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IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER	**The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990**
BETWEEN	**LECRETIA SEALES**
	Plaintiff
AND	**ATTORNEY-GENERAL**
	Defendant

AFFIDAVIT OF PETER LINDLEY REAGAN AFFIRMED 2015

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Next Event: 6/5/15
- 5 MAY 2015
THE HIGH COURT
WELLINGTON

I, **PETER LINDLEY REAGAN**, of Portland, Oregon, United States of America solemnly and sincerely affirm:

Introduction

1. I am a retired general practitioner, residing in Oregon, United States of America.

2. I have been asked to give evidence concerning my experience in dealing with patients' requests for physician aid in dying under Oregon's Death With Dignity Act 1997 ("**DWDA**"). My affidavit addresses the following subjects:

    (a) the process of issuing a prescription for life-ending drugs under DWDA; and

    (b) the response of patients to receiving such a prescription.

3. I have read the High Court Code of Conduct for Expert Witnesses and agree to comply with it.

Personal profile

4. I entered University of Oregon Medical School in 1973, graduating in 1977. I interned at Good Samaritan Medical Center in Portland then, after two more years of general practice, I finished the family practice residency at Oregon Health Sciences University in 1983.

5. I helped found Portland Family Practice in Portland and practised there from 1983 until my retirement in 2011. My practice ran the gamut from obstetrics and newborn care, through to hospital internal medicine, assisting at surgery, and end of life care.

6. I was active in training medical students and residents throughout my practice. I also helped in the hospital medical staff at Adventist Medical Center, as well as in the County Medical Society and the Oregon Academy of Family Practice. I was an Associate Adjunct Professor at the University of Oregon Health and Sciences University between 1998 and 2005, and have published four articles in peer reviewed journals.

7. Since my retirement in 2011, I have worked for Compassion and Choices, a non-profit organisation working to improve patients' rights and choices at end of life (including, but by no means only, access to aid in dying), in a volunteer capacity as a regional medical director. Since 2015, I have been hired as one of two national medical directors at Compassion and Choices.

8. I annex a copy of my CV as exhibit "**PR01**".

Prescribing under the DWDA

9. I was the first doctor in Oregon to write a prescription for life-ending drugs under the DWDA (although at the time I was unaware of that). During my time in practice I wrote 15 to 20 prescriptions under the DWDA. I would estimate that about two-thirds of my patients took the medication. That is consistent with the experience of others. In Oregon, since prescriptions

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started under the DWDA, approximately 65% of those who received a prescription used the medication.

10. Obtaining a prescription under the DWDA can be quite a commitment for a sick person. For example, the law requires three different forms (from the attending and consulting physicians, and the patient themselves) and a psychiatric evaluation may be required. There is then no guarantee a patient will have access to aid in dying. Nevertheless, some patients want to go through it, even when I have told them that hospice care will probably keep them comfortable. Some patients want to know that they have control.

11. A conversation about aid in dying is also an important opportunity to identify whether there are any aspects of care that are not being optimised. In my experience, physicians will take every step to ensure that symptoms that might be causing the request are identified and appropriate treatment implemented.

12. While the formal requirements of the law are clear, that only sets a minimum process. The actual practice is much more organic than that and, in my experience, doctors are careful to ensure all other medical professionals with knowledge of the patient are consulted. Whether I was the prescribing physician or the second, consulting physician, I would consult with appropriate specialists and with the hospice. It is an important prescription to write and physicians take the same kinds of precautions and follow the same kinds of processes that they would for other important medical decisions.

13. In Oregon, the ethics of prescribing life-ending drugs has been subject to careful and on-going review. After the ballot passed in 1994, the Center for Ethics and Healthcare brought together a consortium of health leaders that would be affected, including the Board of Nursing, a Board of Pharmacy, the hospital ethics departments of all the major metropolitan hospitals, and the Oregon Hospice Association. That consortium produced guidelines in 1998 which they revised in 2008 and which remain in use (annexed as exhibit "**PR02**").

14. The operation of the DWDA is very much part of the practice of medicine in Oregon. In addition, medical students in Oregon receive training on the operation of the law. Physicians in Oregon know what constitutes good practice in this area.

The effect on patients of having a prescription available

15. When terminally ill patients realise that a prescription is an option, it is amazing how dramatic their relief can be. Having choice and control over ending one's life is very important to many people. I have seen patients visibly relax in an exam room once they knew that it was an option for them; as if an enormous weight had been removed. That is, the option of a prescription addresses the lack of control, and the uncertainty that arises from a terminal illness, which is a very significant cause of distress for some patients.

16. One example stands out particularly clearly from my practice. I had one patient with terrible lung disease who requested life-ending drugs. It is very difficult to provide an accurate prognosis for lung disease, and I was

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uncertain whether he fell within the six month life expectancy required to be considered "terminal" under our law. I thought that he did, but I explained that he would need to see a consultant. I told him that I did not know for sure that he would qualify given his illness. He went home and shot himself that night. If I had been able to give him more hope that he would have control, I think that he would have waited.

17. In contrast, I had another patient, a woman in her early 50s dying of metastatic renal cancer. I had delivered her babies. When it became clear that her cancer was incurable she and her husband came to me and very clearly stated that they wanted to know that I would support them in writing a prescription should the desire arise. In her case I could assure her that, in my view, she met the criteria and so there would be no problem with getting a prescription should she request it. For her that was equivalent to going through the process, since the outcome was not in doubt. I kept expecting her to ask me to start the process but she never did. Instead her life was around being a fabulous mom to her young adult children, deepening her relationship with her husband and writing inspiring poetry. I know that her ability to do this was helped by her confidence that her death could be on her own terms.

18. My experience of the benefit that control has for patients is not unique. After the first year of operation of the DWDA, Barbara Combs Lee and James Werth reviewed the files of 34 patients who had approached Compassion in Dying that year for aid in dying (Combs Lee and Werth *Observations on the first year of Oregon's Death with Dignity Act* 2000 (6) Psychology, Public Policy and Law 268-290). Of those 34 patients, 10 took the medication. The authors concluded that six patients had been sufficiently certain of killing themselves by other means that the authors considered them to be cases of averted suicide. They also identified two cases of "averted homicide" by avoiding "mercy killings". I annex a copy of that article as **"PR03"**.

19. As I have already noted, once patients have that control through the prescription of life-ending drugs, more than one-third of patients end up not taking the drug. I could never tell which patient would. Some patients are very clear that they intend to take the pill as soon as they get it, but even for some of those people, simply having the pill is enough and they ended up not taking it. It seems that for some people, the person is happy to live the rest of their lives without ever taking it.

20. Irrespective of whether the patient takes the drug, the availability of a life-ending drug removes a significant source of distress and gives them the chance to connect much more strongly with family and friends while they live. That is a very real and meaningful benefit for all concerned. For those who do take the drug, it provides an opportunity to be with their family and friends and loved ones at the end and to die in exactly the way they want to. What has been very consistent in my experience is that the people involved, the patient and the family, say that the prescription has really made a big difference to the final phase of life. Family and patient are relieved and find the prescription an enormous help.

21. The nature of my practice meant that I was not involved in providing day to day management of symptoms for terminal patients. In my experience, the most important benefit that I saw was patients' ability to engage with

their families again, and to have difficult and meaningful conversations about the patient's life and how they would like to live their final days.

22. Those conversations were much harder to have before aid in dying was legally available. I remember clearly one tragic example that occurred before the DWDA was law. The patient was a very sweet guy. He was very ill with heart disease and lung disease and was in and out of hospital constantly. He had asked me when he was in hospital "is there anything I can do, is there any way we can manage this situation so I don't have to come in here? This is just terrible. I spend my whole life either recovering from a hospitalisation or coming in for the next one." I had to say that there was not. He had a good specialist and good care, but there was nothing more we could do. When he was released from hospital he killed himself by slitting his wrists with a pair of sewing scissors that he found around his retirement home. Later, one of his best friends came to me in agony because he did not have a chance to say "how can I help?"

23. That patient would never have talked to someone about his intentions because he would not have wanted to put anyone in jeopardy. The fact that under the DWDA a person can ask the question without putting anyone else - a physician or a family member - in a potentially illegal position, allows important communication to occur. It gives the family a chance to intervene, and it creates an opportunity for a different kind of conversation with physicians that can in some cases reduce the patient's need to take their own life.

24. That is true at the prescribing stage, but also at the point the patient decides to take the drug. Under our system, a patient can now say "I've decided I'm going to take this pill on Tuesday". That gives the family and friends an opportunity to talk to the patient about that decision. At the end of that conversation the patient may choose not to take the medication, or to wait a little longer. But if the patient still wants to take the medication, the family will understand how the patient feels and why. That understanding is really important, no matter what the patient finally does. The communication is the key, and making it illegal makes talking about it illegal, or potentially illegal. Talking about death matters and is therapeutic for everyone. I think that is one of the greatest benefits of the DWDA law.

25. Those are also the reasons why I do not think of what happens in aid in dying as suicide. I cannot comment on the psychology of the two processes but, in my experience, the effects are very different. Suicide is a lonely death and leaves behind devastated family and friends. It is very different to saying goodbye to everybody in your bedroom and going to sleep, with everybody holding your hand. Aid in dying is not lonely or furtive or separating in the way the way suicide is. Instead, it is communal and affirming. I found the aid in dying deaths that I attended to be very stately, poignant and inspiring. They did not make family and friends feel guilty, because they have had the chance to understand that it is the patient's decision and that it is what the patient wants and why they want it.

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Conclusion

26. In my experience, aid in dying is beneficial to patients and to families. The prescription itself is therapeutic because it helps foster better communication with loved ones and reduces significant sources of distress for those patients who desire aid in dying. For my patients, I believe that the ability to make autonomous decisions about their last days was of great importance to them. It was not something that came from me or was about me; and the final decision whether to use the drug or not was never one that I was able to predict. My patients had control over the final decision and they really valued that control.

AFFIRMED at Portland, Oregon, United States this 1 day of MAY 2015 before me: Benjamin K Maciariello

Peter Lindley Reagan
Peter Lindley Reagan

A person duly authorised to administer oaths in Oregon
State of Oregon
County of Multnomah

OFFICIAL SEAL
BENJAMIN K MACIARIELLO
NOTARY PUBLIC-OREGON
COMMISSION NO. 469273
MY COMMISSION EXPIRES JUNE 14, 2016

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"PR01"

Peter Reagan MD

Curriculum Vitae

Professional experience	
• Haverford College, BA Physics	1968
• Reed College Master of Arts in Teaching	1970
• Taught high school in Portland and in Alaska	1969 - 1973
• Medical School OHSU, MD degree	1973 - 1977
• Rotating Internship, Good Samaritan Hospital, Portland	1977 - 1978
• General Practice, Cascade Health Care, Portland	1978 - 1980
• Founded Portland Family Practice	1980
• FP Residency, OHSU, Portland	1981 - 1983
• Board certification, American Board of Family Practice	July 1983
• Portland Family Practice Private group family practice. Practice has included a lot of obstetrics (about 1,500 deliveries) as well as assisting at surgery, in and outpatient medical care for all ages and a lot of minor surgery. I did approximately one vasectomy every two weeks for a total of approximately 1,500 procedures.	1983 - 2011
• Adventist Hospital Family Practice Chair	1986 - 1990
• Adventist Hospital Medical Staff President	1994 - 1996
• Adventist Hospital QA Chair	1998 - 2000
• Associate Adjunct Professor, OHSU Precepting family practice residents for seven year at Gabriel Park Clinic.	1998 - 2005
• Member of board of Medical Society of Metropolitan Portland	1996 - 1998
• Current member and serving on Board of Directors, Oregon Academy of Family Physicians	Current
• Active in teaching Medical Students, presentations at OHSU and precepting in our clinic	1985 - 2005
• Retired from clinical practice	August 2011

1 May 2015

This is the annexure marked **"PR01"** referred to in the affidavit of **Peter Lindley Reagan** affirmed at Portland, Oregon this 1 day of May 2015 before me

Signature ....

~~A person duly authorised to administer oaths in Oregon, United States of America~~

State of Oregon
County of Multnomah

OFFICIAL SEAL
BENJAMIN K MACIARIELLO
NOTARY PUBLIC-OREGON
COMMISSION NO. 469273
MY COMMISSION EXPIRES JUNE 14, 2016

Publications

"Common Sense and a Thick Hide: Caring for one's Family Members" archives of Family Medicine [1994, 3/7 pp 5999-604]

"Helen" [The Lancet of April 10 1999]

"Physician Assisted Death: Dying with Dignity?" [The Lancet Neurology October 2003 Vol 2 # 10 pp 637 ff

Awards

Carpenter teaching award, OHSU, FP Department	2005
School of Medicine, Volunteer Faculty Recognition Award	2010
Moorestown Friends School Alumni, Alice Stokes Paul Lifetime Merit Award	2014
National Aeronautic Association National Safety Award, for work in paragliding accident reporting and safety improvement	1997

"PR02"

Psychology, Public Policy, and Law
2000, Vol. 6, No. 2, 268–290

1076-8971/00/$5.00 DOI: 10.1037//1076-8971.6.2.268

OBSERVATIONS ON THE FIRST YEAR OF OREGON'S DEATH WITH DIGNITY ACT

Barbara Coombs Lee
Compassion in Dying Federation

James L. Werth Jr.
University of Akron

Using data from the files of Compassion in Dying, we describe 34 individuals who approached Compassion wanting to use the Death with Dignity Act and who died during the first year of the Act's implementation. Of these 34, 10 died using medication prescribed under the Act. Using first-hand data from the dying individuals, their families, and their health care teams, we provide comparisons between predicted outcomes and actual experiences, discuss important elements of the physician–patient relationship, and describe several averted suicides and homicides. We also review changes in end-of-life care in Oregon and provide recommendations about issues in need of further research.

In November 1994 the people of Oregon passed, by citizens' initiative, the Oregon Death with Dignity Act ("Act").[1] The Act allows a mentally competent, terminally ill Oregon adult resident to request, and an Oregon licensed physician to prescribe, medication that may be used to assist in dying.[2] Almost immediately, a federal District Court agreed to hear a constitutional claim against the new law and issued an injunction preventing it from going into effect; the lawsuit proceeded with hearings, motions, and appeals through the District, Appellate, and U.S. Supreme Courts over the next few years.[3] When it became apparent that opponents would ultimately lose this lawsuit, the Oregon Legislature

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Barbara Coombs Lee, Compassion in Dying Federation, Portland, Oregon; James L. Werth Jr., Department of Psychology, University of Akron.

Correspondence concerning this article should be addressed to Barbara Coombs Lee, Compassion in Dying Federation, 6312 SW Capitol Highway #415, Portland, Oregon 97201. Electronic mail may be sent to BCoombsLee@aol.com.

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[1] Or. Rev. Stat. § 127.800–127.995 (1995). *See also* The Task Force to Improve the Care of Terminally Ill Oregonians, *The Oregon Death with Dignity Act: A Guidebook for Health Care Providers* (1998; "DWDA Guidebook"); Mark O'Keefe, *Assisted-Suicide Measure Survives Heavy Opposition*, Portland Oregonian, November 10, 1994 at A1.

[2] A comprehensive description of the Act is beyond the scope of this article. In summary, it establishes criteria and procedures as a safe harbor for the patient's attending physician to prescribe medication the patient may take to hasten death. The good faith participation of other persons is also protected, but only the physician is authorized to prescribe and only the patient to administer, the medication. Rules from the medical licensing board require the physician to work cooperatively with a participating pharmacist to dispense the medication.

[3] On October 27, 1997, the Ninth Circuit decision in *Lee v. State of Oregon*, 107 F.3d 1382 (9th Cir. (Or.) 1997), vacated both an initial ruling by Judge Hogan of the United States District Court for Oregon, *Lee v. State of Oregon*, 891 F.Supp. 1429 (D.Or. 1995) and the permanent injunction, *Lee v. State of Oregon*, 891 F.Supp. 1439 (D.Or. 1995), due to lack of standing and ripeness. The law was implemented after the Supreme Court denied certiorari, *Lee v. Harcleroad*, 118 S.Ct. 328 (U.S. 1997), and the state Attorney General's office received the paperwork. For a review and analysis of the Hogan decisions *see* Michael A. Cohen, *Plaintiffs' Standing in Lee v. Oregon: The Judicially-Assisted Demise of the Oregon Death with Dignity Act*, 74 Or. L. Rev. 741 (1995).

BENJAMIN K MACIARIELLO
COMMISSION NO. 469273
MY COMMISSION EXPIRES JUNE 14, 2016

Peter Lindly Reag
1 May 2015

This is the annexure marked "PR02" referred to in the affidavit of Peter Lindley Reagan affirmed at Portland, Oregon this 1 day of May 2015 before me

Signature ....

A person duly authorised to administer oaths in Oregon, ~~United States of America~~
State of Oregon
County of Multnomah

placed a measure on the ballot to repeal the Act.[4] This repeal measure failed in the November 1997 election by a vote of 40–60.[5]

As soon as the repeal failed, two members of the United States Congress sought and received a letter opinion from the Administrator of the Drug Enforcement Administration (DEA) stating that providing federally controlled substances in compliance with the Act violated federal drug law.[6] While this opinion underwent review at the U.S. Department of Justice, officials in Oregon proceeded with implementation, relying on the opinion of the Oregon Attorney General that the Administrator's letter lacked the force of law.[7] On June 5, 1998, Attorney General Reno released her finding that the federal Controlled Substances Act of 1970 did not prevent a state from legalizing and regulating the use of controlled substances for assisted dying.[8] The decision prompted Representative Hyde (R IL) and Senator Nickles (R OK) to introduce bills to criminalize the provision of medication for the purpose of hastening death—targeting the Act and imposing penalties retroactively on Oregon physicians.[9]

Although the bills made it out of the House and Senate Committees, they never came to a floor vote. One reason they failed was the strong opposition from numerous prominent organizations such as the American Medical Association and National Hospice Organization. Although these organizations opposed Oregon's

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[4] Richard L. Worsnop, *Oregon Residents to Vote Again on "Right-to-Die" Law*, San Diego, Union-Tribune, September 22, 1997 at A-1.

[5] Kim Murphy, *Voters in Oregon Soundly Endorse Assisted Suicide*, Los Angeles Times, November 5, 1997 at A-1.

[6] Thomas A. Constantine, Letter to Hon. Henry J. Hyde, November 5, 1997. *See* also, Steve Suo and Erin Hoover, *DEA Deems Suicide Law Illegal*, Portland Oregonian, November 8, 1997 at A1.

[7] Letter from David Schuman, Deputy Attorney General of Oregon to Jonathan Schwartz, Assistant Attorney General, U.S. Department of Justice, December 3, 1997. *See* also Suo & Hoover, *supra* note 5, for a report that the Governor expected Oregon physicians to be able to operate under Oregon law without interference.

[8] Neil A. Lewis, *U.S. Won't Prosecute Doctors Who Aid Suicide via Oregon Law*, New York Times, June 6, 1998 at 1.

Although some may oppose this practice, *see* Daniel Callahan and Margot White, *The Legalization of Physician-Assisted Suicide: Creating a Regulatory Potemkin Village*, 30 U. Richmond L. Rev. 1, 20-1 (1996) and Rita L. Marker and Wesley J. Smith, *The Art of Verbal Engineering*, 35 Duquesne L. Rev. 81 (1996), in this article we do not use the term "assisted suicide." Even though the word may be technically correct (we note that it would also be correct to use it to describe someone who withholds or withdraws life-sustaining treatment), "suicide" has been associated with irrationality, impulsiveness, and mental illness. Its use promotes an assumption that the dynamics are the same for the mentally competent, terminally ill person who wants "assisted suicide" as they are when a person impulsively "commits suicide" in a state of mental distress. James L. Werth, Jr., *How Do the Mental Health Issues Differ in the Withholding/Withdrawing of Treatment Versus Assisted Death?*, 41 Omega 259 (2000); David M. Smith and David Pollack, *A Psychiatric Defense of Aid-in-Dying*, 34 Community Mental Health J. 547, 548, 551 (1998). We believe that there are substantial differences in the dynamics of these two situations. For that reason we use the terms "assisted death" or "assisted dying" to refer to the situation where a physician prescribes a medication knowing that it may be self-administered by the patient to hasten death. James L. Werth Jr. and Judith R. Gordon, *Helping at the End of Life: Hastened Death and the Mental Health Professional, in* Innovations in Clinical Practice: A Sourcebook, Volume 16 387, 385–398 (Leon VandeCreek, Samuel Knapp, & Thomas L. Jackson, Eds. 1998).

[9] *Assisted Suicide Bill Introduced*, Associated Press Report, June 26, 1998 [1998 WestLaw 6687502]; The Lethal Drug Abuse Prevention Act, H.R. 4006/S. 2151, 105th Cong. (1998).

Act, they lobbied against the Hyde/Nickles bills because of a concern that the bills would have a "chilling effect" on the provision of adequate care for dying people.[10] Some support for this fear may be found in a report from Oregon indicating that in the last few months of 1997 patients and family members reported an increase in pain and a decrease in adequate palliation.[11] There is some speculation that the publicity related to the DEA letter led to concern on the part of physicians that they might lose their narcotic prescription licenses. Thus they were more cautious in prescribing these powerful pain-killing medications.[12]

It was in this environment during 1998 that terminally ill Oregonians began to approach their physicians with the desire to gain access to the option provided by the Act. A number of these patients and/or their physicians contacted Compassion in Dying of Oregon to obtain information and assistance to comply with the Act.[13] This is the first report of those contacts.[14]

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[10] *Congress Unlikely to Act on Oregon's Assisted-Suicide Law,* Salt Lake Tribune, September 25, 1998, at A24; John Hughes, *A bill that would have overridden Oregon's . . .*, Associated Press Political Service, October 15, 1998 [1998 WestLaw 7455264].

A similar concern of a possible chilling effect on the practice of medicine arose when a Kansas court found a physician guilty of attempted murder and murder for his palliative treatment of dying individuals. The Court of Appeals of Kansas ultimately reversed the lower court, but only after Dr. Naramore served many months in jail. *State of Kansas v. Naramore,* No. 77069, 1998 WL 417567 (Kan. App. July 24, 1998).

[11] Susan Tolle and Kathleen Haley, *Pain Management in the Dying: Successes and Concerns,* Newsletter of the Board of Medical Examiners (Fall 1998); Erin Hoover Barnett, *Oregon Study finds Increase in Pain among the Dying,* Portland Oregonian, October 7, 1998 at C4.

This report is in marked contrast to earlier data indicating that there had been tremendous gains in improving palliative care and the quality of the dying process of Oregonians, *infra* notes 90–96 and accompanying text.

[12] *Id.;* Erin Hoover Barnett, *Hope Slips Away in Final Vigil,* Portland Oregonian, November 25, 1998 at A1. This is the final article in a four-part series describing the dying process of Brian Lovell, a man with colon cancer who had wanted to utilize the Act to hasten his death. This article details his difficulty in getting the medication he needed to alleviate his pain.

[13] Some may be concerned about the objectivity of this report, given that it is being coauthored by the Executive Director of an advocacy organization. We have tried to minimize potential objections in two ways. First, we focus on the raw numbers. However, we also recognize, and want to emphasize, that there are people behind each "case" and every number; therefore, we include anecdotal information. To the extent possible, these descriptions include material that has been presented through public media outlets. With other cases we provide brief examples to illustrate the points we are making but which have not been publicized through outside media. We trust that the commentators and readers will understand that although our desire to provide full and accurate information about use of the Act is strong, even stronger is our commitment to protect the confidentiality of Compassion's clients, their families, and their caregivers.

[14] It must be emphasized that this is a descriptive report based on general information gathered by Compassion staff and professional volunteers through their patient, physician, and family member contacts. Most was documented in a contemporaneous manner, but some retrospective investigation filled in missing information. The organization has not conducted a scientific, investigative research project. Therefore, there will be little statistical analysis in this article and not every question a reader may want answered will be able to be addressed. However, we believe the data that are reported are as complete as can be expected from a service-based organization, that it is one of the most complete data sets available, and that it addresses some key issues in the debate over physician-assisted death.

In regard to this last point, Ann Alpers and Bernard Lo[15] stated that some of the important questions that needed to be answered after the Act had been implemented included how many people inquire about the Act and how many actually begin and complete the process; how have physicians attempted to provide comfort care; do referrals to hospice eliminate requests for assisted death; will physicians and patients comply with the requirements of the Act; will actions not sanctioned by the Act occur, such as active euthanasia or the assisted deaths of non-terminally ill individuals; and "most important, will terminally ill patients receive more compassionate care, better relief from suffering, and more sense of control over their illness?" This article answers many of these questions for the individuals who have contacted Compassion in Dying of Oregon ("Compassion").

The remainder of the article is divided into six major sections. First there is a general description of Compassion's clients who have qualified for the Act and have died, then a summary of the Oregon Health Division's report is provided for comparison purposes. This is followed by descriptions of elements of suffering, and this first section ends with an overview of the use of mental health evaluations. The second part discusses our experience relative to some of the dire predictions that accompanied debate about the Act. The third major section focuses on the physician–patient relationship and describes how the Act has led to changes in the interpersonal dynamics between dying persons and their doctors as well as some responses from significant others. Two brief sections highlight how the Act has helped to avert several suicides and homicides while also improving end-of-life care for Oregonians. Finally, there is an outline of questions that remain unanswered.

Data About People Who Have Considered Using the Act

Compassion's Clients

Since 1993 Compassion in Dying, a nonprofit charitable organization started in Washington State, has provided information, consultation, and emotional support to terminally ill, mentally competent adults who wish to consider assisted dying by self-administration of medication as one of their end-of-life options. Compassion's team of volunteers includes nurses, psychologists, physicians, and clergy as well as laypeople from the community who help patients, their families, and their physicians examine the choices available to achieve peaceful and humane deaths.

In Oregon, Compassion officially began to serve patients in January 1998, but Compassion staff from the national organization (Compassion in Dying Federation) had been receiving and responding to calls from patients and families since October 28, 1997. Data from this date are included in this survey in order to present as complete a picture as possible of 1 year's experience.

Between October 28, 1997 and the same date a year later, Compassion received over 350 information requests related to the Act. Some of these were general questions, others were for written material, but only 56 were from people

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[15] *Physician-Assisted Suicide in Oregon: A Bold Experiment*, 274 J. Am. Med. Assoc. 483, 487 (1995).

who ended up being qualified for the Act and who stayed in contact with Compassion long enough for them to be evaluated and followed. These were from patients with a terminal illness and a likely prognosis of less than 6 months who were rational and mentally competent. Thirty-four of these patients died during the year. This report reviews the experiences of these individuals.

Twenty-seven of the 34 who died had cancer, with lung cancer being predominant. Three had end-stage lung disease, 2 had end-stage heart disease, 1 had amyotrophic lateral sclerosis, and 1 had AIDS. Each gender is almost equally represented, with 19 men and 15 women. All were Caucasian. Ages ranged from 25 to 94, with a mean age of 66.8. The 22 people who are still living are comparable to the 34 who have died in terms of diagnosis, gender, and age. Fifteen of the 22 have cancer, 2 have lung disease, 1 has heart disease, 2 people have amyotrophic lateral sclerosis, 1 has AIDS, and 1 has Parkinson's disease. Fifteen of those still alive are women, and 7 are men; the age range is 28 to 79, with a mean of 63.

In our cohort of 34 patients who died, 20 died naturally in the course of their disease. Fourteen of these had no apparent hastening from any medical or personal intervention. We designated five as "deaths due to double effect," because death in these patients occurred, at least in part, as an unintended consequence of the medication required to address their distress and symptoms.[16] Several were patients who had stopped breathing while receiving rapidly increasing doses of intravenous (IV) morphine. We designated one as a death while "terminal sedation" (or "anesthetic coma") controlled the pain of his total bowel obstruction that was not amenable to conventional therapies. This patient received no artificial nutrition or hydration and died 18 hours after IV sedation began. Four patients died as a result of their voluntary decision to stop eating and drinking.[17] Ten patients ingested medication obtained under the Act and died as a result. Five of these individuals were men, and 5 were women. None of the 34 had a disability other than that secondary to their terminal illness. See Table 1 for a summary.

The 10 patients who took medication to assist their deaths fell into, and remained in, a coma within 1–10 min. Time to death ranged from 10 min to 11.5

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[16] For a critical analysis of the "rule of double effect," *see* Timothy E. Quill, Rebecca Dresser, and Dan W. Brock, *The Rule of Double Effect—A Critique of its Role in End-of-Life Decision Making*, 337 N. Engl. J. Med. 1768 (1997).

[17] For comparisons of these different ways of hastening death, *see*, Timothy E. Quill, Bernard Lo, and Dan W. Brock, *Palliative Options of Last Resort: A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia*, 278 J. Am. Med. Assoc. 2099 (1997); Ann Alpers and Bernard Lo, *Does It Make Clinical Sense to Equate Terminally Ill Patients Who Require Life-Sustaining Interventions With Those Who Do Not?*, 277 J. Am. Med. Assoc. 1705 (1997); Franklin G. Miller and Diane E. Meier, *Voluntary Death: A Comparison of Terminal Dehydration and Physician-Assisted Suicide*, 128 Ann. Internal Med. 559 (1998); Alan Meisel, *Physician-Assisted Suicide: A Common Law Roadmap for State Courts*, 24 Fordham Urb. L. J. 817 (1997); David Orentlicher, *The Legalization of Physician-Assisted Suicide*, 335 N. Engl. J. Med. 663 (1996); David Orentlicher, *The Supreme Court and Physician-Assisted Suicide: Rejecting Assisted Suicide but Embracing Euthanasia*, 337 N. Engl. J. Med. 1236 (1997).

Table 1
Summary of Compassion Patients Discussed in This Article

56 Qualified patients[a]	
34 Deaths	22 Still living
14 No hastening	
5 Double effect	
1 Terminal sedation	
4 Voluntarily stopping eating and drinking	
10 Used medication under the Act	

[a] From 350 information requests.

hr, with most occurring within 50 min.[18] Ten different attending physicians completed all the requirements of the Act and provided the medication.[19]

Oregon Health Division Report

The Oregon Health Division is required to issue reports about the use of the Act.[20] Balancing intense interest in how the Act was working with concerns about confidentiality, the Health Division stated it would not issue a preliminary report until at least 10 people had received medication under the Act. It took until mid-August to reach this number, even though approximately 21,000 people died over this same period of time.[21] On August 18, 1998, the Health Division reported on 10 people who had received prescriptions, 8 of whom had used the medications to hasten death. Some, but not all, of these eight deaths were of Compassion clients; the other deaths discussed in the present article occurred after the State's report was issued. They will, however, be included in the Health Division's year-end report, which should be issued in January 1999.[22] Although the focus of this article is on Compassion's clients, the Health Division data are summarized below.

The State's August report indicated that the physicians prescribing the med-

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[18] Joseph Schnabel and Gary Schnabel, *Pharmacy Information, in* DWDA Guidebook, *supra* note 1, 33, 33–7 stated that most people would die within 5 hours of taking medication, but the process could last up to 24 hours. They also indicated that the person would usually lose consciousness within 5–15 minutes and remain comatose until death.

[19] This practice is in contrast to the research done by Ezekiel J. Emanuel, Elisabeth R. Daniels, Diane L. Fairclough, and Brian R. Clarridge, *The Practice of Euthanasia and Physician-Assisted Suicide in the United States: Adherence to Proposed Safeguards and Effects on Physicians,* 280 J. Am. Med. Assoc. 507 (1998), who claim that in the majority of cases of physician-assisted death proposed guidelines are not followed. However, their data were collected in states where physician-assisted death is illegal; therefore, the opportunity to completely follow proposed guidelines is difficult if not impossible.

[20] ORS 127.865(3).

[21] Joseph B. Frazier, *8 in Oregon Have Used Suicide Law,* Rocky Mountain News, August 19, 1998 at 31A; Erin Hoover Barnett, *Assisted Suicide, One Year Later,* Portland Oregonian, October 27, 1998 at A1.

[22] Barnett, *supra* note 19.

ications followed all of the Act's requirements.[23] The 10 patients reported by the state were all Caucasian, 5 men and 5 women, with a mean age of 71. Cancer was the precipitating condition in nine of the cases; heart disease was the other. The 8 people who took the medication did so at varying times after receiving it. The span ranged from the day the pills were received to 16 days later, with an average of 2 days. The 2 patients who died of their illness lived an average of 10.5 days after receiving the medication. The 8 who took the medication died an average of 40 min later with a range up to 7 hr. There were no complications reported in any of the deaths.

The data presented herein are less complete than the Health Division information in some areas because, although every completed request must be reported to state authorities, this article covers only those patients or physicians who have contacted Compassion during the process. However, in contrast to the State's data, Compassion's data include patients who made inquiries about the availability of the Act but did not complete the request procedures. This was either because circumstances related to their illness prevented them from doing so or they decided on another course.

Elements of Suffering

Individuals are asked to examine a list of "elements of suffering" Compassion provides[24] and identify those they are experiencing. They are also asked which of these would be important in their choosing an assisted death if they should ultimately do so.[25] In the few cases where information was not obtained by the time of death, we asked the family[26] to provide their best assessment of the patient's experience and answer the same questions on the patient's behalf. We have information on the elements of suffering for 25 of the 34 people who died. The two most common elements of suffering identified are physical discomfort other than pain (listed by 13 of the 25) and dependence on others for personal care (also listed by 13). These two categories are followed by being restricted to bed or wheelchair most of the time (12), loss of control over bodily functions (12), loss of control in general or fear of loss of control (10), severe pain (9), and loss of autonomy (9).[27] As for which factor would determine whether the choice of assisted death was exercised, we found that the majority of responses were the

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[23] Frazier, *supra* note 19.

[24] Modified from Anthony L. Black, Jeffrey I. Wallace, Helene E. Starks, and Robert A Pearlman, *Physician-Assisted Suicide and Euthanasia in Washington State,* 275 J. Am. Med. Assoc. 919 (1996).

[25] For another way of characterizing the reasons behind people's desire for death, *see,* Robert A. Pearlman, Kevin C. Kain, Donald L. Patrick, et al., *Insights Pertaining to Patient Assessment of States Worse Than Death,* 4 J. Clin. Ethics 33 (1993).

[26] We define the term "family" broadly, using the same definition as Melinda Lee, *Family Needs and Concerns, in* DWDA Guidebook, *supra* note 1, 17, 17–19, "Because some patients' closest relationships are with friends, not members of their family, in this discussion, we use the term 'family' broadly to refer to the terminally ill individual's most intimate relationships, which may include spouse, common law partner, unrelated living companion(s), close friends, children, or family of origin."

[27] Patients could list more than one element for half of 1998 and then the questionnaire was changed to only allow one response from the "determinative" portion. Therefore, the numbers add

loss of control or the fear of loss of general control (7) and loss of control of bodily functions (6).[28]

The statements of one articulate patient[29] were typical of the feelings of many: She had no problem with pain control, but she believed she had progressed to the point that she was "no longer living, but just existing." Weakness and fatigue had become prominent. Further, in spite of a surgical colostomy, recto-vaginal fistulas[30] had become so severe that she was unable to find relief from continuous oozing of fecal matter through the vagina. She faced imminent degradation of function requiring round-the-clock physical care, cleaning, and feeding. She found the prospect of continued life like this, with the knowledge that it heralded a relentless progression toward death, "more painful than any of the pain from cancer."[31]

Only 4 patients indicated severe pain would be determinative in a desire for assisted death. One of these 4 and 1 other person also indicated dependence on others for personal care would be determinative. Of the 4 patients who said becoming a burden to others was at least an element of their suffering, 2 also thought it might influence their decision.[32] However, it should be noted that families objected to the patient's naming of "burden" as an element of suffering and tried to convince these patients that caring for them was in fact an honor and privilege.[33] Nevertheless, 4 patients insisted that having an illness that distracted their families from other worldly concerns caused them significant suffering.

Mental Health Evaluation

Oregon law requires an evaluation by a licensed psychiatrist or psychologist if either the attending or consulting physician suspects that the patient may have impaired judgment due to clinical depression or another psychiatric disorder.[34]

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up to more than 25 but are not as high as they would have been had the original questionnaire been retained.

[28] *Id. See* also, Terri Schmidt, *The Meaning Behind a Patient's Request, in* DWDA Guidebook, *supra* note 1, 5, 5–6; Margaret A. Drickamer, Melinda A. Lee, and Linda Ganzini, *Practical Issues in Physician-Assisted Suicide,* 126 Annals Int. Med 46, 46–7 (1997). It is important to note that although financial concerns, specifically "concern about medical costs," was an option for both elements of suffering and determinants of assisted dying, this item was selected by only one patient as an element and by none as determinative of a decision to have assisted dying. Nevertheless, money is still an issue that must be reviewed with dying individuals and their families. Daniel Field, *Financial Issues, in* DWDA Guidebook, *supra* note 1, 42.

