

HEALTH DECISIONS

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With Gratitude: A Salute to Bob Macauley

BY CINDY BRUZZESE

s many have heard, the much loved and highly respected Bob Macauley will be leaving The University of Vermont Medical Center in June to become Cambia Health Foundation Endowed Professor of Pediatric Palliative Care at Oregon Health and Science University.

Oregon's gain is most certainly Vermont's loss—but I can think of no



person more deserving or better qualified to take on this exciting and prestigious position.

For the past several weeks

I have struggled to find the words to express my unending gratitude to Bob—on both a professional and personal level.

I first met Bob when I was working for the Madison-Deane Initiative (MDI) at the VNA of Chittenden and Grand Isle. As I was leaving MDI to take on the Executive Director role at VEN, Bob contacted me and offered to set up a time to "talk ethics" once I got settled. I don't think he knew then, nor did I, just how frequently I would be calling. A trend that I am quite sure will continue despite the forthcoming geographic distance!

Always generous with his time and expertise, a gifted teacher, empathic listener and skillful navigator of complex ethical issues, I feel privileged to have launched my ethics career under his supportive guidance. Thank you Bob for your time, your talent, your generous spirit and your friendship.

Go well into life now, What days, what months, What years may be.

Go well into life, The joy and hurt of all its moods.

Go well into life now, And when you need us, always know, That here you will find The hands of friends.

- John Hanley Morgan

Well wishes from friends across the state:

"I met Bob Macauley when I worked at the Vermont Medical Society (VMS). He was a stunningly effective advocate for the issues he was passionate about —ethics, children, palliative care, and mental health.

Vermont has much better access to pediatric palliative care, particularly for children on Medicaid, thanks to Bob's advocacy; he brought families to the legislature to testify movingly about their choices to comfort their dying children. Bob was just as passionate about all children's health, speaking to the legislature as a pediatrician, ethicist and as a father about the importance of removing the philosophical exemption to immunization requirements for schools, recalling his own daughter's experience of pertussis. The exemption was removed.

Under Bob's guidance Vermont developed reasonable and thoughtful laws and forms that clarify patients' ability to establish advance directives and implement them by requesting DNR/COLST orders. He raised a strong clear voice expressing ethical concerns with mental health patients awaiting treatment for long periods of time in emergency departments. Whenever Bob was on the legislative witness list, I relaxed. He has an incredible ability to reach his listeners hearts and emotions, while at the same time presenting information that is evidence-based and data-based and he invariably says the perfect thing to accomplish the task.

A teacher in the best and most ancient sense of the word, understanding the power of stories, Bob gave numerous presentations for VMS, VEN and many other groups.

Thank you Bob! You will be missed and I hope you will come back to Vermont!"

- Madeleine Mongan, JD

"I have always greatly appreciated Bob's expertise and thoughtful approach to complex ethical issues. He has this ability to help people see both sides of difficult questions. His service to our patients and region has been exceptional. He will be truly missed."

– Stephen Leffler, MD, FACEP Chief Medical Officer, The University of Vermont Medical Center

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is to promote ethics as
a core component of
health care and health care
decision-making

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"Bob Macauley has been an invaluable member of our Division's Ethics Committee for several years, focusing on critical health care and end-of-life decision making for people under public guardianship. He listens deeply to the presenters and is able to quickly distill complex, multifaceted information in a way that everyone can understand. Most importantly, he expressly values the lives of people with developmental disabilities and cares deeply about preserving the quality of life for each individual while not subjecting the person to interventions which would be unduly burdensome for that person. While Bob is clearly compassionate regarding the individuals being discussed, he clearly values the commitment and efforts of the caregivers and guardians who are struggling with these difficult decisions. It is not an exaggeration to say that people "hang on his every word" and always feel more at peace after talking with Bob."

> – Jackie Rogers and June Bascom, Office of Public Guardian

"Is it possible to be at once saddened by the departure and elated by the possibilities of a treasured colleague/friend who is changing coasts? Yes! I know it is because Bob Macauley, who is both, makes me feel just that way. We love you and will miss you, Bob. Go Ducks!"

– John M. Saroyan, MD FAAP HMDCB FAAHPM, BAYADA Home Health Care | Physician Medical Director (SNW)

"Oregon's gain, without question—but I hope Bob keeps writing too, and tells tales from his years in Vermont."

- Stephen Kiernan, Author

"Congratulations, Bob! What a wonderful opportunity! It is sad to think of Vermont without you, but we have been so blessed to have had you for 15 years. The Central

Vermont Ethics Committee has grown and matured with your help. You gave us the confidence and skills to tackle difficult ethical issues, knowing you were always there if we needed you. And personally, I can't thank you enough for helping me along the way. I learned so much from you. I wish you and your family all the best in Oregon. They are very fortunate to have you as their Chair."

- Marilyn Hart, retired physician

"Bob, it has always been great working with you on the VEN Board. I have admired your thoughtful, well-reasoned perspective, always expressed in a gentle, respectful manner. Despite leaving Vermont, where your legacy will live on, I look forward to further collaboration."

