



Health Decisions

A publication of the Vermont Ethics Network
Working to promote ethics as a core component of health care and health care decision-making

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Shared Decision Making: An Overview

by Denise Niemira, MD

Shared decision-making is a collaborative interaction between a patient and his or her healthcare provider in making treatment decisions. The term itself has been used in a narrow and specific sense to refer to a program which provides standardized patient education information focusing on particular health care decisions, usually those for which there is no clear “best” treatment option. The information is presented in several formats, sometimes interactive and is derived from current evidence based best practices. It is designed not only to help patients understand the likely outcomes of various treatment options but to think about the risks and benefits of each choice in terms of their personal values and goals. The program provides patients with information/tools to bring to the discussion they will have with their healthcare provider in making a treatment decision.

Shared decision-making in a broader and more general sense refers to a model of caregiver/patient relationship in which collaboration becomes the hallmark of decision-making. This replaces previous models of physician centric paternalism and patient dominated rights with a model in which dialogue based on mutual trust and respect for each other’s role leads to the best possible decision for the individual patient. It encompasses but is not restricted to Shared Decision Making in the narrow sense. It potentially includes all treatment decisions, even those in which there is clear evidence based “best” treatment. *Continued on Page 3*

25 Years of Vermont Ethics Network

by Jean Mallary and Cindy Bruzzese

2011 will mark the 25th Anniversary of the Vermont Ethics Network. As we make plans for our celebratory year and set priorities for the future, we are reminded of our history and of why still, some 25 years later, VEN’s work remains crucial.

The Vermont Ethics Network (VEN) got its start, in 1986, as a project funded by an educational grant from the Robert Wood Johnson Foundation to the Vermont Health Policy Council (VHPC) to explore ethical issues around death and dying. It seemed simple on the surface, but those issues were to encompass the larger questions, as stated in the grant: “Who Lives, Who Dies, Who Decides, Who Pays?” This was 1986, when the growing awareness of patient autonomy and the questioning of medical authority via the Living Will movement were converging with a renewed health care reform effort. The Robert Wood Johnson Foundation, through similar grants to other states, was interested in capturing this energy and challenging the citizens of the country to think about the place and priority of health and health care in their lives - both on a personal level and in the arena of public policy. *Continued on Page 2*

Anniversary *Continued from Page 1*

It was a challenging assignment: to design a project that sensitively made the transition from the very emotional issues around decisions at the end-of-life to contemplation of the limits and burdens of medical care. The project also needed to appeal to a wide spectrum of society and to the professions as well. Additionally, there was the task of recruiting and training enough volunteer facilitators to extend the reach of the project throughout Vermont -- all within a limited span of time (2 years), a limited budget (about \$25k per year, plus overhead provided by the VHPC) and a small staff (2).

For this project ("Taking Steps") VEN developed a modus operandi which later served also for the Advanced Directives Clinics initiative and a pair of projects on health care reform (Vermont Health Decisions and Neighbor to Neighbor). The M.O. could be labeled "Democracy invades the sanctum of Medicine." In close cooperation with Paul Wallace-Brodeur of the Vermont Health Policy Council, VEN:

- *Gathered a group of expert and dedicated advisors to brainstorm the major parameters and outline of the project;*
- *Educated its staff, volunteers and partners, through journals, books, media and articles from varied sources;*
- *Consulted with other grant project directors and with respected ethics institutions such as the Hastings Center;*
- *Found the right people to create the audiovisual discussion starters, and oversaw development of the script;*
- *Set up criteria for facilitating discussions and, through networking, recruited individuals willing to volunteer considerable time and put aside their biases in the interest of thoughtful deliberation;*
- *Put together a two-day training conference and prepared an exhaustive facilitator's manual;*
- *Set up two hour discussions across the state through town clerk offices, libraries, senior centers, hospitals and hospices, schools, churches, the Grange, and the like;*
- *Sent out facilitators in pairs to cover the discussion and submit a written report on each meeting;*
- *Held a mid-course correction meeting of facilitators;*
- *Held a final day and a half conference, planned next steps, wrote and distributed a final report.*

After the original **Taking Steps** project and successful legislation passing the Durable Power of Attorney for Health Care (DPA/HC) in 1988, VEN, supported by grants from the Prudential Foundation and then Vermont's Health Care Authority, turned its attention to the ethical issues in the public arena of health care reform. Our next two projects wrestled with the concept of limits and setting priorities in health care (**Vermont Health Decisions**, 1990) and preparing Vermonters for the changes inherent in Act 160, Vermont's landmark health reform effort (**Neighbor to Neighbor**, 1993).