[29] The descriptive characteristics of some of the patients, family members, and caregivers may have been changed in an attempt to protect confidentiality.

[30] These are breakdowns of the tissue between the rectum and vagina.

[31] Personal recorded conversation with a patient dying of ovarian cancer, approximately 30 min prior to her self-administration of medication to assist her dying.

[32] *See also,* Lee, *supra* note 24, at 17.

[33] This is consistent with recent research on "caregiver burden," which has documented that the amount of caregiving required is not necessarily related to the perceived "burden" felt by the significant other. Laurel C. Beery, Holly G. Prigerson, Andrew J. Bierhals, Lisa M. Santucci, Jason T. Newsom, Paul K. Maciejewski, Stephen R. Rapp, Amy Fasiczka, and Charles F. Reynolds III, *Traumatic Grief, Depression and Caregiving of Elderly Spouses of the Terminally Ill,* 35 Omega 261 (1997). *See also,* Lee, *supra* note 24, at 17.

[34] For a review of the literature discussing depression as the primary factor considered to impair

Compassion does not collect data on whether the dying person was referred for psychiatric or psychological evaluation. The Oregon Health Division requires either a positive finding of no psychological disorder or a statement of referral for evaluation as part of the attending physician's report. When a mental health consultation is obtained, a report entitled the "Psychiatric/Psychological Consultant's Compliance Form" is required. Information from these forms will likely be included in the Division's year-end report.

At least one Oregon physician has adopted a personal policy to refer any patient requesting assistance in dying to a psychiatrist for a mental health evaluation.[35] This is controversial, as it places the psychiatrist or psychologist in the position of a gatekeeper and poses potential risks to the patient, the professionals themselves, and the professions as a whole.[36] Psychiatrists who receive referrals for such evaluations apparently approach them very cautiously. One Oregon psychiatrist has stressed that when he received a referral because an attending physician had raised the question of depression impairing judgment he felt obligated to not only rule out each and every symptom of depression but also evaluate and eliminate every objection that a critic of assisted death could possibly raise.[37] Such an evaluation represents a substantial barrier for the patient to overcome.

It is clear that a few physicians presume that a request under the Act is prima facie evidence of a clinical depression. But a patient may have reason to question such a presumption. The patient who underwent the exhaustive evaluation described above reacted with surprise that anyone would suspect she was clinically depressed. "I've never been like that," she said, as she explained that her remedy for any sadness in her life was always to "work it out" in her garden.[38]

Comparisons Between Predicted Outcomes and Actual Experience

During the vigorous debate that occurred over the 4½ years of public consideration in Oregon and elsewhere, a number of predictions were made about what would happen if the Act were passed and, later, if it were not repealed. A few of the dire predictions that have not been observed are worth noting. For example, during the 1997 political campaign there was much speculation that large doses of

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judgment related to a request for assisted dying, *see* James L. Werth Jr., *Clinical Depression and the Desire for Death Among Persons with Terminal Illnesses,* 5 Social Pathology 22 (1999).

[35] This course of action is recommended in several places in the DWDA Guidebook, *supra* note 1: Frank Baumeister and Patrick Dunn, *Attending Physician and Consulting Physician,* 22, 20–26; Linda Ganzini and Toni Farrenkopf, *Mental Health Consultation and Referral,* 31, 30–32; Kelly Hagan, *Liability and Negligence,* 53, 46–55.

[36] Mark D. Sullivan, Linda Ganzini, and Stuart J. Youngner, *Should Psychiatrists Serve as Gatekeepers for Physician-Assisted Suicide?* 28(4) Hastings Center Report 24 (1998). However, see Werth, *supra* note 8 for a different perspective.

[37] Personal conversation with a psychiatrist who performed the psychiatric evaluation on the first person in Oregon announced as having hastened death by using the Act. *See* James L. Werth Jr., G. Andrew H. Benjamin, and Tony Farrenkopf, *Requests for Physician-Assisted Death: Guidelines for Assessing Mental Capacity and Impaired Judgment,* 6 PSYCHOL. PUB. POL'Y & LAW, 348–372 (2000), for a review of capacity to form reasoned decisions and a process to evaluate the presence of impaired judgment.

[38] Taped conversation with a terminally ill patient who had made a request under the Act.

the recommended medication would cause vomiting, aspiration, and seizures.[39] In Compassion's 10 cases of medication ingestion, there was no nausea or vomiting. Because we have taken the precaution of ensuring that an antiemetic is taken prior to taking the lethal medication, it is uncertain whether a tendency toward vomiting exists or whether an antiemetic satisfactorily protects against the possibility.[40]

It was also predicted that dying people would migrate to Oregon and attempt to establish residency so that they could avail themselves of the new law.[41] All 34 patients discussed in this report were long-term residents of the state, having lived in Oregon for years, many for most or all of their lives. We are unaware of any terminally ill patients moving to Oregon to seek aid-in-dying. The Compassion in Dying Federation maintains a separate telephone counseling service for terminally ill patients in other states. In response to questions about the possibility of moving to Oregon to use the Act, Federation staff members always state that, to our knowledge, Oregon physicians are unable and unwilling to accommodate such a plan. To do so a physician would have to (a) accept a new and unknown dying patient into the practice, (b) falsely certify that the recent émigré is a bone fide resident and qualified under the Act, and (c) participate in a request outside the context of an established therapeutic relationship. Physicians are understandably hesitant to agree to (a) and (c) under any circumstances. The false certification involved in (b) would be illegal, and such conduct would fall outside the intended purpose of the Act, thereby depriving the physician of the immunities to civil, criminal, and professional sanction granted by the Act.[42]

Another prediction was the occurrence of assisted deaths in public and inappropriate locations.[43] All 10 of our patients took their medication in the home. In each case family members, physician,[44] clergy, Compassion volunteers, or hospice personnel or a combination thereof were present. The attending physician was at five of the deaths. No patient died alone.

In only one case was the location of death an issue. As one patient's plans to use the Act solidified, the owner of the foster home where she had lived for 3 years refused the patient's request to die in the home. The owner considered refusing her tenant's request to be inherent in the right to "opt out" granted by the

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[39] David Reinhard, *Welcome to Die-Rite,* Portland Oregonian, June 8, 1997 at F04. *See also* Smith & Pollack, *supra* note 8, at 553–54.

[40] *See* Schnabel & Schnabel, *supra* note 16, at 35, for a brief discussion of why anti-emetic medications should be used.

For discussions of "botched" attempts see Stephen Jamison, *When Drugs Fail: Assisted Deaths and Not-So-Lethal Drugs,* 4 J. Pharmaceutical Care in Pain & Symptom Control 223 (1996); Russel Ogden, *Euthanasia, Assisted Suicide, and AIDS* (1994) at 89–90.

[41] Yes on 51 Committee, *Six Important Facts,* September, 1997. "Measure 51" was the attempt to repeal the Act. The Measure failed, 40–60, *supra* notes 3 and 4. *See* also David Lodzinski, Friends of Malheur and Harney Counties, *Measure 16 Poses a Striking Danger to Residents of Oregon and Its Quality of Life,* State of Oregon Special Election Voters' Pamphlet, Arguments in Favor of Measure 51, November 4, 1997; Ezekiel J. Emanuel and Elisabeth Daniels, *Oregon's Physician-Assisted Suicide Law: Provisions and Problems,* 156 Arch. Int. Med. 825, 828 (1996).

[42] Hagan, *supra* note 32, at 47.

[43] Larry V. Newman, State Medical Examiner, Testimony before the House Judiciary Committee, Oregon State Assembly, March 11, 1997. Dr. Lewman suggested that resorts at the coast or public parks might become likely settings for assisted dying.

[44] Baumeister & Dunn, *supra* note 32, at 24.

conscience clause of the Act.[45] This situation necessitated a move shortly before the person died from the original foster home to another whose owner shared the patient's philosophy about end-of-life choices. Although the move had the potential to cause tremendous stress on the patient, efforts by her physician, the hospice team, and Compassion volunteers eased the move, and the patient expressed no concern or distress. The physician, hospice social worker[46] and nurse, and the patient's loved ones all attended the patient's hastened death in the new home.

A commonly voiced concern was that physicians and patients, as well as health care systems, would turn to physician-assisted death as a means of managing symptoms and cutting costs.[47] However, the results have been very different from these dire predictions,[48] not only for those who have contacted Compassion,[49] but also for all Oregonians. Instead of the quality of care and of the dying process decreasing, the evidence is that the Oregon health care systems are doing much better in caring for terminally ill residents now than they were prior to 1994.

Another argument was that the weak, the vulnerable, and the disabled would "become the chief victims" of legalized assisted dying; and it was also implied that women would be more likely to avail themselves of the option of assisted death.[50] In fact, an equal number of men and women in this report hastened death by using the Act. Further, there is no person with a disability, other than that secondary to their terminal illness, among the group of 34. In addition, there is no evidence[51] among our set of clients nor among the State's reported cases of any form of manipulation or victimization occurring, at least not in the direction of hastening death (as opposed to prolonging the dying process).[52]

Finally, a few predicted that the suicide rate among Oregon youth would be

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[45] ORS 127.885(4). *See also* Bonnie Reagan, *Conscientious Practice, in* DWDA Guidebook, *supra* note 1, 7–9.

[46] The National Association of Social Workers has a policy statement that states that social workers can be present at an assisted death if the client requests the social worker's presence, *Client Self-Determination in End-of-Life Decisions, in* Social Work Speaks (3rd ed.) 60, 58–61 (1994).

[47] *See,* Herbert Hendin, *Seduced by Death: Doctors, Patients, and Assisted Suicide* (1998) at 244.

[48] *See* notes 86–92, *infra,* and associated text.

[49] *See* notes 39–40 *supra,* and associated text.

[50] Ellie Jenny, *Measure 16 Discounts the Disabled,* State of Oregon Special Election Voters' Pamphlet, Arguments in favor of measure 51, November 4, 1997; Kenneth R. Stevens, *Measure 16 Destroys Trust Between Patient and Physician,* State of Oregon Special Election Voters' Pamphlet, Arguments in favor of measure 51, November 4, 1997. These are also common fears raised about assisted death in general, *see* New York State Task Force on Life and the Law, *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context* (1994) at ix; Susan M. Wolf, *Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia, in* Feminism & Bioethics: Beyond Reproduction, 282–317 (Susan M. Wolf Ed. 1996).

[51] By "no evidence" we mean that Compassion volunteer professionals, the attending and consulting physician, and any additional health and mental health care personnel did not report being aware of any coercion or pressure being present. Similarly, significant others did not report any coercive actions on the part of other people. The State's report also concluded that there had not been any indication that the deaths were anything but voluntary.

[52] *See* fn 60, *infra,* and accompanying text for an example of how financial reasons may have been involved in the prolonging of the dying process of one woman.

adversely affected by implementation of the Act.[53] However, the number of youth and rate of youth suicides have actually declined, from 37 in 1994 to 43 in 1995, 38 in 1996, and 30 in 1997,[54] in spite of a rising population.

Elements of the Physician–Patient Relationship

Rising Expectations

It has been suggested that the intense public discussion of the Death with Dignity Act has produced heightened expectations among patients and families for comfort and control of symptoms at the end of life.[55] This hypothesis finds some support in our experience.

In 12 of the 34 cases, palliative care[56] underwent a marked improvement subsequent to the patient's request for an assisted death. For some people the request precipitated enrollment in hospice or consultation with a palliative care specialist, which led to new modes of treatment. For others, care that was already in place was intensified to provide better symptom management.[57] A typical example of this phenomenon is a patient with emphysema who contacted Compassion 2 weeks before his death. As the patient began a request under the Act, discussions also proceeded on how to diminish the breathlessness and air hunger he experienced. Hospice personnel introduced morphine sulfate, which gave the patient symptomatic relief. He died peacefully and naturally 13 days later. With outcomes such as this, families have generally been relieved at the cessation of their loved one's distress and thankful for a gentle death.

For 11 of the 34 people, however, the family experienced significant distress because they believed the choice the patient would have preferred had been foreclosed, and the care provided was not entirely successful in relieving the patient's anguish.[58] A categorical refusal from the physician to participate in an assisted death under the Act may exacerbate this perception. For example, one

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[53] Yes on Measure 51 Committee, *A Deadly Message. Oregon's Suicide Law Is Sending the Wrong Message to Our Youth.* Campaign literature received in Oregon homes on October 22, 1997.

[54] George Eighmey, *Don't Link Aid in Dying, Youth Suicide,* Portland Oregonian, Nov. 15, 1998 at B5.

[55] Staff Writers, *Study Finds Pain Went Up Sharply Among Dying in Late '97,* Associated Press Wire Service, October 7, 1998; Barnett, *supra* note 10. This study found that overall the pain levels reported by family members in Oregon are lower than those reported nationally, but in November and December of 1997, family members reported a significant increase in the level of pain experienced by loved ones dying in hospitals.

[56] According to Ann Jackson and Martin Skinner, *Comfort Care, Hospice, and Palliative Care, in* DWDA Guidebook, *supra* note 1, 10, 10–14, palliative care "focuses on reducing or abating physical and other symptoms of a terminal illness."

[57] The success of these interventions, following a request for physician-assisted death, is in marked contrast to a national study that found that attempts by a trained nurse to improve the dying process of patients were unsuccessful. SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients,* 274 J. Am. Med. Assoc. 1591 (1995). It is also different from the dying process of perhaps a majority of people. Joanne Lynn, Joan M. Teno, Russell S. Phillips, et al., *Perceptions by Family Members of the Dying Experiences of Older and Seriously Ill Patients,* 126 Annals Int. Med, 97 (1997).

[58] For research support of these caregivers' perceptions about how much suffering dying people may experience, even while under medical care, *see* Lynn et al., *supra* note 52.

family believed that when the patient's request for assisted death was refused,[59] the physician specifically stated that a peaceful, quiet death could be assured. In fact, the family had to witness a very difficult death. Hospice personnel who attended the death worked hard to control symptoms and provide a gentle death. Nevertheless, they thought that they could not allow the patient's wife into the room because the circumstances were too unpleasant. The wife remains bitter and angry that the patient suffered at the end and was deprived of the choice he wanted—a peaceful, assisted death. She also believes that if he had been allowed to take medication under the Act, she would have been able to be at his side when he died.

Delay in the Articulation of a Request

Patients in our group of 34 varied in the period of time during which they considered options and made plans for an impending death. Our initial contact with patients ranged from 2 days to 167 days prior to their deaths, with a mean of 36.4 days. The 10 patients who ingested medication under the Act pursued their inquiry over a much longer period of time. They began the request process from 15 to 167 days before their deaths, with a mean of 62.2 days.

For 11 people the initial inquiry preceded death by less than 15 days, which is too short a period to complete the necessary procedures and obtain a prescription.[60] One hypothesis that may account for this apparent delay in attempting to utilize the Act is that all patients, even those who would be inclined to seek the option of assisted dying, hold on to the hope of a miraculous cure or remission that will prolong their lives indefinitely. Only when their deteriorating condition presents incontrovertible evidence that the end is near does denial give way to acceptance.[61]

Delay in Processing a Request

When patients ask about assisted dying, they frequently report that the response from the physician is to try to distract the patient or provide reassurance about the likely circumstances of death so that patients will believe that assisted dying is unnecessary.[62] The perception of our patients is that these physicians are

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[59] Physicians and other health care professionals, such as nurses and pharmacists, can decline to participate in any aspect of an assisted death without penalty. Schmidt, *supra* note 26; Reagan, *supra* note 42; Hagan, *supra* note 32, at 47.

[60] The waiting period is at least 15 days following a formal request to the attending physician. ORS 127.840 § 3.06.

[61] *See* Margaret P. Battin, *Going Early, Going Late: The Rationality of Decisions about Suicide in AIDS*, 19 J. Med. & Phil. 571 (1994).

[62] Commentators note that physicians should assure patients that they will accompany the patient on the journey to death regardless of what hardships are encountered—so long as such statements are true. The physician should also indicate whether he or she will provide medication under the Act. It is important to avoid making promises that cannot be fulfilled. Timothy E. Quill, *Doctor, I Want to Die, Will You Help Me?*, 270 J. Am. Med. Assoc. 870, 873 (1993); Baumeister & Dunn, *supra* note 32, at 25; Hagan, *supra* note 32, at 47. Some have stated that there should be consequences for physicians and other care providers who violate professional standards in these circumstances. Kathleen Haley and Susan Tolle, *Responding to Professional Non-Compliance, in* DWDA Guidebook, *supra* note 1, 40, 40–1.

evasive, so it appears as if physicians must be very careful to prevent the perception that they are stonewalling or abandoning the patient.[63]

The experience of one family left them particularly disillusioned. The mother had been told liver cancer had spread throughout multiple organs and even an optimistic prognosis was 3 months. When she made a request under the Act, however, the physician appeared to change the message, saying he was not totally convinced she was terminally ill, and ordered further tests. When she died less than 1 month later the family was convinced that both the physician and hospital had pursued their own self-interest in ordering additional costly tests instead of treating their mother's discomfort and following her wishes to shorten the dying process.[64]

As discussed above, patients may state their first request for an assisted death as they begin to perceive a precipitous decline in function or exacerbation of symptoms. Understandably, these individuals would naturally believe that they have a rapidly closing window of opportunity to have a choice in how they die. Delays arising from the physician's own values, or a desire to reduce legal risk, that do not give full weight to the patient's preferences, have been perceived by patients and their caregivers as an imposition on patient's autonomy.[65]

Patients generally understand and are supportive of precautions related to assessing mental competence, nonimpaired judgment, and whether the request is enduring and rational.[66] They have willingly accepted encouragement toward hospice care and the consideration of other alternatives such as intense comfort care, terminal sedation, and stopping eating and drinking.[67] In fact, 27 were enrolled in hospice when they died. Of the 10 who took medication to assist their dying, 7 were in hospice, and 2 were offered hospice but believed they were already receiving excellent care and refused it. For the remaining person who had an assisted death the hospice status is unknown.

However, patients expect that once the other options have been considered and efforts at palliative care have been made, they will not be prevented from utilizing the Act.[68] When they perceive that, even after overcoming every legitimate safeguard, the answer from the physician is still "No," they often feel misled and betrayed.[69] One patient, angry that her "sanity" was questioned

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[63] Timothy E. Quill and Christine K. Cassel, *Nonabandonment: A Central Obligation for Physicians,* 121 Annals Int. Med. 368 (1995).

[64] Written account of Richard A. Thomas, who asked that his report of his mother's experience be publicized.

[65] Hagan, *supra* note 32, at 47.

[66] Werth, Benjamin, & Farrenkopf, *supra* note 34; Ganzini & Farrenkopf, *supra* note 32; Melinda A. Lee, Linda Ganzini, and Kenneth Brummel-Smith, *When Patients Ask About Assisted Suicide: A Viewpoint from Oregon,* 165 Western J. Med. 205, 206–07 (1996); Drickamer, Lee, & Ganzini, *supra* note 26, at 147–48.

[67] *See* Jackson & Skinner, *supra* note 51.

[68] *Id.* at 12.

See Linda L. Emanuel, *Facing Requests for Physician-Assisted Suicide: Toward a Practical and Principled Clinical Skill Set,* 280 J. Am. Med. Assoc. 643 (1998) for a description of a process that leads the person requesting physician-assisted death through a detailed evaluation, which includes explicit attempts to "dissuade" the person from the request for physician-assisted death, and then ends with declining even a fully rational, informed request for assisted death.

[69] Misleading the patient and failing to provide a timely referral is a serious breach of the duty

without any supporting evidence, complained about a doctor who "wasted" 24 days of precious time. These 24 days were occupied with an initial evaluation of the request, a 2-week follow-up appointment on the general principle of not rushing a decision, additional tests to assess a progressive cough, and consideration of a 3-week course of antidepressants. The patient said the delay made her feel "put off," and her family articulated the ethical duty as follows:

> If a doctor does not want to participate they should say right up front, at the first visit, "We're not willing to participate." Don't say "We'll think about it. We'll let you know." Or "We're open minded."[70]

Another family perceived that an initial promise given to the patient that the doctor would provide medication under the Act was an evasion technique because it was retracted when the patient suffered a sudden decline. In retrospect, this family believes that because the patient had been very vocal about his intention to make a request under the Act if the occasion ever arose, several doctors in the community, all of whom were involved in the patient's care, conspired to keep the patient's diagnoses and prognoses a secret.[71] Because of this, the family believes the patient was prevented from understanding the significance of the pain he experienced and planning for an imminent death.

It is undeniably important that the attending physician be satisfied that both the requirements of the Act and any personal requirements, such as a demonstration of untreatable suffering, are met. But our experience indicates that physicians should also carefully examine their personal beliefs and values and give the patient an early and honest account of their willingness to participate in the Act.[72] If for any reason the physician cannot honor the patient's request, the patient should be notified as soon in the evaluation process as feasible so that the patient can make plans based on that knowledge. Physicians who categorically reject the possibility of ever complying with the Act should notify their patients of that fact early in the course of a terminal illness, and certainly as soon as the patient broaches the subject.[73]

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of care. Hagan, *supra* note 32, at 47; Baumeister & Dunn, *supra* note 32, at 20–21; Norbert Novak, *Patient Rights and Responsibilities, in* DWDA Guidebook, *supra* note 1, 15–16. It may be reportable, *see* Haley & Tolle, *supra* note 57.

[70] Personal conversation with patient and family members, recorded several days prior to the time of death.

[71] If true, this would represent a breach of the ethical duty of truth-telling and a conspiracy to do the same. Hagan, supra note 32, at 47, 50; Novak, *supra* note 64, at 15. It may be reportable, *see* Haley & Tolle, *supra* note 57.

[72] This course of action is recommended in several places in the DWDA Guidebook: Reagan, *supra* note 42, at 7; Novak, *supra* note 64, at 15; Baumeister & Dunn, *supra* note 32, at 20–1; Hagan, *supra* note 32, at 47.

[73] *Id.* The same holds for mental health professionals who are called in to evaluate whether the dying person's judgment is impaired. Ganzini & Farrenkopf, *supra* note 32, at 30. These authors reported that research with Oregon psychiatrists and psychologists revealed that opponents of assisted death might use the evaluation as a way to prevent the person from receiving the requested assisted death. *Id.*

Problems With Communication

We have observed a number of instances where the patient and the physician differ in their interpretation of what has been said and decided during conversations about end-of-life choices.[74] Patients have thought that a comment such as "You know I don't want to go on like this" constitutes a request for assistance under the Act. The doctor's response that "Everything will be done to achieve comfort" has been interpreted as acquiescence.

Other types of miscommunication can occur. One doctor's suggestion of "Why don't you just stop eating" was taken at face value, and the patient endured 34 days without food before being told it was necessary to stop drinking as well.[75] The patient died on day 44 of the fast after experiencing inadequately treated burning of the eyes and tongue.

As a result of these experiences, we are convinced that absolute clarity is crucial. Patients have a desire for specific and detailed information about the likely progression of symptoms such as fatigue, breathlessness, and pain, and how they are to be treated.[76] In particular, patients who have experienced one or more spasms of coughing, choking, or air hunger seek information about how this can be avoided as the mode of death. Some patients are comforted by a vague assurance that, "We won't let you suffer." But others are not; they want specific information about how such an emergency is to be prevented. One such patient was Ray Frank,[77] who struggled with breathlessness from the kidney cancer that had spread to his lungs. He had experienced the panic of air hunger and sought a specific plan to avoid suffocation as a terminal event.[78] For patients like this, the conversation must be forthright and detailed in order to allay their fears. One seasoned oncologist who has had a number of patients make requests under the Act reported that conversations about end-of-life options that include assisted dying tend to be long, intimate, and compelling. She tells her colleagues, "They will remind you of why you wanted to become a doctor."[79]

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[74] Miscommunication can occur for a variety of reasons. For example, Lawrence J. Schneiderman, Robert M. Kaplan, Robert A. Pearlman, and Holly Teetzel, *Do Physicians' Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences?*, 4 J. Clin. Ethics 28 (1993), showed that physicians' predictions of patients' desires correlated with their own desires and not with their patients.' Thus, the physician may interpret ambiguous statements in a manner consistent with his or her own beliefs and desires instead of what the patient really wants. *See also,* SUPPORT Principal Investigators, *supra* note 52.

[75] For a discussion of voluntarily stopping eating and drinking as a means of hastening death, see Quill, Lo, & Brock, *supra* note 15, at 2099–100.

[76] *See,* Jonathan Gavrin and C. Richard Chapman, *Clinical Management of Dying Patients,* 163 Western J. Med 268 (1995), for an overview of these matters.

[77] Christopher Reed, *Oregon Fights to Keep Death Dignified,* The Guardian (UK), September 19, 1998. Relates the story of Ray Frank who had both lung and kidney cancer and asked a friend to bring him a shotgun so that he could kill himself to end his suffering. However, the passage of the Act "brought him peace of mind" according to a friend.

[78] William Claiborne, *In Oregon, Suicide Option Brings a Kinder Care,* Washington Post, April 29, 1998 at A1. *See also* Barbara Coombs Lee, *The Key to Ray Frank's Locked Room,* Daily Astorian, January 21, 1998.

[79] Nancy S. Crumpacker, *Death With Dignity Act,* Newsletter of the Oregon Chapter of the American College of Physicians, August, 1998. Available at www.acponline.org/chapters/OR/newsletters/newss-aug98.htm.

Family Participation

Although the Act does not mandate participation by the family,[80] such participation predominates in these 34 cases. When a patient contacts Compassion, it is usually in association with immediate family members. Frequently both patient and family members place the initial call and participate via telephone extensions. A patient often designates one family member to play the lead role in reaching out for information and bringing it back for consideration by the group. This person is almost always a female member of the family—the wife, daughter, or mother of the patient. Other members of the family play more supportive roles for the patient, the primary caretaker, and each other. Men in these families have played important roles in supporting others through impending and postdeath loss and grief and protecting the family from possible threats to their privacy. Yet, only the patient may make a request under the Act, so after initial information is obtained the patient must take the initiative to speak to the physician and carry through the entire request procedure.

Understandably, planning for the death of a loved one is an extremely difficult task for any family.[81] Our families have generally been more hesitant than the patient to confront the inevitability of death and make plans for it. They do so only at the patient's urging and when it becomes clear that this is both what is necessary and what the patient desires. If a family member places the first call to Compassion, it is common for them to explain that they are calling because the patient has been asking for some time about the new law. Families often describe the journey through their own reluctance as "Doing what *he* wants, because what I want isn't important," or "Letting him know I support him whatever he decides." Having the family gather together in support of the dying person's last wish has been an intensely loving and uplifting experience for all involved.[82] One woman announced after a long night of preparing, witnessing, and grieving a death together that, "This was the greatest gift of love we could give to [the family member who died] and the hardest thing for us. This is what families should do for one another."[83]

In our experience, patients are enormously sensitive to the feelings of the family members who will survive them, and they take those feelings into account in their decisionmaking. In several cases patients have subordinated their own desires about a mode of death to those of even one family member who objects.

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[80] Lee, *supra* note 24.

[81] For a brief discussion of the needs of the family of a dying person, *see* Paul B. Bascom and Susan W. Tolle, *Care of the Family When the Patient Is Dying*, 163 Western J. Med. 292 (1995). Because of the nature of the organization, Compassion has not collected comprehensive data on the different ways that clients' deaths impact the families.

[82] For research on the impact of assisted death on involved significant others *see* Molly Cooke, Linda Gourlay, Linda Collette, Alicia Boccellari, Margaret A. Chesney, and Susan Folkman, *Informal Caregivers and the Intention to Hasten AIDS-related Death*, 158 Arch. Int. Med. 69 (1998); Stephen Jamison, *Final Acts of Love: Families, Friends, and Assisted Dying* (1995); James L. Werth Jr., Daniel J. Holdwick, Mollie K. Mount, and Laura J. Pitman, *The Legacy of Hastened Death* (April 1997) (unpublished manuscript, on file with the second author).

[83] Personal conversation with the mother of a patient who died.

For example, one woman decided to forego taking medications under the Act because one daughter objected on religious grounds.

There also seems to be a strong desire to die in the presence of loved ones.[84] It has been recommended that if family is going to be present, but the physician is not, then the loved ones should be fully informed about how the medication is to be prepared and taken and about the potential complications.[85] Of our 10 assisted deaths, no one died alone. Eight had immediate family, and they were all in attendance, sometimes three generations. Two had no family, but they did have a combination of close friends, hospice nurse and social worker, and physician in attendance.

Averted Suicides and Homicides

Eight of the 34 patients said that they had already planned other ways to end their lives when they made their first request under the Act. Sometimes these were violent means, including the possible use of a gun. However, the prospect of a peaceful assisted death dissuaded them from plans that, if carried out, would have had a devastating impact on their families.[86] We refer to these as "averted suicides." Among our 34 patients, 6 had been sufficiently certain of completing their suicide plan to be in this category. Again, the example of Ray Frank is instructive. While Mr. Frank was hospitalized for symptom management he asked his physicians if he qualified for legal assistance in dying. After his doctors indicated they would not participate, he asked his friend, Noranne Clayton, to purchase a shotgun so he could die on the day of his expected discharge. Instead, Ms. Clayton called Compassion. We referred Mr. Frank to a physician who treated his symptoms aggressively and began procedures for a request under the Act. This so relieved his anxiety about the circumstances of his death that he never bought the gun, never spoke of suicide again, and died naturally within the next 2 weeks.[87]

There are other situations where patients plead with family members to end their lives. The temptation to do so can be great if the dying person is perceived to be enduring significant suffering. Families have considered suffocation, carbon monoxide poisoning, opiate overdose, or a combination of these. However, with the availability of the Act, family members have not felt compelled to take such extreme action, which would likely have led to both legal[88] and psychological[89] consequences. We call these "averted homicides." We have had two of them

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[84] *See* Cooke et al., *supra* note 77; Werth et al., *supra* note 77; Jamison, *supra* note 77.

[85] Lee, *supra* note 24, at 18; Baumeister & Dunn, *supra* note 32, at 22, 24–25.

[86] Marilyn J. Hauser, *Special Aspects of Grief After a Suicide, in* Suicide and its Aftermath: Understanding and Counseling the Survivors, 57–70 (Edward J. Dunne, John L. McIntosh, & Karen Dunne-Maxim eds. 1987).

[87] Reed, *supra* note 72; Claiborne, *supra* note 73; Coombs Lee, *supra* note 73.

[88] A family member who took such an action could be convicted of homicide, even if the intent was to relieve suffering. A recent case in Nebraska where a man shot his terminally ill wife to end her suffering illustrates how desperation can drive family members to extreme, and illegal, acts in an effort to help their loved ones. Scott Canon, *Killing Draws Nebraska Town into Painfully Personal Debate,* Kansas City Star, November 16, 1998 [1998 WL 2571713].

[89] *See* Jamison, *supra* note 37; Ogden, *supra* note 37; Michael E. Holtby, *Social Work, Suicide, and Self-Deliverance.* 1(3) National Social Work AIDS Network Readings and Writings 29 (1996).

among these 34 patients. In one instance the spouse readily admitted that, "If it weren't for [the availability of the Death with Dignity Act] I would be in jail tonight."[90] The spouse had called Compassion in a last desperate attempt to find a quick and gentle way to end the patient's suffering. The patient was in severe distress, believing that a transient period of confusion and sedation related to increased pain medication would soon become more continuous and pronounced. Spinal collapse and breathlessness added to the sense of intolerable agony. The spouse became convinced that helping the patient to die imminently was the only loving thing to do. On an urgent basis, we were able to visit the home, contact the physician, and assure the couple that the procedures for a legal assisted death were begun. The spouse was able to coax the patient into enduring the symptoms until all the requirements of the law were met. In the end they experienced a peaceful, legal death under the Act, lying together and embracing one another. As they talked about the wonderful life they had shared the patient lost consciousness and died a short time later.

Like most states, Oregon does not keep statistics on the number of suicides and homicides that occur in the setting of a terminal illness. Thus, it will not be possible to accurately assess the degree to which availability of legal assisted dying prevents homicides and suicides among dying patients.[91]

End-of-Life Care

Recently Tolle and Haley[92] reported that physicians in Oregon have reason to be proud because of tremendous gains made in end-of-life care since the first vote on the Act in 1994. Oregon leads the nation in advance care planning and in respecting the rights of the terminally ill to limit life-sustaining treatment. Over 170,000 neon pink Physician Orders for Life Sustaining Treatment (POLST) forms have been distributed throughout the state. They are being used by most Oregon hospice programs and long-term care facilities. Tolle and Haley also reported that most people want to die at home, and Oregon physicians are respecting this choice more often. Oregon has the lowest rate of in-hospital deaths among the 50 states; only 31% of Oregonians die in acute care hospitals.[93]

The only medical college in the state, the Oregon Health Sciences University,

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[90] Statement to two Compassion in Dying representatives upon their leaving the home following an urgent visit.

[91] There is evidence that a high percentage, perhaps even a majority, of people who die by assisted deaths are not reported as "suicides" but instead their deaths are attributed to their diseases. *See* Jamison, *supra* note 77 (140 assisted deaths, 15 reported as suicide); E-mail exchange with Russel Ogden, (June, 1998), related to Ogden, *supra* note 37 (34 assisted deaths, at least 9 were reported as suicide; Thomas A. Preston and Ralph Mero, *Observations Concerning Terminally Ill Patients Who Choose Suicide,* 4 J. Pharmaceutical Care in Pain & Symptom Control 1831 (1996) (24 assisted deaths, none attributed to suicide).

[92] Tolle & Haley, *supra* note 11. *See also* Melinda A. Lee and Susan W. Tolle, *Oregon's Assisted Suicide Vote: The Silver Lining,* 124 Ann. Int. Med. 267 (1996); Susan W. Tolle, *Care of the Dying: Clinical and Financial Lessons from the Oregon Experience,* 128 Ann. Int. Med 567 (1998).

[93] Erin Hoover, *Oregon Has Comfortable Lead in Nation's End-of-Life Care,* Portland Oregonian; April 1, 1998 at B1.

has added 14 class hours on end-of-life care to its first-year curriculum.[94] In 1995 the medical school hired a palliative care specialist and created a comfort care team. This brought an opportunity for students to work with dying patients enrolled in home hospice programs. A series of education programs on pain control was also developed for professionals.[95]

Since voters passed the Act in 1994, morphine use has soared, not only in Oregon but also in California and around the nation. In September of 1997 researchers reported that Oregon had gone from number 11 to number 1 in per capita distribution of morphine, because of a 70% increase in medical use of the drug. Wholesale per capita distribution was over 50% higher in the state than the U.S. average in the first 6 months of 1996, according to DEA records.[96] Unfortunately, this impressive trend did not continue during the period when the DEA threatened to punish Oregon physicians. Despite this downturn, Oregon has remained in the top six states in the nation in per capita use of morphine and ranked fifth for the first three quarters of 1998.[97]

Perhaps most telling of all has been the dramatic increase in the number of Oregonians who die under the care of hospice. According to the Oregon Hospice Association and Oregon Center for Health Statistics, the number of people dying in hospice has increased from 21% in 1994 to almost a third as of Autumn 1998.[98] This compares favorably with a national average of 17% and ranks Oregon third in the country in hospice utilization. Finally, nearly all terminally ill residents have been covered by the Oregon Health Plan. This caused the number of uninsured individuals enrolled in hospice programs to drop from 15% to 2% since 1994.

Unanswered Questions

This summary of the people who have approached Compassion and the description of trends related to end-of-life care in Oregon are a first step in the exploration and discussion of the impact of the Act. However, there remain many unanswered questions. We highlight only a few here because Rosenfeld[99] has compiled a more exhaustive catalogue of research issues.

Specifically in regard to Oregon, there are many questions that are, to some degree, unanswerable, and others that can only be answered by the state agency charged with monitoring implementation of the Act. These include the following: How thorough is the reporting to the State—are there cases of assisted death that

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[94] However, the professors in these classes are apparently reluctant to discuss the Act, and students may have to take it upon themselves to initiate a discussion. Sheri Fink, *Suicide Topic Rare in OHSU Classrooms,* Portland Oregonian, Aug. 12, 1998 at A1.

[95] Sheri Fink, *Providing Comfort When There's No Cure,* Portland Oregonian, August 12 at D12.

[96] Wire and staff reports, *Oregon Use of Morphine Tops That of Nation,* Portland Oregonian; September 26, 1997 at B1.

[97] Phone conversation with DEA staff, November 18, 1998.

[98] William Claiborne, *In Oregon, Suicide Option Brings a Kinder Care,* Washington Post, April 29, 1998 at A1; Patrick McMahon, *Law has Changed How Oregonians Die,* USA Today, July 15, 1998 at 2A.

