from personal experience to further stimulate the exchange of values and beliefs.

Crawshaw, who is a psychiatrist, urges facilitators to look for suffering. “People are reticent to talk about suffering,” he says. “Both patients and doctors suffer around end-of-life issues, and when we allow them to talk about why they are suffering, we have a constituency.”

3. As participants speak out and listen to each other, the TL lists and articulates the values embedded in the stories and explanations, highlighting common ground but honoring complexity: “We clearly want the system to preserve life where possible if quality of life can be maintained, but prevent unnecessary suffering. . . .”

4. Ultimately, the small group either agrees to disagree, agrees, or reaches a compromise.

#### Act Three: Summarizing Values

1. C summarizes from each small group’s record, marking dominant, repeated values and convergences.

2. C performs the “authenticity check”: “Does anyone want to object to or clarify values?”

3. Leaders thank participants and promise feedback.

4. A meeting report is written and later incorporated into a summary report of all meetings.

## How OHD Engages Citizens in the Health Policy Process

*Continued*

A checklist of values questions to bear in mind—one of many in the report—was provided to help clients determine how guidelines could be structured to add benefit to the Plan's prioritized list. The report asks, "Could guidelines...  
...enhance the respectful treatment of patients?  
...improve patient security?  
...enhance equity among persons with various health conditions?  
...lead to improved health of the community?  
...reduce medical waste?  
...minimize bureaucratic waste?"

OHD's policy guidelines cannot always be this clear and sharply focused, because policy questions may be very complex, and citizen values may conflict.

Still both public and private sector policy makers praise the richness and uniqueness of OHD's values information, regarding it as a welcome alternative to more standard public preference inventory methods, like polls, interest group advocacy, party politics, and satisfaction surveys.

"Surveys force people into boxes," says D'Anne Gilmore, Deputy Administrator, Office for Oregon Health Plan Policy & Research. "OHD comes in without a box—their reports will be a synthesis of the full range of values identified so policy makers can balance out different points of view and remain open to hybrid models and compromises." ■

## A Word of Encouragement to Other States

It is tempting to imagine that OHD's remarkable credibility and policy impacts are a function of Oregon's unique political environment. Certainly the state has a variety of characteristics that facilitate citizen deliberation and reform: a small, homogeneous population, an open and proactive political tradition—a legacy of its New England settlers—a single medical school, rugged individualism, and a certain idealism and passion.

Yet Crawshaw and other OHD stalwarts insist that health decisions organizations are possible and necessary in every locality to ensure that the health care system reflects the values of an informed community. "There are passion and idealism in other states," says Crawshaw. "But every state has to understand its realpolitik. You have to know the 16 people who run the state and are the policy receptor sites, the major obstructionists, and the three geniuses who will spark reform. This means leaders from professions, media organizations, and the grassroots. Then you build a strategy and allocate time and money. In West Virginia, you have to do it the West Virginia way." ■

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### Oregon Health Decisions

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## State Initiatives in End-of-Life Care

### Information About the Series

"Oregon Health Decisions: Lighting the Way to Common Ground" is the second in a series of briefs profiling promising new policies and practices in end-of-life care. Series issues 1–4 focus on reforms in Oregon. Profiles of reforms in other states are now being planned.

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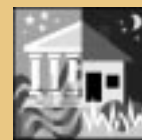
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*We urge readers to send comments and suggestions regarding this and subsequent briefs via letter or e-mail.*



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