

HEALTH DECISIONS

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Vermont Ethics Network Says Goodbye to Founder

A Tribute to Arnold Golodetz, MD - 1928-2012

BY BETSY DAVIS

rnold's own words, "How can I be so ungracious as to forget the good things I've experienced in those 83 years, starting on day one with the gift of life, and with it an amazing service contract?" frame his lifelong commitment to making a difference—and make a difference he did! Many of us are aware of his enormous contribution to the Visiting Nurse Association—particularly to his (and his wife, Ginny's) commitment to the VNA Family Room and early childhood education—and as one of the founders of the Vermont Ethics Network (VEN). He has shown an innate curiosity and understanding of social, ethical and general humanity issues through-out his life, providing a

powerful influence in molding organizational values and program design. He wanted to fix things and make it better for people.

Discussion with other VEN founders reveals Arnold's thoughtful and scholarly research contributions to the priorities and direction of VEN. The process was not always tidy considering the complexity of the issues, but he was always prepared, had consulted research and ethicists, listened carefully and always showed up. He loved being part of the process, even when it was messy. He described VEN as

"part of a revolution, a popular movement—the field of battle was Medicine, and the big question was "Whose Life is it anyway?" and "Who Lives Who Dies." Once a direction was decided and values defined, he had a "steely" resolve to move VEN to action. He was a major influence in developing the first *Taking Steps* booklet and the original Advance Directives legislation and a vigorous advocate in their widespread use. He was a tireless educator, writing countless papers on issues, speaking at conferences and on radio shows and driving hundreds of miles to participate in community meetings.

Another example of Arnold's selfless contribution came when VEN concluded the "Project on Death

in America" grant in 1998 with a report of the community meetings titled "Vermont Voices on Death and Dying" which integrated all the comments of participants across the State. Arnold organized and wrote that report and was pressed to have his name listed as the author. In characteristic fashion, he demurred saying: "this is a report from Vermonters and any byline would detract from the important things they have to say to us." He was a true gentleman scholar.

There are many other examples of Arnold's influence



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is to promote ethics as
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Vermont Ethics Network
61 Elm Street
Montpelier, VT 05602
Telephone: 802-828-2909
Fax: 802-828-2646
Email: ven@vtethicsnetwork.org

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Meditation

Arnold Golodetz, MD

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Post-operatively, the surgeon bestowed on me my new status—cancer person.

So I joined a new community; and remembered Father Damien, one morning on Molokai, saying to his flock: "Fellow lepers."

Now what? I'm 83. Shall I tremble, shall I cry out? Are there straws I can clutch?

But wait; death at 83 is not premature. I have successfully logged a normal life span. Can I not say I have lived long enough? Would I be greedy if I asked for more?

Still, the culture I live in has its imperatives echoing in my ears. Fight! The obituary should say: *He battled bravely*. Dylan Thomas roars in my ear, drunkenly as usual: "Rage, rage...". But why should I?

No thanks, I've run out of rage, perhaps even of tears. How can I be so ungracious as to forget the good things I've experienced in those 83 years, starting on day one with the gift of life, and with it an amazing service contract? (The Latins called it *V is Medicatrix Naturae*—the healing power of Nature—ready to repair whatever wear and tear my journey causes.) But any service contract has a lifetime maximum.

I must brush up on what the Stoics had to say.

Now cometh the oncologist, with offerings. Poisons for my malevolent rebel cells. He calls it treatment, all dressed up in numbers, probabilities. Twenty percentage improvement in this, ten percent risk of that. It sounds like *Purgatorio*, with promise of *Paradiso* quite uncertain. I must weigh benefits against harms; but what counts as benefit, what as harm? And whose interests matter? Mine? My family's? Those who pay the bills?

Who pays? That does matter. I have insurance; that is, I belong to a population that has pooled its resources, creating a "commons" that each of us can draw on if needed. But I remember the "Tragedy of the Commons."* If all graze on the commons ad lib, the commons becomes exhausted. We're there right now. The question of fair shares comes up, insistently.

The oncologist is back, with offerings of marginal benefit for high cost. How shall I answer him?

What do I want—a "tame" death or a "wild" one? Phillippe Aries† suggested this so-oversimplified contrast. *Tame* is at home, among family and neighbors; it implies acquiescence, an acceptance of truth, a death congenial to one's philosophical core. (Can I find within myself such a core?) *Wild* is to be found in the Intensive Care Unit, or any place dominated by lies and denial. Consider, for example, the *Death of Ivan Ilyich* as described by Tolstoi.

I must think out my own path to tame.

*Garrett Hardin, Science, 162(1968) †The Hour of Our Death, Oxford University Press, 1981v on the ethics of the health care system and early childhood education, but space doesn't permit except to again quote from Arnold's summary of the history of VEN:

"Prudence suggests that society benefits if its members are as healthy as possible. Decency—the morality of the Golden Rule—points in the same direction. One can argue about what 'happiness' should mean, but at the least we can agree that the 'pursuit' of happiness requires opportunity, and that opportunity starts with a decent level of health and education."