[99] Barry Rosenfeld, *Methodological Issues in Assisted Suicide and Euthanasia Research,* 6 PSYCHOL. PUB. POL'Y & LAW, 559–574 (2000).

are going unreported? How many people are referred to psychiatrists or psychologists for evaluations? How many people have been "disqualified" from using the Act because the attending or consulting physician or the mental health consultant thought the person's judgment was impaired? How many people abandon their request once they have received treatment for any mental or physical conditions causing or related to aspects of their suffering? Many more could be asked. However, except for the first, the same questions one might ask about assisted dying also should be asked about withholding or withdrawing life-sustaining treatment, voluntarily stopping eating and drinking, and terminal sedation. We do not have comprehensive data on any of these other forms of hastening death, even though virtually all of the concerns related to abuse of the Act apply at least equally to them.[100]

There are also many questions about the impact on the caretakers and loved ones of the person who has died after taking medication prescribed under the Act. We do not have complete information about the impact on these individuals. However, the few studies[101] available demonstrate that to apply findings from studies on survivors[102] of suicide to survivors of assisted death is inappropriate. In fact, it has been hypothesized that survivors of assisted death would be more similar to survivors of withholding and withdrawing treatment than to survivors of suicide.[103] But, as was the case with dying patients, we do not have data comparing the impact on survivors of different types of hastened death. We need both cross-sectional and longitudinal studies that will show how various forms of hastening death affect survivors; how to assist survivors if their loved one experienced a difficult death; and how children are impacted by the dying process and mode of hastening death. We also need more information about the impact on all professionals involved, including their responses, ethical concerns, and knowledge needs.

Finally, more broadly, we need to know how the Act is impacting the end-of-life expectations of the Oregon public. It is often hypothesized, "If [people] know something is available to [them] and will remain available till [they are] moved to seize it, the chances of [their] seizing it are thereby much reduced."[104] With the Act in place, we have the opportunity to find out how true this is, not just for people who are ill but for everyone, because all citizens may have use for the Act at some point in their lives. Have the fears of the public been diminished due to the existence of the Act? Or, conversely, as opponents of the Act posit, are

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[100] *See* Werth, *supra* note 7; Werth & Gordon, *supra* note 7.

[101] Cooke et al., *supra* note 77; Werth et al., *supra* note 77; Jamison, *supra* note 77.

[102] Individuals who have had a person close to them die by suicide are referred to as "survivors of suicide." Thus, this term does not refer to people who attempted suicide but "survived" unless they also happen to have had a significant other die by suicide.

[103] Werth, *supra* note 7.

[104] Jerome A. Motto, *The Right to Suicide: A Psychiatrist's View,* 2 Life-Threatening Behavior 183, 188 (1972). *See also* Smith & Pollack, *supra* note 8, at 547; Erin Hoover Barnett, *Suicide Law Still Draws Emotional Responses,* Portland Oregonian, December 28, 1998 at A01 (interview with four physicians, one of whom describes the peace a patient found once she received a prescription); Erin Hoover Barnett, *Dilemma of Assisted Suicide: When?,* Portland Oregonian, January 17, 1999 at A01 (story about Pat Matheny, a man with ALS who receives a prescription under the Act but continues to delay using it).

people more fearful of the end of life? And, more narrowly, are different groups of citizens more concerned than others? If so, how might these fears impact their decisionmaking?

The list of questions is daunting because researchers have only been able to study how the legality of assisted death will actually impact people since late 1997. However, with the Act in place, these issues can begin to be explored. Only when the data are collected and analyzed can policy decisions be based on facts instead of conjecture.

Conclusions

Data emerging from Oregon are unique in that they reflect the first experiences of terminally ill patients who are seeking legal assistance in dying. If one accepts the premise that previous reporting may contain inaccuracies because of the necessity to have secret or covert communication, or that patients' experiences and motivations are distorted through third-person documentation,[105] then the advent of open and legal communication and first-person reporting provide tremendous advantages for researchers and policymakers. We think the developments in Oregon represent a remarkable opportunity to add to our knowledge of the hopes, fears, and values of dying people and how best to meet the needs that will emerge.

From the experience of Compassion in Dying in the first year under the Oregon Death with Dignity Act, it appears as though the Act is working as the drafters had planned and that the abuses forecasted by opponents have not materialized. Only 10 Compassion clients have actually used the Act to hasten death through prescribed medication, whereas a larger number of dying people have died more peaceful, comfortable deaths knowing that medication to assist dying could be available. In addition, several potential violent suicides and homicides were prevented because dying people could instead use the Act. The safeguards in the Act have been followed, no abuses have been reported, and there have been no complications associated with the assisted deaths that have occurred. The most common factors associated with the decision to utilize the Act have been nonpain physical suffering, dependence on others, loss of autonomy, and loss of control or fear of losing control. This latter finding may be in part due to the tremendous advances in pain management in Oregon since the Act was first passed in 1994.

Although there have already been many positive changes in the end-of-life experience for Oregonians, and the Act is serving its intended purpose, there are at least two areas where improvement in care is necessary. First, patients and their loved ones need to communicate more clearly with physicians about what is expected, what will be provided, and what procedures will be followed. Related

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[105] Back, Wallace, Starks, & Pearlman, *supra* note 22; Ezekiel J. Emanuel, Diane L. Fairclough, Elisabeth R. Daniels, and Brian R. Clarridge, *Euthanasia and Physician-Assisted Suicide: Attitudes and Experiences of Oncology Patients, Oncologists, and the Public,* 347 Lancet 1805 (1996); Diane E. Meier, Carol-Ann Emmons, Sylvan Wallenstein, Timothy Quill, R. Sean Morrison, and Christine K. Cassel, *National Survey of Physician-Assisted Suicide and Euthanasia in the United States,* 338 N. Engl. J. Med. 1193 (1998).

to this is the second point: Physicians who are opposed to assisting death must be honest with their patients who want to explore use of the Act as a legitimate end-of-life option. For physicians to string patients along with the hope that with enough delays the patients will be persuaded not to utilize the Act is unfair and unworthy of a professional. Yet, patients must also take responsibility for stating their needs and intentions forthrightly. We believe that patient and physician education will help to ameliorate these two concerns.

Substantial headway has been made in Oregon to improve end-of-life care and increase the number of deaths outside institutions and in the company of family and friends. The Death with Dignity Act has already eased the suffering of many Oregonians and their loved ones. We hope these trends will continue.

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

Developed by
The Task Force to Improve the Care of Terminally-Ill Oregonians

Convened by
The Center for Ethics in Health Care, Oregon Health & Science University

Patrick Dunn, M.D., Task Force Chair and Co-Editor
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This is the annexure marked **"PR03"** referred to in the affidavit of **Peter Lindley Reagan** affirmed at Portland, Oregon this 1 day of May 2015 before me

Signature ....
A person duly authorised to administer oaths in Oregon, ~~United States~~ of America
State of Oregon
County of Multnomah

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BENJAMIN K MACIARIELLO
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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

1. Purpose of the Guidebook

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

About the Task Force

In November 1994, Oregon voters passed the Oregon Death with Dignity Act. This unprecedented passage of a measure to allow competent, terminally ill adult patients to obtain a physician's prescription for drugs to end life sparked intense public debate, opened discussions among health care professionals and institutions, and initiated a complex series of judicial challenges. After extensive judicial, legislative, and public review, the Oregon Death with Dignity Act has become law (see Appendix A, *The Oregon Death with Dignity Act*).

The initial passage of the Oregon Act catalyzed the Center for Ethics in Health Care, Oregon Health & Science University, to convene the Task Force to Improve the Care of Terminally-Ill Oregonians. The Task Force is a consortium of health professional organizations, agencies, and institutions which seek to promote excellent care of the dying and to address the ethical and clinical issues posed by enactment of the Oregon Death with Dignity Act. While individual Task Force members and the organizations they represent have differing viewpoints and values regarding the Oregon Act, the Task Force has endeavored to maintain a neutral position on this issue. We appreciate that Oregon is a geographically and culturally diverse state. The contents of this Guidebook are meant to honor this diversity and facilitate access to all aspects of the highest quality of care for Oregonians.

Patrick Dunn, M.D. chairs the Task Force. Susan Tolle, M.D. chairs the Subcommittee on Resources for Compassionate Care of the Dying. Bonnie Reagan, M.D., R.N. chairs the Subcommittee on Guidelines for the Oregon Death with Dignity Act. The overall goal of the Task Force has been to thoughtfully consider how to improve end-of-life care in our state. Our mission statement reflects this broad charge.

Mission of the Task Force

Share information, experience, and understanding of available resources for the care of terminally ill Oregonians and assist in the development and coordination of services where needed. Through open and respectful communication, we wish to facilitate understanding of diverse viewpoints and cooperate to improve the care of all terminally ill persons and their loved ones.

Facilitate the development of professional standards relating to the Oregon Death with Dignity Act that will protect vulnerable persons; set standards for quality care of the dying; and respect the values and privacy of persons in need of care, health care professionals, and health care systems.

Develop and coordinate educational resources on all aspects of the competent and compassionate care of terminally ill patients for the health care community and the general public.

Foster relationships and networking on issues related to compassionate care of the terminally ill.

Some aspects of improving the care of dying Oregonians are beyond the scope of this Task Force. For example, a terminally ill patient may not have access to adequate comfort care resources. To provide a means for obtaining a prescription under the Oregon Act without access to comfort care may place undue pressure on a patient and his/her family. The Task Force strongly endorses universal access to hospice care in Oregon. We encourage public policymakers to develop methods and funding to assure that all Oregonians have access to comfort care resources such as hospice in the final months of life.

About the Guidebook

Without endorsing or opposing the principles embodied in the Oregon Death with Dignity Act, the Task Force has developed this Guidebook for Health Care Professionals as a collective response to its enactment. We designed the Guidebook to be a useful resource for health care professionals and institutions as they contemplate the Oregon Act's implications for practice. Underlying this work is the assumption that regardless of the health care professional's personal view regarding the Oregon Act, open communication, consideration of comfort needs, and respect for divergent views are necessary components of care. We present ethical and practical guidelines to enhance compassionate care whether or not a physician or health care system is willing to participate in providing a prescription as set forth in the Oregon Act.

We developed the Guidebook originally through discussion and debate, followed by identification of issues and consensus development in Task Force meetings. Individual Task Force members researched and drafted chapters, which were then reviewed by the entire group and revised to reflect group consensus. Organizations represented on the Task Force and other interested parties were asked to review and comment on the final draft of the first edition of the Guidebook. The Guidebook is revised by Task Force consensus periodically to remain current with ethical standards, the law, and clinical practice. Participation by any professional organization, including the Center for Ethics, does not constitute an endorsement of this document, nor does it indicate a particular viewpoint about the Oregon Death with Dignity Act. Publication of this document is not our only responsibility.

We recognize the controversy regarding terms to describe the provisions under the Oregon Death with Dignity Act. "Physician-assisted suicide" or "physician-assisted death" are terms used in the medical and bioethics literature to refer to a physician providing information or the means for a patient to end his/her own life. The Oregon Act specifically states that the ingestion of a lethal dose of medication under the Oregon Act is not considered suicide. To comply with statutory definitions, the Oregon Department of Human Services no longer uses the term "physician-assisted suicide" to describe the practice. In this Guidebook, we use the terms "the Oregon Death with Dignity Act" or "ODDA" or "the Oregon Act" to refer to the provisions under Oregon law.

How to Use the Guidebook

In creating a new legal option for terminally ill patients, the Oregon Death with Dignity Act has added a new dimension to medical practice. This Guidebook was designed to be a comprehensive reference book on all aspects of putting the Oregon Act into practice. Some users may wish to read it from beginning to end, while others will prefer to skip to chapters that interest them. Because each chapter can stand alone, some ideas appear in more than one chapter. Wherever possible, we have used cross-referencing to direct the reader to more in-depth discussions of ideas in other chapters.

Each chapter begins with a philosophy section, followed by guidelines and references. Longer chapters have headings to direct the reader. The references are of two types: some are footnotes found in the text of the chapter; others are resources suggested for follow-up or additional reading. The guidelines are recommendations for practice based on Task Force consensus. We recognize that many patients who request a prescription as set forth in the Oregon Act will never receive a prescription.[1,2,3] Of those who do receive a prescription, a significant number never take it and die of their underlying condition. We also acknowledge that health systems and physicians will have differing views about the acceptability of providing such a prescription and about the appropriate degree of involvement. Our intent in developing the Guidebook has been to carefully think through scenarios in detail and to recommend actions that will optimize care and minimize harm, no matter where the health care professional sets the limit of involvement along the spectrum of possible scenarios. In our discussions we go beyond the letter of the law because the attending physician is the health care professional who is most intimately involved with the patient at this time and who has the greatest responsibility under the Oregon Act. This is an attempt to envision how the Oregon Act should be implemented in practice.

The Oregon Revised Statute citation of the Oregon Death with Dignity Act, hereafter referred to as the Oregon Act or ODDA, is not given each time it is mentioned in the text. The full text of the Oregon Act can be found in Appendix A, *The Oregon Death with Dignity Act.* Throughout the guidebook, we refer to Oregon Revised Statute as ORS and Oregon Administrative Rules as OAR.

Another Task Force project, *The Final Months of Life: A Guide to Oregon Resources,* is available on the Center for Ethics web site.

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Acknowledgments

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2. The Meaning Behind the Patient's Request

Written February 1998; Revised: October 2004, March 2005, September 2007, December 2008

This chapter has been written primarily for the attending physician who has the initial discussion with a patient who requests a lethal dose of medication. However, it is applicable to others who may be involved in the care of a terminally ill person who requests a prescription under the Oregon Death with Dignity Act. For example, when surveyed almost two thirds of hospice nurses and social workers in Oregon reported having at least one patient ask them about the option during the previous year.[1]

Complex questions of motivation on the part of the patient and health care professionals arise when a patient begins this discussion. The patient's choices may involve an interactive set of factors that include the patient's religion, the doctor-patient relationship, perceptions of quality of life, and other psychosocial circumstances.[2] A health care professional may be motivated by compassion for the patient, feelings about participating in the Oregon Death with Dignity Act, or moral and religious beliefs, when considering how to respond. Whether or not a health care professional chooses to participate, he/she has an obligation to openly discuss the patient's concerns, unmet needs, feelings, and desires about the dying process. The physician and patient should explore each of these issues in depth. Open communication is a vital part of any end-of-life decision making.

Supportive communication will help patients with life-threatening illnesses make informed decisions about end-of-life care including advance directives, do-not-resuscitate orders, completion of a POLST form, hospice or palliative care, and other options. Only by appreciating the range of available options for end-of-life care can a patient make rational choices about the dying process. The patient may initiate a discussion in the context of these issues. If the patient asks about the Oregon Death with Dignity Act the attending physician should assess the patient's understanding of his/her illness, motivations, and desires.

The American Medical Association (AMA) has recommended that regardless of a physician's moral views on responding to a patient's request for a lethal dose of medication, the physician has an obligation to explore the meaning behind the question with the patient and provide reassurance that the patient will not be abandoned, nor symptoms left untreated, during the dying process.[3,4] Learning the meaning behind the patient's question and attempting to respond to the patient's concerns can be a potent therapeutic intervention.[5] Most patients who initially consider obtaining a lethal dose of medication do not persist with their requests when they feel their concerns are effectively addressed.[6] While approximately one out of 1,000 dying Oregonians obtain and use a lethal dose of medication, 17% personally considered it as an option.[7]

Although requests for a lethal dose of medication are often attributed to uncontrolled pain, research has shown that other physical symptoms, as well as psychological or existential distress, may be equally or more important (see *Mental Health Consultation*). For some patients, unresolved prior loss, feelings of frustration and hopelessness, or perceived lack of support from loved ones may produce anxiety or depression. It has been said that terminally ill patients who are used to being in control may be particularly prone to difficulties during this time. Existential issues like futility, meaninglessness, disappointment, remorse, death anxiety, or a disturbed sense of personal identity can contribute to a patient's suffering.[8] A study of patients in Oregon and Washington with ALS found that hopelessness was a factor in considering making a request under the Oregon Death with Dignity Act .[9] In 1999, physicians in Oregon reported that the most common reasons patients made requests for a lethal dose of medication were loss of independence, poor quality of life, and because they feel ready to die and have a desire to control the circumstances of death. Pain and other physical symptoms counted as less than half.[10] According to the second year report on the Oregon Death with Dignity Act from the Oregon Department of Human Services - Health Division, family members reported that a loved one requested a lethal dose of medication for several reasons, including loss of autonomy, loss of control of bodily functions, an inability to participate in activities that make life enjoyable, and a determination to control the manner of death.[11] These findings have remained consistent. According to the 2007 State Health Division report on Oregon's Death with Dignity Act, the most commonly reported concerns were decreasing ability to participate in activities that make life enjoyable (86%), losing autonomy (100%) and loss of dignity (86%).[12] All these studies suggest that the reasons for making a request are complex, not simply a matter of symptom control.

In addition to probing the patient's issues, the attending physician needs to contemplate his/her own motivations and beliefs. He/she will have emotional reactions and will need to consider the personal consequences of agreeing to provide a lethal dose of medication. The attending physician's beliefs about death and the meaning of pain and suffering are likely to impact how he/she interacts with patients and presents care options (see *Attending Physician and Consulting Physician*). Health care professionals need to explore their own attitudes about suffering. From this introspection, they can develop their own perspectives on care of the dying. Their beliefs will be transferred to their care of patients.[13]

In deciding how to proceed, physicians must act in ways that are consistent with their personal beliefs and respectful of the health system in which they practice, while still respecting the beliefs of the patient (see *Conscientious Practice*). After exploring the issues and alternatives, some health care professionals will choose to honor the patient's request. Others will decide that participating in the Oregon Death with Dignity Act violates their moral or professional code or their institutional mission. Some physicians who may agree with the Oregon Act philosophically may decide against participating with a particular patient or a particular set of circumstances. Currently, Oregon physicians explore interventions to relieve suffering when patients request a lethal dose of medication, and in the many cases the patients do not continue to pursue the request.[6,7,9]

Guidelines

2.1 When a patient asks about the Oregon Death with Dignity Act, the health care professional's initial response should be to explore the meaning behind the question, regardless of his/her personal views or willingness to participate. Loss of control, abandonment, financial hardship, burden to others, and personal or moral beliefs may be areas of concern to many patients.

2.2 The attending physician should seek to understand what constitutes unacceptable suffering in the patient's view. Pain, other physical symptoms, psychological distress, and existential crisis are potential causes of suffering.

2.3 The attending physician has an obligation to explore treatment for symptoms for which there are treatment options available. This includes hospice, psychological support, and other palliative care.

2.4 The attending physician should reflect on his/her own beliefs and motivations and the policies of the health care system, and consider the impact of those motivations on decision-making with patients near the end of life.

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3. Conscientious Practice

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The issue of obtaining a prescription for the purpose of ending life raises many ethical considerations and generates great differences of opinion, touching on questions and values rooted in philosophy, religion, and morality. The rights of patients and their surrogates to participate in medical decision-making is a firm principle in American bioethics. Because patients may make choices that challenge or conflict with the ethical codes or moral values of health professionals who care for them, it becomes necessary to state the principles of conscientious practice and how they apply to the Oregon Death with Dignity Act.

Conscientious practice applies to both participants and non-participants in the Oregon Death with Dignity Act. Physicians, other health care professionals, and health care systems have deeply-held values regarding end-of-life issues. It is important to recognize the rights of persons with conflicting views. Conscientious practice is the action that comes of respecting one's own moral beliefs while at the same time respecting the moral beliefs of others.

Conscientious objection arises from the concept that people are not obligated to perform acts that violate their conscience, even if the acts are legally or professionally sanctioned. Conscientious objection by health care professionals is a principle that is upheld by professional codes of ethics, for example, the refusal of a nurse to participate in an abortion done in a hospital. The Oregon Death with Dignity Act endorses conscientious practice and respect by stating unequivocally "No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his/her life in a humane and dignified manner."[1]

Sometimes patients' and health care professionals' rights directly conflict with each other under the Oregon Act. The patient's right to privacy may conflict with the rights of health care professionals to make informed personal decisions. This applies particularly to emergency personnel who may not have access to information about a patient's wishes but who have to make resuscitation decisions quickly (see ***Emergency Department and Emergency Medical Services***). In this chapter, we examine some of the potential conflicts and, where possible, offer suggestions for resolution.

Patients have the right to information regarding their conditions and treatment options. When a patient asks about obtaining a prescription as set forth in the Oregon Act, the attending physician may give information about this option. The attending physician has no responsibility under the Oregon Act to initiate a discussion about obtaining a prescription. Whether the attending physician should initiate this conversation when discussing options is not discussed in the Oregon Act, and is left up to the individual health care professional. We believe that the attending physician should not initiate the discussion, because if he/she does, the patient may feel pressured, even though obtaining a prescription under the Oregon Act is a legally available option.

An individual health care professional, such as a physician or a hospice nurse, who is opposed to the Oregon Death with Dignity Act, may want to refrain from discussing it with an inquiring patient. However, the desire to avoid discussion of what is morally reprehensible to the health care professional may prematurely stifle discussion of the patient's overall needs. The Council on Ethical and Judicial Affairs of the American Medical Association, in its 1992 report, "Decisions Near the End of Life," urges physicians to examine "the needs behind the demand" for an active end to life. "The existence of patients who find their situations so unbearable that they request help from their physicians to die must be acknowledged, and the concerns of these patients must be a primary focus of medicine."[2] An AMA report issued two years later states: "Requests for physician-assisted suicide should be a signal to the physician that the patient's needs are unmet and further evaluation to identify the elements contributing to the patient's suffering is necessary. Multidisciplinary intervention, including specialty consultation, pastoral care, family counseling and other modalities, should be sought as clinically indicated."[3]

Through open communication with the patient, the health care professional may discover a true difference in values regarding this aspect of end-of-life care. Exploring these differences at the time the patient initially requests a prescription under the Oregon Act may prevent difficult time-pressured decisions and actions later. The health care professional can work with the patient to find an agreeable course of action; sometimes this means the patient must find another provider. The health care professional may decline to help in finding a new professional as part of his/her conscientious practice; however, he/she may not obstruct the change (for physicians, see *Attending Physician and Consulting Physician*). It bears emphasizing that if the health care professional cannot accommodate the patient's desire for a prescription under the Oregon Act, he/she must try to meet the other needs of the patient while transfer of care is being arranged.

All health care professionals have a right to know whether their care of patients involves actions that would be morally objectionable for them. This applies to all health care professionals, including hospice nurses and pharmacists, who have rights to be knowing participants. Nevertheless, attending physicians must respect the confidentiality of the patient's request unless otherwise waived (see *Liability and Negligence*).

Like health care professionals, institutions and health care systems also have the right to refuse to participate in the Oregon Death with Dignity Act. This right was further defined in the 1999 legislative revision of the Oregon Act, permitting health care systems to impose certain restrictions and sanctions on health care professionals assuming that the professionals are notified first of that policy (see *The Oregon Death with Dignity Act*). Institutional refusal may create conflicts for both patients and health care professionals. An attending physician may wish to provide a prescription for an eligible patient under the Oregon Act but be prohibited from doing so by the institution or system. In such an instance, his/her responsibility to the system conflicts with responsibility to the patient. The physician may also be limited in his/her ability to refer the patient to another physician for continuity of care if the patient's health care system doesn't participate in the Oregon Death with Dignity Act or restricts referrals (see *Attending Physician and Consulting Physician*). Systems that choose not to participate in the Oregon Act should notify patients and health care professionals in advance. It may also be important for institutions to inform prospective employees about policies that might influence their desire for employment.

The health care institution has certain obligations to patients, such as ensuring continuity of care and fulfilling medical needs. For a patient who chooses to participate in the Oregon Death with Dignity Act, there are many possible interactions with the system: relationships with the attending physician, the consulting physician, the psychiatrist or psychologist, the pharmacist, and the hospice staff (see *The Role of Other Health Care Professionals*). Only rarely would someone be an inpatient at the time the prescription is self-administered, making interactions with hospital nursing staff and other support staff likely.

Systems and institutions need to communicate expectations to employees about the care of a patient who chooses to take a lethal dose of medication as set forth in the Oregon Act and develop plans to ensure continuity of care in the event of conscientious objection by a staff member. Although most patients will choose to take the medication in the privacy of a home, if a patient is in a hospice or other health care facility, employees should be expected to provide for the patient's other care needs or arrange transfer of care in an appropriate manner. Difficulty transferring from a health care professional unwilling to participate in the Oregon Act to another who is willing may be compounded when the system itself is opposed to participation in the Oregon Death with Dignity Act. Health care systems may need to consider transfers between systems to maintain conscientious practice.

To date, financial issues have not been identified as a primary factor in patients' requests for prescriptions pursuant to the Oregon Act.[4,5]

Health care systems may want to develop multidisciplinary forums that would allow staff members to voice concerns about controversial procedures and practices. Systems will also need to develop processes for resolution of conflicts. The hospital ethics committee or system ethics resource may be the most obvious forum for conflict resolution and discussion of the Oregon Act.

The Oregon Death with Dignity Act is controversial in our society; therefore concern for the privacy of the people in situations involving a terminally ill patient's request for a prescription under the Oregon Act is critical. Privacy of patients, families, and health care professionals must be respected so that decisions can be made without threat of harassment or intimidation.

Guidelines

3.1 Conscientious practice refers to taking professional actions that are consistent with one's moral and ethical beliefs and avoiding actions that are contrary to one's beliefs.

3.2 Health care workers, institutions, and systems have the right to refuse to participate in the Oregon Death with Dignity Act.

3.3 Systems that elect not to participate in the Oregon Death with Dignity Act should notify patients and health care professionals in advance.

3.4 Health care systems and health care professionals need to develop guidelines to ensure continuity of patient care should the system or health care professional be unwilling or unable to participate in the Oregon Act. Skilled and humane care should be provided until transfer of care is complete, so that abandonment does not occur.

3.5 Expectations about care of the patient who chooses to participate in the Oregon Act need to be communicated to employees so that continuity of care can be maintained. Although taking the lethal dose of medication would usually occur in the privacy of a home, if a patient is in a hospice or other health care facility, employees should be expected to provide for the patient's other care needs or arrange transfer of care in an appropriate manner.

3.6 Health care systems need to develop a process for the resolution of conflicts.

3.7 Patients and health professionals have the right to privacy and freedom from harassment or intimidation, whether they choose to participate in the Oregon Death with Dignity Act or not.

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4. Hospice, Palliative Care, and Comfort Care

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Hospice enrollment of persons who ingested lethal medication under the Oregon Act increased to 88% in 2007, from 76% in 2006, the lowest rate since 1998. . Pain or fear of pain decreased to 33%, from 48% in 2006, the highest rate. Between 1997 and 2005, 87% of those who used a lethal dose of medication were enrolled in hospice, and pain or fear of pain, at 22%, was not considered a major factor.[1] This observation leads the Task Force to reaffirm its recommendation of referrals to hospice for persons who are interested in a prescription under the Oregon Death with Dignity Act, or any other end-of-life option, if they are not already receiving hospice or palliative care services. Oregon hospices respect the right of dying Oregonians to choose legal end-of-life options. The high quality of hospice and palliative care in Oregon is offered as one explanation for the low number of deaths under the Oregon Act.[2]

Persons in their final months of life have a variety of needs, including comfort, family support and counseling. Most benefit from care or consultation with an interdisciplinary group such as hospice or palliative care teams. The physician has an ethical obligation to explore and offer such options, and a legal obligation to offer alternatives when a patient no longer responds to other treatment or requests a prescription for medication to end his/her life. Health care professionals should know about hospice and palliative care, as well as other end-of-life options. When concerns are identified and addressed, patients are less likely to ask for or use a prescription under the Oregon Act.[3]

Hospice, palliative care and comfort care are defined separately in state and federal laws governing health care benefits and reimbursement. This chapter provides a brief overview of these services and benefits and how to access them.

Palliative care and "comfort care", as defined under the Oregon Health Plan, are medical and related services designed to alleviate pain and other symptoms. Hospice is a coordinated group of services that focus on comfort measures and palliative care and is available to a patient/family/caregiver during the dying process and bereavement. Hospice, palliative care and comfort care for the terminally ill are available throughout Oregon.

Hospice

Hospice is a coordinated program of care across all settings that utilizes an interdisciplinary team to provide palliative care and other support to a patient and family.[4] Hospice establishes pain and symptom control as an appropriate clinical goal. The hospice plan of care is developed by a team comprised of the patient's attending physician/nurse practitioner/clinician, and the hospice medical director/physician, nurse practitioner, nurse, social worker and spiritual or other counselor. Other team members include home health aides, therapists, dietitians, bereavement counselors and respite volunteers. Patients, family members and caregivers participate in developing and implementing the plan of care, choosing those hospice services most appropriate or desirable. Providing support for the family is a key advantage of hospice. Patients enrolled in hospice have access to hospice personnel 24 hours a day, seven days a week, for telephone advice or home visits. All hospice patients receive a psychosocial evaluation from a social worker and psychosocial issues are monitored by the hospice team. A psychosocial evaluation will assess for mood disorders and allow screening for patients appropriate for further evaluation by a mental health professional, as required under the Oregon Act. A new study recommends more thorough examination for depression among those requesting a lethal dose of medication under the Oregon Act.[5]

Hospice offers support or respite for the primary caregiver on an intermittent basis, but it does not routinely provide substitute caregivers. Some patients are able to manage their care without a primary caregiver, especially during the earlier stages of their illness, and some patients are willing to risk safety for independence. Others will reconsider living arrangements as the disease progresses, accepting or hiring a caregiver or moving. Sometimes all that is needed is a neighbor or relative or hospice volunteer to look in on a patient on a regular basis. The costs of substitute caregivers may be covered by a long-term care or custodial care benefit or carved out of a hospital benefit.

The hospice team manages the patient's care across all settings, admitting patients to an inpatient facility when necessary for acute or respite care. More than 92% of hospice care is provided in the patient's home or place of residence. Hospice teams care for patients who live in nursing facilities, residential or assisted care facilities, foster homes, and residential and inpatient hospices. Approximately 2% of hospice patients in Oregon die in a hospital.[6]

Palliative Care

Palliative care, a newly recognized medical subspecialty, focuses on reducing or abating physical and other symptoms of an illness or condition. The goals of palliative therapy are to achieve comfort, to manage symptoms and to improve quality of life. Palliative care benefits may be covered by health plans, sometimes on a case-by-case basis.

Palliative care services, as separate from hospice services, are provided by inpatient palliative care teams palliative care specialists and hospices. Palliative care services may be provided by independently defined or incorporated "palliative care programs."

Comfort Care

Comfort care is a benefit of the Oregon Health Plan. Comfort care includes hospice, palliative care, and services under the Oregon Death with Dignity Act. It is not limited to care provided through a hospice program. Comfort care, in this context, does not include diagnosis or cure-oriented treatment or active treatment intended to prolong life.[7]

Hospice, Palliative Care, and Comfort Care Benefit Plans

Hospice is a covered benefit under the Medicare Hospice Benefit, the Oregon Health Plan, CHAMPUS (Civilian Health And Medical Program of the Uniformed Services), the Department of Veteran Affairs, and private and employee health insurance plans. Hospice is most often reimbursed on a per diem basis. Attending and consulting physicians are reimbursed for medical services and oversight. The hospice benefit usually covers the costs of all medical and other services related to the terminal illness, including drugs, biologicals and inpatient admissions, although the patient may be asked to make a small co-payment. The savings in out-of-pocket expenses to patients and their families can be considerable. Bereavement services following the death of the patient are also covered.

Hospices in Oregon may practice "open access", broadening admission criteria to include persons who are receiving or considering treatment or medication that may have the effect of prolonging life.[8]

The Task Force to Improve the Care of Terminally-Ill Oregonians supports universal access to hospice and comfort care. We support public policies that would 1) expand the Oregon Health Plan's Hospice Benefit to cover uninsured or underinsured Oregonians, usually the working poor, and 2) ensure that health plans offered in Oregon include a comprehensive hospice benefit for the last months of life.

Medicare Hospice Benefit The Medicare Hospice Benefit is available to qualified patients eligible for Medicare Part A. The patient may choose any Medicare-certified hospice. Patients who elect the Medicare Hospice Benefit have access to medical services not related to their terminal diagnosis through their regular Medicare Part A, B, and D coverage or MedAdvantage plan, as long as premiums are paid. The Medicare Hospice Benefit is independent of any MedAdvantage, health maintenance organization (HMO) or Medicare supplemental health plan.

Medicare does not offer a defined palliative care benefit. Medicare managed care plans may, however, cover palliative care services.

Oregon Health Plan The Oregon Health Plan's Hospice Benefit mirrors the Medicare Hospice Benefit and is available to OHP Standard and Plus clients who have a terminal illness or condition. Qualified clients also have access to a "comfort care benefit" or palliative care on a fee-for-service basis. Hospice services must be provided by a hospice listed on the State of Oregon's Hospice Registry. Comfort care services may be provided by a hospice or other qualified individuals or agencies.

Other Health Plans Most private and employee health plans offer a comprehensive hospice benefit of coordinated services and reimburse the hospice on a per diem basis. Under Oregon law, a hospice benefit may not exclude or limit core hospice services. Some health plans will create a hospice benefit for their terminally ill clients, if not otherwise covered, out of unused skilled nursing, hospitalization, or custodial care benefits. Most health plans offer or will consider comfort care or palliative care benefits for their clients who are undergoing life-prolonging treatment, whose estimated life expectancy is longer than six months, or whose prognosis is still unpredictable.

Private Pay or Uninsured Patients Hospices generally use a sliding fee scale to bill for services and provide services without regard to a patient's ability to pay.

Eligibility

Individuals are eligible for hospice and comfort care, under the Oregon Health Plan's Medicaid Demonstration Project, and for hospice, under the Medicare Hospice Benefit and most health plans, when estimated life expectancy, in the physician's judgment, is less than six months, if the disease follows its natural course.[9] Medicare services must be medically necessary. Local coverage determinations (LCDs) have been formally adopted by fiscal intermediaries under CMS (Centers for Medicare and Medicaid Services) to specify clinical criteria for establishing a patient's six-month prognosis. LCDs may be used as a guideline, but clinical judgment is a more important factor. Persons who elect comfort care or hospice under Medicaid, Medicare, and most health plans, will be required to waive coverage for other treatment related to the terminal diagnosis. Election statements include acknowledgment by the patient of the palliative nature of care.

Making Referrals to Hospice

Referrals to hospice should be timely. The attending physician, if a patient has one, and the hospice medical director or physician must certify that, in their judgment, the patient has a life expectancy of six months or less, if the disease follows its normal course. If prognosis is uncertain, hospices will make an assessment. Hospice physicians are also available to make visits to provide information about hospice. Recertification is required periodically throughout the illness. Patients whose condition stabilizes or improves may no longer meet eligibility requirements. Patients who are discharged or who revoke a hospice benefit during any certification period are immediately eligible for any remaining benefit periods. The hospice medical director or physician may act as a patient's attending physician. Under state and federal law, a hospice patient's "attending physician" includes nurse practitioners. However, nurse practitioners may not certify or recertify a terminal prognosis.

Preparing Patients for Hospice

An early and frank discussion between doctor and patient about the disease and its expected outcomes allows a patient to make informed end-of-life decisions when treatment for cure or remission is questionable. Informal surveys at support group meetings of people with life-threatening illnesses suggest that possible death is a common thought at the time of diagnosis and may be an opportune time to have a brief conversation about what a patient will want to know. When physicians dismiss comments about death, they may inadvertently create barriers to future discussions and timely referrals to hospice and palliative care.

Oregon Health and Science University's palliative care team is finding that open and honest discussions about end-of-life options are of great value in the decision-making process.[10] A one-time physician consultation about end-of-life options is available through hospices. Hospice teams may make assessments related to prognoses. CMS considers the prognosis an estimate, based on the clinical judgment of the attending physician and the hospice medical director. A referral to hospice is a "win-win" proposition: a patient can revoke a hospice benefit at any time, if he/she changes his/her mind; and a patient will be discharged, if he/she is no longer has a limited prognosis.

"Why didn't we have hospice sooner?" is the most common complaint of hospice patients and families. The median length of stay in an Oregon hospice program, the time between admission and death, was 18days in 2007. Most hospice benefits are unlimited; it is not true that patients are discharged because they live longer than six months. *Hospice Care: A Physician's Guide,* is available at the *Oregon Hospice Association* website.[11]

Hospice, DNR Orders, and POLST Orders

Do-not-resuscitate (DNR) orders are not required for hospice patients. All hospices in Oregon use Physician Orders for Life-Sustaining Treatment (*POLST*) forms, and options are not limited to comfort measures.[12] A hospice plan of care, however, is not likely to include emergency calls and intensive care unit (ICU) admissions. Unless an emergency is unrelated to the terminal illness and otherwise covered by insurance, patients and families may have to assume costs associated with a call to 9-1-1.

Hospice, the Oregon Death with Dignity Act, and Other End-of-Life Options

Options for terminally ill Oregonians include hospice, palliative care, comfort care, pain management, the right to refuse or withdraw treatment, and the right to request a prescription for medication to end life.

