

compassion & choices arizona

Support. Educate. Advocate - Choice and care at the End of life

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Winter 2013

Dedicated to educating and expanding compassionate end-of-life choices for all Arizonans including the right of terminally ill adults access to physician aid in dying as a fundamental civil right.

Comments from our Board President, Freda Anderson



legislation that will require all medical and beliefs for end-of-life care. providers to offer comprehensive end-oflife counseling to terminally ill patients.

Tucson introduced SB 1304 at the start of this year's legislative session. The contents of the bill, outlined in the insert, would ensure that terminally

ill patients are legally entitled to information about all of their end-of-life treatment options, including the potential risks and benefits of each option, as well as the right to refuse treatment altogether.

To date, only two states; New York and California have enacted such laws. To ensure this becomes law in Arizona, we need each of you to ACT NOW. Visit our website www.choicesarizona.org for ways to personally contact your own state representatives, whether by phone, e-mail, letter, fax, or better still, make an appointment to meet with them. If you're not sure who they are, the web page will show you how to find out. Contact them in your capacity as a private citizen, and share our web address with any non-members who support our cause.

In case you are thinking that your input does not matter, I urge you to take a stand and let your opinion be known. Without each and every one one of you, we cannot effectively bring about the change we all fight for.

One voice can make a difference; collectively we will be heard.

While here in Arizona we never lose sight of achieving aid in dying for every competent, terminally ill individual, we continue to "spread the word" and educate as many in our communities as we can reach about the legal options that do exist currently.

Remember that we always have the legal right to say no to life-prolonging treatment we personally may not wish for ourselves. We always have the legal right to ask our physician for alternative options for end-of-life care.

However, until legislation is in place, we also need to take responsibility for obtaining those answers that

We are very excited to announce enable us to make informed decisions that best meet the introduction of Senate Bill 1304, our own needs and are consistent with our own values

In Memoriam: Earl Wettstein (1931-2013)

Arizona State Senator Linda Lopez of We are saddened to report the death of the founder of our state organization, Earl Wettstein. He died suddenly of a heart attack January 9 in Tucson at the age of 81.

> Earl founded our organization in 1997 under the name Arizonans for Death with Dignity. With Earl as prime instigator, a "gang of four" -- consisting of Earl, John Westover, Vickie Fischer and Jeanne Chittenden -- traveled around the state speaking on behalf of what was then called the Hemlock Society. This resulted in the creation of new chapters in Casa Grande, Sun City, Mesa, Sierra Vista, Yuma and Flagstaff. Each chapter



Earl Wettstein

sent a couple of delegates to meet in the Phoenix metro area to form the statewide chapter that today is known as Compassion & Choices Arizona. Earl was elected the first president.

Earl was recognized by the national organization as Hemlock's Outstanding Volunteer in 1997-1998, their top honor. In 2001 he was added to the national Board where he served for two years. Earl served as state president until 2004, when he wrote:

"I leave this position with a great sense of having done something significant with my life. I am going to devote myself now to being a painter, and although I enjoy it immensely, I am sure I will not get the sense of accomplishment that I have gotten from founding this state organization. Thanks for believing in me and for giving me the opportunity to serve. It has been my pleasure."

Earl ran his own advertising agency in Tucson for 31 years until his retirement in 1995. He was a Renaissance man who lived life to the fullest each and every day: AdMan, Artist, Writer, Playwright, Community Leader, Activist, Volunteer. He is survived by his wife, Sherie, and children, Lisa and Gillian.

Maggie's Story

We are extremely grateful for Maggie's story — a perfect example of taking control of one's own destiny no matter what the prognosis — and the unique and invaluable role our End-of-Life Consultation service offers to anyone, whether member or not, and at no cost. A single call to 1-800-247-7421 is all it takes to make the difference between despair and hope.