All told, from 1986 - 1994, VEN trained 99 facilitators and held over 420 discussions with 8350 participants. Special mention should be made of one other major project, the "**Advance Directives Clinics**," launched in 1992 in response to the federal Patient Self-Determination Act. These "clinics," with their emphasis on the concept of patient informed consent, together with comprehensive training of facilitators, were really a keystone of VEN's work and have been continuing, in one form or another, since that time.

The pace of VEN's work during those first years was both exhausting and exhilarating. From Dr. Arnold Golodetz, a key supporter and contributor to VEN from the beginning: "There was something romantic about this early stage of VEN. It was something new and fresh, something that appealed to emotion, something that promised a fine future, a better world. That is quite characteristic of a movement."

First of all, we were pioneers in an early movement of health care consciousness, with all the excitement and passion a movement inspires. Secondly, we were a real network, attracting all manner of people dedicated to exploring new paradigms in health care decision-making, people devoted to examining the ethical dilemmas inherent in medicine and public policy, and finally, people open to VEN's unique process of presenting those dilemmas to the public.

Shared Decision Making *Continued from Page 1*

Shared decision-making in this sense involves a dialogue in which the health care professional's clinical experience and fiduciary responsibility are used to inform and guide the patient's choice among the various options for treatment according to the patient's personal preferences and goals. Shared Decision Making tools may be part of the process or may not be available or appropriate for the particular decision. Honest communication is critical. The patient must trust that his caregiver is willing to listen to his use of alternative therapies and that criticisms are based on evidence of harm and not on prejudice. He must be willing to disclose barriers to compliance with therapy including financial and transportation issues as well as problems with dosing intervals or forms. Professionals must be willing to sacrifice "best" practices for "reasonable" practices but be able to point out incongruities between patient's perceived short term benefits and desired long term goals.

The process is not always easy and smooth even with best intentions in both parties. It may be incremental and involve compromises. Smaller, easier decisions that build trust and go well may form the basis for more critical, difficult ones at a later date.

The balance between autonomy and beneficence in the clinical setting is a delicate one that shifts with time and individual preference. Shared decision making is an attempt to incorporate that balance into treatment decisions. It depends on patients who can express their values and goals, ask questions, define their limits and reevaluate their choices in response to changing situations. It depends on providers who are willing to listen, able to compromise and define best practice as what works best for the patient. Perhaps it depends on honest conversations about expectations and goals and willingness to compromise long before any major treatment decisions need to be made.

Additional Resources for Shared Decision Making:

- The complete chapter on Shared Decision Making by Dr. Denise Niemira. Found in Chapter 8 of the *Handbook for Rural Ethics: A Practical Guide for Professionals* at: <http://dms.dartmouth.edu/cfm/resources/ethics>
- The Center for Shared Decision-Making at Dartmouth Hitchcock Medical Center. They offer:
 - One-on-one counseling sessions for any medical condition
 - A Decision Aid Library of helpful videotapes, audiotapes, booklets, CD-ROMs, and websites
 - A Healthcare Decision Guide to help you work through a decision on your ownVisit http://www.dhmc.org/shared_decision_making.cfm for more information.
- Ottawa Hospital Research Institute: Ottawa Decision Aids at: <http://decisionaid.ohri.ca/decaids.html>
- Ottawa Personal Decision Guide – to help people assess their decision-making needs for any health related situation. <http://decisionaid.ohri.ca/decguide.html>
- The Foundation for Informed Decision Making at: <http://www.informedmedicaldecisions.org>

Message from the New Board Chair: Betsy Davis, RN MPH

VEN's summer issue of *Health Decisions* outlined the tremendous progress made in programming and outreach in addressing complex ethics issues on many fronts in the past year. This is due in large part to the amazing creativity and energy of our now not so new Executive Director, Cindy Bruzzese, but also to the committed leadership of all our Board members. At our Annual Meeting on October 28th, we recognized two of those leaders, Rev. Patrick McCoy and Kevin Veller, for their many years of dedication and service on the VEN Board.