Hospice respects and supports a patient's right to choose any or all legal options. Oregon's hospices will not refuse to admit or care for a patient or deny support to a patient's family because the patient intends to end his/her life under the Oregon Death with Dignity Act. Hospice policies differ in the extent of involvement, and some hospices allow employees to be at the bedside of a patient when a lethal dose of medication is self-administered. Other programs provide all aspects of hospice care, but ask staff to leave the room when a lethal dose of medication is taken. The Oregon Hospice Association and Oregon's hospice professionals recommend and encourage referrals and admissions to hospice during the fifteen-day waiting period following a request for a prescription or at any time before the medication is self-administered, if the patient is not already enrolled in hospice.[13]

Hospice philosophy seeks to neither hasten death nor prolong life, but hospices support the aggressive treatment of symptoms even if medication or other treatment may inadvertently affect the course of the disease. Comfort measures, such as good pain control, blood transfusions, or short-course radiation, may have the effect of prolonging life. Others, such as sedation or general anesthesia for severe pain and symptoms, may hasten a patient's death. Patients who are especially concerned about distressing symptoms may be comforted to know that sedation to unconsciousness is a treatment option.[14]

The Task Force is concerned that federal attempts to prohibit the use of controlled substances under the Oregon Death with Dignity Act may have a negative impact on pain and symptom management at the end of life. Regulatory scrutiny is a factor in physician reluctance to prescribe pain medications, even if necessary to control symptoms.

Hospices have developed guidelines to support patients who choose to discontinue nutrition and hydration as a means of hastening death. Patients should be informed of their right to refuse nutrition and hydration when complying with the informed decision provision of the Oregon Death with Dignity Act. Stopping nutrition and hydration may be an option for patients who are unable to self-administer medication.[15]

The *Oregon Hospice Association* has chosen to serve as a resource for honest and open communication about all of Oregon's legal end-of-life options. Because the Oregon Death with Dignity Act is currently a legally available option in Oregon, the Oregon Hospice Association has developed a bulletin that introduces the Oregon Act in the context of other end-of-life options to help facilitate conversations.[16]

Guidelines

4.1 The Task Force encourages physicians to talk to patients about the medical outlook and the possibility of hospice and palliative care early in the course of a life-threatening illness. Physicians may assist patients and their families in meeting with a hospice or palliative care team as early as possible for information, if not for referral, should the disease progress. Most patients and families are comforted by knowing what support will be available if the disease cannot be controlled, but may need encouragement to take these steps.

4.2 Physicians should become familiar with hospice and palliative care resources in their communities. Physicians can contact the Oregon Hospice Association, (888) 229-2104 or at info@oregonhospice.org. Oregon's Hospice Registry is located at *Oregon Hospice Association*. The Oregon Hospice Association keeps the Registry on behalf of the State of Oregon. A comprehensive list of resources is available.

4.3 Physicians should complete the necessary documents of admission as soon as possible after a patient decides to enter a hospice program. Hospices can begin providing services on the day of referral and complete the admission process within 24 hours.

4.4 Hospices encourage attending physicians to manage their patient's care after admission to hospice. If a physician chooses not to do so, he/she may refer the patient to the hospice medical director or another palliative care or hospice physician or clinician. Medical directors of hospice programs are a resource available to attending physicians of hospice patients.

4.5 If a patient decides not to enroll in hospice or other palliative care program, we strongly recommend that the physician ensure that necessary care is provided from another source. As the patient's needs change, the physician is encouraged to explore again the prospect of hospice care.

4.6 When a patient requests a prescription to end his/her life, the Oregon Death with Dignity Act requires physicians to inform patients of feasible alternatives, such as hospice admission or comfort care consultation, if the patient is not already enrolled in a hospice program. Both patients and their families will benefit from hospice support during the required waiting period.

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Website Resources

Oregon Hospice Association

National Hospice and Palliative Care Organization

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5. Patient Rights and Responsibilities

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Health care systems, health plans, health care professionals, and institutions recognize the mutual responsibilities in the partnership as health care professionals and patients. Understanding these mutual commitments is essential for respecting the dignity of each patient, the integrity of each health care professional, and the core values of the institution. In this chapter we will review patients' rights and responsibilities under current standards of practice, then those specific to the Oregon Death with Dignity Act.

Health professionals have a duty to provide considerate and respectful care and to treat patients with dignity at all times. Patients have the right to receive information about their care and to have questions answered honestly. Patients, within the context of their primary relationships, are the principle decision-makers concerning their own health care. The process by which a competent patient agrees to or refuses medical intervention is called informed consent. Health care professionals must give a patient, in a manner the patient can readily understand, material information about his/her diagnosis, the course of a disease process, prognosis, treatment options, expected outcomes, possible complications, and the consequences of refusal in order for the patient to be able to give informed consent. In order to make truly informed decisions about care, patients also need the freedom to explore feelings and spiritual needs in an environment that shows respect for their ethnic, cultural, or religious values. Health care systems have a duty to promote that freedom by providing supportive social work services, counseling services, and spiritual/pastoral services that will enhance patients' decision-making.

Patients have a right to expect that the confidentiality of their health care history will be respected by their caregivers and health care institutions to the extent provided by law. Confidentiality applies to communications and medical records.

In those rare instances when a physician believes that a patient's refusal to divulge information to a third party puts that party at risk for serious harm, the physician should seek legal and ethical advice to determine if the sharing of information with that party, even without the consent of the patient, is legally or ethically permissible or required. If the physician feels that he/she has a personal duty to protect some third party that is not recognized by the law, it can in some instances be permissible for that physician to exercise a degree of influence to persuade the patient to divulge information or to give permission to the physician to divulge it. A physician should never coerce the patient to divulge such information, even if ultimately the physician feels ethically obligated to do so himself/herself.

Patients have the responsibility to communicate their medical history and treatment goals, stressors, fears, and needs as completely and accurately as possible. They are responsible for letting health care professionals know when they have unrelieved pain, distressing symptoms, and/or suffering so that the health care professionals can promptly evaluate and treat them.

Patients are responsible for voicing their concerns about treatment goals or procedures and informing their physicians if they cannot or will not follow a treatment plan. Although patients do not have to explain or justify themselves to their physician, doing so may be helpful to finding an alternative approach or promoting the quality of the physician/patient relationship. Patients and their health care professionals have a responsibility to engage in some form of advance care planning so that, in the event the patient should become unable to make decisions for him/herself, health care professionals will have guidance as to how to proceed. A patient may do this by executing an advance directive for health care and/or name a health care representative to make decisions as provided under Oregon law. Patients who choose not to execute such decisions should be aware of the surrogate law in Oregon so that they will know who, in the absence of an advance directive or health care representative, will be making their care decisions for them.

Patients facing the end of their life especially should have access to a compassionate, knowledgeable, interdisciplinary team that is committed to understanding their needs. In addition, consultation with hospice, supportive care, or palliative care teams may enhance the comfort of both the patient and loved ones (see *Hospice, Palliative Care, and Comfort Care*).

Patients often need help from and for their significant others in accepting death. They should be given the opportunity to die in peace and in a setting reflecting their dignity, and not with the sense that they are alone. Meaningful presence, generous hospitality, and faithful companionship are essential. Oregon law[1], as well as traditional principles in health care ethics, requires that patients from whom life-sustaining procedures or artificially administered nutrition and hydration are withheld or withdrawn shall be provided humane care to ensure comfort and cleanliness. "Medication, positioning, warmth, appropriate lighting and other measures to relieve pain and suffering" are listed as essential elements of compassionate and skilled care in Oregon's 1993 advance directive statute.[2]

The Oregon Death with Dignity Act makes specific reference to rights and responsibilities within the patient and health care professional partnership. Health care professionals have a duty to give patients honest and accurate prognostic information while respecting cultural values. Patients have a right to know if they have a life-threatening illness that will probably result in death within six months because they may wish to make personal plans, seek hospice benefits, or request a prescription for a lethal dose of medication as set forth in the Oregon Act. An eligible patient who desires a lethal dose of medication must make two oral requests and, after a 15-day waiting period, one written request for the medications (see Appendix A, *The Oregon Death with Dignity Act*).

Patients have a right to know whether their health care professionals are willing to participate in the Oregon Death with Dignity Act and provisions under the Oregon Act are allowed in their health care system (see *Conscientious Practice*). Patients have a right to know any limitations of their health insurance plan with regard to the Oregon Death with Dignity Act and any potential conflicts of interest that may impact decisions about care. Patients need also to respect the integrity of their health care professionals and the institutions where they access care. Oregon law allows individuals, insurance plans, and institutions or systems to exercise a right not to participate in the Oregon Act. Oregon law does not consider referral by one physician who chooses not to participate in the Oregon Death with Dignity Act to one who will to constitute participation in the Oregon Act, although it does not require a physician to do so. Similarly, the law does not require insurance companies to consider the Oregon Act as a covered benefit. Both physicians and patients have a responsibility to be aware and respectful of each other's personal convictions and the institutional policies that may apply to them.

Eligible patients who choose to request a prescription under the Oregon Act have a responsibility to consider the needs of health care professionals other than the attending physician involved in their care (see *The Role of Other Health Care Professionals* and *Emergency Department and Emergency Medical Services*). This is necessary to ensure conscientious practice and to prevent unexpected problems, such as an uninformed emergency medical technician (EMT) attempting resuscitation after finding the patient comatose following taking the lethal dose of medication. If the patient is unwilling to inform a health care professional, he/she should consider terminating the relationship.

When the Oregon Death with Dignity Act is the reason for a change of physician, the physician, health care system, or health plan may decline to help in finding a new physician as part of their conscientious practice. They may not, however, obstruct the change. The health care professional must continue to offer humane and skilled care until the transfer is complete (see *Conscientious Practice*).

Guidelines

5.1 Patients have the right to all material information about their medical condition and prognosis in order to be able to make informed decisions about treatment.

5.2 Patients have a right to be told if they have a life-threatening illness that will probably result in death within six months so that they can make personal plans, which may include seeking hospice care or requesting a prescription under the Oregon Act.*

5.3 Patients have a right to know whether or not their health care professional, insurance plan, or system will participate in or support the Oregon Death with Dignity Act, and a responsibility to be respectful of the convictions that underlie those policies.

5.4 Patients who plan to take a prescription obtained under the Oregon Act have a responsibility to consider the needs of family and health care professionals other than the attending physician to respect conscientious practice and to prevent unexpected problems.

5.5 If a patient seeks to change physicians in order to obtain a prescription under the Oregon Act, the transferring physician must continue to offer humane and skilled care until the transfer is complete.

** Not all cultures have the same appreciation for direct information regarding diagnosis and prognosis, so this "right to be told" will often need to be nuanced with cultural sensitivity.*

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6. Family Needs and Concerns

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Patients exist in a complex social network that includes family, friends, and other intimate relationships. These relationships provide the support and foundation for the patient's values, beliefs, and priorities, and often empower the patient to exercise autonomy. Because some patients' closest relationships are with friends, not members of their biological family, we use the term "family" broadly to include spouse, significant other, children, close friends, and other intimate relations.

The number of patients who personally consider the option of the Oregon Death with Dignity Act and talk with family about the option is far greater than the number of those who ultimately take a lethal dose of medication under the Oregon Act.[1] Seventeen percent of terminally ill persons at some point consider taking a lethal dose of medication, while one person in a thousand ultimately takes the medication as prescribed under the Oregon Death with Dignity Act.[2]

Family members and friends can provide knowledge of a patient's values over time and insights into personality and character which may aid a physician caring for that patient. Any decision that affects a patient affects the family; decision-making at the end of life can profoundly affect the lives and memories of the patient's family and friends. In this chapter, we explore the role of the family when a terminally ill patient requests a lethal dose of medication.

The process for requesting a lethal dose of medication starts with the patient. Most patients have discussed their wishes and values regarding the dying process with their family members long before this specific request occurs. Others may approach the subject with family when they are close to wanting the prescription. Still others may choose not to disclose their wishes to family for a variety of reasons, including protection of those persons, fear of being hurt or rejected, a lack of closeness with family, or a difference in religious or moral views. In a survey of physicians' experiences with the Oregon Death with Dignity Act, for 80% of the patients requesting a prescription under the Oregon Act, family members knew of the request.[3] Physicians spoke with family members about the request in 73% of patients. Nine percent of patients kept their intentions from their families and five percent had no family to inform.

If a patient announces a wish to use a prescription under the Oregon Act, there are several responses that may occur. Searching the meaning behind the patient's request is important not only for the physician and other health care workers but also for family and friends (see *The Meaning Behind the Patient's Request*). Issues and concerns may be alleviated by a frank discussion with family members. Supportive interventions such as referral to hospice, referral to a mental health professional, or an improvement in pain management may not only improve the dying process for the patient but may impact the patient's desire for a prescription under the

Oregon Act. In the Ganzini study, 46% of patients for whom major interventions were made changed their minds about participation in the Oregon Death with Dignity Act.[3]

Good communication is critical at such an intense time, as values and attitudes need to be discussed and decisions made. These issues can be difficult to discuss even in families with a history of open communication and supportive relationships. The conversations may increase or alleviate stress. The dying process does not automatically ensure that communication will come easily and effectively for families. Families have styles of communication that they bring to the dying process. In addition, the patient's moods and symptoms, created by the disease and by its treatments, can affect communication.

Communication becomes particularly important when the dying person is considering participating in the Oregon Death with Dignity Act, especially to clarify the issues that motivate the person to do so. Open communication, perhaps with the help of a health care professional or counselor, can help to clarify and correct assumptions and may even change the patient's wishes for a lethal dose of medication. At the least, good communication may help to generate solutions to problems and ease the dying process for all concerned. Discussion regarding the dying process can bring relief to patients and families, or it may increase tension due to the difficult nature of the subject.

There is no question that supportive intervention benefits dying patients and their loved ones.[4] Assistance with practical matters (e.g., bathing, food preparation, errands) can be invaluable and can relieve stress for both patients and caregivers. The need for psychosocial and, as appropriate, spiritual support for patients and families is of great importance. Evaluation and treatment of distress, anxiety, and depression is helpful in maintaining quality of life throughout the dying process. Such support is available through home health services or hospice. Different hospices have different policies with regards to the practice of the Oregon Death with Dignity Act. Patients and families are urged to clarify the policy of their specific hospice program when considering participation in the Oregon Act. Other *community resources* may be available.

Some patients, despite substantive interventions, are determined to obtain prescriptions under the Oregon Act. Some may have families who are willing to support them or who are opposed to this option. Of those who are opposed, some family members may eventually be swayed by the patient's arguments or circumstances and others will remain opposed. This may affect the patient's final decision, as in the case of a patient with amyotrophic lateral sclerosis (ALS), featured in the series "*On Our Own Terms*", by Bill Moyers, who did not pursue obtaining a prescription for a lethal dose of medication largely out of respect for his wife's religious beliefs.[5] For those patients who do obtain prescriptions under the Oregon Act, and who choose not to inform some or all of their family members, their wishes not to disclose should generally be respected by health care professionals on the basis of confidentiality. However, there may be circumstances that create concerns regarding an adverse impact on family members, and would indicate the need for further dialogue.

The patient who desires a lethal dose of medication needs to explore this option with his/her physician and clarify the physician's willingness to participate in the Oregon Act (see *Attending Physician and Consulting Physician*). If the physician is unwilling, the persistent patient will need to find a physician who is willing to participate; sometimes the family helps with this search. If a willing physician is found, there still may be other health care professionals and institutions involved whose moral values don't allow participation in the Oregon Act. Patients and their families are urged to respect these values (see *The Role of Other Health Care Professionals*). The non-participating physician who has a significant relationship with the patient may still participate in some aspect of the patient's care, as agreed to by the patient and participating physician (see *Attending Physician and Consulting Physician*).

The Oregon Death with Dignity Act focuses almost exclusively on the patient and physician. However, the statute references the family in several instances. The physician is required to recommend that the patient notify the next of kin of his or her request for medication under the Oregon Act (although the law states that a patient who declines or is unable to tell next of kin shall not have his or her request denied for that reason). One of the two witnesses to the patient's written request can be a relative. In the 1999 amendment to the Oregon Act, the physician is required to counsel the patient about the importance of having another person present when the medication is taken. This may be family, although there is no published data. Finally, like health care professionals, family members and others have legal immunity from prosecution for being present at the time of the patient's ingestion of the lethal dose of medication, if the requirements of the Oregon Act have been met.

Most of the literature on the subject of the Oregon Death with Dignity Act specifically, and ingesting a lethal dose of medication generally, acknowledges the primary role of the patient in decision-making. Many patients request assistance under the Oregon Act because of loss of autonomy and a determination to control the manner of their death.[6] Some families have discussed this issue for years and are familiar and comfortable with their loved one's attitudes.[7] Some family members start out being opposed to their loved one's decision, for various reasons, including religious and moral beliefs, denial of the seriousness of the disease, or a desire to rescue the patient. A prominent reason is the sadness that family members feel at the impending loss of their loved one. In some cases of completed death by a lethal dose of medication, the family eventually comes to terms with the patient's decision, feeling that it was right for that patient. Barry Siegel summarizes this process: "It was hard to imagine that someone wanted to go, someone you didn't want to let go. ... And yet, Joan now realized, it wasn't so much that Mark wanted to go. He needed to go. It was right for him, she decided, so that meant it was right for her."[8] Other family members remain opposed to the request, sometimes altering the patient's decision.[5]

In the published reports on the Oregon Death with Dignity Act, as well as in cases from the Netherlands, commonly a great deal of interaction exists between the family and the health care team. Often the contact is only with physicians, but it may involve nurses, pharmacists, social workers, other members of the hospice team or health care system, and volunteers. In Oregon, a number of family members expressed frustration at not being able to find health care professionals to help them, but once they had an attending physician, that person coordinated care.[6] Because this law is relatively new, it is unfamiliar ground for many health care professionals as well as families.

Patients and families have expressed the need for information about the process of participation in the Oregon Act. This information and planning should include:

a. The specific requirements and process of the Oregon Act, including a timeline.

b. Alternatives to the Oregon Death with Dignity Act, including comfort care, hospice care, and pain control.

c. Discussion of disclosure to family members; discussion of who will be present at the time the patient takes the lethal dose of medication, including health care professionals or volunteers.

d. Suggesting that *Advance Directives* and *Physician Orders for Life-Sustaining Treatment* (*POLST*) are appropriately completed and available where the patient is receiving care.

e. An idea of what to expect during the ingestion itself, and contingency plans if things do not proceed as expected, especially if the death takes longer than expected. Death may not be immediate and may take hours.

f. Discussion of the availability of the attending physician, either in person or by phone, to deal with questions and complications, or for support.

g. Information on funeral arrangements, including a plan to have the attending physician notify the hospice and funeral home that the death was expected and that he/she will sign the death certificate.

It is natural for a person who is terminally ill to withdraw from worldly attachments – things, places, people. Written discussion about any rituals associated with taking a lethal dose of medication are lacking, aside from the practical details of the preparation of the medication and its ingestion. There may be more of a need for a family or caregiver to have a ritual than for the dying person.

Bereavement is the experience of and adjustment to the loss of a loved one after death.[9] It may begin before death as anticipatory grief, a phenomenon that has been described as rehearsal for loss. Numerous variables affect the grieving process, including the circumstances of the death itself.[10] Traditionally, bereavement following suicide has been described as complex and more difficult to resolve due to the nature of the cause of death.[11] There is no written information on how legally permitted death by a lethal dose of medication affects bereavement, and the traditional literature on bereavement following suicide cannot be easily generalized to the bereavement experience following participation in the Oregon Death with Dignity Act.

Theoretically, with participation in the Oregon Act, there may be some opportunity for discussion and closure, and available data suggests that some family members seem to develop respect for the loved one's choice, even if different from their own.[6,7] Some families indicated that supporting their loved one's wishes in these matters has been comforting, as the perceived suffering has been relieved. These aspects may make bereavement easier. However, any complications that occur, or the perception or fact of disapproval by family members or others in the community, could make bereavement more difficult.

One frequent theme in the published literature is the concern about secrecy during the process leading up to, during, and after the death by a lethal dose of medication, which can make the grieving process last longer and be more difficult.[7] This is especially true when such a death is done illegally:

> "One of the ways that people normally deal with their grief is by talking about the death. This option is closed to them in an assisted death, unless one has participated with other family members or close friends. Those who assist may come to feel that they have no one they can talk to, no one with whom they can share what may well be one of the most powerful experiences of their lives. They may be too frightened or ashamed to tell others in their own family or their closest friends, who might not be supportive of such an act."[12]

In Oregon, it remains difficult for some to be open about the manner of death under the Oregon Act:

> "For Beth, the hardest part has been continued public opposition to assisted suicide. She has felt stung by opponents' remarks to the media about assisted suicide. She has worked to reconcile her mom's death with her own faith, ultimately believing in a merciful and forgiving God. But Beth has not told many people how her mother died. She still goes back and forth in her mind about it."[13]

Families who are involved with the Oregon Death with Dignity Act have strong and sometimes conflicting needs and emotions about this intense experience: "Family members expressed profound grief over their loss. However, mixed with this grief was often great respect for the patient's choice. One man said about his wife of almost 50 years, 'She was my only girl: I didn't want to lose her...but she wanted to do this."[6] And, after the death of a young person, her mother thanked the physician and said: "In preparing her ingestion, I gave my daughter the most important gift I could give, and the most difficult one I could give."[14] It should be noted that this is an emerging field of study, and more data is needed to understand the full impact of the Oregon Death with Dignity Act on bereavement, family, and community relationships.

The following are suggested as guidelines for participating physicians and other health care professionals in working with families:

Guidelines:

6.1 It is important for health care professionals to recognize the critical role that family and friends play in the life and care of a patient. Families can provide knowledge of a patient's values and personality. Families are profoundly affected by the care of the patient at the end of life.

6.2 It is also important to recognize the different responses family members may have to a patient's request for a prescription under the Oregon Act. Some may be supportive, others may become supportive, and still others may be consistently opposed.

6.3 Physicians who agree to participate in the Oregon Death with Dignity Act are required to recommend to the patient that the next of kin be notified of the request for a lethal dose of medication. However, a refusal to do so does not in itself make a patient ineligible for the Oregon Act. Some patients have difficult relationships or religious or moral differences with family members; their decisions regarding disclosure generally should be respected on the basis of confidentiality. However, there may be circumstances which create concerns regarding an adverse impact on family, and that would indicate the need for further dialogue.

6.4 Physicians are required to counsel patients about the importance of having another person present when the medication is taken. The Oregon Act does not require another person to be present.

6.5 Patients and family members have a great need for information about the Oregon Act and its requirements, what to expect during the ingestion of a lethal dose of medication itself, and what to expect afterwards. Also, the attending physician should confirm that the members of the health care team are willing to participate. It behooves the attending physician and other appropriate health care professionals or volunteers to supply the needed information in as much detail as possible, and to plan strategies for care. This planning should include:

a. The specific requirements and process of the Oregon Act, including a timeline.

b. Alternatives to the Oregon Death with Dignity Act, including comfort care, hospice care, and pain control.

c. Discussion of disclosure to family members; discussion of who will be present at the time the patient takes the lethal dose of medication.

d. Suggesting that *Advance Directives* and *Physician Orders for Life-Sustaining Treatment* (*POLST*) are appropriately completed and available where the patient is receiving care.

e. An idea of what to expect during the ingestion itself, and contingency plans if things do not proceed as expected, especially if the death takes longer than expected. Death may not be immediate and may take hours.

f. Discussion of the availability of the attending physician, either in person or by phone, to deal with questions and complications, or for support.

g. Information on funeral arrangements, including a plan to have the attending physician notify the hospice and funeral home that the death was expected and that he/she will sign the death certificate.

6.6. Health care professionals should understand the special needs of families involved with the Oregon Death with Dignity Act for discussion of their experiences and the concern about secrecy. The secrecy may prolong the grieving process.

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

7. Attending Physician and Consulting Physician

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

In this chapter, we use the following terms as defined by the Oregon Death with Dignity Act in order to describe the physician's roles and responsibilities. "Physician" means a doctor of medicine or osteopathy licensed to practice medicine by the Oregon Medical Board. "Attending physician" refers to the physician who has primary responsibility for the care of the patient and treatment of the patient's terminal disease. A "consulting physician" is a physician who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's disease.

The physician's unique professional responsibility to his/her patients is particularly evident in a patient's last months of life. The physician offers the patient relief from suffering through compassion and palliative care. When asked about the Oregon Act, some physicians may have examined their personal and professional values and determined the degree to which they could be involved. Other physicians may still be struggling with the issue and feel uncertain about their own values and how to respond to a patient's request. Physicians will be more effective in their care of terminally ill patients if they have examined their values regarding end-of-life care and the Oregon Death with Dignity Act.

Traditionally, physicians have had difficulty talking about death with their patients. They have been taught to cure; therefore, not to do so could signify failure. Instead of wanting a prolonged life at all costs, many patients are now asking physicians to provide high quality treatment and excellent palliative care, and some are asking assistance in ending life.

Advance planning about one's own dying, as challenging a consideration as it is for patients, can be a powerful process for physicians. This personal exploration can deepen understanding about the nature of suffering and the goals of medicine.[1] We encourage all physicians to discuss their values with loved ones and to make their end-of-life care preferences known, and consider completing an advance directive. This personal exploration may help the physician to clarify his/her feelings about other aspects of end-of-life care, such as those provided under the Oregon Act.

In probing a deeper understanding of personal values regarding the Oregon Death with Dignity Act, the physician does not function alone. He/she must consider these values in the context of relationships with colleagues, institutions, and organizations. Discussing provisions of the Oregon Act with colleagues in advance can promote respect for differing values and prevent unwanted conflicts. Some physicians may prefer greater privacy and choose not to discuss such a sensitive issue with colleagues.

The physician also must be aware of the policies of his/her professional group, care setting, health system, malpractice carrier, health plans, and professional organizations. These policies may conflict with the physician's values (see ***Conscientious Practice***). Provisions clarified the relationship of health care professionals and institutions under the Oregon Act in the amended law (see ***Section 9, ORS 127.865***; ***Liability and Negligence***; and Appendix A, ***The Oregon Death with Dignity Act***). The goal of these provisions is to respect the values of health care institutions and their health care professionals. Institutions (such as a hospital system) may prohibit a physician from participating under the provisions of the Oregon Act on its premises if the institution has previously notified the physician in writing of the non-participation policy. A physician who violates institutional policy may be subject to loss of privileges, loss of membership or other sanctions provided in medical staff bylaws, termination of lease or other property contract, and termination of contract. These sanctions are not reportable to the Oregon Medical Board. The physician may still participate if he/she acts outside the course and scope of his/her role in the institution. The scope and circumstances for sanctions are complex and are covered in more detail in chapter 15 of this Guidebook, ***Liability and Negligence***.

Physicians' professional organizations have taken different positions on the provisions of the Oregon Act. The American Medical Association (AMA), among others, is opposed as described in its Code of Medical Ethics:

> "It is understandable, though tragic, that some patients in extreme duress such as those suffering from a terminal, painful, debilitating illness may come to decide that death is preferable to life. However, allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.
>
> Instead of participating in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that cure is impossible. Multidisciplinary interventions should be sought including specialty consultation, hospice care, pastoral support, family counseling, and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication."[2]

During the 1994 referendum campaign, the Oregon Medical Association (OMA) chose to neither support nor oppose the Oregon Death with Dignity Act, consistent with the nearly evenly divided views of its membership. In July 1997, the Executive Committee of OMA's Board of Trustees agreed to an operational policy for the association to support repeal of Oregon's Death with Dignity Act, as mandated by the action of the House of Delegates in April 1997. The organization did not join or endorse coalitions to campaign in support of or in opposition to repeal of the Oregon Act.

The position of the American College of Physicians-American Society of Internal Medicine (ACP-ASIM) is as follows:

> "[It] does not support the legalization of physician-assisted suicide. The routine practice of physician-assisted suicide raises serious ethical and other concerns.

> Legalization would undermine the patient-physician relationship and the trust necessary to sustain it; alter the medical profession's role in society; and endanger the value our society places on life, especially on the lives of disabled, incompetent, and vulnerable individuals. The ACP-ASIM remains thoroughly committed to improving care for patients at the end of life."[3]

The position of the American Academy of Hospice and Palliative Medicine (AAHPM) is described here:

> Despite all potential alternatives, some patients may persist in their request specifically for physician-assisted death (PAD). The AAHPM recognizes that deep disagreement persists regarding the morality of PAD. Sincere, compassionate, morally conscientious individuals stand on either side of this debate. AAHPM takes a position of "studied neutrality" on the subject of whether PAD should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care. Whether or not legalization occurs, AAHPM supports intense efforts to alleviate suffering and to reduce any perceived need for PAD.[4]

While the Oregon Medical Board has taken no position, in 1993 it adopted a statement of philosophy on pain management in acute conditions and in terminal illness (see Appendix E, *Oregon Medical Board Statement of Philosophy*). It has also amended its rules to clarify that good faith compliance with the Oregon Act will not subject licensees to discipline for unprofessional conduct. In 1999, the Board took the unprecedented step of disciplining a physician for egregious under-prescribing of medication needed for the comfort of seriously ill and dying patients.

One of fifty patients with a terminal condition asks his/her physician about the provisions of the Oregon Act.[5,6] When a patient requests a prescription under the Oregon Act, the physician must explore the meaning behind the question (see *The Meaning Behind the Patient's Request*). Patients may communicate one thing, yet mean quite another. Patients frequently visit physicians with a particular symptom yet have deeper worries that remain hidden. Eliciting hidden factors may promote healing and reduce suffering.[7]

According to the Oregon Department of Human Services, Health Services surveys, physicians report that patients request a prescription under the Oregon Act for several reasons, including loss of autonomy (100%), a decreasing ability to participate in activities that make life enjoyable (86%), and loss of dignity (86%).[8]

Interviews with patients' families also indicated that these patients were often determined to control the timing and manner of their death.[9] A statewide survey of Oregon physicians found that important considerations in patients' decisions to request a prescription for a lethal dose of medication included unrelieved or anticipated symptoms (pain - 43%, fatigue - 31%, and dyspnea - 27%). Financial burden to others (11%) and lack of social support (6%) were found to be uncommon reasons for requests for a prescription under the Oregon Act.[10]

Examining the meaning behind the request for a prescription under the Oregon Act may lead to new physical or psychosocial interventions that might obviate the patient's desire for a prescription under the Oregon Act.[11,12] (see *The Meaning Behind the Patient's Request*). Control of pain or other symptoms, referral to a hospice program, or a trial of antidepressant medication has been found to alter the requests of 46% of patients who had sought a prescription under the Oregon Act.[10] Research indicates that most patients request the medication to remain in control, avoid a period of dependence on others before death, and because of existential reasons, such as not seeing any point in continuing to live. These patients wish to avoid being a burden on others, even when family members find caring to be meaningful.[10]

The health care team should attempt to help the patient find meaning, and maximize the sense of control in all aspects of their lives. Since the Oregon Act was enacted improvements in end-of-life care has been a focus of education of health care professionals. In a survey of Oregon physicians experienced in caring for patients with terminal illness, 76% indicated that they had made efforts to improve their knowledge of the use of pain medications in end-of-life care.[11] In the Netherlands such improvements in care may have resulted in a "modest decrease in the rates of euthanasia and physician-assisted suicide".[13] (see *Hospice, Palliative Care, and Comfort Care* and *Mental Health Consultation*).

Also, sensitive discussions about end-of-life issues give terminally ill patients the opportunity to express their life values orally and in writing by completing an advance directive. These values can best be respected by the physician completing a Physician Orders for Life-Sustaining Treatment (*POLST*) form (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*).

For some patients, clarifying preferences for life-sustaining treatment, discovering underlying reasons for the request, and addressing unmet needs may not relieve the desire for a prescription for medication to end life. After thoughtfully considering his/her own values, the attending physician has the right not to participate in the provision of a prescription under the Oregon Act. Through open communication with the patient, the physician may discover a true difference in values regarding this aspect of end-of-life care. Exploring these differences at the time the patient initially requests a prescription under the Oregon Act may prevent difficult time-pressured decisions and actions later. The physician can work with the patient to find an agreeable course of action; sometimes this means the patient must find another physician. The physician may decline to help in finding a new physician as part of his/her conscientious practice; however, he/she may not obstruct the change.[14] In fact, a significant percentage (59%) of patients, ultimately receive their prescription under the Oregon Act from a physician other than their original attending physician.[8] In this situation, the goals are to honor the integrity of both patient and physician, to preserve the continuity of the relationship if possible, and to prevent abandonment of the patient.

The attending physician may feel more comfortable collaborating in the overall care of a patient with a colleague who is willing to provide the prescription under the Oregon Act. Alternatively, the attending physician may prefer to transfer care of the patient to a colleague who agrees to assume all aspects of care, including participation under the Oregon Act. Some attending physicians may feel that providing such a referral is participating in the Oregon Act and may not be willing to assist in any way. These physicians should consider referring the patient to their office administrator, the hospital medical staff office, the local medical society, the patient's health plan, or another resource. As with any other transfer of care the attending physician has a duty to provide the patient's records in a timely manner and to offer care, including comfort measures, until the patient has had a reasonable time to find alternative care.

For the attending physician who is willing to provide the prescription the patient requests, there are specific responsibilities defined in the Oregon Act (see *Oregon Department of Human Services Reporting* and Appendix B, *Oregon Department of Human Services Reporting Documents*).[14] Prior to writing a prescription, the attending physician must be personally confident that each safeguard has been met and documented. The remainder of this chapter will focus on the participating attending and consulting physicians' roles and responsibilities as set forth in the Oregon Act.

Qualifications of the Patient Under the Oregon Act

The attending physician must determine if the patient is eligible for a prescription for medication for the purpose of ending his/her life as outlined in the requirements of the Oregon Act (see Appendix A, *The Oregon Death with Dignity Act* and *Liability and Negligence*). First, the attending physician must determine that the patient is an Oregon resident over 18 years of age. The 1999 Oregon legislature clarified the Oregon Act's definition of residency. Factors demonstrating Oregon residency include but are not limited to: possession of an Oregon driver's license, registration to vote in Oregon, evidence of property lease or ownership in the state, or most recent filing of an Oregon tax return. Second, the physician must determine that the patient has a terminal disease, defined by the Oregon Act as having a condition with less than six months to live. Several studies indicate there is inherent inaccuracy in predicting the course of a patient's illness and exact timing of expected death.[15,16,17,18] Despite this challenge, attending physicians are called upon to use their best judgment in making such predictions. The difficulties of making these predictions are practical barriers to some terminal patients who need earlier referral for high quality end-of-life care, such as hospice.[19] Third, the attending physician must determine that the patient is capable of making his/her own health care decisions and has made the request voluntarily. In determining the decision-making capacity of a patient, the patient must be able to understand the information provided (medical diagnosis, prognosis, potential risks associated with taking the medicine), weigh this information and communicate a choice. The physician is required to determine that the patient does not have a mental health condition that impairs judgment. Oregon primary care physicians have appropriately expressed doubt about their ability to diagnose depression in patients who qualify under the Oregon Act.[20] Mental health professionals have similar difficulty in distinguishing a major depressive disorder from the effects from the underlying terminal illness. Despite this challenge, of the 49 people who died by lethal medication under the Oregon Act in 2007, none were referred for mental health evaluation.[8] Further in a study of 58 individuals seeking a prescription under the Oregon Act, one in four were assessed to have major depressive disorder.[21] Of the 18 who received a lethal prescription three were diagnosed with major depression. All three died by lethal ingestion within two months of the research interview. This suggests that the practice of the Oregon Death with Dignity Act through 2006 did not adequately protect all mentally ill patients from receiving prescriptions for lethal medications and there is need for more vigilance and systematic examination for depression. If the physician is concerned that such a condition exists, the physician is required to refer the patient for counseling (see *Mental Health Consultation*). Given data indicating the lack of adequate mental health assessment and the gravity of the decision to prescribe under the Oregon Act, it is strongly recommended that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the Patient Health Questionnaire (*PHQ-9*). If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist (see *Mental Health Consultation*).

Requirements of the Oregon Act for Consultation

The Oregon Act requires the attending physician to consult with a second physician to confirm the diagnosis and to determine that the patient is capable and acting voluntarily. In selecting a consulting physician, the attending physician should consider three issues. First, the consultant should have expertise in managing the patient's terminal disease, including palliative therapies. Second, the consulting physician must be willing to serve as a consultant for a patient who is seeking a prescription under the Oregon Act. Finally, the consulting physician should not have a financial or other relationship that has the potential to constitute a conflict of interest.

The consulting physician is responsible for providing a thoughtful second opinion about the patient's diagnosis, prognosis, and capacity for health care decision-making, and the voluntary nature of the request. This consulting opinion is distilled from careful review of medical records, patient interview and examination, and other means to clarify the patient's condition, mental state, and prognosis. Like the attending physician, the consulting physician needs to sensitively explore the meaning underlying the patient's request for a prescription under the Oregon Act (see *The Meaning Behind the Patient's Request*). The consultant's involvement is a process that includes patient, family (as allowed by the patient), and other health care professionals and may require more than a single patient encounter.