We keep Maggie and all those in a similar situation in our thoughts, and, as a constant reminder why you and I should ACT NOW to support the current legislation that is a stepping stone to the ultimate goal of aid in dying for all those who qualify.

Margaret O'Brien Scott, known to friends and loved ones as Maggie, is dying. Not as quickly as the doctors told her she would, fortunately, as they gave her only a nine-to twelve-month prognosis. A ten-month delay in her diagnosis changed a 90% recovery prognosis to a terminal Stage 4 diagnosis of rare transitional cell kidney cancer.

In Her Own Words:



Mayo Clinic detected a malignant kidney tumor after misdiagnoses by two other physicians. A hopeful prognosis turned grim after surgical removal of my left kidney and numerous malignant lymph nodes. The cancer was incurable.

Maggie O'Brien Scott My first post-surgical decision was whether to undergo a toxic and risky chemotherapy protocol. Even with chemotherapy the prognosis was poor. With support of my Mayo oncologist, I declined chemotherapy in favor of quality of life. The first step was to recuperate from major surgery with a vegetarian-centered diet to boost my immune system.

Despite excellent medical care at Mayo, I was in freefall emotionally. I returned to my home in Sedona, AZ, to seek support and guidance from family, friends and professionals. Family and friends rallied around me, professionals did not. My husband and I consulted a local oncologist, but soon realized that a patient who declines chemotherapy may not fit the medical business model. My requests for guidance and mental support went unheard when chemotherapy was taken out of the equation.

I was overjoyed to hear about a local cancer support group in my community. My husband and I met with the social worker who facilitated this group. During our consultation, a subtle undercurrent emerged that I was too emotional to join her "flock." We understood the message that I was dying of cancer, not a "survivor," not a fighter, and therefore not welcome in the group because I might upset other members.

At my family and friends' insistence I continued to seek professional counseling to regain quality of life in face of a terminal diagnosis. A clinical psychologist in Flagstaff brought focus to my dilemma, together with an urgent appeal for me to return to Mayo for psychiatric help. With conservative medical intervention from my Mayo psychiatrist, I was able to regain a semblance of my former emotional stability and physical stamina. It was the "quality of life" that I had sought, not a cure for my cancer, but a glimpse of hope.

Eighteen months ago an article appeared in my local newspaper about three upcoming meetings sponsored by Compassion & Choices. I had never heard of this organization, despite six months of conversations about terminal illness with doctors, psychologists, and hospice personnel. I attended all the meetings and met with the Sedona chapter leader. She told me about the end-of-life counseling program at C&C. I immediately joined and followed up with a call to national headquarters inquiring about their end-of-life counseling. Within one day a very special client services consultant came into my life.

Compassion & Choices is still in my life eighteen months later. My counselors communicate with me frequently. They give me hope that I have a voice in how to end my life when that time comes, a choice that brings me peace of mind and dignity. A gentle passing is all I ask, not a prolonged scenario of dependence on caregivers.

Continued on page 5

SB 1304

Introduced by Senators Lopez, Bradley, Gallardo, Hobbs: Jackson Jr.

AN ACT

Amending title 32, chapter 32, article 1, Arizona Revised Statutes, by adding section 32-3216; relating to health professionals.

Be it enacted by the Legislature of the State of Arizona:

Section 1. Title 32, chapter 32, article 1, Arizona Revised Statutes, is amended by adding section 32-3216, to read:

32-3216. Palliative care; terminally ill patients; definitions

A. If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner shall offer to provide the patient with information and counseling regarding palliative care and end of life options that are appropriate to the patient. The information and counseling may be provided orally or in writing. This information must include at least the following:

- 1. The range of options appropriate to the patient.
- 2. The prognosis, risks and benefits of the various options.
- 3. The patient's legal rights to comprehensive pain and symptom management at the end of life.
- 4. Information regarding other appropriate treatment options if the patient wishes to initiate or continue treatment.
- B. If the attending health care practitioner is unwilling to provide the information prescribed pursuant to subsection A of this section, the attending health care practitioner shall refer or transfer the patient to another physician or registered nurse practitioner who is willing to do so.
- C. If two or more persons are a patient's attending health care practitioners, each one of them is responsible to provide the information required pursuant to this section unless they agree to assign that responsibility to a specific attending health care practitioner.
- D. If a patient lacks capacity to reasonably understand and make informed choices relating to palliative care, the attending health care practitioner shall provide information and counseling under this section to a person with authority to make health care decisions for the patient. The attending health care practitioner may arrange for information and counseling under this section to be provided by another professionally qualified individual.
- E. For the purposes of this section:
- 1. "Appropriate" means consistent with applicable legal, health and professional standards, the patient's clinical and other circumstances and the patient's reasonably known wishes and beliefs.
- 2. "Attending health care practitioner" means a person who has the primary responsibility for the care and treatment of a patient and who is either a physician who is licensed pursuant to chapter 13 or 17 of this title or a registered nurse practitioner who is licensed pursuant to chapter 15 of this title.
- 3. "Palliative care" means health care treatment, including interdisciplinary end-of-life care and consultation with patients and family members, to prevent or relieve a patient's pain and suffering and to enhance the patient's quality of life. Palliative care includes hospice care.
- 4. "Terminal illness or condition" means an illness or condition that can reasonably be expected to cause a patient's death within six months after diagnosis, whether or not medical treatment is provided to the patient.

The Arizona Palliative Care Information Act

SB 1304 requires patients be offered information on palliative care and end-of-life options available to them when they are faced with a terminal illness or condition, thereby empowering them to make choices consistent with their desires, values and beliefs.

Why You Should Support This Bill

- Encourages honest and open patient/physician discussion about treatment options and goals of care
- Empowers the patient to make informed health care decisions
- May facilitate earlier admission to palliative care and hospice, resulting in improving pain, treatment of symptoms, and quality of life

Compassion & Choices is dedicated to improving care and expanding choice at the end-of-life. We believe that patients are able to make the best choices for their own care when they are fully informed of all end-of-life options, including withdrawal of life prolonging care (such as ventilators, feeding tubes, cardiac devices, medication, dialysis, etc.), voluntary stopping eating and drinking (known as VSED), palliative care; and aggressive pain and symptom management (including palliative sedation).

To date, only two states, California and New York, have enacted laws giving patients the legal right to know their treatment options. Everywhere else, including Arizona, it may be up to the doctor's discretion as to what he or she wants to tell you.

As Kathryn Tucker, Director of Legal Affairs for Compassion & Choices; asserts: "The right of patients to make their own informed end-of-life decisions, and to have those decisions honored, is a basic human right. Dying patients deserve to have the broadest range of choice and care, and the autonomy to decide what they want for themselves."

To show your support for SB 1304 **Contact Your Legislator Now!**

Go to our website www.choicesarizona.org where you can find information on how to contact your state legislators, the best ways of doing so, and links to find out who they are if you don't already know. Please contact all three of your state legislators: two Representatives in the House, and one Senator.

If you want to help enact change in our laws, it is essential to ACT NOW.

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In The News ...

PBS Frontline program "The Suicide Plan"

video.pbs.org/video/2304058290

On November 13th of last year, FRONTLINE aired its special report on aid in dying in America. The provocative title, which does not accurately reflect what our mission and goals are, nonetheless offered an in-depth view into one of the most polarizing social issues of our time. The special featured interviews with Compassion & Choices president, Barbara Coombs Lee, as well as a Compassion & Choices client who candidly discussed why she intended to end her suffering. The special also showed the contrast between the work of Compassion & Choices and the Final Exit Network.