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Message from the Board Chair *Continued from Page 3*

Rev. Patrick McCoy, Chair of the Board for the past several years, helped steer VEN during a critical time of transition. Kevin Veller served as Chair of the Governance and Nominating Committee and led the process to identify and recruit new Board members. Beyond their numerous contributions and patient leadership over the years, we will miss Patrick's gentle persistence and Kevin's energy and humor!

This year we elected and welcomed four new Board members at the Annual Meeting: Lynn Burgess, Penrose Jackson, Bill Nelson and Beth Cheng Tolmie. An orientation meeting was held with our new members and if that meeting is any indication of the level of interest and wisdom among them, we're very fortunate to have all four with VEN as we move into our 25th Anniversary year!

We're fortunate to have several of VEN's founders: Jean Mallory, Michele Champoux, and Arnold Golodetz, all involved in the formation of VEN, assisting as members of the Anniversary Planning Committee. The timing for looking forward to the next 25 years is fortuitous when considering the rapidly evolving landscape of health care reform, economic challenges and an aging population. The need for broad discussion of values and ethics related to equity, fairness and end-of-life challenges, is well known. We look forward to engaging the Vermont community in these discussions in the coming year.

Meet VEN's Newest Board Members

Lynn Burgess, MDiv BCC, is Director of Chaplaincy for Northeastern Vermont Regional Hospital in St. Johnsbury, Vermont, where she is also chair of the Ethics Committee. She has been at NVRH for seven years. Before that she was a chaplain at Mendota Mental Health Institute in Madison, Wisconsin, where she was a charter member of the Ethics Committee there, as co-chair and then chair. Lynn was also a member of the multi-institution ethics committee of the Department of Health and Family Services. She participated in many bioethics continuing education courses at the Medical College of Wisconsin, has a longstanding interest in end-of-life issues, palliative care, and informed consent. Lynn's first career was in nursing, graduating from the University of Tennessee. She attended both Nashotah House and McCormick Theological Seminary, graduating from McCormick with a MDiv. Her Clinical Pastoral Education Residency was held at Gunderson Lutheran Medical Center in La Crosse, Wisconsin, with a focus on intensive care and psychiatry. She is a Board Certified Chaplain with the Association of Professional Chaplains and currently serves on their Advocacy Commission and Nominating Committee. Lynn is ordained by the Presbyterian Church (USA) and serves on the Presbytery Council of the Presbytery of Northern New England.

Penrose Jackson is Director of Community Health Improvement at Fletcher Allen Health Care. Beginning in 1983 she has served on the boards of health care organizations including the Medical Center Hospital of Vermont and the Vermont Health Foundation (VHF). Since 1996, she has also served as the staff to the VHF, overseeing grants to community-based organizations whose efforts advance the VHF's mission of improving the health of the communities it serves.

Ms. Jackson served for thirteen years as the first Executive Director of the Church Street Marketplace, a pedestrian mall in Burlington, Vermont. Subsequent to that, she filled similar positions at the National Gardening Association and the Intervale Foundation. Her community commitment has been extensive and includes board chair positions with the Burlington City Arts, Champlain Initiative, Childcare Resource and Referral Center, Chittenden County Regional Planning Commission, Ethan Allen Homestead, First Night Burlington, Greater Burlington YMCA, Leadership Champlain, South Burlington Rotary Club, KidSafe Collaborative, Linking Learning to Life, and Women Helping Battered Women. In early 2008 Ms. Jackson served as chair of the American Health Association's "Go Red for Women" Vermont luncheon.