As with the attending physician, the Oregon Act requires that the consulting physician determine that the patient does not have a mental health condition that impairs judgment. Again, given data indicating the lack of adequate mental health assessment and the gravity of the decision to prescribe under the Oregon Act, it is strongly recommended that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the *PHQ-9*. If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist (see *Mental Health Consultation*).

The consulting physician is required to complete the documentation under the Oregon Act as described by the *Oregon Department of Human Services*.

Physician Responsibilities for Informed Decision

The attending physician should continue to explore and offer alternatives, assure comfort, and remind the patient that he/she can change his/her mind about the plan of treatment at any time, including the request for a prescription for medication to end life. The Oregon Act specifically requires that the patient be informed of his/her diagnosis, prognosis, potential risks, feasible alternatives, (including, but not limited to, comfort care, hospice care and pain control) and probable results of taking the prescribed medication. The statute also requires that the patient be given an opportunity to rescind the request for a prescription under the Oregon Act at the end of a fifteen-day waiting period and make an informed decision immediately before the attending physician writes the prescription for medication. Of note, studies show that a majority of patients seeking a prescription under the Oregon Act were enrolled in hospice during this waiting period.[8,9] At this time the physician should inform the patient that the Oregon Department of Human Services has a role in collecting information relevant to the Oregon Act. Each step of this process should be documented in the patient's medical record. It can be done most easily using the Oregon Department of Human Services forms (see Appendix B, *Oregon Department of Human Services Reporting Documents*).

Planning for the Patient's Death

Once a qualified patient has carefully considered his/her options and has requested a prescription under the Oregon Act, the attending physician should address a number of planning issues. These include exploring relationships with family and other health care professionals; completing an advance directive and POLST document; obtaining the medication; planning the self-administration of the lethal dose of medication; and making funeral arrangements.

Relationship with Family

Most people do not want to die alone. The attending physician is required by law to recommend to the patient that he/she inform the next of kin about the request for a prescription for medication to end life. If the patient intends to take the medication, the attending physician should clarify whom the patient wants to inform about the decision. Some patients may choose family members and significant others to be aware or present. If a patient declines any family involvement, the attending physician should explore the meaning behind this decision (see *Family Needs and Concerns* and *Emergency Department and Emergency Medical Services*). Although most patients prefer dying in a private setting, the attending physician is required by the Oregon Act to counsel the patient about the importance of not taking the medication in a public place.

Once family members or close friends are aware of the request for a prescription under the Oregon Act, the physician should be available to explore their feelings and beliefs about the patient's desire. This can be a time of family closeness and sharing. Family conflict is a reason for the physician to look more deeply, just as it is when considering the withdrawal of life-sustaining treatments. Sometimes these conflicts can be addressed best by referral to or consultation with other resources, such as family or community support services, pastoral or spiritual care, hospice team members (if applicable), or ethics committee consultation. For hospice patients, the team routinely assesses psychosocial and spiritual aspects of care.

The attending physician also may establish with the patient whom he/she would like present at the time of self-administration. The physician may inform family or friends of potential complications as desired by the patient. In working closely with the patient, the attending physician can help support family members, lessening their suffering and easing grief.

Relationship to Other Health Care Professionals

The attending physician has responsibility not only to the patient and family (as the patient allows) but also to other involved health care professionals (see *The Role of Other Health Care Professionals* and *Pharmacists and Pharmacy-Related Issues*). Each health care professional has the right to choose whether or not to participate in the provisions under the Oregon Act (see *Conscientious Practice*). The attending physician has the responsibility to explain to the patient the importance of notifying these other health care professionals if he/she plans to take the medication to end life as set forth in the Oregon Act. The decision to disclose must be based on the need for the other health care professional to know about the planned self-administration of the lethal dose of medication in order to give him/her an opportunity to decide whether or not to participate. Some health care institutions have developed a confidential central resource to provide referrals thereby maintaining privacy for each patient and all health care professionals. The attending physician should discuss with the patient whether the physician or other health care professional(s) will be present for the patient's self-administration of the lethal dose of medication. The attending physician or other health care professional(s), especially hospice, may be able to provide comfort care to the patient and family, avoid notification of emergency medical services, and notify the funeral home and/or other proper authorities.

Importance of an Advance Directive and POLST

If not already available, advance directive and Physician Orders for Life-Sustaining Treatment (POLST) documents should be completed to ensure that patient preferences are honored (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). Without an advance directive or POLST containing a do-not-resuscitate (DNR) order, the patient has a greater risk of receiving unwanted interventions.

The attending physician should inform the patient (and family, as allowed by the patient) that involvement of emergency medical services may result in a resuscitation attempt and/or notification of the Medical Examiner or local law enforcement officials (see *Oregon Department of Human Services Reporting*). The authority may investigate, allowing for limited public disclosure about the patient, questioning of the family or retention of the body for investigative purposes. If hospice is not involved, family should be told that instead of calling 9-1-1 when the patient dies, the funeral home should be contacted.

Obtaining the Medication

If the attending physician is registered as a dispensing physician with the Oregon Medical Board, he/she may dispense medication directly, including ancillary medications to minimize the patient's discomfort. If the attending physician is not a dispensing physician, then with the patient's written consent, the attending physician must deliver the written prescription either personally or by mail to the pharmacist, who will then dispense the medication to either the patient, the attending physician, or an expressly identified agent of the patient (see *Pharmacists and Pharmacy-Related Issues*). The prescribing physician should contact the pharmacist and inform the pharmacist of the prescription. The pharmacist has the opportunity to decide whether or not to participate. Should he/she choose not to participate, the refusing pharmacist may, but is not obligated to, suggest a pharmacist who is willing to fill the prescription under the Oregon Act (see *Conscientious Practice*). Compassion & Choices (*www.compassionoforegon.org*, phone: 503-525-1956, email: *or@compassionandchoices*) advocates for the Oregon Act and is the only resource known to the Task Force to maintain a list of pharmacists willing to participate.

There are substantial challenges for patients, attending physicians, and pharmacists concerning the dispensing of medication under the Oregon Act. These challenges include the need to protect patient privacy, to ensure a thoughtful, informed decision process, to prevent diversion of a lethal dose of medication to others, to protect the right of conscientious practice of the dispensing pharmacist, and to encourage accurate reporting to the Oregon Department of Human Services.

The attending physician and patient together can carefully consider how to obtain the medication. The physician can present two options to the patient: 1) the attending physician can obtain the medication; or 2) the patient or family can obtain the medication from a pharmacy. Although the first option may have some benefits, the Oregon Board of Pharmacy is not aware of any cases in which the medication has been delivered to the physician to hold until the intended time. The experience reported to the Board is that family members are usually the ones obtaining the medication and usually near the time of ingestion. Regarding the second option, the attending physician is required to give or mail the written prescription to the pharmacist and must inform the pharmacist of the intent. The pharmacist who is willing to fill the prescription is required to offer counseling regarding its use and complications. The pharmacist is also responsible for notifying the attending physician of the date the prescription was filled. The Oregon Department of Human Services requires the attending physician, pharmacist, or health system to file a copy of the dispensing record with the department (see *Oregon Department of Human Services Reporting*; Appendix B, *Oregon Department of Human Services Reporting Documents*; and *Pharmacists and Pharmacy-Related Issues*).

Planning the Self-Administration of the Lethal Dose of Medication

The attending physician should discuss with the patient the details of taking the medication. The attending physician can inquire about the time and place with the patient, family, and other involved health care professionals with whom the patient has consented to share the information. The timing of the patient's self-administration is best planned in advance to allow the attending physician and/or other support persons to be present. The physician's presence assures continuity of care with other members of the health care team, and avoids involving covering colleagues who conscientiously are opposed to the Oregon Act or are less informed about the patient's plan for taking the medication to end life in accordance with the Oregon Act. If present, the attending physician can offer counsel and support to the patient and family during and after the patient's self-administration of the medication. If not present, being available by phone at the pre-arranged time will provide some support to patient, family, and other health care professionals. If the attending physician cannot be continuously available from the patient's self-administration until death, he/she should inform covering colleagues of the patient's plan.

Complications may occur in some cases of self-administration of the lethal dose of medication under the Oregon Act (see *Pharmacists and Pharmacy-Related Issues*).[8,9,22,23] Complications include side effects such as nausea, vomiting, seizures and prolonged time (greater than four hours) from ingestion of the medication until death.

By the end of 2007, 341 patients died after ingesting a lethal dose of medication.[8] Complications were reported for 20 patients. Of these, 19 involved regurgitation and none involved seizures. The median time between ingestion and unconsciousness was 5 minutes with a range of 1 to 38 minutes. The median time between ingestion and death was 25 minutes with a range of 1 minute to 48 hours. One patient (2007) lived 3 ½ days and one (2005) regained consciousness after ingesting the lethal dose of medication and then died 14 days later from his illness rather than from the medication. Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

Comfort measures consistent with patient preferences as documented in advance directive and POLST documents remain appropriate. Under the Oregon Act, physicians are *not* legally permitted to provide a lethal injection if the patient's self-administered medication does not result in death. Such an act could leave the physician open to homicide charges and disciplinary action.

Funeral Arrangements

Most patients have wishes regarding how his/her body will be cared for after death and how he/she would like family and friends to reflect on his/her life. However, it is often challenging for patients to talk about death and funeral arrangements. The attending physician or other health care professionals, especially hospice, can help facilitate this aspect of end-of-life care. Once determined, the patient's wishes can be communicated to loved ones and made available once death has occurred. Making the arrangements with the funeral home in advance has major advantages. Not just talking, but signing the contract, makes the move to the funeral home smoother and without involvement of emergency medical services.

After Death Occurs

If the patient dies as a result of self-administering the lethal dose of medication, the physician continues to have responsibility, as with other patient deaths, for supporting loved ones in their bereavement. A note or card sent by mail can help the bereavement of those who cared for the patient. It is helpful to notify office staff that the patient has died so that subsequent contacts by the office with family members can be handled with sensitivity. The manner of death should not be disclosed to persons not previously involved. Family members are encouraged to dispose of any unused medication after the patient's death to avoid accidental or purposeful ingestion by others. Usually the physician does not have to notify the medical examiner. Hospice deaths occurring more than 24 hours after hospice enrollment do not need to be reported to the medical examiner or investigated. [24]

The attending physician is responsible for completing the death certificate as provided by the funeral home. The death certificate has been designed to ensure confidentiality of the patient's medical condition(s) and the cause of death (see ***Oregon Department of Human Services Reporting***). The Oregon Department of Human Services recommends that the attending physician complete the death certificate with the underlying terminal condition(s) as the cause of death, and the manner of death as "natural". The required "Reporting Physician Interview Form" completed by the physician after the patient's death will alert the Oregon Department of Human Services whether the death was from ingesting the lethal dose of medication or from the underlying disease.

Physician Experience with the Oregon Act

There is little written on the effect that the Oregon Death with Dignity Act has on physicians and other health care professionals. There is even less written on how refusing to participate impacts the physician. To our knowledge, this topic has not been formally studied. There are a number of first hand accounts that describes the physician experience. These are available through first person reports or newspaper articles and may not be statistically representative.[25]

From these stories, there are several repeating themes. One theme is the difficulty of deciding whether or not to prescribe under the Oregon Act. One Oregon physician is quoted in The Oregonian about his feelings after he was asked by a colleague to consider being involved in a case: "I was frightened. I was honored. Worried in the sense of whether I was up to the details and the emotional impact and all that. I was trembling."[22] Another Oregon physician, who voted against the Oregon Death with Dignity Act, published the story of his struggle, writing that his intellect and his soul "engaged in unresolvable debate."[23] A Dutch physician, writing in a book about euthanasia, described the decision in this way: "[I]t is the most difficult decision a physician can make in his or her professional life,"[26] and another Dutch physician, in the same book: "I spend months pondering the details of the situation before I ever come to a decision. My patient's plight invades every aspect of my thinking... I can say that each time a patient asks me for help in dying, it is like starting a Herculean task all over again."[27] In a statewide survey of Oregon physicians, one third indicated that they would never provide a patient with a prescription under the Oregon Act for religious or moral reasons.[10,20] Little is written about the feelings these physicians may have if a long-standing patient transfers care to obtain a prescription under the Oregon Act. According to the Oregon Department of Human Service data, 59% of patients who took a prescription were reported to have made a request of more than one physician before finding a doctor who was willing to prescribe.[6]

Refusing to participate has taken its toll on some physicians. One Dutch physician, quoted above, wrote of a patient for whom he refused to participate in prescribing a lethal dose of medication: "This is the only case I have regretted – because she really meant it when she asked me to help her die... I worry she felt abandoned... was this patient harmed more by my refusal to comply with her wishes for euthanasia than she would have been if I had agreed?"[28] An Oregon physician, quoted in The Oregonian, spoke of his patient's anger when he refused: "Before the law went into effect, I had one specific request in my life from a person who would have qualified, and he died absolutely white-hot furious because I refused. He died in a fury over a period of weeks. And when he was admitted to a nursing home and I went to see him frequently, because I felt I owed it to him, there was nothing but fury that he had for me."[29]

These individual stories give us only a partial picture of how physicians feel and respond to patient requests. Those physicians who believe providing a prescription under the Oregon Act is wrong and therefore may feel less conflicted declining a patient's request may be underrepresented in media reports. In addition, those physicians who wish to maintain their privacy about this sensitive issue may have points of view or concerns and their views are also likely to be underrepresented in media reports.

After the Oregon Death with Dignity Act was implemented, Oregon physicians often recommended interventions to patients for relief of their suffering. In 46% of cases where interventions were accomplished, the patients' desire for a prescription under the Oregon Act was altered.[10] One of the consequences of the Oregon Death with Dignity Act is that many physicians in Oregon have been educated in end-of-life care and have more alternatives to offer patients, ones which are universally endorsed by medical ethics groups. However, some patients who persist in their request for a prescription under the Oregon Act may continue to seek physicians who are willing to participate. In some circumstances, patients may be unable to find a willing physician.[6]

Working through the process as defined in the Oregon Act is burdensome in the amount of work and time spent, as well as emotional expenditure. Both in the Netherlands and in Oregon careful documentation is required. One Oregon physician is described as saying of the process: "I remember feeling trembly. Every time I checked things off, I felt it was really happening."[30]

After the experience of participating, according to anecdotes from Oregon physicians, and writings from Dutch physicians, there is often a huge emotional impact. Dr. Gerritt Kimsma of Amsterdam says: "Euthanasia and assisted suicide bring out intense grief, as you have developed a deep relationship with the patient who will die. You have a very personal relationship with the dying patient, more so than with other patients. You, the doctor, become more vulnerable. You have to let go of the patient. You will have feelings of guilt, and you should have feelings of guilt... It is highly emotional for the doctor; it can throw you off your feet. It can cause you to become dysfunctional. It is hard to cope with; it is a huge and impressive action. You need to brace yourself for it."[31] Dr. Kimsma also speaks of secrecy surrounding the assisted death as making the grieving process more difficult.

Physicians who have written or publicly spoken about participating under the Oregon Act also speak of new appreciation for what their patients experience: "I have also redefined intolerable suffering. I now believe that it may occur in ways quite different from those that we as physicians normally consider and that intolerable suffering is best defined by the patient. My patient was suffering at the core of her being without agonizing pain, anorexia, or night sweats. She had become increasingly dependent on others for virtually all activities. Her dignity, her self-esteem had been stripped away. The vitality of her being had passed. Yes, her life, as she defined it, had become futile."[32] The physician quoted in The Oregonian said: "As Helen's doctor during her last days, I developed an emotional bond with her and her family in the many hours of forthright conversation I had with them. This depth of relationship allowed me to see for myself how intensely she wanted to die. I remain profoundly transformed by her reality."[33]

Physicians who have described their experiences in Oregon, though few in number, have agreed that the act of participation should be difficult: "I have a feeling of responsibility that I can't say I'm entirely proud of. I did what I thought was right, given bad choices... it's better to not feel good about this."[33] And, "My emotional turmoil in greater part reflected my entrance into uncharted territory for physicians. Although we have accepted our roles as comforters in end-of-life care, we have not struggled with or found solutions to active roles in aiding patients in accomplishing their deaths. I am grateful for the great disruption in my emotional stability that this experience precipitated. This act should never be easy, never routine. It should be among the most difficult and disquieting acts we embark upon."[23]

Guidelines

7.1 Physicians should explore their own values regarding end-of-life care and determine in advance whether they would assist, refer, or transfer the care of a patient who requests a prescription for the purpose of ending life.

7.2 Physicians may wish to discuss their values regarding ODDA with colleagues in advance of any patient request.

7.3 Physicians should be aware of and respect the policies of the institutions in which they practice and not participate in the Oregon Act on the premises of a non-participating institution.

7.4 Physicians should consider the consequences of participating or not participating under the Oregon Act within the context of the community in which they practice.

7.5 It is always appropriate for the attending physician to explore the meaning underlying a patient's request for a prescription under the Oregon Act.

7.6 The attending physician is obligated to identify and where possible treat physical, emotional, and spiritual pain and suffering experienced by the patient, understanding that such interventions may avert a patient's desire for a prescription under the Oregon Act.

7.7 The attending physician and/or consulting physician may choose to participate under the Oregon Act or not based on his/her personal or professional values.

7.8 Physicians who choose not to participate in provisions under the Oregon Act should strive to treat the patient with respect, preserve the continuity of the relationship, and ensure that the patient is not abandoned if it is not possible to preserve the patient-physician relationship. The physician must not hinder the transfer of care and must provide care until transfer of care is complete.

7.9 For the attending physician who is willing to provide a prescription for a lethal dose of medication, there are specific responsibilities defined in the Oregon Act.

> a. The attending physician must verify that the patient qualifies under the Oregon Act, including a confirmation of residency.
>
> b. The attending physician must arrange for a second physician to confirm the patient's diagnosis, prognosis, potential risks, feasible alternatives, (including, but

not limited to, comfort care, hospice care and pain control), probable results of taking the prescribed medication and capacity in making the decision. When the consulting physician practices outside the attending physician's professional group, it reduces the appearance of a financial or other conflict of interest.

c. We strongly recommend that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the Patient Health Questionnaire *(PHQ-9). Other possible instruments could be used.* If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist. **d.** The attending physician must ensure an informed decision as defined in the Oregon Act.

e. The Oregon Act requires the attending physician to counsel the patient as to the importance of notifying family members if the patient has decided to take the medication for the purpose of ending life. The attending physician also is required to counsel the patient to avoid taking the lethal dose of medication in a public place.

f. If the patient plans to take the medication, the attending physician should prepare the patient and family (if the patient agrees) for potential complications. Physicians should encourage patients to complete an advance directive and Physician Orders for Life-Sustaining Treatment (POLST) form, which includes a do-not-attempt-resuscitation (DNR) order.

g. The attending physician should work with the patient to identify any members of the health care team that might be involved if the patient decides to take the lethal dose of medication. The physician, with the patient's consent, should disclose the patient's plan to other health care professionals so they can decide whether or not to participate.

h. The attending physician may dispense medication, if registered, or with written patient consent is required to inform and deliver or mail the prescription to the participating pharmacist. The physician should inform the pharmacist in advance about the prescription.

i. The attending physician and/or other support persons are encouraged to be present at the time the patient takes the lethal dose of medication to help provide comfort to the patient and family.

j. The attending physician is responsible for providing care to the patient, arranging comfort care including pain medication and limiting life-sustaining treatment as directed by the patient's wishes. It is illegal for the physician to administer a lethal injection or otherwise intentionally cause the patient's death.

k. After a patient dies from taking medication prescribed under the Oregon Act, the attending physician should notify and comfort family members. Physicians are encouraged to develop bereavement procedures to help grieving family members.

l. The attending physician is responsible for completing the death certificate, accurate and complete notes in the medical record, and providing appropriate documentation to the Oregon Department of Human Services as outlined in Appendix B, *Oregon Department of Human Services Reporting Documents.*

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8. The Role of Other Health Care Professionals

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Oregon's Death with Dignity Act (ODDA) implies a relationship between a terminally ill person and his/her physician. However, a terminally ill patient is likely to have established ongoing relationships with other members of the health care team, both professional and volunteer, in addition to the physician.

The team approach is essential in supporting the terminally ill patient and family. The entire health care team, including physicians, pharmacists, nurses, nurses aides, social workers, spiritual care providers, and other health care professionals, as well as volunteers, must recognize that in providing care to a patient who requests a prescription for medication to end life, roles frequently overlap, especially in the provision of support and psychosocial care. A collaborative approach, open communication, and respect for the patient are essential.

The impact of place of death on health care professionals is different depending on the setting. The place of death for those who utilized the Oregon Death with Dignity Act from 1998-2006 is overwhelmingly at home. "Home" is defined by the Oregon Department of Human Services (ODHS) as the place of residence excluding a long-term care facility or hospital. Hospice is provided wherever the patient lives, crossing all settings; 291 out of 341 (86%) of those Oregonians who utilized the Oregon Act were enrolled in hospice.[1] The option of ODDA has prompted the need for health care professionals, such as long-term care facilities, hospices, assisted living, and other community based settings, to maintain policies and procedures that acknowledge the Oregon Act and that tailor their practices to meet their mission of caring for dying patients.

Nurses and social workers are often the professionals with whom patients choose to talk regarding end-of-life decisions. They are trained to evaluate patents' and families' medical and psychosocial needs. They are in a pivotal position to evaluate requests for exploration of the Oregon Act in the context of the patient's experience. They explore the meaning of the request, alleviate symptoms that may be contributing to the patient's distress, and facilitate communication between the patient, family, and health care team (see *The Meaning Behind the Patient's Request* and *Hospice, Palliative Care, and Comfort Care*).[2-8] Studies suggest that nurses and social workers employed in hospice, despite their personal opinions about the Oregon Act, respect patients' autonomy and self-determination in end-of-life decisions.[9] Nurses and social workers struggle with the complexities of this option, yet their professional values and ethics guide exploration and assessment of the request within the philosophy of hospice care.[10,11] In addition, individuals in pastoral care and clergy may have an ongoing relationship with the patient for spiritual support. Ultimately, the patient will decide with whom, among members of the health care team or his/her support system, he/she will choose to discuss this important decision.

A nurse practitioner or physician assistant may be involved with a patient who desires medication to end life in accordance with the Oregon Death with Dignity Act, but the Oregon Act allows only for the attending physician (as defined in the Oregon Act) to write a prescription for a patient to self-administer for the purpose of ending life. Nurse practitioners and physician assistants, who may have prescriptive authority in Oregon, are not authorized by the Oregon Act to serve as the attending or consulting physician and so cannot prescribe under the Oregon Act. Nurse practitioners and physician assistants may respond to patient inquiries for information about end-of-life options. Referral to an attending physician will be necessary for continued assessment and decision-making within the provisions of the Oregon Act.

Volunteers play an important role in many end-of-life care settings and their involvement on the hospice team is mandated by law. Volunteers perform a wide range of support and assistance to health care institutions, the terminally ill person, and his or her family. Because volunteers provide so many different services at end of life, it is possible that a volunteer may know about or be involved in the decision-making process regarding use of the Oregon Death with Dignity Act. Health professionals who care for the terminally ill and utilize volunteers should develop policies and standards of practice for the role and responsibilities of the volunteer in relation to the Oregon Act, including language about conscientious objection by unpaid or non-professional staff. This information should be included in orientation activities.

Personal care professionals and aides give personal care to patients who are dying and sometimes see patients more frequently and for longer periods than other health professionals. Because of this, the personal care professionals or aides may develop relationships with patients that could make them aware of patients' thoughts regarding the use of the Oregon Death with Dignity Act. Health care professionals who care for the terminally ill and utilize personal care professionals or aides should develop policies and standards of practice for the role and responsibilities of the health care workers in relation to the Oregon Act, and include this information in orientation activities.

Balancing the right of the patient to confidentiality with the "need to know" of health care professionals is a significant issue. The Oregon Act specifies that all health care professionals shall have the right to choose whether to participate, but does not ensure them the right to know about the patient's request for a life-ending medication.[12] If informed, a health care professional could choose to continue to give appropriate care or exercise the right for conscientious practice under the law. If not informed, health care professionals could become unknowing participants in the process of a patient utilizing the Oregon Act regardless of their personal views (see *Conscientious Practice*). As is the case with other legally authorized medical interventions, health care professionals may be caught in the middle of conflicting personal and professional values and loyalties. The health care professional may personally disagree with a patient's decision to end life as set forth in the Oregon Act, but feel an ethical and professional responsibility to provide all legal options to all patients, including those who request medications as provided under the Oregon Act. The resulting internal conflict may make it difficult for the health care professional to decide whether or how to participate in ongoing care for the patient.[13,14]

Each health care professional should consider personal and professional values and ethics, and determine whether he/she might be willing to be involved when a patient decides to request a prescription under the Oregon Act, or maybe the professional will always decline to be involved for reasons of conscience. If a health care professional has responsibility to care for a patient who requests a prescription for medication to end life, but declines to participate, the professional should inform the employer as soon as possible and ask for assistance in transfer of responsibility. When the health care professional has contracted directly with an individual patient who is considering utilizing the Oregon Act, the professional who objects to involvement should work with the patient to transfer responsibility to another qualified health care professional.

Health care professionals, especially those who care for patients with terminal illness, should be familiar with the Oregon Death with Dignity Act and related administrative rules and evolving case law. They should also be familiar with their agency's policies and procedures within the Oregon Act, and the ethical and moral issues associated with end-of-life decisions, personal choice, advance directives, and POLST (Physician's Orders for Life Sustaining Treatment). Some health care institutions, considered health care professionals under the Oregon Act, will choose not to participate in the Oregon Act and individual health care professionals must respect the mission, values, and policies of these institutions. Discussions between the patient and the health care professional regarding end-of-life options, including Oregon's Death with Dignity Act, should not, however, be prohibited by institutional policy (see *The Meaning Behind the Patient's Request*).

Health care professionals may need to review cases, both formally and informally, where ODDA was chosen by a patient. This review allows staff to discuss their concerns, review cases after the death, and/or to debrief situations that may warrant further discussion or intervention. Health professionals may already have mechanisms in place that deal with staff or employee concerns that arise from the request for exploration and/or use of ODDA, the implementation of the Oregon Act, and/or a review of the case after the death. These could include team meetings, ethics committees, staff support, or bereavement follow-up.

The Oregon Act requires the physician to counsel the patient to have another person present when the patient takes the medication. A health care professional may be the person present when the patient takes the medication to end life, but the level of assistance he or she may give to the patient is not clear. Lack of clarity in the Oregon Act leaves it to licensed health care agencies and professional organizations to establish policies and standards regarding assisting patients in self-administering medication as set forth in the Oregon Act. A qualified patient who is capable of requesting the prescription under the Oregon Act may not be able to self-administer the medication without assistance. The Oregon Act is clear that no individual is authorized to end a patient's life by lethal injection, mercy killing, or active euthanasia.[15] In making a decision to assist a patient with self-administering the medication, the health care professional should be certain that the patient remains in control of the decision, timing, and every aspect of the action.

A health care professional may not know all of the details regarding the patient's decisions about ODDA, advance directives or POLST. However, the professional is responsible within his or her scope of practice and with the available information to assess the patient's condition and to provide appropriate intervention. A decision to initiate life-saving interventions should be based on the information available about the patient's decisions regarding ODDA, advance directives, POLST and on professional judgment.

Under the Oregon Act the patient may rescind his or her request at any time and for any reason without regard to his or her mental state.[16] If, after taking the prescribed medication, the patient indicates a change of mind, any health care professional who is present or called should take steps to initiate life-saving measures. An added complexity occurs when a family member, rather than the patient, communicates the patient's decision to rescind. The potential for conflict between the patient and family on this matter puts the health care professional in a difficult position with regard to appropriate action. The Oregon Act clearly provides that only the patient may rescind the decision.

Guidelines

8.1 Health care professionals who care for patients with terminal illness should consider their personal values and ethics relative to participation under the Oregon Act.

8.2 Within his or her competence and scope of practice, the health care professional should explore the meaning behind a patient's request for a lethal dose of medication, determine what information or other care options the patient may need, and refer the patient to his or her attending physician.

8.3 The health care professional who declines to care for a patient who plans to take medication to end life under the Oregon Act should arrange a transfer or request assistance from the employer to transfer responsibility for the patient to another qualified health care professional.

8.4 Health care professionals may already have mechanisms in place that deal with staff and/or employee concerns that arise from the exploration or request for ODDA, the implementation of the Oregon Act, and/or case review. The professional may want to consider the utilization of existing resources, such as team meetings, staff support groups, ethics committees, or bereavement coordination to debrief cases which the staff believe need further discussion or intervention. Health care professionals might consider the development of new or different ways to address staff concerns.

8.5 The Oregon Act allows the patient to rescind the request for ODDA at any time. If after taking the prescribed medication the patient changes his/her mind, a health care professional who is present or called should take steps to initiate life-saving interventions.

8.6 A decision to initiate life-saving interventions will be based on professional judgment and on the available information about the patient's decisions regarding ODDA, advance directives and POLST.

8.7 A health care professional who is with the patient when he or she takes the medication should provide care and comfort to the patient and family. The Oregon Death with Dignity Act does not provide guidance on the degree of assistance with self-administration that may be given by another person. Nurses in particular have questions concerning this issue. The Oregon Act does not alter the existing standards and scope of practice of nurses in Oregon.

8.8 A health care professional that utilizes volunteers should develop policies and standards for the roles and responsibilities of the volunteer in relation to the Oregon Death with Dignity Act, and inform the volunteer of these guidelines in orientation. A health provider that employs personal care professionals or aides should develop policies and standards for the roles and responsibilities of the employee in relation to the Oregon Death with Dignity Act, and inform the employee of these guidelines in orientation.

8.9 The Oregon Act does not alter the existing standards or scope of practice for Licensed Clinical Social Workers or those working toward licensure in Oregon. Social workers should refer to the National Association of Social Workers (NASW) Code of Ethics and to the Policy Statement from NASW on End-of-Life Decisions, and the practice guide entitled NASW Standards for Social Work Practice in Palliative and End-of-Life Care.[17]

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9. Mental Health Consultation

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The Oregon Death with Dignity Act outlines a specific role for psychiatrists and psychologists. If the attending or consulting physician believes that the patient may be suffering from a "psychiatric or psychological disorder, or depression causing impaired judgment," a mental health evaluation is mandated. Either a licensed psychiatrist or licensed psychologist may perform the evaluation. Once the patient is referred, the attending physician may write a prescription under the Oregon Act only if the mental health professional assesses that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment. In addition, the mental health professional should evaluate if the person is "capable," that is, "has the ability to make and communicate health care decisions, including communication through persons familiar with the patient's manner of communication if those persons are available."[1] The mental health consultation as outlined in the Oregon Act, is a form of a capacity or competence evaluation, specifically focused on capacity to make the decision to hasten death by self-administering a lethal dose of medication. In the first ten years after enactment of the Oregon Death with Dignity Act, 11% of persons who died by a lethal dose of medication were evaluated by a mental health professional.[2] None of the 49 people who died by lethal prescription in 2007 were referred for a mental health evaluation.[3]

Mental health professionals may choose not to provide this type of consultation for conscientious reasons (see *Conscientious Practice*). In a survey of 290 U.S. forensic psychiatrists, 24% believed that psychiatric consultation for the purposes of determining competence for ingesting a lethal dose of medication was unethical.[4] Oregon psychiatrists and psychologists are divided on the ethical permissibility of the Oregon Death with Dignity Act. A 1995 survey of Oregon psychiatrists revealed that 56% support the implementation of the Oregon Act, but one third endorse that legal ingestion of a lethal dose of medication should never be permitted.[5] In a 1996 survey of Oregon psychologists, 78% supported enactment of the Oregon Death with Dignity Act.[6]

The American Psychological Association (APA) "Working Group on Physician Assisted Suicide" neither supports nor decries the Oregon Act, but encourages psychologists to be informed about policy and research related to the Oregon Act, to be aware of their own views and possible biases regarding eligibility for the option, and to be sensitized to possible social pressures that may contribute to the perception that vulnerable populations are more expendable. Psychologists are also advised to "fully explore alternative interventions (including hospice/palliative care, and other end-of-life options such as voluntarily stopping eating and drinking) for clients considering" this alternative.[7]

Mental health professionals' views on the ethical permissibility of the Oregon Act are likely to influence the standards used in diagnosing a mental disorder and determining whether the mental disorder causes impaired judgment. In the survey of U.S. forensic psychiatrists, those who were morally opposed to the Oregon Act were more likely to advocate a more stringent standard for evaluating competence and more likely to believe that depressive disorders would automatically render a patient incompetent to choose ingestion of a lethal dose of medication.[4] Oregon psychiatrists' and psychologists' positions on legalization of the Oregon Act influenced their willingness to evaluate patients who request a prescription under the Oregon Act and how they would follow up an evaluation. For example, 72% of psychiatrists opposed to the Oregon Act would refuse to perform this type of evaluation, compared to only 33% of those who favored the Act.[5] Despite majority support for legalization of the Oregon Act, only 36% of psychologists in Oregon were willing to perform these evaluations.[6] Interviews with physicians in Oregon who have received requests under the Oregon Act confirm their difficulties in finding a mental health professional to evaluate the patient, especially if a home visit is required (Ganzini, unpublished data). Most psychiatrists and psychologists who opposed the Oregon Act would work to prevent the patient from taking the medication to end his/her life, even if they found the patient competent. These data suggest that mental health professionals who are either strong proponents or opponents of this Oregon Act may have difficulty objectively evaluating patients and should consider declining. The mental health professional should disclose personal biases to the attending physician at the time of referral. The patient's therapist should not serve in this capacity, though he/she may provide invaluable insights to the mental health consultant.[8]

The Evaluation Process

The psychiatrist/psychologist should hold a valid Oregon license and have experience in psychiatric diagnosis, capacity evaluations, and evaluation of medically ill patients. Experience in working with dying patients in other settings may be helpful. Mental health professionals are qualified to evaluate capacity because of their expertise in diagnosing psychiatric disorders, examining mental status, and understanding irrational forces that influence decision-making. The consultation will usually include a record review, discussion with the referring physician, patient interview and assessment, and caregiver and family interviews (with the patient's consent). Eighty-six percent of patients who die by ingestion of medication under the Oregon Act are enrolled in hospice[2] and hospice practitioners may have important insights into potentially reversible conditions and mental state. If the mental health consultant perceives a conflict of interest, financial or otherwise, which might influence his/her decision-making, he/she should decline to perform the evaluation. Mental health professionals may decline to evaluate the patient or to even suggest colleagues who could evaluate the patient for conscientious reasons.

The evaluation should focus on assessing for mental disorders such as depression and delirium, the patient's decision-making capacity, and factors that limit decision-making capacity such as mental disorders, knowledge deficits, and coercion. Dementia may co-occur with a terminal illness. Mild dementia does not automatically disqualify a terminally ill person from Oregon's law; the evaluator must determine whether the patient retains capacity for medical decisions. The ability to understand the nature of the intervention, risks, and benefits of a prescription under the Oregon Act may be straightforward, but the ability to understand the risks and benefits and likelihood of success of alternative interventions can be difficult, especially for very ill patients, and should be a focus of the interview. Patients should be able to appreciate the information as shown by the ability not only to understand the facts but also to apply the information to his or her own situation.

The mental health professional is obligated to maximize the patient's ability to perform well on the examination.[9] The patient should be seen individually, as he/she may feel more comfortable talking about concerns such as being a burden to others. Many patients imagine an adversarial process. Rapport is important. Ill patients may tire easily. The examiner should be prepared to modify the examination based on the patient's tolerance. An extended evaluation may not always be feasible, depending on the patient's preferences, physical condition, limited time to live, financial constraints, and geographic location. Seeing the patient in his/her residence rather than the mental health professional's office may diminish the patient's exhaustion. Instruments such as the Geriatric Depression Scale,[10] the Folstein Mini-Mental State Examination,[11] or the Neurobehavioral Cognitive Status Examination[12] may be useful adjuncts to assess mood and cognition.

