

Oregon Angels

Portland Support Group meets 10am Sept. 12 at Legacy Good Samaritan Hosp.

New support group up and running in Bend Organizer Ann Ray Havelock: "I thought I was alone."

Like a lot of people living with scleroderma, this Central Oregonian had a terrible experience learning about her condition.

"The day I was diagnosed, I was depressed, having suffered for 1-1/2 years," recalled Ann Ray Havelock, a 69-year-old resident of Bend, married for nearly 45 years with 4 children, 9 grandchildren and 6 great-grand child-

ren. "The P.A. told me I have scleroderma, gave me a paper with all the tests she wanted me to take, and dismissed me. I walked out of her office stunned, devastated and alone."

Unlike a lot of people, she decided to take charge of her situation, and perhaps help others in the process.

"My husband was working out of town with no daytime telephone service, and this was early on Monday. So I went through emotional trauma even after I talked to him that evening. It was three nights later before he came home," noted the busy hairstylist, magazine editor, and church lector. "I am now
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Now for a unique perspective on the nationwide controversy over a concept that was . . .

Truth, lies, and distortion:

*Health care reform's proposed
Advance Care Planning Consultation*

by Ann Jackson, MBA

I've been invited by the editor to comment about the "Advance Care Planning

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Truth, lies, and distortion on proposed Advance Care Planning Consultation

Consultation," a seemingly innocuous provision that has become fodder for the media.

I was asked to do this because, as the director of the Oregon Hospice Association (OHA) for more than 20 years, I am exceptionally well-informed about health care and health care insurance for those who are dying. I was the spokesperson for OHA and strongly believe that persons speaking from positions of authority must speak the truth.

Oregon is recognized as a leader in end of life care and 80 percent of dying Oregonians have completed an advance directive. More than 50 percent are enrolled in hospice, most through the Medicare Hospice Benefit. Hospice is considered the Gold Standard at the end of life.

In the past weeks, hospice and advance directives have become political targets throughout the country. That Oregon has been "progressive" in state health care reform has made it, too, a target, for those whose interests lie in advancing their own political agendas. Their distorted truths and outright lies are a great disservice to all.

I remain involved in end-of-life care, working with private clients, participating in research, writing and presenting, often about how options are selected and decisions made—by choice or by default. My clients have a strong preference for making their own decisions.

I was asked to comment, too, about health care reform—and the Advance

Care Planning Consultation—because I was diagnosed with systemic sclerosis in 2000 (and with multiple sclerosis in 1990). I consider myself to be in good health—and darn lucky. I've been insured by the same carrier/contractor since 1968, a private, not-for-profit health plan, which also participates in Medicare. One doesn't rock the boat—if one can avoid it—with "pre-existing conditions". I've had symptoms of both diseases since I was a teenager.

The Advance Care Planning Consultation (Section 1233) is intended to offer Medicare beneficiaries an opportunity to have a comprehensive conversation with their health care practitioner(s) about advance care planning options, such as living wills and health care powers of attorney.

The consultation is to be voluntary, not mandatory, and reimbursable under Medicare once every five years or, more often, if a patient experiences a "qualifying event". Qualifying events include diagnoses of conditions or diseases that are life-threatening, terminal, or chronic; admissions to long-term care or nursing facilities; and to hospice. A diagnosis of scleroderma, and complications related to scleroderma, are qualifying events.

The original version of the bill neither required counseling nor did it specifically prevent conversations about assisted suicide or euthanasia. An amended version, however, makes counseling "optional" and declares it illegal for "suicide" or "assisted suicide" to be

promoted or listed among end of life options. Health care practitioners in Oregon, Washington, and Montana would be prohibited from informing residents in their respective states about a legal right to physician-assisted dying.

The Advance Care Planning Consultation does not create a "death panel" whose purpose would be to deny care that prolongs life for vulnerable Americans—or that would hasten death. By definition, Medicare beneficiaries, because they are elderly or disabled, are vulnerable Americans.

Although the focus of the Advance Care Planning Provision is on Medicare beneficiaries, every adult should appoint a health care representative and complete an advance directive. Every state has granted its residents the right to make health care decisions in advance, to identify preferences at the end of life, and to appoint health care surrogates to speak on behalf of a patient in a crisis. The assumption is made, when an advance directive is not available, that the person wants life-sustaining interventions. For many people, that assumption is false.

During public debates about Oregon's Death With Dignity Act, in 1994 and 1997, a primary reason for supporting physician-assisted dying as a legal option was a fear of being hooked up to machines and kept alive artificially. An advance directive and health care representative are far more effective remedies.

The Advance Care Planning Consultation remains controversial
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Bend support group up and running as Oregon's second such unit

working with the clinic to make sure that (kind of experience) doesn't happen to newly diagnosed patients in the future."