A native of central New York State, Ms. Jackson graduated from the University of Vermont. She also participated in UVM's masters' degree program in American history and attended the John Marshall Law School in Chicago. From 2003-4 she participated as a fellow in the American Hospital Association's Health Forum fellowship, "Creating Healthier Communities." She is currently enrolled in Saint Louis University's Certificate Program in Community Benefit.

Currently, she co-chairs Vermonters Taking Action Against Cancer, chairs Linking Learning to Life, serves as treasurer for the Vermont Public Health Association, and sits on the boards of the South Burlington Rotary Club, KidSafe Collaborative, University of Vermont Alumni Board, Burlington Legacy, Vermont Historical Society, and the Champlain Initiative.

William A. Nelson, MDiv, PhD, is Director of Rural Ethics Initiatives and Associate Professor of Community and Family Medicine at The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School. He also is an adjunct Associate Professor at New York University's Robert Wagner Graduate School of Public Service. Until 2003, he was Chief of the Ethics Education Service for the Department of Veterans Affairs' National Center for Ethics in Health Care, which he co-founded. He completed his undergraduate work at Elmhurst College, received a MDiv. from Andover Newton Theological School, and a Ph.D. from Union Institute and University.

He is the 1984 recipient of the United States Congressional Excalibur Award for Public Service for his efforts concerning the ethical care of the terminally ill. From 1986-1989, he was a W.K. Kellogg National Leadership Fellow studying US and international health care policy. In 2004, the Department of Veterans Affairs established the annual competitive William A. Nelson Award for Excellence in Health Care Ethics for "significant and sustained contributions to the Department through health care ethics..." In 2006 Dr. Nelson was awarded an Honorary Doctorate of Humane Letters from Elmhurst College. And from 2008-9, he was a National Rural Health Association Leadership Fellow.

The author of over 75 articles and book chapters; he has delivered hundreds of invited lectures, papers, seminars, and workshops on organizational and clinical ethics topics in the US and internationally. Dr. Nelson is the Principal Investigator of several federal and state funded research studies fostering an evidence-based approach to ethics. Dr. Nelson co-edited *Managing Ethically: An Executive's Guide*, (2nd ed. 2010, Health Administrative Press). And also is editor of the NIH funded 2009 e-book; *Handbook for Rural Health Care Ethics: a Practical Guide for Professionals*. He is a regular contributor to *Healthcare Executive's* "Healthcare Management Ethics Column." He also is the ethics consultant to the American College of Healthcare Executives.

Beth Cheng Tolmie, MSW, EdD, is a research and evaluation project consultant who lives in South Burlington, Vermont. Her consultation activities consist of social policy research with incarcerated women, criminal justice and court diversion programs, health organizations, and education and social services agencies. Primary interests include collaboration, organizational change, quality improvement, program implementation and the integration of services for children, youth and families in Vermont.

Beth received a Master's in Social Work degree from the University of Vermont in 1996. For several years she worked with an area agency on aging and studied the needs and service networks available to elders. Subsequently, Beth was employed by the Vermont Department of Health for twelve years in operation and program management roles. She has more than ten years experience in creating, implementing, and managing long-term strategic visions for programs, departments and agencies within education, government and non-profit environments. As a 2008 graduate of the University of Vermont's Educational Leadership and Policy Studies doctoral program, Beth has most recently pursued work as a consultant, coordinating and conducting research and evaluation studies.



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To:

News and Upcoming Events

NEW Vermont Ethics Network Website

VEN's Website has a brand new look with expanded content. Visit it today at:
www.vtethicsnetwork.org

National Palliative Care Summit

March 14 - 15, 2011 at the Loews Philadelphia Hotel, Philadelphia, PA ~ For more information visit: www.PalliativeCareSummit.com

Diane Meier, MD to come to Burlington

March 28, 2011 ~ For more information visit:
<http://vtpcrc.vtdesignworks.com/index>

VT-NH Hospital Ethics Committee Meeting

April 18, 2011 ~ Auditorium E & F

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- **TALK** to others about your values and future health care wishes.
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- **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 our *Taking Steps* Booklet, contact us by phone at 802.828.2909 or via e-mail at ven@vtethicsnetwork.org.