In the absence of a mental disorder, evidence of coercion or knowledge deficits, most patients will qualify for the Oregon Act. Attending physicians are unlikely to refer patients whom they know well or who are calm, lucid, and rational to a mental health professional. At the other end of the spectrum, physicians are likely to refer patients with severe depression or delirium for treatment, not a capacity evaluation. Cases in which some psychological symptoms are present and decision-making capacity is questionable or marginally compromised are the most likely to need referral. Although mental health professionals are skilled in diagnosing mental disorders, determining the role of a mental disorder such as depression on decision making is more difficult, even by expert assessment. In surveys of Oregon mental health professionals, only 6% of psychiatrists and psychologists were very confident that they could determine whether a mental disorder was influencing the judgment of a person requesting a prescription under the Oregon Act, if they only saw the patient once.[5,6] They were more confident about assessing decision-making capacity over an extended period of time.[5,6] In a study of 290 U.S. forensic psychiatrists, "58% indicated that the presence of a major depressive disorder should result in an automatic finding of incompetence for the purposes of obtaining assisted suicide".[4] As such, of the two components of the mental health assessment (presence of a mental disorder and determination of its influence) the greatest weight in determining eligibility for obtaining medication under the Oregon Act should be on whether or not a mental disorder such as depression can be diagnosed.[13]

The consulting mental health professional should feel free to communicate to the attending physician the standard he/she used for capacity and his/her degree of confidence regarding the determination of capacity.[4,5,14] Even if the evaluator cannot say with confidence whether the patient has or lacks decisional capacity, the attending physician will be able to use the information that the mental health professional provides. The consultant can suggest interventions to enhance capacity, ask to reevaluate the patient after treatment is provided, or recommend a second opinion from another mental health professional.[15] Once the patient is referred for a mental health evaluation, the attending physician may write a prescription for a lethal dose of medication only if the mental health professional can state that within his/her standards, the patient meets the criteria of the Oregon Death with Dignity Act.

Even when a mental disorder is absent and decision-making appears intact, psychotherapeutic interventions may relieve suffering. The mental health clinician's traditional role includes helping patients with coping and decision-making. As such, it is important for the mental health professional to understand the patient's overall situation and factors contributing to his/her request for medication with which to end life. These factors may include the patient's access to or attitudes about medical care, communication with the attending physician, his/her quality of life, belief system, life history, financial and family issues and experiences with deaths of others (see *Hospice, Palliative Care, and Comfort Care* and *Financial Issues*). The mental health consultant should explore with the patient the attitudes of family members or a decision to conceal the request for a prescription under the Oregon Act from the family (see *Family Needs and Concerns*). The mental health professional should also assess communication in the relationship between the attending physician and the patient.

The mental health consultant should support autonomous choice and attenuate the anguish of the dying process.[14] The patient may dread particular aspects of the future; struggle to find meaning in remaining life; feel guilt, low self-worth, anger, or worry about being a burden to others. Previous experiences with other dying persons may distort the patient's understanding of alternatives. Illness or personality may impede the patient's ability to think flexibly or to consider other alternatives. The request for a prescription under the Oregon Act may be an attempt to cope with loss of control and pending dependence on others.[16-19] The mental health consultant can help by reframing alternatives for the patient, exploring other methods for the patient to maintain control, and countering negative thinking.[17] The patient may question the mental health professional's motives, however, if the consultant puts too much emphasis on finding alternatives.[19]

Many patients may qualify under the Oregon Act yet still benefit from supportive counseling. The mental health consultant may choose to recommend individual supportive psychotherapy, family therapy, or referral to spiritual or other support services. Many of these services are available to those enrolled in hospice. If the mental health professional finds the patient competent and without a mental disorder that is influencing the desire to obtain a lethal dose of medication, refusal of further mental health treatment by the patient does not constitute a legal barrier to receiving a prescription for a lethal dose of medication.

Mental Disorders that may Influence Decision-Making

Mental disorders are the most common reasons why decision-making capacity is impaired, but not all psychiatric disorders automatically impair decision-making abilities. Disorders such as Alzheimer's disease occur in half of people over age 85 causing both difficulty in remembering the details of the illness and impairing the patient's ability to weigh risks and benefits and, applying the information to his/her own situation.[20,21] Studies of geriatricians, psychiatrists, and neurologists show high levels of disagreement among these professionals when assessing the ability of persons with mild Alzheimer's disease to make medical treatment decisions, though consistency can be improved when clinicians are made aware of applicable legal standards.[22,23] Some very physically ill patients will have mild cognitive impairments not meeting the criteria for dementia. These patients may not be impaired in their capacity to understand the risks and outcome of ingesting a lethal dose of medication or to recite the alternatives (e.g., hospice), but their ability to truly appreciate complicated palliative alternatives with their attendant uncertainties may be taxed.

Delirium is common in the final weeks of life, especially when high doses of opioids are needed to control pain.[24,25] Delirium is characterized by problems with attention, concentration, and memory. Delirium almost universally impairs decision-making capacity, and even when subtle can affect a patient's ability to see options clearly and make an informed decision and may lower inhibitions to ingesting a lethal dose of medication.[23] However, impairments in decision-making capacity due to delirium can wax and wane. Some patients will have suffered delirium during some portion of their treatment and may miss critical information regarding their disease. This lack of information can be overcome with patient education after the delirium has resolved.

Alcohol misuse may continue into the terminal period. Although the patient may meet the criteria under the Oregon Act for a prescription, he/she may impulsively ingest the medication. The attending physician should be advised of these concerns.

Depression is a common diagnosis among terminally ill patients desiring hastened death.[17,26-28] Oregon primary care physicians have appropriately expressed doubt about their ability to diagnose depression in these patients,[29] though in a recent survey of physicians who received requests, only 9% were uncertain if the patient had depression and no patient about whom the physician was uncertain received a prescription under the Oregon Act.[16] Even for mental health professionals, diagnosing a major depressive disorder in terminally ill persons can be difficult. What appear to be depressive vegetative symptoms such as weight loss and loss of energy may be due to the underlying disease in terminally ill patients. Mild psychological symptoms such as sadness, hopelessness, and difficulty experiencing pleasure may be realistic responses to a terminal prognosis and the limitations of severe medical illness. Unremitting low mood and anhedonia, despair, despondency, and pervasive low self-esteem are hallmarks of significant depression. Psychotherapy and medications are effective for treatment of depression in terminally ill persons. The patient's life expectancy and ability to tolerate antidepressant medications may limit treatment options. While psychostimulants are effective within several days of initiation, other medications take several weeks to be effective.[25]

Depression may impair patients' ability to understand their options, diminish the ability to appreciate the benefits of life, and magnify the burdens. Studies of elderly patients interested in life-sustaining medical treatment indicates that mild-moderate depression has little effect on patients' treatment decisions, but severe depression has a substantial effect.[28,30] A survey of Oregon physicians about their experiences with requests for prescriptions under the Oregon Act suggests that most proceed cautiously. Although 20% of patients who requested a prescription were depressed, none received a prescription from the surveyed physicians.[16] However, in a study of 58 individuals seeking a prescription under the Oregon Act, one in four were assessed to have major depressive disorder.[31] Of the 18 who received a lethal prescription, 15 (83%) had no evidence of a mood disorder, but three were diagnosed with major depression. All three died by lethal ingestion within two months of the research interview. This suggests that the practice of the Oregon Death with Dignity Act through 2006 did not include adequate assessment of all patients for mental health conditions that could impair judgment. Specifically, more vigilance and systematic examination for depression for these patients is needed.

Outside the context of terminal illness, the relationship between suicide and depression is very strong: some psychiatric disorder is present at the time of death in 90% of completed suicides.[13]

Treatment of psychiatric disorders in those who attempt suicide is very effective in abolishing suicidal ideation. This is the basis for our recommendation that patients who request a medication for the purpose of ending life be systematically screened for depression and referred for a mental health evaluation if screening indicates depression. Screening instruments that could be used include the *Patient Health Questionnaire-9* (*PHQ-9*), which is reliable, validated, and easy to administer. Further study is needed to determine whether depression treatment will alter desire for a prescription under the Oregon Act in terminally ill patients.

Guidelines

9.1 We strongly recommend that all patients who request a lethal prescription under the Oregon Act be screened for depression with a validated instrument such as the *PHQ-9. Other possible instruments could be used.* If the screening indicates possible depression, the person should be referred to a psychiatrist or a psychologist.

9.2 Mental health professionals with strong personal biases for or against the Oregon Act should consider declining the consultation. Biases should be disclosed to the attending physician at the time of the referral.

9.3 The mental health consultant has two roles. The first, as outlined in the Oregon Death with Dignity Act, is to determine the patient's specific capacity to make the decision to hasten death by self-administering a lethal dose of medication. The second, a traditional role, is to evaluate for any remediable sources of suffering.

9.4 Mental health professionals may decline to participate in any aspect of the Oregon Act.

9.5 When a mental health consultant cannot make a determination of capacity with confidence, the consultant can suggest treatments, reevaluate, or recommend a second mental health evaluation.

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

10. Pharmacists and Pharmacy-Related Issues

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The Oregon Death with Dignity Act presents a number of professional and ethical questions for pharmacists because the focus and the end point of the Oregon Act is the prescription for a lethal dose of medication that they may be asked to fill (see *Conscientious Practice* and *The Role of Other Health Care Professionals*). This chapter addresses some of the ethical challenges of pharmacists' participation in the Oregon Death with Dignity Act. Regardless of the details of any particular clinical situation, persons with terminal illness, their families, and their caregivers must be treated with the utmost of professional care, confidentiality and respect.

Information for Pharmacists

The Oregon Act states, "No health care provider shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the provision to a qualified patient of medication to end his or her life in a humane and dignified manner."[1] As defined by the Oregon Act, the term "health care provider" includes the pharmacist and a "health care facility." Pharmacists who choose to participate are encouraged to adopt policies and procedures for dispensing and medication counseling, as well as for the confidential handling of prescriptions and any required reporting forms for prescriptions written under the Oregon Act.

ORS 127.885, subsection 4.01 of the Oregon Act was amended in 1999 to provide that a health care facility may prohibit an employee from participating in the Oregon Act on the premises of the facility. Pharmacists must know their employers' policies regarding the Oregon Act. The Task Force encourages respect for the ethical positions of both individual pharmacists and of each health care facility. Pharmacists are bound by confidentiality requirements under Board of Pharmacy rules (OAR 855-041-0103) and all other legal and ethical standards for confidentiality of patients' health care information.

It is possible that a patient or family member may ask a pharmacist for information about the Oregon Death with Dignity Act. The pharmacist must be respectful of these inquiries. However, these patients should be referred to their attending physician to explore their questions and concerns in greater detail (see *The Meaning Behind the Patient's Request*).

The idea of participating in the Oregon Death with Dignity Act may evoke personal, moral and ethical questions for health care professionals (see *Conscientious Practice*). In deciding whether or not to participate, pharmacists need to examine their personal and professional ethics, and any policies of their employer related to the Act, so that they are prepared to meet their clinical, ethical and legal responsibilities in case they are asked to dispense a medication pursuant to the Oregon Act.

Resources exist that may assist the pharmacist. The *American Pharmaceutical Association* and *American Society of Health System Pharmacists* have published position statements outlining the professional responsibilities of a pharmacist when faced with moral, religious or ethical controversies. The *Oregon Board of Pharmacy* has issued a position statement describing pharmacists' professional responsibility when faced with a moral or ethical dilemma.

The Non-Participating Pharmacist

Many pharmacists choose not to participate in the Oregon Death with Dignity Act. If a non-participating pharmacist receives a request from a physician to dispense medication under the Oregon Act, he/she should immediately inform the physician of his/her decision to not participate. The non-participating pharmacist may refer the physician to a pharmacy or pharmacist who is willing to participate. However, the pharmacist is under no obligation to make such a referral. If the non-participating pharmacist does not know of a pharmacist who is willing to participate or chooses to not provide a referral, he/she should inform the attending physician.

A pharmacist who has declined to participate may be asked to furnish the patient's prescription records to the attending physician or participating pharmacist to assure appropriate continuity of care. The patient's medication history may be relevant, both in terms of continued pain and symptom management and in terms of any drug therapy that could impact the absorption, distribution or metabolism of the anticipated use of the lethal dose of medication. Pharmacists must maintain the privacy of patient records; however, when specifically requested, pharmacists must provide this information to a physician and/or another pharmacist who are actively involved in the patient's care.

The Participating Pharmacist

For pharmacists who are not precluded from participation by their employer and who choose to dispense medication pursuant to the Oregon Act, the professional, legal and regulatory standards that apply to all medication dispensing must be followed. Upon dispensing, pharmacists are required to review available patient information and each prescription drug order to assure therapeutic appropriateness. The pharmacist should consult with the physician if any questions arise regarding a prescription or a patient's drug therapy. In addition, pharmacists are required to provide information and counseling about the medication when dispensing any new medication or any refilled prescription that has a change in directions, dose, route of administration or conditions or circumstances that could impact the patient's current therapy. Medication counseling should include information on matters that a reasonable and prudent pharmacist would deem significant.

Medication counseling must be provided to the patient or the patient's agent orally and in person whenever practical. Patient counseling for medications to end life pursuant to the Oregon Act should be conducted in a private area, well away from other patients and pharmacy personnel, to assure confidentiality and comfort. The most effective patient counseling occurs in an atmosphere free of distractions. Oral counseling by the pharmacist is not required when the patient refuses or when the pharmacist determines that another form of counseling is more appropriate. Examples include when the medication is given to the physician who will personally provide the medication and counseling to the patient, when another health care professional would appropriately provide counseling, or when another form of counseling would be more appropriate (OAR 855-019-0230). The pharmacist may offer to provide medication counseling over the telephone for patients who are unable to pick up their own medication. Ultimately, the pharmacist must determine the most reasonable method to provide necessary information for the appropriate use of the medication in every circumstance. Pharmacies should have a policy or procedure in place for documenting patient-specific information and medication counseling.

OAR 333-009-0010(3), adopted by the Oregon Department of Human Services - Public Health Division in 1999 and amended in 2006, requires that any health care professional (pharmacist, physician, or health system), within 10 calendar days of dispensing medication pursuant to the Oregon Act, must file a copy of the Dispensing Record Form (see *Forms*) with the State Registrar, Center for Health Statistics, 800 NE Oregon Street, Suite 205, Portland, OR 97232 by mail or in person, or by facsimile at (971) 673-1201. Information to be reported must include the patient's name and date of birth; the prescribing physician's name and phone number; the dispensing health care provider's name, address, and phone number; the name and quantity of medications dispensed; the date the prescription was written; and the date the medication was dispensed.

Drug Information

There may be a misperception among the general public and some health care professionals that the ingestion of a lethal dose of medication will immediately cause death in every case. Experience under the Oregon Act indicates that the time from medication ingestion to death is variable. For most individuals, death occurs in less than four hours. According to the Oregon Department of Human Services[2], by the end of 2007, 341 patients have died under the terms of the law. Complications were reported for 20 patients. Of these, 19 involved regurgitation and none involved seizures. The median time between ingestion and unconsciousness was 5 minutes with a range of 1 to 38 minutes. The median time between ingestion and death was 25 minutes with a range of 1 minute to 48 hours. One patient (2007) lived 3 ½ days and one (2005) regained consciousness after ingesting the lethal dose of medication and then died 14 days later from his illness rather than from the medication. Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

As part of the decision-making process, patients need to talk with their attending physicians to plan for the possibility of unexpected outcomes, such as delayed death or other complications, when the patient self-administers the medication. If the patient has shared with family his/her wishes to take medication to end life, then the family should be included in these discussions. The patient and anyone else who will be present when the patient self-administers the medication must be informed of the probable time line of outcomes following ingestion. It must be explained that the medication may act more rapidly or more slowly than expected.[2,5]

Besides the information available in the DHS Annual Reports, some of the organizations listed under resources at the end of this chapter have developed recommendations for specific drug combinations and sequences of administration, which are available to physicians and pharmacists. Further information and reports from the Netherlands regarding specific drug combinations are also available.[8-10] The Task Force has not independently evaluated this information and does not advise on specific medications used under the Oregon Act.

Information for Physicians

When an attending physician writes a prescription for medication pursuant to the Oregon Act, personal communication with a pharmacist in order to determine his/her willingness to dispense it will help ensure confidentiality and avoid presentation of the prescription to a pharmacist unwilling or unable to participate. The Oregon Act and the Oregon Medical Board's administrative rule, OAR 847-015-0035, require this advance communication in order for the attending physician to personally issue the prescription to the pharmacist. This contact will also allow the attending physician and pharmacist to work together on medication-related details, allow them to confer regarding any questions about drug, dose, or route of administration, and to discuss patient medication counseling issues. It is an opportunity for the attending physician and the participating pharmacist to discuss how the medication will be prepared, picked up, or delivered. The pharmacist may help facilitate the process by delivering the medication to the physician's office or to the patient's home (see *Attending Physician and Consulting Physician*).

If the attending physician obtains the prescribed medication from the pharmacist and personally presents it to the patient, then the attending physician and patient can choose the date and time for medication delivery and arrange to have counseling provided in the privacy of the home or office. This will avoid possible concerns about lack of privacy or confidentiality in public areas of a pharmacy or hospital. In this scenario, the physician assumes responsibility for providing appropriate medication information to the patient and, with the patient's permission, family members. If the attending physician and patient desire, the pharmacist may be able to deliver the medication to the patient's home at an appropriate time.

A pharmacist who provides medications for the attending physician to present directly to the patient must assure that the attending physician is provided information on preparation, stability, storage, and any other information necessary to assure safety and efficacy. The attending physician should confer with the pharmacist regarding important issues about the specific drug or drug combination. The pharmacist should discuss any questions or concerns with the physician. The attending physician should assess the patient's knowledge of the medication and its proper use, the purpose and expected outcome of ingesting the medication, and the voluntary nature of taking the medication. The attending physician should also tell the patient: 1) how to safely and properly store the medication; 2) how to mix or prepare the medication; 3) that complications are possible; 4) what to do in the event of a complication and 5) disposal instructions in the event the medication is not taken. Special instructions might include sequence and timing when more than one medication is being prescribed. The attending physician should allow time and encourage the patient to ask questions. If the patient or caregiver picks up the medication at the pharmacy, the pharmacist should provide similar medication counseling to the patient or caregiver.

Physicians who have registered with the Oregon Medical Board to be dispensing physicians may personally prepare and dispense medications to their patients if they choose. Medications may be purchased from a licensed pharmacy, pharmaceutical wholesaler, or manufacturer. The Board's statutes and administrative rules found in ORS 677.089 and OAR 847-15-025 set guidelines for this practice.

Guidelines

10.1 Pharmacists, like other health care professionals, may choose to not participate, and are under no obligation to participate. If unwilling or unable to participate when asked by a physician, the pharmacist must inform the physician that they will not participate. The pharmacist must provide the pharmacy records upon request by the physician and may assist the physician in finding a willing pharmacist, but is under no obligation to do so.

10.2 It is the Oregon Board of Pharmacy's position that pharmacies must have policies and procedures in place to address employees' potential moral and ethical conflicts.

10.3 Pharmacists must be aware of and respect their employer's institutional policies regarding the Oregon Act before making any decision whether or not to participate.

10.4 Pharmacists need to assess their personal feelings and convictions about the Oregon Death with Dignity Act in order to appropriately respond to inquiries from physicians, patients, and others.

10.5 A participating pharmacist must be contacted by the physician prior to issuing a prescription under the Oregon Act. Attending physicians and pharmacists need to confer before a prescription is written to determine the pharmacist's willingness to participate and resolve other important details, such as drug preparation, stability and storage requirements, and patient medication counseling.

10.6 If the pharmacist has any question about the purpose or details of any prescription, it is his/her duty to confer with the prescriber and have those questions answered.

10.7 The attending physician may obtain the prescribed medication from the pharmacist and present it to the patient personally. The pharmacist can facilitate this by delivering the medication directly to the physician's office or to the patient's home.

10.8 The participating pharmacist should be prepared to discuss important pharmaceutical information and patient instructions with the physician. The attending physician assumes responsibility for advising on appropriate drug use when providing the medication directly to the patient.

10.9 Pharmacies should develop policies and procedures to ensure confidentiality for patients, physicians, and pharmacists in handling prescriptions issued pursuant to the provisions set forth in the Oregon Act.

10.10 The dispensing health care professional (pharmacist, physician, or health care facility) must report to the Oregon Department of Human Services within ten calendar days of dispensing a lethal dose of medication pursuant to the Oregon Act. The appropriate form can be found on the *DHS website*.

References

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Resources

Oregon Hospice Association
P.O. Box 10796
Portland, OR 97297
888-229-2104
info@oregonhospice.org
http://www.oregonhospice.org

Compassion and Choices
PO Box 101810
Denver, CO 80251-1810
800-247-7421
info@compassionandchoices.org
www.compassionandchoices.org

Compassion and Choices of Oregon
P.O. Box 6404
Portland, OR 97228
(503) 525-1956
contact@compassionandchoices.org
www.compassionoforegon.org

Physicians for Compassionate Care Educational Foundation
P.O. Box 6042
Portland, OR 97228-6042
(503) 533-8154
www.pccef.org

Internet

A variety of Internet resources can be found via commonly available search engines.

Oregon Board of Pharmacy
Oregon Department of Human Services

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11. Emergency Department and Emergency Medical Services

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Many patients who come in contact with the emergency medical services (EMS) system or go to a hospital emergency department (ED) near the end of life may not desire potentially life-saving interventions. When a patient self-administers a lethal dose of medication as set forth in the Oregon Act, the EMS system or an ED may become involved if complications develop, if the ingestion does not result in death, or if the time between self-administration and death is longer than the patient and family expect. In the Netherlands, complications or technical problems with euthanasia, as practiced there, were found in about 10% of cases.[1] According to the seventh-year report (2004) from the Oregon Department of Human Services – Health Services, in none of the cases of the 208 persons who died using the Oregon Act was EMS called to intervene. Delayed deaths have been reported. One patient survived 48 hours following the ingestion of a medication prescribed under the Oregon Act and one patient regained consciousness after taking the medication.[2] Over the ten years of the Oregon Act, 20 of 341 patients had a complication, 19 of these regurgitating some of the medication.[3] Emergency medical services were called for 4 patients, 3 to pronounce death and one to help a patient who had fallen.

Thus, even with careful planning, it is possible that deaths which take longer than expected might lead to occasional ambulance calls and transport to emergency departments. Although it has been rare to date, emergency physicians may care for patients who are brought to the ED. When this happens, emergency physicians will be faced with making critical decisions. While always providing comfort measures, they need to consider the circumstances under which potentially life-sustaining procedures can be refused or withheld after self-administration of the lethal dose of medication by a terminally ill person. While the Oregon Act states that health care professionals may decline to provide a prescription for medication to end life, it does not address moral objection by emergency care professionals or how to handle a delayed death. (see *Liability and Negligence* and Appendix A, *The Oregon Death with Dignity Act*). A study of emergency physicians in Oregon found that the 69% supported the Oregon Act, but 19% believe it is immoral.[4] Similarly, a study of emergency medical technicians (EMTs) found that 68% supported the Oregon Act while 17% believed that withholding resuscitation for patients who had ingested the lethal dose of medication is immoral.[5]

Attending physicians have an obligation, therefore, to educate their patients and, when possible, those who will be with the patients, about what to expect if they or their family members call 9-1-1 or go to an emergency department. That response may vary from one EMS system to another, or in the ED, depending on the physician who is on duty. It is possible that patients will get more life-sustaining treatment than they desire. It is strongly recommended that physicians make written documentation of their patient's wishes available at the bedside and accessible to emergency personnel, including a Physician Orders for Life-Sustaining Treatment (*POLST*) form with a do-not-resuscitate (DNR) order (see Appendix C, *Advance Directives and Physician*

Orders for Life-Sustaining Treatment). POLST is widely recognized and honored by EMS in Oregon, Washington and many other states (see *POLST*).[6]

The Oregon Death with Dignity Act requires the patient to self-administer the lethal dose of medication. Problems with involvement of EMS and the emergency department can be avoided if the attending physician is present or readily available at the time the patient ingests the medication (see *Attending Physician and Consulting Physician* and *Family Needs and Concerns*).

The Oregon Act contains no guidance for providing information to other health care professionals, such as emergency personnel, about the wishes and plans of patients (see *The Role of Other Health Care Professionals*). This opens up the possibility that a patient could arrive in the ED or be treated and possibly transported by EMTs without adequate documentation of his/her wishes regarding life-sustaining treatment or without evidence of compliance with the Oregon Act. Without this information, it will be difficult for emergency professionals to make resuscitation decisions. This underscores the importance of having available appropriate end-of-life orders, such as the *POLST*.

Conflicts may occur between the policies of the institution and the conscience of an ED professional (see *Conscientious Practice*). The potential for conflict also arises if a physician alone decides for or against resuscitation when other members of the health care team have strong personal beliefs. Allowing for moral objections in practice in the ED is problematic because of the need for rapid resuscitation decisions. Most institutional policies regarding conscientious practice rely on the ability to substitute health care professionals from other units in the institutions, which often is not feasible on an urgent basis in the ED.

Hospitals and EDs need to develop policies and procedures about making treatment decisions for terminally ill patients who have self-administered a lethal dose of medication pursuant to the Oregon Act. These policies must address several areas of concern, including: a) circumstances, if any, under which the hospital would allow such a patient to die without potentially life-saving interventions; b) provision of comfort care in the ED to terminally ill patients who have self-administered medications pursuant to the Oregon Act; c) documentation required for honoring patient wishes about life-sustaining therapy; and d) procedures for honoring conscientious practice by staff who are unwilling to withhold resuscitation from a patient who has ingested a lethal dose of medication pursuant to the Oregon Act.

EMS systems should develop protocols that address how paramedics and EMTs should respond if called to the scene where a person has taken a lethal dose of medication pursuant to the Oregon Act (see Appendix F, *Sample EMS Protocol*). EMTs and paramedics treat patients based on written protocols from their physician supervisor or orders from a physician at a base station hospital. Supervising EMS physicians should develop protocols to provide direction to EMTs in making resuscitation decisions for a patient who has taken medication pursuant to the Oregon Act. In most cases, these complex decisions should involve on-line medical consultation. If they haven't already, EMS systems also should develop protocols for honoring patient preferences regarding potentially life-sustaining treatment at the end of life, including POLST and DNR orders in the out-of-hospital setting. If the patient dies, EMS involvement likely will result in notification of the Medical Examiner, who may pursue further investigation (see *Oregon Department of Human Services Reporting*).

Guidelines

11.1 Attending physicians should counsel their patients and family members or caregivers (with the patient's permission) about what to expect after the patient takes medication in compliance with the Oregon Act, including the probable length of time between administration and death and side effects of the medication. This counseling should include what to expect if they call 9-1-1 or go to an emergency department.

11.2 Attending physicians and patients should consider completing advance directives and the POLST, which include DNR orders, to provide written direction about patient wishes when the patient is later unable to express them (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). Provisions need to be made to have these documents available should EMS be called to respond.

11.3 Hospitals and EDs need to develop policies and procedures for treating terminally ill patients who have taken medication pursuant to the Oregon Act. These policies must address the withholding of potentially life-saving interventions, the provision of comfort care, and procedures for conscientious practice by ED personnel.

11.4 EMS systems should develop protocols that address how paramedics and EMTs should respond if called to the scene of a terminally ill person who has ingested medication obtained under the Oregon Death with Dignity Act and how to honor patient preferences near the end of life, as documented by advance directives, the POLST form and other DNR orders (see Appendix F, *Sample EMS Protocol*).

References

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2. Niemeyer D, Leman R, Hopkins D, Kohn M. Seventh Annual Report on Oregon's Death with Dignity Act. March 10, 2005. Department of Human Services, Health Services, Office of Disease Prevention and Epidemiology, Portland, Oregon.

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12. Responding to Professional Non-Compliance

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act establishes guidelines and safeguards described in Oregon statute ORS 127.800 to 127.890, 127.895, and127.897. Through this guidebook, we have identified appropriate professional standards in the broader care of terminally ill persons and specifically reviewed quality of care practices related to professional compliance with the Oregon Death with Dignity Act.

Participation in the Oregon Death with Dignity Act may involve (in addition to physicians) a variety of health professionals who hold state licenses. Physician assistants, nurses, nurse practitioners, psychologists, social workers, pharmacists, and emergency personnel are all licensed or certified professionals, and, while they cannot order a prescription under the Oregon Act, they may be involved in various other capacities with the Oregon Act from direct patient care to counseling (see *The Role of Other Health Professionals* and *Mental Health Consultation*). Licensing boards are responsible for regulating and disciplining health care professionals. To hold a state license is a privilege and confers upon the holder the obligation to practice in a competent, professional, and legal manner.

Throughout the Guidebook we have outlined some anticipated concerns for those participating in the Oregon Death with Dignity Act. No doubt others will arise. If a health care professional is aware of a physician or other health care provider who is non-compliant with the safeguards as outlined in the Oregon Act, or otherwise delivers significantly substandard care, he/she must report that individual to the appropriate licensing board. For example, if a physician provides a lethal dose of medication to a clearly incompetent patient or to a patient who is not terminally ill, or a nurse administers an injection with the intent to kill rather than for comfort, a report must be filed with the respective licensing board. Likewise, a physician who repeatedly provides grossly inadequate measures for comfort of their dying patients must also be reported.

This obligation to report is not new. Licensees must report to the appropriate licensing or certifying board those licensees who are medically incompetent, engage in unprofessional conduct, or have a physical or mental impairment that affects their ability to safely practice their profession. There is a legal requirement for health care professionals to report a fellow health care professional within their same discipline. Failure to report a fellow licensee may result in disciplinary action against the professional who knew of the inappropriate or illegal conduct. A professional in a different discipline may be ethically required to report to the appropriate board. Reporting to a physician group, insurance carrier, hospital, clinic, or an agency responsible for care may also be required. These groups should be consulted independently regarding reporting obligations. At the time a prescription under the Oregon Act is written, the prescribing physician is required to report information regarding the patient to the *Oregon Department of Human Services*. Failure to report in a timely fashion is considered non-compliance with the Oregon Act, and Department of Human Services will report to the appropriate licensing board.

For further information, see *Oregon Department of Human Services Reporting*.

If there are questions about a physician's or other health care provider's practice relative to appropriate comfort care or participation in the Oregon Act, the licensing board should be contacted. Since the goal of comfort care is to relieve pain and suffering, dying patients should receive sufficient dosages of appropriate medications. In particular, medications to relieve suffering should not be withheld on the basis of physiologic parameters when patients continue to experience pain. Opioids and other controlled substances should not be withheld because of fear of hastening death; however, it is essential to document the need for medication in the patient's medical record. Each board has an administrator and skilled medical professionals on staff to provide assistance.

Guidelines

12.1 Health professionals must report to the appropriate licensing and certifying board professionals who engage in medical incompetence or unprofessional conduct. Failure to report a licensee in the same profession may itself result in discipline against the license of the professional who knew of the illegal conduct.

12.2 If there is a concern about the conduct of a professional in another health care discipline, there is an ethical obligation to act. There may be a requirement for institutional or professional board reporting.

12.3 If a health professional has questions about the appropriateness of a practice relative to comfort care or participation in the Oregon Death with Dignity Act, he/she should consult the staff of the appropriate licensing board for guidance.

12.4 Physicians and other health care providers with prescriptive authority need to ensure that patients receive sufficient dosages of appropriate medications for the relief of pain and suffering. The Oregon Medical Board encourages physicians to employ skillful and compassionate pain control for dying patients. The Oregon Medical Board investigates allegations of under prescribing for pain in the same manner as over-prescribing.

12.5 Licensees should not report another professional to the licensing board simply because the other professional has cooperated with the request for a prescription under the Oregon Act. The Oregon Medical Board does not consider good faith compliance with the Oregon Act unprofessional conduct.

Resources

While not authorized to write or fill a prescription under the Oregon Death with Dignity Act, other health care providers may be involved and on occasion may have the need to report to the appropriate licensing board.

Oregon State Board of Clinical Social Workers
3218 Pringle Road SE, Ste 240
Salem, OR 97302-6310
(503) 378-5735
oregon.bcsw@state.or.us
http://www.bcsw.state.or.us/

Oregon Department of Human Services
Oregon Public Health Services
800 NE Oregon Street, Ste 930
Portland, OR 97232
(971) 673-1222
ohd.hr@state.or.us
http://oregon.gov/DHS/ph
http://www.oregon.gov/DHS/ph/pas/index.shtml
http://www.oregon.gov/DHS/ph/pas/pasforms.shtml

Oregon Medical Board (Physicians, Physician Assistants, EMT Scope of Practice)
1500 SW First Avenue, Ste 620
Portland, OR 97201-5826
(971) 673-2700
bme.info@state.or.us
http://www.oregon.gov/OMB/

Oregon State Board of Nursing (RNs, LPNs, CNAs, NPs)
17938 SW Upper Boones Ferry Rd.
Portland, OR 97224-7012
(971) 673-0685
oregon.bn.info@state.or.us
http://www.osbn.state.or.us/

Oregon Board of Pharmacy
425 State Office Building
800 NE Oregon Street #150
Portland, OR 97232
(971) 673-0001
pharmacy.board@state.or.us
http://www.pharmacy.state.or.us/

Oregon Board of Psychologist Examiners
3218 Pringle Road SE, Ste 130
Salem, OR 97302-6309
(503) 378-4154
oregon.bpe@state.or.us
http://www.obpe.state.or.us/

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13. Financial Issues

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Terminally ill patients may inquire about a prescription for a medication to end life for many reasons. With motivations ranging from pain or fear to philosophical or religious beliefs, each patient who expresses an interest in the Oregon Death with Dignity Act will do so for uniquely personal reasons (see *The Meaning Behind the Patient's Request*). This chapter discusses the health care professional's duty to ensure that real or perceived financial pressures do not inappropriately influence the patient's evaluation of all end-of-life options, including the request for a prescription under the Oregon Act.

For a growing number of Americans, financial issues are an important factor in medical decisions. More than one in ten Oregonians is uninsured, while many more are underinsured, particularly for end-of-life care. Hospice care is available to patients eligible for Medicare who elect hospice benefits and to patients eligible for the Oregon Health Plan. Most private Oregon insurers also offer coverage of hospice and home health services. Palliative and comfort care, however, commonly are left out. Some patients may have adequate health insurance, but lack the resources to pay for personal needs, in-home care, and other non-medical expenses associated with terminal illness and/or extended hospitalization. Payments for medications can also be a burden. While Medicare now offers a prescription benefit, it is important for beneficiaries to choose a plan that covers the medications they need. For those with severe pain, medications can be very expensive. The Task Force supports universal access to hospice and comfort care and encourages policy makers to allocate funding to assure access to comfort care for all terminally ill Oregonians.

Financial considerations have long played a role in end-of-life decision-making.[1] One study on the impact of illness on patients' families found that nearly a third of the families reported losing most of their savings or primary source of income as a result of a major illness.[2] Concerns about leaving family and loved ones in a perilous financial position following a terminal illness is one reason why many people complete advance directives and refuse life support.[3]

The Oregon Department of Human Services has reviewed data each year of the characteristics of patients who died after ingesting medication received under the Oregon Death with Dignity Act. Of the total of 341 ODDA patients, 63% had private insurance, 36% had Medicare or Medicaid, 1% had no insurance.[4] Nine (3%) patients mentioned financial implications of treatment as being an end-of-life concern. While experience with the Oregon Death with Dignity Act does not indicate that financial concerns are a primary motivator, health care professionals should be careful to identify patients who are considering a request for a prescription for a medication to end life as an answer to pressing financial concerns. Health care professionals can then more fully explore options with those patients.

Health care professionals should be aware of alternative sources of coverage for end-of-life care. The Oregon Health Plan (OHP) may be an option for low-income patients. OHP covers "comfort care," including hospice, in-home health services, pain management, and costs associated with the Oregon Death with Dignity Act. The federal Medicare program provides a prescription drug benefit and a hospice benefit, but does not cover a prescription under the Oregon Act. Federal funds may not be used to pay costs associated with the Oregon Act. HMOs may nonetheless elect to provide coverage of the Oregon Death with Dignity Act so long as coverage does not utilize federal funds, but not all have elected to do so. For more information on hospice, see *Hospice, Palliative Care, and Comfort Care.*

The potential impact of provider reimbursement on life support decisions is not a new issue. Some have long expressed concern that financial incentives in a fee-for-service mode encouraged excessive care, even beyond what the patient and/or family may have wanted. Changes in health care reimbursement practices have increased public concern about financial incentives that may influence patient care decisions in the other direction. Reimbursement methods can create actual or perceived conflicts for those caring for terminally ill patients with expensive, resource-intensive conditions. Patients and their families may fear that the quality of their care will be limited by the health care professional's financial considerations.

Conflict of interest refers to any situation in which an individual with responsibility for others might be influenced, consciously or subconsciously, by financial or personal factors that involve self-interest. End-of-life care is not the first context in which the conflict between a health care professional's patient care duties and personal financial interests has arisen. Because the dying process can be stressful, patients and families may experience heightened concern over real or perceived conflicts of interest. Those providing care to terminally ill patients must be particularly sensitive to this issue and remain willing to address it candidly should the need arise.

Guidelines

13.1 Any evidence that personal financial factors are underlying the patient's interest in a prescription for medication to end his/her life should be fully explored.