- Bill Nelson, Dartmouth Policy Institute

"Home-baked bread for our retreats, stimulating presentations on complicated topics, generous with time, listening intently even to questions of little consequence, imbued with a deep faith in these faithless times—what I will miss about Bob Macauley."

- Ann Mallett, Fellow VEN Board Member

"As a new legislator I became very interested in Hospice care and why children with serious life-threatening illnesses were not receiving this service. Dr. Bob Macauley helped me understand not only why the children were not receiving Hospice care, but why they would not want to. With his encouragement and support I started working on what the legislature could do to provide a service to children that he envisioned and designed, The Vermont Pediatric Palliative Care Program. Thank you Bob."

- Rep. Bill Frank

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"Dr. Bob Macauley has been a champion for quality, person-centered end-of-life care in our community and beyond. He is a highly skilled, dedicated and compassionate physician who has provided wonderful care to VNA clients and wise counsel to our clinical staff for many years. Vermont is better for having Dr. Macauley practice here. The VNA Hospice and Palliative Care team wishes him and his family well as they embark on this new chapter. We are forever grateful for his work and friendship."

- Judy Peterson, CEO, VNA of Chittenden and Grand Isle Counties

"A man for all seasons ... and for ever so many reasons. VNA's Madison-Deane Initiative salutes you, Dr. Bob Macauley! In our focused efforts to educate others about quality care at the end of life, you have been our loyal friend, respected mentor and generous collaborator. Your gentle, compassionate presence, coupled with your broad expertise has made a difference for so many, including future doctors being trained and the community we all serve. It is with our deepest gratitude that we thank you for being our partner in this important work. We extend our heartfelt wishes to you, dear friend, and to your family as you enter your new community and step into the prestigious position for which you are eminently prepared.

With love and gratitude,
 VNA's Madison-Deane Initiate,
 Changing the face of dying.



TAKING STEPS VERMONT

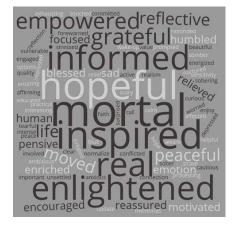
Who's Your Person? ... What's Your Plan?

ho's Your Person ... What's Your Plan? is a Chittenden & Grand Isle based collective impact initiative comprised of nine organizations working to partner with local businesses and organizations to provide educational opportunities for staff and employees to learn about advance care planning.

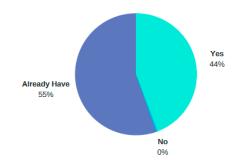
This spring the collaborative hosted a series of film screenings using the *FRONTLINE* documentary *Being Mortal*. This film investigates the practice of caring for the dying. It follows author and surgeon, Dr. Atul Gawande, as he shares stories from the people and families he encounters. The film sheds light on how a medical system focused on a cure often leaves out the sensitive conversations that need to happen so a patient's true wishes can be known and honored at the end.

Attendees were asked to provide feedback after watching the film and participating in a facilitated discussion. Below is a snapshot of what was learned from those who attended a screening and the actions they now plan to take:

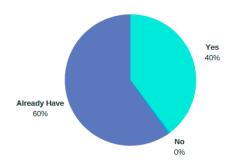
What one word describes how you feel after watching and talking about "Being Mortal"?



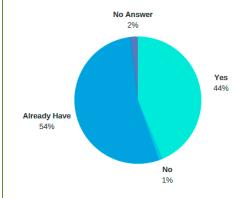
Action – Think about the importance of having my end-of-life care wishes in writing:



Action – Decide on the person I want to make health care decisions for me if I'm unable to speak for myself:



Action – Put my end-of-life wishes in writing in an Advance Directive:



Collaborating Organizations in the Initiative: Age Well, BAYADA, Cathedral Square, Howard Center, OneCare Vermont, Support and Services at Home (SASH), The University of Vermont Medical Center, Vermont Ethics Network, VNA of Chittenden & Grand Isle Counties





Vermont Ethics Network has developed materials, as part of its Taking Steps Vermont Initiative, to support a *stepwise* approach to advance care planning.

Sudden accident or illness can happen to anyone at any time regardless of age or state of health. Preparing in advance minimizes conflict and uncertainty about health care decisions that may arise and who is authorized to make those decisions when a person is unable to speak for themselves. At each step there is a corresponding advance care planning tool/form to support documentation of patient preferences and priorities.

Step 1: Who's Your Person?

For all adults 18 years of age or older with decision-making capacity.

Tool: Form to Appoint a Health Care Agent.

Step 2: What's your Plan?

For adults with chronic illness or those seeking to give more specific information about their values, preferences and what matters most to them.

Tool: Short or Long Form Advance Directive.

Step 3: Are There Limits?

For individuals who are seriously ill or dying, or who are certain they would not want life-prolonging interventions (regardless of the clinical context).

Tool: Do-Not-Resuscitate (DNR)/Clinician Order for Life Sustaining Treatment (COLST) Order.