May all of us who have been touched by Arnold's wisdom, continue to pursue this definition of Happiness. He will be missed.

With thanks to Jean Mallary, Michelle Champoux and John Campbell for their reflection and thoughtful input to this tribute.

Making Wise Choices Together: Evidenced-based Shared Decision Making

BY ROBERT MACAULEY, MD

he United States spends far more on health care than any other developed nation—over \$2.5 billion, or 18% of Gross Domestic Product. Yet despite spending so much, we still rank 37th in the world in overall health care (according to the World Health Organization). How, then, can we improve quality while also reining in costs?

One intriguing proposal is the "Choosing Wisely" approach (www.choosingwisely.org). First proposed by Dr. Howard Brody in an influential 2010 editorial in the New England Journal of Medicine, this approach recognizes that much of the medical care that physicians provide—and patients demand—has been shown to provide minimal or no clinical benefit. Dr. Brody challenged each medical specialty to identify its "top five" such tests or procedures, many of which were common or expensive (or both). (Examples include ordering x-rays for low back pain and prescribing antibiotics for a sore throat not caused by strep.) Recognizing that doing more is not always better for patients, this approach proposes doing less in order to foster health and save money.

Here it is important to note that this is not about rationing care that might be beneficial. Quite the opposite, this is about avoiding tests and treatments that are as likely to make the patient worse as to make him better. It is also not a return to the paternalism of ancient medicine, because these are merely recommendations which are meant to be discussed with the patient, who ultimately makes the final decision. In many cases, when informed of the lack of benefit, patients will agree to forgo unhelpful tests or procedures. When the patient continues to request them, though, the physician may still order them, while at the same time providing critical perspective as to how to interpret the results and outcomes.

This represents a fundamental—and, some would argue, long overdue—shift in the role of the physician from focusing exclusively on each individual patient to considering the needs of all patients. Nearly thirty years ago, another influential editorial in the *New England Journal* asserted that "physicians are required to do anything that they believe may benefit each patient, without regard to costs." The most recent "Physician's Charter," on the other hand, demands that physicians work toward "the wise and cost-effective management of cost-effective resources."

An important first step is refraining from doing tests and performing procedures that don't help people. Such wise choices lead to both improved patient care as well as cost savings.

The Challenge with Screenings: How to Choose

BY REV. DIANA F. SCHOLL

EN scored a slam dunk with it's September conference at Lake Morey "When Less is Better" featuring Dr. Howard Brody, family practice doc and clinical ethicist working at the Institute for Medical Humanities at the University of Texas, Galveston. Dr. Brody led a stellar group of speakers looking at the many sides of how we assess risk and benefit to the patient when tests and treatments are routinely prescribed even if the science no longer stands behind them. Combined with the Choosing Wisely campaign and the Consumer Union effort to inform patients about particular issues they might need to decide about, healthcare professionals, patients, and advocates came together to wrestle with this slippery topic. We were even brave enough to bring in the issue of cost and how unnecessary treatment or overdiagnosis can increase costs without corresponding increases in survival rates. Tough stuff!

And this issue just does not go away. On October 24, 2012 the New York Times published Tara Parker-Pope's "Mammogram's Role as Savior is Tested" in their Well blog. This was just a continuation of many years of Times coverage of the growing controversy over the usefulness of widespread mammogram screening as well as 10 years of discussion in medical journals and 30 years of research. But I now call it the prequel to a lively, passionate debate both on the editorial pages of the Times and the New England Journal of Medicine (NEJM) that took off again on November 1, 2012. These two publications are usually considered the "publications of record" in their fields though many others of course publish excellent medical research, news and commentary.

Parker-Pope pulled no punches quoting the famous Dr. Susan Love ("Screening is not

prevention. We're not going to screen our way to a cure.") and giving us data too: "Among the 60% of women with breast cancer who detected the disease by screening, only about 3% to 13% of them were actually helped by the test..."

Wondering about the costs? Hundreds of millions spent over the years on awareness campaigns is conservative and "\$5 billion spent annually on mammography screening." That's "billion" with a "b"! Why? Patients and physicians have been convinced of the "magic" of screening and the promise it held in the early 70's to do more than the science is showing that it can actually achieve.

It's important to quote Parker-Pope here: "One of the reasons screening doesn't make much difference is that advances in breast cancer treatment make it possible to save even many women with more advanced cancers." This fact is stated over and over again in the research so that we can be clear that no one is saying that we should just let women die of breast cancer because we don't want to pay for screening for everyone. No death panels here I assure you. As Dr. Love says: "Screening is but one of the tools we have to reduce the chance of dying of breast cancer." Screen some women at high risk; screen others less aggressively; screen others not at all until they reach 40.