13.2 Physicians, hospitals, and others who may be perceived to have a direct or indirect financial interest in the care delivered to their patients should be sensitive to patient and family concerns about whether the financial interests impact care. Health care professionals must be willing to initiate an open discussion of these issues, including full disclosure of the provider's financial interest in the care provided to the patient, if and when the need arises.

References

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14. Oregon Department of Human Services Reporting

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The Oregon Death with Dignity Act allows terminally-ill Oregonians to self-administer a lethal dose of medication obtained with a physician's prescription. The law requires the Oregon Department of Human Services, Public Health Division, to collect information pertaining to compliance with the Oregon Act. These reporting requirements are essential for determining how many individuals receive prescriptions and ingest medications pursuant to the Oregon Act, and for assessing whether or not the safeguards built into the Oregon Act are being followed. In addition, the Oregon Department of Human Services must make available to the public an annual statistical report. The Department of Human Services' annual reports are available on the *Oregon Department of Human Services* web site and have been published as articles in the New England Journal of Medicine.[1-5] These reports offer insights into care of the dying and the impact of the Oregon Act in Oregon. While it is of paramount importance that accurate data be collected regarding implementation of the Oregon Act, the need for accurate data must be balanced with the concern for the confidentiality of patients and their health care professionals.

As specified in the Oregon Act, the Department of Human Services is required to "make rules to facilitate the collection of information regarding compliance with this Act" and to "annually review a sample of records maintained pursuant to this Act." The Department of Human Services adopted administrative rules in 1997, updated these rules in 1999 to reflect changes in the statute made during the 1999 legislative session, and updated them again in 2006.

The provisions of the administrative rules are described below (see *Oregon Department of Human Services Oregon Death with Dignity Act* site for a copy of the rules and the forms developed to assist physicians in documenting compliance with the requirements of the Oregon Act). The rules specify three reporting requirements. First, within seven calendar days of writing a prescription for medication to end the life of a qualified patient, the attending physician shall send the following completed, signed and dated documentation by mail to the State Registrar, Center for Health Statistics, 800 NE Oregon Street, Suite 205, Portland OR 97232, or by facsimile to (971) 673-1201: 1) The patient's completed written request for medication to end life; 2) one of the following reports prescribed by the Department: "Attending Physician's Compliance Form", or "Attending Physician's Compliance Short Form" accompanied by a copy of the relevant portions of the patient's medical record documenting all actions required by the Oregon Act; 3) "Consulting Physician's Compliance Form" prescribed by the Department; and 4) "Psychiatric/Psychological Consultant's Compliance Form" prescribed by the Department, if an evaluation was performed. Second, within 10 calendar days of a patient's ingestion of lethal medication obtained pursuant to the Oregon Act, or death from any other cause, the attending physician shall complete the "Oregon Death with Dignity Act Attending Physician Interview" form prescribed by the Department. Third, within 10 calendar days of dispensing medication pursuant to the Oregon Death with Dignity Act, the dispensing health care provider shall file a copy of the "Pharmacy Dispensing Record Form" prescribed by the Department with the State

Registrar, Center for Health Statistics, 800 NE Oregon St., Suite 205, Portland, OR 97232; or by facsimile to (971) 673-1201. Information to be reported to the Department shall include: (a) Patient's name and date of birth; (b) Prescribing physician's name and phone number; (c) Dispensing health care provider's name, address and phone number; (d) Medication dispensed and quantity; (e) Date the prescription was written; and (f) Date the medication was dispensed.

Attending physicians are encouraged to inform patients of the requirement that the Department of Human Services have access to data regarding implementation of the Oregon Act. They may wish to have the patient's written request for enacting the provisions of the statute include a statement of consent for release of medical records to the Department of Human Services. The patient and attending physician should discuss post-death arrangements as part of the overall plans. As discussed in the chapter, *Attending Physician and Consulting Physician*, the attending physician may want to be present at the time of death or make arrangements to be notified by the family immediately following the death. The attending physician could then notify the funeral home that this is an expected death and that he/she will be signing the death certificate. The death certificate will then be filed and processed according to routine procedures and the death will not go into the medical examiner's system. The Medical Examiner is required to investigate any death that is suspicious (i.e., not natural or expected).[6] In addition, if Emergency Medical Services (EMS) are present at the time of death the Medical Examiner will be called. Because medical examiner investigations allow for limited public disclosure,[7] the confidentiality of the patient cannot be assured in these instances. Additionally, family members may be questioned regarding the circumstances surrounding these deaths.

The death certificate originates in the mortician's office, and is sent to the physician to complete the cause of death information. The death certificate is then sent back to the mortician's office, which files it with the local health department. Finally, the death certificate is forwarded to the Department of Human Services, State Registrar for Vital Records. While the confidentiality of the death certificate can be assured once it has reached the local health department and the Department of Human Services, physicians must ensure confidentiality in the clinical setting. Because death certificates have multiple purposes, including settling the estate as well as for public health information, the Department of Human Services suggests physicians record the underlying terminal conditions as the cause of death and mark the manner of death "natural", rather than recording that the patient ingested a lethal dose of medication prescribed under the Oregon Death with Dignity Act. Death certificates should not be left on desktops or at nurses' stations. Health care professionals and institutions might consider implementing a policy of keeping all death certificates in envelopes marked "confidential" until they are formally filed.

Confidentiality is of paramount importance in ensuring compliance with this Oregon Act. The Oregon Act ensures that "information collected shall not be a public record and may not be made available for inspection by the public" (see *Liability and Negligence*). Thus, information regarding the identity of patients, health care professionals, and health care facilities obtained by the Department of Human Services with respect to compliance with the Oregon Act shall be confidential. Summary information released in Department of Human Services' annual reports will be aggregated to prevent identification of individuals, physicians, or health care professionals complying with the Oregon Act. Death certificates are also confidential: OAR 333-11-096 (1) states that the Department of Human Services "... shall not permit inspection of, or disclose information contained in ... death records, or issue a copy of ... any such record unless ... satisfied that the applicant has a direct and tangible interest in such record."

The Oregon Act does not assign enforcement authority to the Department of Human Services and is silent on what action the agency should take if non-compliance is encountered. When problems with documentation or reporting from physicians are encountered, the Department of Human Services will query those health care professionals for clarification. If the Department of Human Services encounters a violation of the Oregon Act, the individual committing the violation will be reported to the appropriate licensing board (see *Responding to Professional Non-Compliance*).

Guidelines

14.1 Physicians are advised to use the forms developed by the Oregon Department of Human Services as a good source of information about compliance with the Oregon Act (see *Oregon Department of Human Services Oregon Death with Dignity Act* site). These forms will serve to document compliance with the legislation and thus are a protective measure for physicians. The forms will ensure that the appropriate steps have been followed, facilitate record keeping, and limit the need for the Department of Human Services to have access to the actual medical record.

14.2 Attending physicians should inform their patients that they should let the physician know if they plan to take the prescription. Otherwise, the death may be investigated by the Medical Examiner. An investigation by the Medical Examiner may involve questioning family members about circumstances surrounding the death and confidentiality cannot be assured.

14.3 Physicians should inform their patients that the Oregon Department of Human Services will have access to forms (or medical records) that contain information regarding the patient's choice to pursue the Oregon Death with Dignity Act.

14.4 We encourage physicians to review their procedures to assure the confidentiality of death certificates.

References

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Resources

Statutes and Rules: General public health authority (ORS 431.110 and ORS 431.120); confidentiality of special morbidity and mortality studies (ORS 432.060); death certificate rules (OAR 333-11-096).

Oregon Administrative Rules: 333-009-0000 through 333-009-0030 (see *Oregon Department of Human Services Oregon Death with Dignity Act* site).

Oregon Department of Human Services forms and annual reports
http://www.oregon.gov/DHS/ph/pas/ar-index.shtml

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

15. Liability and Negligence

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The following discussion and guidelines examine a range of potential legal pitfalls in the Oregon Death with Dignity Act[1] (the "Oregon Act") and the precautions that may be taken against them. The best defense against liability, however, is to make sure that patients receive appropriate care, that only qualified patients are supplied with medication to end life, and that only the limited assistance authorized by the Oregon Act is given. The Oregon Act does not permit active euthanasia, mercy killing, or lethal injection, no matter how compelling the circumstances.[2] It is essential to verify and document the terminally ill patient's basic qualifications: Oregon residence, at least 18 years of age, terminal illness, sufficient mental capacity, volition, an informed decision, and compliance with the procedure for oral and written requests.

The goal of minimizing liability may conflict with a provider's concept of ethical practice or the privacy of patients and other providers. In such circumstances, choices should be informed by an appreciation of the risks involved. This chapter points out a few of the most obvious potential conflicts between risk management and other values.

This chapter reflects the Oregon Act's focus on the obligations of attending and consulting physicians. However, many of the guidelines are equally applicable to health care providers generally.

The touchstone of the guidelines is documentation. The Oregon Act contains many new and unfamiliar procedural aspects. It is therefore critical, and in many cases obligatory, to document compliance with the Oregon Act.[3]

Identifying Existing Legal Resources and Obligations

The health care provider's first step should be to identify what legal or other resources are available in evaluating the decision to participate in the Oregon Act. Health care providers should contact the administrator of their group or plan to determine what assistance is available. If no such resource is available, then the physician should ask for a referral to a knowledgeable advisor.

Health care providers should review contracts, policies, and bylaws of the organizations and facilities with which they are currently affiliated. See "Contracts and Credentials," below. Agreements with other providers and with health plans may address the subject of the Oregon Act directly or indirectly. Policy documents or other contracts may be referred to but not included in these agreements. Copies of these referenced documents should be obtained.

The physician's group or clinic or its insurance representative should consult in advance and in writing with the malpractice insurance carrier to determine if it will confirm in writing coverage for damages and the costs of defense in a suit arising under the Oregon Act. Malpractice coverage typically contains an exclusion from coverage for intentional (as opposed to negligent) injury. The Oregon Act obviously contemplates acts intended to produce fatal consequences. When these acts fail to produce death but do produce injury to the patient, will this exclusion apply? Similarly, in cases where the prescription does produce death, but in a patient later determined not to have been qualified, how will the insurance carrier respond? Will the insurance carrier pay the costs of defending claims? To ensure coverage for such liabilities, answers to these questions should be obtained and documented before assisting patients under the Oregon Act.

It is advisable to determine in advance whether colleagues and employees, including allied staff, intend to exercise their right not to participate in activities authorized by the Oregon Act. The Oregon Act[4] prohibits a "health care provider" from taking disciplinary or punitive action against any person who refuses to participate.. "Health care provider" includes health care facilities.[5] It is clearly preferable to discuss and resolve the question of participation with other members of the care team before it arises as a result of a patient's request. Such discussions should respect provider privacy. It is important to remember that a person may participate or not on a case-by-case basis, regardless of previous consent to participation (see *Conscientious Practice*).

Responding to a Patient's Request Under the Oregon Act

Whether or not a provider chooses to participate, the patient's request for medication to end life triggers time-sensitive obligations under both the Oregon Act and the common law. On the one hand, a provider has a common law duty not to unreasonably delay treatment or abandon the patient. On the other hand, a prescription may be written under the Oregon Act only after a "waiting period" of at least 15 days.[6] It is important for the attending physician to document the date of the first oral request, respond promptly to the patient's request and document all responses.

Inquiries into the reasons for the patient's request should be made and the patient's responses explored and documented (see *The Meaning Behind a Patient's Request*). The provider should also determine and document the patient's mental state and any needs for more effective symptom management (see *Hospice, Palliative Care, and Comfort Care* and *Mental Health Consultation*).

If the attending physician decides not to participate, he/she promptly needs to provide the patient with a referral or a source of information about participating providers. The Oregon Act describes a legal medical practice, and the attending physician who declines to participate may not abandon the patient.[7] A timely referral to a participating provider or to a resource for information concerning participating providers should minimize claims of abandonment. The referral or the information provided to the patient should be documented.

Providers whose objection to the Oregon Act extends even to the provision of referrals or information must weigh their ethical concerns and the liability risks. At a minimum, however, the provider should not hinder in any way the transfer of care to a participating provider. Records must be transferred to the new attending physician.[8] Comfort care and other needed treatment should be provided in the interim.

Determining the Patient's Qualifications

Determining the patient's qualifications under the Oregon Act is the initial responsibility of the attending physician, and only the attending physician is authorized to dispense or prescribe medication under the Oregon Act.[9] The attending physician is primarily responsible for the patient's terminal care, and assumes responsibility for ensuring compliance with the Oregon Act by all health care providers involved prior to writing a prescription or dispensing medication.[10] When a patient is being treated by more than one physician, it is critical to identify who is the attending physician. The attending physician should document both oral and written communications to the care team, the patient, and the patient's family on this point.

The attending physician's first determination should be whether the patient meets the Oregon Act's nonmedical qualifications; that is, whether the patient is 18 years of age and an Oregon resident.[11] A long-standing physician-patient relationship is the best assurance of these basic qualifications. Regardless, all patients must be asked to "demonstrate" Oregon residency.[12] Oregon residency is not defined by the Oregon Act, but factors demonstrating residency include without limitation: an Oregon driver's license, Oregon voter registration, an Oregon tax return for the most recent tax year, and owning or leasing property in Oregon. Documentation of these and other Oregon connections should be obtained and a copy filed in the medical record.

The attending and consulting physicians must determine the patient's capability.[13] If, in the opinion of either physician, the patient may be suffering from a mental disorder or depression impairing judgment, a referral for an evaluation by a psychiatrist or psychologist is obligatory.[14] All such referrals should be documented. A copy of the psychiatrist's or psychologist's report must be filed in the patient's medical record.[15] The attending physician is responsible for ensuring that the report is filed in the medical record.[16]

The prudent attending physician will make a referral for psychiatric or psychological evaluation. The literature raises doubts about the ability of many physicians to diagnose a mental disorder or depression (see *Mental Health Consultation*).[17] Although the Oregon Act does not mandate referral in all cases, it will be the rare case when a referral is not legally prudent.

The attending physician should strongly consider referring the patient and family to an appropriate hospice program or others in their community who can provide social work and support services. Tending to the emotional needs of family members and to the communication between the care team and the family is helpful in avoiding liability claims (see *Family Needs and Concerns*).

The attending and consulting physicians must determine whether the patient is suffering from a "terminal disease;" *i.e.*, a disease which is "incurable and irreversible," and which will, "within reasonable medical judgment, produce death within six (6) months."[18] The attending and consulting physicians also must determine if the patient is "voluntarily" requesting assistance.[19] Both determinations require the exercise of professional judgment, and that judgment must be rigorously documented. Doubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication. A conservative approach to these decisions will provide greater legal protection.

The attending and consulting physicians should also take care to document an awareness of the patient's broader circumstances and a sensitivity to any indication that the patient's request is coerced or the product of the undue influence of friends, family, or others. Neither age nor disability alone are sufficient to qualify a patient under the Oregon Act.[20]

Timing, Documentation, and Rescission

The Oregon Act requires two oral requests and one written request by the patient before the prescription may be written.[21] The first oral request must be at least 15-days in advance of the prescription.[22] The second oral request must be at least 15-days after the initial oral request.[23] Thus, the shortest time permitted between the patient's initial oral request and the writing of a prescription is 15-days. Both oral requests must be documented in the medical record,[24] and such documentation should include the dates, times, and circumstances of the requests.

The written request must be made at least 48 hours in advance of the prescription.[25] The attending physician is responsible for ensuring that the written request is filed in the medical record,[26] and the date, time, and circumstances of the presentation of the written request should be documented. The written request must be properly witnessed by two persons, neither of whom may be the attending physician.[27] One witness must not be a relative by blood, marriage, or adoption, an heir, or an operator or employee of a health care facility where the person is a patient or resident.[28] If the person making the written request is an inpatient in a health care facility, one of the witnesses must be designated by the facility.[29]

The Oregon Act requires that the patient's written request conform substantially to the form of request set out in the Oregon Act.[30] The form provided in ORS 127.897 should be copied exactly and used without changes (see Appendix A, *The Oregon Death with Dignity Act*).

The Oregon Act appears to contemplate that the patient will not make a written request until after being examined by both the attending and consulting physicians.[31] This assumption is reflected in the form of written request specified by the Oregon Act: "I am suffering from __________, which my attending physician has determined is a terminal disease and which has been medically confirmed by a consulting physician."[32] Thus, the attending physician should obtain the written request only after the consulting physician has confirmed and documented the patient's terminal disease.

If other persons are present when an oral or written request for a prescription under the Oregon Act is made, their presence should be noted in the chart. It is advisable to have a consenting member of the care team otherwise aware of the patient's request for the prescription present at the time of the second oral request.

While the patient must be capable and make a request for a prescription in the specified manner, the patient's mental capability and proper procedure are irrelevant to a rescission of the request.[33]

Thus, the patient may rescind a request for a prescription at any time in any manner regardless of his/her mental state. Any indication that the patient wishes to rescind the request should be explored immediately, the resulting inquiry documented, and doubts resolved in favor of rescission. We also recommend the adoption of a protocol requiring other health care professionals to communicate the rescission immediately to the attending physician if he/she is not present.

The patient should be informed at the outset that a request for a prescription may be rescinded at any time in any manner regardless of the patient's mental state. The provision of this information should be carefully documented along with the information required for an informed decision.

The attending physician must offer the patient the opportunity to rescind at the time of the second oral request. A prescription may not be written otherwise.[34] Moreover, documentation of the opportunity given the patient to rescind is not just good practice, it is required by the Oregon Act.[35] If family members or other persons are present when the opportunity to rescind is offered, then their presence should be documented in the patient's medical record. We also recommend that a consenting member of the care team who is already privy to the patient's request be present when the opportunity to rescind is offered, and that such team member's presence be documented as well.

The Oregon Act requires the attending physician to recommend that the patient notify his or her next of kin of the patient's request for a prescription. (see *Family Needs and Concerns*).[36] The Act does not specify when the attending physician is to make this recommendation, but we suggest that it be done as soon as possible following the first oral request. After recommending that the patient notify his or her next of kin, the physician may not refuse to participate solely because the patient cannot or will not notify them.[37]

The Oregon Act also requires that the attending physician counsel the patient about the importance of having another person present when they take medication authorized by the Oregon Act and of not taking the medication in a public place.[38] The patient's estate is deemed liable under the Oregon Act for the costs incurred by governmental entities as a result of the patient taking medication in a public place, including attorney fees for enforcing such a claim.[39] The attending physician's communication of these facts to the patient should be documented in the medical record. To date, there have been no reports of deaths occurring in a public place.

An "Informed Decision" is More Than "Informed Consent"

Oregon's Informed Consent Law is familiar to providers.[40] It requires the physician to provide a general description to the patient of the nature of the procedure, and information about the risks involved, if any, and the viable alternatives, if any. The physician must also ask the patient if he/she wants a more detailed explanation of the procedure and its material risks and viable alternatives and then, if requested, provide an explanation satisfying the patient's concerns.

For there to be an "informed decision" under the Oregon Act, however, the patient must be fully informed regardless of whether a detailed explanation is requested.[41] The physician is not given the option of providing a general description and then asking the patient if more detail is desired.

The attending physician must provide that detail as a matter of course; without it, there is no "informed decision." Failure to satisfy the Oregon Act's specific "informed decision" requirements will expose the provider to civil liability and, potentially, criminal penalties.[42]

The Oregon Act requires specific information to be conveyed to the patient:

a. His/her medical diagnosis;

b. His/her prognosis;

c. The potential risks associated with taking the medication to be prescribed;

d. The probable result of taking the medication to be prescribed, and the possibility that, although most deaths occur within three hours, death may take longer:[43]

e. The feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.[44]

Like "informed consent," an "informed decision" under the Oregon Act involves the discussion of risks and alternatives. Note, however, that the Oregon Act specifically requires that the alternatives of comfort care, hospice care, and pain control must be discussed,[45] that the patient be informed of his/her diagnosis and prognosis, "the probable result" of taking the medication,[46] and the possibility that, "although most deaths occur within three hours, [the patient's] death may take longer."[47]

Documentation of an "informed decision" is required by the Oregon Act and is ultimately the responsibility of the attending physician.[48] Both the attending and consulting physician must document the communication of this information to the patient.[49] Informed consent is typically documented in the medical record with the notation "PARQ," for "Procedure, Alternatives, Risks, and Questions." An "informed decision" under the Oregon Act involves the communication of more information than is reflected by the notation "PARQ," and requires no less than a detailed discussion of all elements of the patient's "informed decision." The "PARQ" notation therefore will not document compliance with the Oregon Act. Compliance with "informed decision" requirements should be documented in considerably more detail; *i.e.*, Diagnosis, Prognosis, Risks, Results, and Alternatives (including comfort care, hospice care, and pain control). We also recommend that the patient be informed at the same time of the right to rescind a request for medication at any time for any reason, and that the provision of this information be documented. The presence of another member of the care team during the "informed decision" discussion is also recommended, and should be documented.

Immediately prior to writing the prescription, the attending physician must confirm that the patient is making an informed decision. Verification of the patient's "informed decision" immediately prior to dispensing medication or writing the prescription is both good practice and required by the Oregon Act.[50] The attending physician should provide and document the same information initially discussed with the patient.

Although not required by the Oregon Act, we recommend that as a part of the informed decision process the attending physician encourage the patient to execute an advance directive. An advance directive may be used to appoint a health care representative authorized to make end-of-life decisions for an unconscious or incapable patient, including the withdrawal of life support and tube feeding. The patient may also express his/her wishes directly with regard to these and other treatment decisions. If a patient takes medication prescribed under the Oregon Act but does not die, then the express directions of the patient or an authorized surrogate will serve to better effectuate the patient's wishes and to maximize the provider's legal protection (see Appendix C, *Advance Directives and Physician Orders for Life-Sustaining Treatment*). The attending physician should document his/her recommendation to the patient regarding the execution of an advance directive. The attending physician also should inform the patient and family that if he/she is not in attendance at the time of death, or called immediately thereafter, or if emergency medical personnel are called to the scene, the death is likely to be investigated by the Medical Examiner. The attending physician should document the provision of this information.

Referrals and Consultations

The attending physician must refer the patient to a consulting physician who is qualified by specialty or experience to make a diagnosis and prognosis of the patient's terminal illness.[51] Judgments by the attending physician as to what experience qualifies a non-specialist to render such diagnosis and prognosis may be called into question. Geography and the availability of physicians willing to consult for purposes of the Oregon Act may make referrals to a consulting physician difficult and to a specialist impractical, particularly in rural areas. Nonetheless, involvement of a consulting physician is required under the Oregon Act. When possible, we recommend the use of a specialist as the surest means of establishing the qualifications of the consulting physician.

Even the appearance of financial conflicts of interest should be avoided. Referrals of managed care patients to other members of a physician's medical group or independent practice association (IPA), particularly in the case of capitated care, may give rise to accusations of financial self-interest in confirmations of terminal illness. Again, while referrals outside the physician's group may be impractical in some areas of the state, in-group referrals should be avoided when possible.

The Oregon Act's definition of "medically confirmed" makes clear that the consulting physician must review relevant medical records in confirming the patient's diagnosis and prognosis.[52] Arrangements for access to the patient's records should be made in advance of examination of the patient. The consulting physician should document the review of records as well as the patient's examination.

The Oregon Act requires the consulting physician to confirm in writing the attending physician's diagnosis and prognosis and verify the patient's capability, volition, and informed decision. Charting the results of the examination may not meet the consulting physician's obligations under the Oregon Act.[53] Separate written confirmation should be supplied to the attending physician. Such verification must be made a part of the patient's medical record.[54] The consulting physician's only sure means of verifying an "informed decision" is to provide the same information as the attending physician.[55] It is recommended that the consulting physician document the provision of the information necessary for an informed decision.

If the attending physician has not referred the patient for a psychiatric or psychological evaluation, then the consulting physician should strongly consider obtaining an evaluation of the patient's capability and the voluntariness of the request.

Dispensing or Prescribing Medication

The attending physician may provide medication under the Oregon Act in one of two ways: by dispensing directly to the patient or by writing a prescription.[56] Different procedures must be followed in each case.

An attending physician may dispense controlled substances directly to the patient only if registered as a dispensing physician with the Oregon Medical Board and certified by the Drug Enforcement Administration.[57] The patient's name, the kind and amount of medication dispensed, and the date it was dispensed must be entered in the controlled substance inventory log required by Oregon statute[58] and Oregon Medical Board rule.[59] The medication must be provided to the patient in a container complying with federal packaging requirements, unless a non-compliant container is requested by the patient, and labeled with the patient's name, the name and address of the attending physician, the date dispensed, the name of the drug, the quantity of drug per unit, directions for use, cautionary statements required by law, if any, and an expiration date.[60] A copy of the label or equivalent information, plus the dispensing physician's phone number and the total amount of medication dispensed, must be filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR, 97232.[61]

Alternatively, an attending physician may write a prescription for medication under the Oregon Act.[62] Such prescription may be written, however, only if the patient consents in writing to the attending physician contacting a pharmacist and informing the pharmacist of the purpose of the prescription.[63] Further, the attending physician must deliver the prescription to the pharmacist personally or by mail.[64] The pharmacist may then dispense the medication to the patient, the attending physician, or an expressly identified agent of the patient, who may be the attending physician.[65] We recommend that, if an agent of the patient is to pick up the prescription, the attending physician identify such agent in writing for the pharmacist.

Three documents must be filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR, 97232 at the time a prescription is written: the "Attending Physician Report and Medical Record Documentation," a copy of the patient's written request for medication under the Oregon Act, and a copy of the consulting physician's report (see Appendix B, *Oregon Department of Human Services Reporting Documents*).[66] In lieu of completing the Department of Human Services' reporting form, the attending physician may check a box at the beginning of the form indicating that relevant medical records will be made available for review by the Department of Human Services.[67] The patient's written authorization for such review should be obtained before the attending physician indicates that the patient's medical records will be made available.

Conscientious Practice

The Oregon Act makes clear that a health care provider may not be required under contract or otherwise to participate in activities authorized by the Oregon Act.[68] In order to avoid unknowing participation, the Oregon Act requires that, with the patient's written consent, the attending physician notify the pharmacist of the purpose of a prescription written pursuant to the Oregon Act.[69]

The Oregon Act also prohibits a health care provider from disciplining or penalizing "a person" who participates or refuses to participate.[70] Use of the term "person" indicates that this provision is intended to protect laypersons as well as health care providers. Although the Oregon Act does not expressly mention employees or applicants for employment, it is likely they also are protected by the Oregon Act.

Health care facilities and providers, particularly those in the public sector, must be aware of constitutional and statutory restrictions on employment policies. Given potential political or religious objections to the Oregon Act, employment criteria which penalize protected classes or speech on this basis may give rise to civil rights liabilities. Providers should consult with counsel before making preemployment inquiries or adverse employment decisions on the basis of employee views on the Oregon Act. Employers should make reasonable accommodations to the religious or sincerely held moral beliefs of employees. The substantial legal expense of defending a civil rights claim is often uninsurable.

Confidentiality and Privacy

Neither the Oregon Act nor any other Oregon statute makes special provision for the confidentiality of requests for medication under the Oregon Act. However, physician-patient communications, including those concerning the Oregon Act, are confidential under state law and federal administrative rules governing patient privacy.[71] While state and federal law generally permit the communication of patient information between providers for treatment purposes,[72] the best practice under the Oregon Act is to seek the patient's consent to disclosure of his/her request for medication before that information is provided to anyone, save for the information necessarily provided to the consulting physician under the Oregon Act. If the attending physician discloses patient information to persons outside the care team without the patient's consent, then he/she may be exposed to civil liability for invasion of the patient's privacy and breach of confidentiality.[73] Ethical considerations may require the attending physician to obtain patient consent.

Seeking the patient's consent to disclose information to other members of the care team is also important for quality care. Providers not informed of the patient's request may complicate or interfere with a qualified patient's wishes. The prudent attending physician will document efforts to seek the patient's consent and the patient's response.

The Oregon Act creates no legal obligation or privilege to inform others of the patient's request. If the patient refuses to consent to information-sharing with other providers, or requests nondisclosure, then the attending physician should accede to the patient's wishes and must document any restriction to which he/she has agreed.[74] The attending physician may still disclose the patient's request for medication to persons supervised, directly or indirectly, by the attending physician.[75] While the patient's right to privacy and confidentiality may conflict with the right of other providers to "opt out" of participation,[50] the attending physician's primary legal duty is to the patient. The attending physician's ethical duties to other providers are discussed in Chapter 8, *The Role of Other Health Care Professionals.*

Employees may have privacy interests in information regarding their participation in activities authorized by the Oregon Act. Such information is unquestionably sensitive and should not be disclosed to third parties without the employee's consent. Providers should take reasonable precautions to prevent the inadvertent disclosure of information concerning employee participation.

Contracts and Credentials

While the general rule is that health care providers may not be penalized for participating, or refusing to participate, in activity authorized by the Oregon Act, a health care provider may prohibit other health care providers from participation on its premises or within the course and scope of an employment or contract relationship. A "health care provider" includes pharmacists and "health care facilities."[76] Hospitals and long-term care facilities are generally thought to be included in the term "health care facility."[77]

"Participation" means acting as an attending or consulting physician or a psychiatric or psychological consultant.[78] However, providing information about the Oregon Act at the request of a patient or referring a patient to a physician willing to provide assistance under the Oregon Act is not considered "participation" which may be prohibited or sanctioned.[79]

The activities of pharmacists and health care facilities are not included within the definition of "participation" in ORS 127.800 to 127.897. It appears therefore that these two categories of health care providers are not subject to prohibitions against participation and may not be sanctioned for doing so. Nonetheless, the Task Force strongly endorses respect for the values of health care providers objecting to participation on their premises or by employees or contractors acting within the course and scope of their employment or engagement.

A health care provider can enforce a policy against participation only if it has provided advance notice of its policy in a separate written statement.[80] Providers accused of violating such a policy must be afforded whatever "due process" would otherwise be available to them before sanctions may be imposed.[81]

Potential sanctions vary with the context: Medical staff privileges or membership may be terminated for participation on the prohibiting provider's premises.[82] However, participation occurring solely within a physician's or other provider's private medical office may not be grounds for discipline, even if on the premises of the prohibiting provider.[83] Moreover, medical staff discipline under the Oregon Act is not reportable to the Oregon Medical Board and violation of facility policy on this point may not be the sole grounds for a report of unprofessional or dishonorable conduct to the Board.[84] A prohibiting provider may terminate leases and other property arrangements to sanction prohibited activity on its premises.[85] Contracts with employees and independent contractors may be terminated for participation on or off a prohibiting provider's premises if that participation occurs within the course and scope of the participant's employment or engagement.[86] However, employees and independent contractors may not be sanctioned for participation outside the course and scope of their employment or engagement.[87]

The enforceability and interpretation of certain contract provisions may be complicated or called into question by the Oregon Act. If a health care provider is in doubt about contractual obligations and rights with respect to the Oregon Act, then competent legal advice should be sought.

Contracts with health care plans or other providers often contain a promise to indemnify the other party. As a general rule, however, malpractice insurance does not cover indemnity for professional liabilities other than those arising from the professional's own fault. Providers should not agree to indemnify health plans or other providers for damages relating to conduct under the Oregon Act without first confirming insurance coverage of such liabilities by their malpractice carrier. Consultation with an attorney or malpractice insurance carrier is advised to determine if such liabilities will be covered. The attending physician should document both inquiries and responses on this issue.

A provider may not lawfully obtain a release of liability from a patient for care which falls below the standard of care or which is intentionally injurious. Such a release is void as against public policy. Providers may not condition participation under the Oregon Act on the patient providing a release from liability. Serious licensure and ethical violations may also arise from an attempt to obtain such a release.

Civil and Criminal Immunities

Providers enjoy civil and criminal immunity for conduct undertaken in "good faith compliance" with the Oregon Act.[88] It is unclear what "good faith" means in this context, or whether compliance deemed not in good faith is insufficient for immunity. In any event, scrupulous attention should be paid to the procedures and documentation demanded by the Oregon Act. Variation from the Oregon Act's requirements, no matter how well intentioned, may result in the loss of immunity and the possibility of review by the Oregon Medical Board.

The Oregon Act grants civil and criminal immunity only for conduct authorized by the Oregon Act.[89] As with any other medical service, "good faith" will not immunize the provider against civil liability for negligence in the delivery of patient care, including that authorized by the Oregon Act, or shield the provider from criminal penalties for intentional wrongdoing. The standard of care for patients receiving assistance under the Oregon Act is no lower than that applicable to any other patient.[90]

The Oregon Act makes it a Class A felony to exert "undue influence" on the patient to request medication or to revoke a rescission of such a request.[91] The term "undue influence" is not defined in the Oregon Act. "Undue influence" in other areas of law defies precise definition, with the courts using a case-by-case approach that takes into account the totality of circumstances. This lack of guidance is particularly troubling given the arguable duty of physicians under the Informed Consent statute to apprise terminally ill patients of the option legally available under the Oregon Act when discussing alternative courses of treatment or palliative care.[92] Thus, while the possibility of criminal prosecution argues forcefully for avoiding any basis upon which a charge of undue influence might be brought, including providing information regarding the Oregon Act, the failure to discuss this legally available alternative may create malpractice exposure. While there is risk in either course of action we recommend that discussions concerning the Oregon Act be initiated by patients.

Guidelines

15.1 The Task Force recommends contacting the administrator of the practice group or health plan to determine what legal or other resources are available in evaluating the decision to participate in conduct authorized by the Oregon Act.

15.2 A health care provider needs to review contracts, policies, and bylaws of the groups and organizations with which he/she is currently affiliated.

15.3 Groups, clinics, or insurance representatives should consult in advance and in writing with their malpractice insurance carriers to determine if they will confirm in writing that coverage for damages and the costs of a defense in a suit arising from the Oregon Act are available.

15.4 It is advisable to determine in advance whether colleagues and employees, including allied staff, intend to exercise their right not to participate.

15.5 Whether or not a health care provider chooses to participate, it is important to document the date and circumstances of patient requests for assistance under the Oregon Act and the provider's inquiry into the reasons for the request. The attending physician needs to respond promptly to the patient's request and document his/her response.

15.6 The attending physician who declines to participate in the provision of a prescription under the Oregon Act should promptly provide the patient with a referral or a source of information about participating providers and document the referral or resource provided.

15.7 The Task Force recommends that health care providers establish and document early on who is the "attending physician;" *i.e.*, the physician primarily responsible for the care of the patient and treatment of the patient's terminal disease. The attending physician is the only physician who may dispense or prescribe medication under the Oregon Act, and is responsible for ensuring compliance with the Oregon Act's requirements by the other health care providers involved.

15.8 An attending physician needs to determine first whether the patient is 18 years of age and an Oregon resident. Documentary proof of residency, such as an Oregon's driver's license, voter registration, recent tax return, or records of property interests in Oregon, should be obtained from the patient and copies filed in the medical record.

15.9 The Task Force recommends mental health consultation for any person desiring a prescription under the Oregon Act. Mental health counseling is especially recommended for patients who are not enrolled in hospice. (A psychosocial evaluation by a social worker is standard practice for patients enrolled in hospice).

15.10 Doubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication.

15.11 The shortest time permitted between the patient's initial oral request and the writing of a prescription is 15 days.

15.12 The statutory form, without changes, should be used for the written request. The statutory form specifies the qualifications of witnesses.

15.13 The written request for a prescription under the Oregon Act must be made at least 48 hours in advance of the prescription. The written request should be made only after the consulting physician has examined the patient and provided medical confirmation of the patient's prognosis, capability, and informed decision.

15.14 Medication may be dispensed directly by the attending physician to the patient only if the physician is registered as a dispensing physician with the Oregon Medical Board and the Drug Enforcement Administration. The medication must be properly recorded in the attending physician's controlled substances log and provided in a container properly labeled and, unless otherwise requested by the patient, compliant with federal container requirements. When the medication is dispensed, the attending physician must supply the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR 97232, with a copy of the log order and the physician's phone number and the total amount of medication dispensed.

15.14a A prescription for medication may be written by the attending physician in lieu of direct dispensing. However, the patient's written consent to disclose the purpose of the prescription to the pharmacist must first be obtained. After obtaining the patient's written consent, the physician must notify the pharmacist of the intended purpose of the prescription and deliver the prescription personally or by mail. The medication may be dispensed by the pharmacist to the attending physician, the patient, or a specified agent of the patient. If the medication is to be dispensed to a specified agent of the patient, then such agent should be identified by the physician to the pharmacist in writing.

15.15 When medication is either dispensed or prescribed, the attending physician must file the "Attending Physician Report and Medical Record Documentation" and a copy of the patient's written request for assistance under the Oregon Act. These are filed with the State Registrar, Center for Health Statistics, Oregon Department of Human Services, 800 NE Oregon St., Portland, OR 97232. See the Oregon Department of Human Services website for *examples of the forms*.

15.16 In lieu of completing the Oregon Department of Human Service's reporting form, the attending physician may check a box at the beginning of the form indicating that relevant medical records will be made available for review by the Oregon Department of Human Service.