Board President Freda Anderson was interviewed twice by Channel 3 recently in connection with a local "mercy killing":

tinyurl.com/phoenixmercy1 tinyurl.com/phoenixmercy2

Maggie's Story (Continued)

Although I have beaten the odds for my cancer, almost two years with no chemotherapy, the cancer has metastasized to my liver and lungs. Three-month interval CT scans continue at Mayo ... my psychiatric care continues ... but no answers as to how and when. My doctors are in accord with my wishes of non-invasive reasonable treatment, no resuscitation, no ICU, but none of them are allowed to offer me end-of-life options in Arizona.

The end-of-life counselors at Compassion & Choices enable me to understand my options. Most importantly, they give me the peace of mind that they will be there for me when I need them, to explain what choices I may have, and give me the courage to make the choice that is right for me. Compassion & Choices is always just a telephone call away, available for everyone at any time. It was a lucky day that I read my local newspaper eighteen months ago.

Reminders

We always need volunteers - no matter what your qualification or how much or little time you can offer. If you have the desire to help with our efforts in any way, please contact us at info@choicesarizona.org.

If you want to stay up-to-date with notifications of upcoming meetings, legislation announcements, etc., by e-mail (we promise you will NOT be bombarded with junk mail), please e-mail us with the words OPT IN in your subject line. It's the easiest, quickest and most eco-friendly way of keeping you updated of what is happening locally.

If you want to renew your membership using a credit card, either visit www.compassionandchoices.org and complete the request online, or call 1-800-247-7421. Or send a check payable to Compassion & Choices to P O Box 14556, Scottsdale AZ 85267.

Visit Us At ...

SCOTTSDALE EXPO - Wednesday, February 20 9am - 1pm: All Things Senior Expo Scottsdale Center for the Performing Arts, 7380 E 2nd Street, Scottsdale.

Compassion & Choices Arizona will have a booth at this FREE event, providing a wide range of information about products, services, programs and other great resources for the valley's 60+ community. Looking for information about senior housing, recreation opportunities, transportation resources, healthcare options or Valley wellness programs? The "All Things Senior" Expo & Tradeshow will provide a "one-stop-shop" for valuable local resources.

Our Grateful Thanks ...

To all the new members who joined Compassion & Choices Arizona in the latter part of 2012. Our membership now stands at 1,060 statewide... and growing!

To members Marta Morando and Gordon Elder for their generous donations to the Arizona organization.

To all those who donate to our National organization but support our efforts in Arizona, you too are very much appreciated.

C&C Arizona Board Members

Freda Anderson – President Margot Champagne – Vice President David Brandt-Erichsen Denny Flaherty Enci Lajos

Advisory Board Members

William E. Haley Robert (Bob) Wallace Irene Weitzman, PhD Compassion & Choices P.O. Box 101810 Denver, CO 80250

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Upcoming Meetings & Chapter News

Upcoming Events: Please check the Events tab on our website www.choicesarizona.org for updates.

ROLAND HALPERN, Community Relations Coordinator for Compassion & Choices National in Denver, will join us to provide an overview of the organization's activities at the national level as well as offering a detailed overview of aid-in-dying legislation throughout the country. Free to both members and non members.

PHOENIX: Sunday, March 3. 2pm – 3:30pm

Burton Barr Central Library, 1221 N. Central Ave, Phoenix, AZ 85004

NORTHWEST VALLEY: Monday, March 4. 1:30pm – 3pm

Coyote-Quail room in the Foundation Center, 14465 R.H. Johnson Blvd, Sun City West AZ 85375

TUCSON: Tuesday, March 5. 11:30am – 1pm

Himmel Park Branch Library, 1035 N Treat Ave, Tucson AZ 85716

GREEN VALLEY: Tuesday, March 5. 4pm – 5pm

Joyner-Green Valley Branch Library, 601 N La Canada Drive, Green Valley 85614

SEDONA: Saturday, April 6. 10:30am – 12 noon

Sedona Community Center

2615 Melody Lane, Sedona AZ 86336

Advance Directives and Other End of Life Legal Documents to outline your end-of-life wishes.