This is a huge topic and attached are the articles relevant to the conversation which I hope you will read and consider. The most important ones for purposes here are Gil Welch's *Times* Op/Ed: "Cancer Survivor or Victim of Over-diagnosis?" on November 21, 2012 and the *NEJM* article on the results of a new observational study "Effect of Three Decades of Screening Mammography on Breast-Cancer Incidence" by Bleyer and Welch published on November 22nd. Links to these

articles will be on the VEN website along with the *NEJM* preview article. That's where you can read the multiple important points made by the experts.

I was very proud to be part of an extremely lively debate in my little corner of Vermont tackling these hard issues the same week that these articles appeared by folks like me: informed but not experts; involved in what happens to our own health and the health/welfare of our friends and community; mostly just regular folks. The conversation was stimulated by one person sharing the *Times* Op/Ed piece by Welch. Many of the points made in the articles were also made by the participants, but here are a few thoughts from Middlebury that stand out:

- Will concern about the cost of mammogram screening make it an excuse (or reason) to deny coverage to those who cannot afford it?
- We all have friends who swear that the mammogram that detected their lump (and the subsequent treatment) saved their lives. Why should we forego that screening if we have the means to have it done and it could save our lives?
- The Letter to the Editor titled "The Value of Mammograms" from docs and one nurse from Sloan-Kettering makes it clear that the medical profession itself is in confusion or at odds on the effectiveness of screening. So how should patients make such a decision if the oncologists can't even decide themselves? Isn't that too big of a decision to put on just a regular patient who is not an expert?

• For so many women having a yearly mammogram gives them "peace of mind." Isn't that important? Isn't that worth something as we weigh all the alternatives?

These are deeply insightful and wise ethical issues to raise as we consider the options of whether to test or treat for any disease. They can help us create excellent guidelines as government (that is, we the people: you and me) begins to take responsibility for deciding who gets what from the medical system. We are all the ethicists in the end. What will we do?

FOR MORE INFORMATION AND ADDITIONAL RESOURCES

New York Times

http://well.blogs.nytimes.com/2011/10/24/mammograms-role-as-savior-is-tested "Mammogram's Role as Savior is Tested" (Parker-Pope; Well Blog; 10/24/2012)

http://www.nytimes.com/2012/11/22/opinion/cancersurvivor-or-victim-of-overdiagnosis.html "Cancer Survivor or Victim of Overdiagnosis?" (Welch; Op/Ed; 11/21/2012)

http://www.nytimes.com/2012/11/28/opinion/the-value-of-mammograms.html "The Value of Mammograms" (Letter to the Editor; 11/27/2012)

http://well.blogs.nytimes.com/2012/11/28/ignoring-the-science-on-mammograms "Ignoring the Science on Mammo-grams" (Newman; Well Blog; 11/28/2012) Also see 321 comments.

New England Journal of Medicine

http://www.nejm.org/doi/full/10.1056/NEJMp1209407 "Cancer Screening Campaigns—Getting Past Uninformative Persuasion" (Woloshin, Schwartz, et al; Perspective; 11/1/2012)

http://www.nejm.org/doi/full/10.1056/NEJMoa1206809 "Effect of Three Decades of Screening Mammography on Breast-Cancer Incidence" (Bleyer & Welch; Article; 11/22/2012) This is the preview. Subscription needed to read the entire article.



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VENOTES

Upcoming Events

DETAILS COMING SOON: VERMONT ETHICS NETWORK – PALLIATIVE CARE AND PAIN MANAGEMENT CONFERENCE

The Palliative Care and Pain Management Task Force is in the process of planning for an April 2013 Conference. Be on the lookout information about date, time, location and featured presenters!

SAVE THE DATE - MAY 10, 2013

Thaddeus Pope, professor of law specializing in health care ethics and medical futility comes to Burlington for Internal Medicine Grand Rounds at FAHC. Mark your calendars!

HOSPICE & PALLIATIVE CARE COUNCIL OF VERMONT

22st Annual Conference Lake Morey Resort, Fairlee, VT Thursday, June 6, 2013

Register Your Advance Directive

HEALTH CARE PLANNING IS FOR EVERYONE: START THE CONVERSATION TODAY!

- TALK to others about your values and future health care wishes.
- GO to www.vtethicsnetwork.org for the Vermont Advance Directive Form and for comprehensive information about Advance Care Planning and Advance Directives.
- COMPLETE your Advance Directive.
- REGISTER your Advance Directive with the Vermont Advance Directive Registry—an easy and secure way to give your health care providers immediate access to your wishes about health care decisions.

For more information about the Vermont Ethics Network, or to order the Taking Steps Booklet, contact us by phone at 802.828.2909 or via e-mail at ven@vtethicsnetwork.org.