15.17 The presence of other persons at the time oral or written requests are made should be documented.

15.18 The patient may rescind a request for a prescription at any time in any manner regardless of his/her mental state. A protocol should be established by the health care provider for immediately reporting a rescission to the attending physician.

15.19 The attending physician should inform the patient of his/her right to rescind the request at the same time information is provided for the patient's informed decision. It is important to document this communication.

15.20 The attending physician must offer the patient the opportunity to rescind at the time of the second oral request. The offer to rescind and the patient's response must be carefully documented. The presence of other persons at the time the offer to rescind is made is recommended and should be documented.

15.21 The attending physician must recommend that the patient notify the patient's next of kin of the request, but the attending physician may not deny assistance under the Oregon Act on the basis of the patient's refusal or inability to notify next of kin. The attending physician should document the recommendation to the patient.

15.22 An "informed decision" by the patient requires that the patient be fully informed of the specified information regardless of whether a detailed explanation is requested.

15.23 The Oregon Act requires specific information to be conveyed to the patient:

a. His/her medical diagnosis;

b. His/her prognosis;

c. The potential risks associated with taking the medication to be prescribed;

d. The probable result of taking the medication to be prescribed, and the possibility that, although most deaths occur within three hours, death may take longer;

e. The feasible alternatives, including, but not limited to, comfort care, hospice care, and pain control.

15.24 The standard "Procedures, Alternatives, Risks, and Questions" (PARQ) chart notation is insufficient to document an "informed decision" under the Oregon Act. The provision of information concerning Diagnosis, Prognosis, Risks, Results, and Alternatives (including comfort care, hospice care and pain control) should be documented.

15.25 Immediately prior to writing the prescription or dispensing medication, the attending physician must verify that the patient is making an informed decision.

15.26 We recommend that the attending physician encourage the patient to execute an advance directive and document this advice in the chart.

15.27 The patient and family should be informed that if the attending physician is not in attendance at the time of death or called immediately thereafter, or if emergency medical services personnel are called in, the death may be investigated by the Medical Examiner. The attending physician should document the provision of this information.

15.27a The patient must be counseled on the importance of having another person present when the patient takes the medication, and of not taking the medication in a public place.

15.28 When possible, the attending physician should refer to consulting physicians who are specialists in the area called for by the patient's terminal disease, and avoid referrals of managed care patients to physicians with whom he/she has a financial relationship.

15.29 The consulting physician should document not only the examination of the patient but the examination of the patient's medical records, confirm in writing the patient's diagnosis and prognosis, and verify the patient's capability, volition, and informed decision.

15.30 If it has not already been done, the prudent consulting physician will refer the patient to a psychiatrist or psychologist to obtain confirmation of the patient's capability and the voluntariness of the request.

15.31 The consulting physician should provide the information necessary to the patient's informed decision.

15.32 The attending physician should obtain the patient's authorization to share relevant information regarding the patient's request for medication with other providers with a need to know. The request for authorization to disclose, and the patient's response, should be documented.

15.33 If the patient refuses to authorize information-sharing with other providers, or requests nondisclosure, then the attending physician should not disclose the patient's request for medication to anyone not supervised, directly or indirectly, by the attending physician. If medication is provided by means of a prescription, however, then the attending physician must obtain the patient's written consent to disclose to the dispensing pharmacist.

15.34 Health care providers may not discipline current or prospective employees for participating or not participating in conduct authorized by the Oregon Act and should protect information concerning employee participation.

15.35 Providers should consult with counsel before making preemployment inquiries or adverse employment decisions on the basis of employee views on the Oregon Act and make a reasonable effort to accommodate the religious or conscientious objections of employees to participation.

15.36 Medical staff privileges and membership may be suspended, revoked, or otherwise limited on the basis of participation on the premises of a health care facility that has provided adequate advance notice of its policy forbidding such participation. Medical staff discipline may not be imposed, however, for participation limited to a physician's or other provider's private medical office.

15.37 Provider agreements may not require participation in activities authorized by the Oregon Act.

15.38 Providers should not agree to indemnify health plans or other providers for damages relating to the Oregon Act without first confirming insurance coverage of such liabilities by their malpractice carrier.

15.39 Providers may not condition participation on the patient providing a release from liability.

15.40 Civil and criminal immunity requires adherence to the procedures and documentation prescribed by the Oregon Act. However, good faith compliance with the Oregon Act will not immunize providers from liability for professional negligence or intentional misconduct. The standard of care for treatment of patients under the Oregon Act is no lower than that required for treatment of other patients.

15.41 Avoid exerting any influence over the patient's decision to request medication or to revoke a rescission of such a request. Discussions concerning the Oregon Act should be initiated by patients.

References

1. ORS 127.800 - 127.897. The Oregon Death with Dignity Act is linked in *Appendix A*.

2. ORS 127.880, § 3.14.

3. See ORS 127.855, § 3.09, regarding mandatory documentation in the medical record.

4. ORS 127.885(2), § 4.01(2).

5. See ORS 127.800(6), § 1.01(6).

6. ORS 127.850, § 3.08.

7. ORS 127.885(7), § 4.01(7); ORS 127.890(3), § 4.01(3).

8. See ORS 127.885(4), § 4.01(4).

9. This conclusion is fairly implied by numerous provisions of the Oregon Act, e.g., ORS 127.815(1)(i) and (k), § 3.0l(1)(i) and (k); ORS 127.885(7), § 4.01(7); ORS 127.897, § 6.01.

10. ORS 127.815(1)(k), § 3.01(1)(k); 127.855(7), § 3.09(7). The Oregon Act actually refers only to the writing of a prescription; dispensing is not expressly mentioned. A fair reading of the Oregon Act suggests the attending physician's oversight responsibilities must be attested to prior either to dispensing or prescribing medication.

11. ORS 127.805(1), § 2.01(1).

12. ORS 127.815(l)(b), § 3.01(l)(b).

13. ORS 127.815(1)(a), § 3.01(l)(a); ORS 127.820, § 3.02.

14. ORS 127.825, § 3.03.

15. ORS 127.855(5), § 3.09(5).

16. ORS 127.815(1)(j), § 3.01(1)(j).

17. Lee ML, Nelson HD, Tilden VP, et al. Legalizing assisted suicide: views of physicians in Oregon. N Engl J Med. 1996;334:310-315.

18. ORS 127.815(1)(a), § 3.01(1)(a); ORS 127.800(12), § 1.01(12).

19. ORS 127.815(l)(a) and (d), § 3.01(1)(a) and (d); ORS 127.820, § 3.02.

20. ORS 127.805(2), § 2.01(2).

21. ORS 127.840, § 3.06.

22. ORS 127.850, § 3.08.

23. ORS 127.840, § 3.06.

24. ORS 127.855(l), § 3.09(l).

25. ORS 127.850, § 3.08.

26. ORS 127.815(1)(j), § 3.01(1)(j); ORS 127.855(2), 3.09(2).

27. ORS 127.897, § 6.01.

28. *Id.*

29. *Id.*

30. *Id.*

31. ORS 127.805(1), § 2.01(1).

32. ORS 127.897, § 6.01

33. ORS 127.845, § 3.07.

34. ORS 127.845, § 3.07.

35. ORS 127.855(6), § 3.09(6).

36. ORS 127.835, § 3.05.

37. *Id.*

38. ORS 127.815(1)(g), § 3.01(1)(g).

39. ORS 127.892.

40. ORS 677.097.

41. ORS 127.815(1)(c), § 3.01(1)(c).

42. ORS 127.885(1), § 4.01(1).

43. ORS 127.897, § 4.01.

44. ORS 127.815(1)(c), § 3.01(1)(c).

45. ORS 127.815(1)(c)(E), § 3.01(1)(c)(E).

46. ORS 127.815(1)(c)(A) and (D), § 3.01(1)(c)(A) and (D).

47. ORS 127.897, § 6.01.

48. ORS 127.815(1)(j) and (k), § 3.01(1)(j) and (k).

49. ORS 127.855(3) and (4), § 3.09(3) and (4).

50. ORS 127.815(1)(i), § 3.01(1)(i).

51. ORS 127.800(4), § 1.01(4); ORS 127.820, § 3.02.

52. ORS 127.800(8), § 1.01(8).

53. See ORS 127.820, § 3.02.

54. ORS 127.855(4), § 3.09(4).

55. ORS 127.815(1)(c), § 3.01(1)(c).

56. ORS 127.815(1)(L), § 3.01(1)(L).

57. ORS 127.815(1)(L)(A), § 3.01(1)(L)(A).

58. ORS 677.089.

59. OAR 847-015-0015.

60. ORS 677.089.

61. OAR 333-009-0010(2).

62. ORS 127.815(1)(L)(B), § 3.01(1)(L)(A).

63. ORS 127.815(1)(L)(B)(i), § 3.01(1)(L)(B)(i).

64. ORS 127.815(1)(L)(B)(ii), § 3.01(1)(L)(B)(ii).

65. *Id.*

66. OAR 333-009-0010(1)(a).

67. *Id.*

68. ORS 127.885(4), § 4.01(4).

69. ORS 127.815(1)(L)(B)(i); § 3.01(1)(L)(B)(i).

70. ORS 127.885(2), § 4.01(2).

71. 45 CFR. Parts 160, 162, and 164, implementing the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

72. 45 CFR § 164.506(a). The HIPAA rules also permit the provider to obtain consent for disclosures related to treatment. 45 CFR § 164.506(b).

73. 45 USC §§ 1320d-5 and 1320d-6.

74. 45 CFR § 164.530(j).

75. 45 CFR § 164.522(a)(B)(iii).

76. ORS 127.885(2), § 4.01(2).

77. ORS 127.800(6), § 1.01(6).

78. ORS 442.015(14).

79. ORS 127.885(5)(d)(B), § 4.01(5)(d)(B).

80. ORS 127.885(5)(d)(B)(ii) and (iii), § 4.01(5)(d)(B)(ii) and (iii).

81. ORS 127.885(5)(a), § 4.01(5)(a); ORS 127.885(5)(d)(A), § 4.01(5)(d)(A).

82. ORS 127.885(5)(c), § 4.01(5)(c).

83. ORS 127.885(5)(b)(A), § 4.01(5)(b)(A).

84. *Id.*

85. ORS 127.885(6), § 4.01(6).

86. ORS 127.885(5)(b)(B), § 4.01(5)(b)(B).

87. ORS 127.885(5)(b)(C), § 4.01(5)(b)(C).

88. ORS 127.885(5)(d)(B)(iv), § 4.01(5)(d)(B)(iv).

89. ORS 127.885(l), § 4.01(1); ORS 127.885(3), § 4.01(3).

90. ORS 127.885(l), § 4.01(1); ORS 127.890(3) and (4), § 4.02(3) and (4).

91. ORS 127.885(7), § 4.01(7).

92. ORS 127.890(2), § 4.02(2). Class A felonies carry a maximum penalty of 20 years imprisonment and/or $300,000 fine. ORS 161.605(l); 161.625(l)(a).

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The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals

Appendix A. The Oregon Death with Dignity Act

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

The State of Oregon provides for an initiative process through which laws may be adopted by a vote of the people. Oregon voters approved such an initiative, Measure 16, on November 8, 1994, and thereby enacted the Oregon "Death with Dignity Act." The statewide vote was 51% in favor and 49% opposed.

Implementation of the Oregon Act was enjoined on December 7, 1994, one day before the Oregon Act's effective date, by order of U.S. District Judge Michael Hogan. On August 3, 1995, Judge Hogan permanently enjoined implementation of the Oregon Act, finding that it violated the Equal Protection Clause of the U.S. Constitution. Lee v. State of Oregon, 819 F Supp 1429 (D Or 1995). The permanent injunction was appealed to the Ninth Circuit Court of Appeals, which ordered the injunction lifted, deciding that the plaintiffs lacked standing to challenge Oregon's law. Lee v. State of Oregon, 107 F3d 1382 (9th Cir. 1997). The plaintiffs' petition for review to the United States Supreme Court was denied on October 14, 1997.

On March 7, 1996, the Ninth Circuit issued an 8-3 decision in another case challenging a Washington State statute criminalizing conduct authorized by the Oregon Act. Compassion in Dying v. State of Washington, 79 F3d 790 (9th cir 1996). The Ninth Circuit overturned the Washington criminal statute and found a constitutional right to such conduct in the Due Process Clause of the U.S. Constitution. The court's opinion took the unusual step of criticizing Judge Hogan's decision, the subject of an entirely separate appeal, and expressly approved the safeguards contained in the Oregon Act.

On April 2, 1996, the federal Second Circuit Court of Appeals held that a New York criminal statute nearly identical to Washington State law was unconstitutional as applied to a terminally ill, competent adult in the final stages of illness. Quill v. Vacco, 80 F3d 716 (2d Cir. 1996). Unlike the Ninth Circuit in Compassion in Dying, the Quill court found no due process interest in conduct authorized by the Oregon Act. Instead, the Second Circuit concluded that New York's laws denied equal protection of the law to competent, terminally ill persons. The court found the law's distinction between the right to refuse or to withdraw life-sustaining treatment and the assistance of a physician to be irrational. Moreover, the court found no legitimate state interest in preserving life in the final stages of a terminal illness.

On June 26, 1997, the U.S. Supreme Court overturned both the Second and Ninth Circuit decisions: Washington v. Glucksberg, No. 96-110, and Vacco v. Quill, No. 95-1858. Glucksberg held that there is no constitutional right to conduct authorized by the Oregon Act under the Due Process Clause. The Court emphasized the limits of patient autonomy and rejected arguments for a constitutional interest in all decisions implicating intimate or deeply personal concerns. Quill held that competent, terminally ill patients are not denied equal protection of the law when physician assistance is prohibited by state law but the withdrawal or refusal of life-sustaining treatment is permitted. The Court endorsed professional and legal distinctions between "physician-assisted suicide" and withdrawal of life support or the "double effect" of aggressive palliative care. Although these cases addressed state laws criminalizing conduct authorized by the Oregon Act, the general approach of the court suggests that it will view state laws such as Oregon's Act, as presenting primarily political, rather than constitutional, issues.

The 1997 Oregon Legislature enacted HB 2954, which referred repeal of the Oregon Act to Oregon voters. The repeal effort was defeated on November 4, 1997, by a 60% to 40% margin.

The 1999 Oregon Legislature enacted SB 491, which amended the Oregon Act effective June 30, 1999. Among other changes, the 1999 amendments:

> a. strengthened the ability of health care facilities to prohibit conduct authorized by the Oregon Act on their premises, while also providing that loss of medical staff privileges or membership for violating such prohibition was not reportable to the Oregon Medical Board;
>
> b. required that physicians either dispense medication under the Oregon Act themselves, if properly registered as a dispensing physician with the Oregon Medical Board, or obtain the patient's written consent to inform the pharmacist of the purpose of the medication and deliver the prescription personally or by mail to the pharmacist;
>
> c. clarified the definitions of residency and medical decision-making capability; and
>
> d. authorized a claim by governmental entities against a deceased's estate for costs resulting from a person hastening death under the Oregon Act in a public place.

On November 6, 2001, U.S. Attorney General John Ashcroft issued an opinion that, if allowed to take effect, would have prohibited the use of controlled substances under the Oregon Death with Dignity Act. Attorney General Ashcroft's opinion interpreted the Controlled Substances Act to the effect that controlled substances could not be used with the intent of hastening death. The Task Force's concern was that the Attorney General's ruling may have had unintended consequences resulting in the under-treatment of pain.

In a statewide survey, some Oregon physicians reported that physicians often under-prescribe pain control medication for those who are dying. One of the reasons reported for this under-prescribing is fear of investigation by the Drug Enforcement Administration (DEA). Under the Attorney General's ruling position, the DEA could have investigated physicians who prescribed controlled substances under the Oregon Act.

On April 17, 2002, U.S. District Judge Robert Jones issued a permanent injunction against Attorney General Ashcroft's order, leaving legal practices under the Oregon Act (with controlled substances) in place. The U.S. Department of Justice immediately appealed from Judge Jones' order to the Ninth Circuit Court of Appeals.

On May 26, 2004, the Ninth Circuit Court of Appeals upheld the injunction granted by the District court. The Ninth Circuit held that the Attorney General's interpretation of the Controlled Substances Act of 1970 (CSA) impermissibly interfered with the state regulation of medical practice, contradicted the plain language of the CSA, and exceeded the authority granted to the Attorney General. Significantly, the Ninth Circuit held that the Attorney General's interpretation of the CSA was not entitled to deference for the reason that it conflicted with patent Congressional intent. The Ninth Circuit denied the Attorney General's request for rehearing on August 11, 2004.

The U.S. Supreme Court accepted review of the Ninth Circuit's decision on February 22, 2005, and heard oral argument on October 5, 2005. On January 17, 2006, the Court affirmed the Ninth Circuit's decision, concluding that the Attorney General had exceeded his authority in interpreting the federal Controlled Substances Act. By a 6 to 3 majority (Chief Justice Roberts and Justices Scalia and Thomas dissenting), the Court held that the Attorney General's interpretive authority did not extend to the criminalization of conduct authorized by state law. The Court further held that the Attorney General's interpretation of the statutory phrases "legitimate medical purpose" and "public interest" was not entitled to deference by the Court given the Attorney General's limited role under the Controlled Substances Act.

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Appendix B. Oregon Department of Human Services Reporting Documents

Written February 1998; Revised: October 2004; Reviewed March 2005, September 2007, December 2008

This Appendix provides links to the following information and documents:

1. *Forms* including:

    Patient Request Form
    Attending Physician Form
    Attending Physician Short Form
    Consulting Physician Form
    Psychiatrist/Psychologist Form
    Pharmacy Dispensing Record Form
    Reporting Physician Interview Form
    Chronology and Death Certificate Extract Form

2. *Legislation*

3. *Rules*

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Appendix C. Advance Directives and Physician Orders for Life-Sustaining Treatment

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

This appendix discusses Oregon's advance directive document and the Physician Orders for Life-Sustaining Treatment (POLST) document, which can be useful in clarifying and documenting treatment preferences for patients who are in their final months of life. These documents allow limits on life-sustaining treatment to be recorded, but do not speak directly to the Oregon Death with Dignity Act. Brief background information regarding these two instruments is described to help the health care professional in this important aspect of end-of-life care.

Advance Directive

The Oregon legislature adopted a revised advance directive law in 1993 [ORS 127.505-127.660]. The purpose of this document is to provide capable adult residents of Oregon a means to make known their preferences for life-sustaining treatments, including artificial fluids and nutrition. These preferences are elicited in the event of specific clinical conditions common at the end of life, including "close to death, permanently unconscious, advanced progressive illness, and extraordinary suffering." In addition, Oregonians can appoint a family member or friend to serve as their health care representative and to act as their agent in making health care decisions if they become incapable due to illness later. These decisions are based on the values of the individual who appoints the agent. An alternate health care representative can be appointed also in the event that the health care representative is unable to participate in the decision-making process. The health care professional who stimulates discussions regarding advance directives and the possibility of future impairment begins a process of communication with the patient and family members. These discussions can be of great benefit when considerations about the wise use of life-sustaining treatment occur in the future.

Despite the utility of written advance directives in clinical decisions, the availability of this helpful tool is frequently unknown and underutilized by patients and their families. The Task Force encourages health care professionals to stimulate advance planning for health care decisions.

For patients who have not appointed a health care representative, Oregon's advance directive statute defines the first of the following who can act as the representative: a guardian of the principal who is authorized to make health care decisions; the principal's spouse or domestic partner; an adult designated by the others on this list who can be located, if no person in this list objects to the designation; a majority of the adult children of the principal who can be located; either parent of the principal; a majority of the adult siblings of the principal who can be located with reasonable effort; any adult relative or adult friend.

Physician Orders for Life-Sustaining Treatment (POLST) and the National POLST Paradigm Initiative

In Oregon, Physician Orders for Life-Sustaining Treatment (POLST) are physician orders that are portable across different care settings. These orders are useful in common situations that most health care professionals encounter.

Have you ever cared for a patient whose wishes to limit life-sustaining treatment were not well documented on transfer? Here is a typical example we hear from colleagues:

A 78-year-old woman with advanced Alzheimer's disease was sent from a nursing home to the hospital with dehydration and respiratory distress. She has not recognized family members for over a year and is having some trouble swallowing. She had a do-not-resuscitate (DNR) order in the nursing home and her family and health care professionals had agreed to respect her prior wishes to focus on comfort and to forego tube feedings and other measures to extend her life. The family was most distraught to find the patient in the intensive care unit (ICU) intubated, restrained, and receiving tube feedings.

In addition to family concerns, emergency medical technicians (EMTs) have also been frustrated, feeling compelled to resuscitate hospice patients with end-stage AIDS or metastatic cancer who arrested during transport from home. Although these patients had DNR orders within their hospice programs, emergency personnel protocols precluded following these orders once the patient was under the care of emergency medical services (EMS).

To solve problems like these, the Center for Ethics in Health Care at Oregon Health and Science University in 1991 convened a multidisciplinary task force of 40 individuals representing such organizations as the Oregon Medical Association (OMA), statewide EMS, hospice, long-term care, and Senior and Disabled Services. In 1995, after four years of development and pilot testing, a document to record medical orders about patient wishes to limit life-sustaining treatment was developed for voluntary use statewide. The document is called Physician Orders for Life-Sustaining Treatment (POLST). It provides physicians, nurse practitioners and physician assistants a way to turn prior advance directive planning (oral or written) into action in a way the health care system can understand and respect. The bright pink document is now used in most Oregon communities. The POLST form allows the physician to record orders in four categories of life-sustaining treatment (cardiopulmonary resuscitation (CPR), other medical interventions, antibiotics, and artificially administered nutrition). It is possible (but probably unnecessary) for orders to be written for full code and all life-sustaining treatment. It is also possible to document medical orders that plan for comfort care, which for some will include an order not to transfer the patient except for comfort. The document does not allow comfort measures to be withheld (e.g., patients who can take food orally with assistance must be fed).

The POLST form is not designed to be completed by patients or family members; it is to be completed by health care professionals. The POLST orders are often completed by nurses or social workers in conversation with patients and their family members, but must be agreed to and signed by the attending physician, nurse practitioner or physician assistant to make the orders valid. The Oregon EMT Scope of Practice (OAR 847-35-0030) has been modified to both protect EMTs and require that these documents be followed. The language of the regulation is: "An Oregon-certified First Responder or EMT, acting through standing orders, shall respect the patient's wishes including life-sustaining treatments. Physician supervised First Responders and EMTs shall request and honor life-sustaining treatment orders executed by a physician, nurse practitioner or physician assistant if available. A patient with life-sustaining treatment orders always requires respect, comfort and hygienic care."

The Oregon Medical Board has defined rules for physicians and physician assistants regarding life-sustaining treatment orders (847-010-0110) as follows:

> 1) A physician or physician assistant licensed pursuant to ORS chapter 677 shall respect the patient's wishes including life-sustaining treatments. Consistent with the requirements of ORS chapter 127, a physician or physician assistant shall respect and honor life-sustaining treatment orders executed by a physician, physician assistant or nurse practitioner. The fact that a physician, physician assistant or nurse practitioner who executed a life-sustaining treatment order does not have admitting privileges at a hospital or health care facility where the patient is being treated does not remove the obligation under this section to honor the order. In keeping with ORS chapter 127, a physician or physician assistant shall not be subject to criminal prosecution, civil liability or professional discipline.
>
> 2) Should new information on the health of the patient become available the goals of treatment may change. Following discussion with the patient, or if incapable their surrogate, new orders regarding life-sustaining treatment should be written, dated and signed.

Numerous organizations in Oregon have endorsed the POLST document and encourage health care professionals to use it for their patients in hospice or long-term care to better document the wishes of those choosing to forego any aspect of life-sustaining treatment. If a terminally ill patient is considering the Oregon Death with Dignity Act, a concurrent wish for a DNR order can be recorded on the POLST form.

Similar physician order programs are developing in many states facilitated by the National POLST Paradigm Initiative Task Force. This organization is working to understand and develop policy, to help with standardization and implementation, and to coordinate research on POLST and POLST-like programs in other states. The overall goal is to help health care professionals honor patient wishes for end-of-life care.

If you would like additional information about POLST, please see the *POLST website* at *http://www.polst.org*, or email the *Center for Ethics in Health Care* or phone 503-494-3965 and ask for a free informational packet.

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Appendix D. The Final Months of Life: A Guide to Oregon Resources

The Final Months of Life: A Guide to Oregon Resources

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Appendix E. Oregon Medical Board Statement of Philosophy

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Oregon Medical Board

Current Statement of Philosophy on Pain Management
Approved April 16, 1999
Amended July 9, 2004

The Board of Medical Examiners (BME) urges the use of effective pain control for all patients, irrespective of the etiology of their pain. This includes, but is not limited to, postoperative pain, chronic pain of diverse etiology, and pain derived from malignancies. Physicians are encouraged to treat pain within the scope of their practice.

Studies have shown that as many as one-half of patients in pain are not given sufficient pain medication to control their pain in an optimal manner. There are three reasons for this failure to achieve adequate pain relief: 1) concern about causing addiction; 2) lack of knowledge about pain management techniques and pain medication pharmacology; and 3) fear of scrutiny and discipline by regulatory agencies. None of these factors, however, should preclude the physician from assuring that the patient has adequate pain control.

The treatment of post-operative pain requires aggressive management and frequent feedback from the patient regarding the adequacy of the pain control prescribed. The potential for addiction is very low when short courses of narcotics are used to treat post-operative pain.

Skillful pain management techniques, including oral, parenteral and, when available, regional pain management techniques can achieve maximum patient comfort and may reduce the total amount of narcotics required.

The BME encourages physicians to become well informed in acute post-operative pain management and to hone their skills in the latest techniques for control of these acute, self-limited episodes of pain caused by surgical procedures.

Management of the patient with chronic nonmalignant pain requires different techniques but a similar degree of skill. In 1995, the Oregon Legislative Assembly passed ORS 677.470-485, commonly referred to as the Intractable Pain Act. This act allows a physician to prescribe or administer controlled substances to a patient diagnosed with a condition causing intractable pain without fear of sanction from the Board of Medical Examiners, so long as that physician complies with the provisions of this statute.

Both this statute and its facilitating Oregon Administrative Rule (847-030-0015) assure that the patient with chronic nonmalignant intractable pain: 1), receives careful assessment, documentation, and management of the pain; 2), receives the assessment and recommendations of a physician specializing in the body area, system or organ perceived as the source of the pain; and 3), executes a signed material risk notice acknowledging receipt of information disclosing the material risks associated with the prescription or administration of controlled substances used in the course of his or her treatment.

Finally, physicians occasionally prescribe narcotics too sparingly for their terminally ill patients. The BME believes that physicians should make every effort to relieve the pain and suffering of their dying patients. This may require either intermittent or continued administration of large doses of narcotics, often well above those dosages that are considered usual in such references as the Physicians Desk Reference (PDR).

Since the goal of treatment is to relieve pain and suffering, dying patients should receive sufficient narcotic dosages to produce the maximal possible comfort. The physician should acknowledge that the natural dying process usually involves declining blood pressures, decreasing respirations and altered levels of consciousness. Narcotics should not be withheld on the basis of physiologic parameters when patients continue to experience pain.

Some physicians frequently express concerns that the use of narcotics in dying patients may hasten death through pneumonia or respiratory depression. For these reasons, at times physicians may have limited the use of narcotics in dying patients out of fear that they may be investigated for inappropriate prescribing or allegations of euthanasia.

The BME is concerned that such fear on the part of physicians may result in inadequate pain control and unnecessary suffering in terminally ill patients. The BME encourages physicians to employ skillful and compassionate pain control for dying patients and believes that relief from suffering remains the physician's primary obligation to dying patients.

Appropriate management of all of these types of pain is the treating physician's responsibility. The standard of care allows neither overtreatment nor undertreatment. As such, the Board will consider clearly documented undertreatment of pain to be a violation equal to overtreatment, and will investigate allegations in the same manner.

—Approved April 16, 1999

—Amended July 9, 2004

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Appendix F. Sample EMS Protocol

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

ADVANCE DIRECTIVES and DO NOT ATTEMPT RESUSCITATION ORDERS

PURPOSE:

This EMS system believes in respect for patient autonomy. The patient with decision-making capacity has the right to accept or refuse medical intervention. This includes the right to specify, in advance, patient preferences when the person is no longer able to communicate wishes.

PROCEDURE:

The EMS system shall honor POLST forms, Advance Directives and other Do Not Attempt Resuscitation (DNAR) orders under the following circumstances:

A. Do Not Attempt Resuscitation: In the pulseless and apneic patient who does not meet the criteria of the ***Death in the Field*** protocol, but is suspected to be a candidate for withholding resuscitation, BLS protocols will be followed until one of the following occurs:

1. The EMT sees a written DNAR, which should be honored, and resuscitation stopped.
2. The patient's physician is contacted and directs the EMTs not to continue resuscitation attempts.
3. The EMTs see a valid Advance Directive or Directive to Physician which directs them not to continue resuscitation.
4. The patient's attorney-in-fact (PAHC or DPAHC) directs the EMTs not to resuscitate the patient.
5. OLMC directs the EMTs not to continue resuscitation.
6. If a person, who is terminally ill, appears to have ingested medication under the provisions of the Oregon Death with Dignity Act (see section F below).

B. Advance Directives: DNAR orders only apply if the patient is in cardiopulmonary arrest. If the patient's PAHC, DPAHC, Directive to Physicians, or other Advance Directive is available to convey the patient's wishes, and the EMTs have seen a copy of the document, the EMTs must honor the treatment preferences as expressed.

C. Physician Orders for Life-Sustaining Treatment (POLST): If a POLST form is available, and it clearly expresses the patient's wishes and is signed by a physician, nurse practitioner or physician's assistant, EMTs shall honor the patient's treatment care preferences as documented in the EMS section of the POLST. [Cite: OAR 847-035-030 (7)] If an electronic registry is available and the POLST form is not immediately available, EMTs may also follow orders documented in the electronic POLST registry.

D. If there are questions regarding the validity, or enforceability, of the health care instruction, begin BLS treatment and contact OLMC.

E. It is always appropriate to provide comfort measures as indicated.

F. **Oregon Death with Dignity Act:** If a person who is terminally ill appears to have ingested medication under the provisions of the Oregon Death with Dignity Act, the EMT should:

1. Provide comfort care, as indicated.

2. Determine who called 9-1-1 and why (i.e., to control symptoms or because the person no longer wishes to end their life with the medication).

3. Establish the presence of DNAR orders and/or documentation that this was an action under the provisions of the Death with Dignity Act.

4. Contact OLMC.

5. Withhold resuscitation, if:

a. DNAR orders are present, and

b. There is evidence that this is within the provisions of the Death with Dignity Act, and

c. OLMC agrees.

DEFINITIONS:

A. **Do Not Attempt Resuscitation Order (DNAR):** An order written by a physician stating that **in the event of cardiopulmonary arrest**, cardiopulmonary resuscitation will not be administered. DNAR orders apply only if the patient is pulseless and apneic.

B. **Health Care Instruction:** A document executed by a person to indicate the person's instructions regarding health care decisions.

C. **Advance Directive:** A document that contains a health care instruction or a power of attorney for health care.

D. Living Will: A document that may confirm an Advance Directive or Directive to Physician informing her/him that if the patient has a terminal illness and death is imminent, the patient would not wish to be placed on artificial life support that will only prolong the process of dying. **In general, the traditional Living Will document alone is not helpful in the out-of-hospital setting because of its multiple restrictions and lack of clarity on when it should take effect.**

E. Attorney in Fact: An adult appointed to make health care decisions for a person.

F. Power of Attorney for Health Care (PAHC): Power of attorney document that authorizes an attorney-in-fact to make health care decisions for a person when the person is incapable.

G. Physician Orders for Life-Sustaining Treatment (POLST): The POLST is a voluntary form, which was developed to document and communicate patient treatment preferences across treatment settings.

1. It includes a section for documentation of DNAR orders and a section communicating patient preferences for EMS care.

2. While these forms are most often used to limit care, they may also indicate that the patient wants everything medically appropriate done.

3. **Read the form carefully!**

4. When signed by a physician (MD or DO), nurse practitioner or physician's assistant, the POLST is a medical order and EMTs are directed to honor it in their Scope of Practice.

5. If the POLST form is not immediately available, a POLST form as documented in the Electronic POLST Registry hosted at MRH (503 494-7333) may also be honored.

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Appendix G. Organizational Statements and Disclaimers

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Providence Health System - Oregon Region

The Providence Health & Services, Oregon Region, (PH&S) is proud to be a member of this Task Force. Through our membership, we have sought to bring our Mission and Values perspective to an important conversation about end-of-life care. Out of respect for the divergent points of views of the participants, this Task Force has sought to take a neutral stance on the issue of assisted suicide. As people of good will struggle with important moral issues, there is an appropriate place for a neutral discussion of issues that need to be addressed.

PHSOR, in fidelity to its Mission, core values and Catholic heritage, is not neutral on this issue. We firmly hold that excellence in end-of-life care does not include, and can be achieved without resort to, assisted-suicide. Healthcare providers associated with PHSOR should consult system policy for more information.

(Rev.) John F. Tuohey, Ph.D.
Director, Providence Center for Health Care Ethics
Chair, Applied Health Care Ethics

Department of Veterans Affairs

Department of Veterans Affairs (VA) patients will receive high quality and compassionate care. Dying patients will be provided with appropriate measures designed to relieve suffering and maximize comfort. In keeping with national VA policy, VA physicians may not provide a prescription for a lethal dose of medication to veterans who are patients in any VAMC. The VA Pharmacy may not fill a prescription for the purpose of providing a lethal dose of medication. The VA does support adequate relief of symptoms, however, even in the case where death may be hastened.

The Department of Veterans Affairs may not subject a part-time physician to censure, discipline, suspension or loss of privilege for participating or refusing to participate in the provisions of a lethal prescription to a veteran who is not an active VA patient and is seen outside normal VA duty hours. A VA physician may inform patients that physician-assisted dying is available elsewhere in the community.

Linda Ganzini, M.D.

Oregon Board of Pharmacy and Oregon State Pharmacy Association

The Task Force has not verified the accuracy of information contained in the references listed at the end of Chapter 10. Independent and patient-specific pharmaceutical advice should be sought to maximize the efficacy of medications prescribed by those participating under provisions of the Oregon Act. Information included in Chapter 10 has been presented by the authors and does not reflect the positions of the Oregon Board of Pharmacy or the Oregon State Pharmacy Association.

Joseph Schnabel, Pharm.D., R.Ph.

Gary Schnabel, R.N., R.Ph.

Health Law Section, Oregon State Bar Association

Chapter 15, Liability and Negligence, is intended solely for the educational use of the reader and is not intended as legal advice. Independent and specific legal advice is advisable to maximize the legal protection of those participating, or not participating, in conduct authorized by the Oregon Act.

Kelly Hagan, J.D.

Oregon Medical Board

The Oregon Medical Board participated on this Task Force, and like the Task Force, is neutral on the issue of assisted suicide. The information included in the Guidebook is presented by the authors and does not necessarily reflect the position of the Oregon Medical Board.

Kathleen Haley, Executive Director

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Appendix H. Definitions

Written: February 1998; Revised: October 2004, March 2005, September 2007, December 2008

Because people at times are confused about the meaning of some of the terms used near the end of life, the following definitions are offered. These definitions are not meant to imply any ethical argument for or against any of the practices.

Doctrine of Double Effect: According to the doctrine of double effect, an action is justified as long as the intention is therapeutic, to relieve pain and suffering, even if there are foreseen but unintended consequences such as death. Based on this principle, medications are used and widely recognized for the purpose of relieving suffering in terminally ill patients even if those medications may hasten death. The concept of double effect originated in Jesuit theological thought and is widely endorsed by professional organizations.

Total Sedation ***(Sometimes called Terminal Sedation):*** Total sedation involves the use of sedative agents to make the patient unaware of symptoms that cannot be eliminated or satisfactorily controlled by the use of pain management, counseling, and other interventions that are clinically appropriate and acceptable to the patient. The most common method is IV infusion of barbiturates. Other agents and routes of administration potentially may be used. Life-sustaining interventions including artificial feeding and fluids may or may not be withheld.

Some people think that the term *terminal sedation* suggests that the sedative drugs are ending the patient's life and that they should only be used when a patient is actively dying. In order to avoid these implications the National Hospice and Palliative Care Organization recommends the term *total sedation.*

Euthanasia: In the practice of euthanasia the physician or nurse practitioner (rather than patient) administers medication that hastens death. Euthanasia can be either voluntary or non-voluntary. Voluntary euthanasia would occur when a competent patient explicitly requests euthanasia. Non-voluntary euthanasia would occur when the patient is incapable of consenting due to mental impairment. Euthanasia is explicitly prohibited by the Oregon Death with Dignity Act and is illegal in all states.