That interest in reducing the pain and trauma for others has resulted in the creation of the state's second regularly scheduled scleroderma support group. Oregon's newest support session now meets the second Thursday each month for an hour at 5:30pm in the Bend Memorial Clinic, 1501 NE Neff Rd. (2nd floor), across from St. Charles Hospital.

"Liz and I were pleased to see the turn out they had for the first meeting in August," Portland Support Group Leader Donna Stone said after she and Oregon Chapter President Liz Orem-Bedel attended the kick-off session.

"Often times people just don't show up for whatever reasons. We met with the group of ladies, four in fact, with scleroderma. They



Some of the attendees at the first Bend Support Group included Donna Stone (left), Ellen Reynolds, Rhonda Hill, Ann Havelock and Annette Brown.

were all glad to share the camaraderie of someone else living with the disease."

The three other women living with scleroderma and Havelock were joined by her hand therapist and a health reporter from the *Bend Bulletin* newspaper, in addition to the Oregon chapter duo.

"Donna and I were thrilled to be included," Orem-Bedel remarked. "We met scleroderma patients we had not yet known. Everyone had an opportunity to share their stories and meet other scleroderma patients. Donna and I answered a lot of questions about the disease and the foundation."

Havelock is more than pleased with the outcome of the first support group session. "I had

no expectations except to help the attendees relax in a comfortable,

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and subject to amendments. It's been removed from health reform bills, but most recently, re-inserted.

That the issue is on the table now, however, presents all of us with an opportunity to confer with our doctors or openly talk with our loved ones about what we would want if we were dying—and what they would want for themselves, if we are unable to speak for our-

selves. And to put it down in writing.

An advance directive is a gift. I encourage you to make that gift to your loved ones.

And, for what it's worth, health care reform is long past due. []

A list of reliable resources is available at <http://www.nhpc.org>

Ann Jackson, MBA is a consultant residing in Portland, and the former Vice President of the Oregon Scleroderma chapter. She was Executive Director of The Oregon Hospice Association from 1988 to 2008.

The OHA is a not-for-profit, public benefit organization, whose goal is to make sure that all Oregonians—and their loved ones—have excellent care as death approaches.

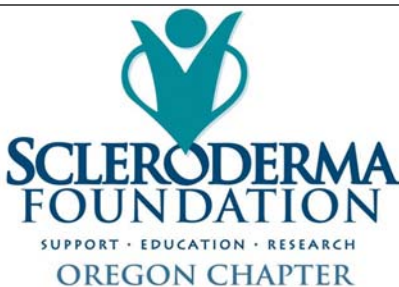


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Look for the Oregon chapter booth at the upcoming **Annual Portland Women's Show in the Oregon Convention Center Oct. 30-Nov. 1, 2009**. Maria Rivelli (left), Liz Orem-Bedel, and Donna Stone are shown at last year's event. "We have had a lot of people asking lots of questions," Outreach Advocacy Director Denise Bates explained. "We also had people who were sick and had some symptoms of scleroderma. They had been looking for answers for years."

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positive atmosphere. They were like me, thinking no one else understood what they were going through. We all asked a lot of questions, and each one told their story."

The support group organizer thinks more than a dozen people in the Bend region are living with scleroderma. And she won't sit still until every one of them, and the entire local health care community, knows about her new group's efforts.

"I am known for persistence and determination when I believe in something," Havelock stressed. "I am appalled at the lack of even the medical field not knowing enough about scleroderma. I contacted Bend KTVZ television, and our

meetings will be on the station in their community calendar. I'm contacting radio stations, and even the Oprah Show (who knows?!) suggesting they look at national. The article in *The Bulletin* should be out this month."

That kind of commitment to awareness and education is sure to go a long way. "Every new person she meets is treated as an old friend," Orem-Bedel said. "This is what makes her such a great support group leader."

Havelock has gone through a lot of trial and errors. "I eventually saw a fourth doctor who said my adrenal and thyroid were good. I then took three months to see a rheumatologist assistant on March 30, 2009. She knew immediately that I had scleroderma,

did several blood tests, chest x-rays and a CT scan on my lungs. Blood tests confirmed I have systemic sclerosis plus a mild amount of pulmonary fibrosis on my lungs.

"The lung doctor will start weaning me off prednisone soon. I have seen a hand therapist, and my hands have improved at least 80 percent. My body is almost like it was two years ago before all this started."

The next Bend Support Group meeting (mzann@bendbroadband.com) is set for Thursday, Sept. 10. Two days later Havelock will be in Portland for the chapter's support group session:

"I have a voice to make things happen and would love it if others would speak out also. But I cannot sit back and wait."