VEN Welcomes New Board Members

Shaden Eldakar-Hein, MD, MS, FACP

haden Eldakar-Hein is a hospitalist at the University of Vermont Medical Center and Assistant Professor of Medicine at the University of Vermont College of Medicine. She serves as director of clinical ethics education in the Internal Medicine residency as well as an ethicist at the medical center. She is also the Associate Program Director of the Internal Medicine Residency and chairs the residency recruitment committee and wellness committee in addition to participation on several hospital wide quality improvement committees and medical education assessment at the College.

Dr. Eldakar-Hein completed her undergraduate work in pre-medicine with psychology and neuroscience minors at Pennsylvania State University, received her MD from Temple University School of Medicine, completed her internship, residency and chief residency in internal medicine at Temple University Hospital and joined the faculty at the University of Vermont Medical Center in 2013. In addition, she has completed her Master of Science work at the Albany Medical College Bioethics Institute with a focus on ethics education.

Dr. Eldakar has won multiple education awards as a medical educator that include induction into the Gold Humanism Society, Osler Teacher of the Year and runner up for University of Vermont GME teacher of the year awarded by the residents. She was inducted into the Teaching Academy at the University of Vermont in 2015. She is a fellow of the American College of Physicians and the regional chair of the hospitalist committee. Dr Eldakar has a great interest in medical education, physician and learner wellness as well as hospital medicine and ethics.

Alden Launer, MDiv

Iden is an ordained United Church of Christ minister currently serving as the interfaith chaplain at Copley Hospital in Morrisville, VT. He has worked in health care chaplaincy at Copley since May of 2001. As a part of his responsibilities he also extends spiritual support to hospice clients who are being cared for by the Lamoille Home Health and Hospice, and he is a member of the Ethics Committee at Copley Hospital. As a focus of his chaplaincy position he also devotes time to the spiritual support and care of staff members at Copley Hospital.

Alden is a graduate of Drew University with a Bachelor of Arts in Religion, and in 1984 received a Master of Divinity degree from Union Theological Seminary in New York City. He completed a year-long Clinical Pastoral Education residency in hospital chaplaincy at Memorial Sloan Kettering Cancer Center in New York City in 1985.

He has served as the minister at two local churches within the Vermont Conference of the United Church of Christ (the West Newbury Congregational Church and the United Church of Underhill) and from 1993-1998 was the chaplain at Porter Hospital in Middlebury, Vermont. While at Porter Alden became a Board Certified Chaplain of the Association of Professional Chaplains, and has maintained that certification.

Alden's wife Patricia is a registered nurse focusing on quality improvement at Bi State Primary Care. They have two children, a daughter Ainsley who is a nurse at Northeastern Vermont Regional Hospital in St. Johnsbury and a son Nathaniel, who is a student at the University of Vermont Rubenstein School of Natural Sciences.

Madeleine Mongan, Esq

adeleine Mongan was Counsel and Deputy
Executive Vice President for the Vermont Medical
Society, representing Vermont physicians from
1996 to the summer of 2016. She worked with the Vermont
legislature, state agencies, academic institutions, non-profits,
and insurers on health care policy and related issues and
provided education and technical assistance to Vermont
physicians on legal issues. Her practice addressed a range of
health law issues including confidentiality, medical records,
licensing, managed care, scope of practice, liability reform,
public health, contracting, administrative simplification, and
fraud and abuse.

In Vermont she served on the Medicaid Exchange Advisory Board, the Area Health Education Centers Advisory Board, the Academic Detailing Advisory Board, and the Governor's Workforce Workgroup and the Vermont Family Network board. She is a member of the Vermont Bar Association (VBA), past chair of the Vermont Bar Association Health Law Committee and a recipient of the VBA community service award. Nationally, she has been a member of the American Health Lawyers Association, the American Society of Medical Association Counsel, and served on the AMA Advocacy Resource Center Advisory Board.

From 1985 to 1995 she worked for the Disability Law Project of Vermont Legal Aid, Inc. and the Vermont Coalition of Disability Rights. Before attending law school, she taught English and social studies in New York and overseas. She received her B.A. from the University of Delaware in 1972, M.A. from Stanford University in 1973, and J.D. from the University of California at Davis in 1983.

She lives in East Montpelier with her husband, Kirby Scarborough, volunteers with English language learners for Central Vermont Adult Basic Education, and serves on the East Montpelier Trails, Inc. board.

Hilary Ryder, MD

ilary F. Ryder is a hospitalist at Dartmouth-Hitchcock Medical Center and Assistant Professor of Medicine and of The Dartmouth Institute, Geisel School of Medicine at Dartmouth. She serves as Chair of the Clinical Ethics Consultation subcommittee, and Associate Medical Director of the Ethics Committee at Dartmouth-Hitchcock Medical Center. She is also the Associate Program Director of the Internal Medicine Residency at Dartmouth-Hitchcock Medical Center and

the Clerkship Director of the third-year Internal Medicine Clerkship at Geisel School of Medicine at Dartmouth.

Dr. Ryder completed her undergraduate work in sociology at the University of Chicago, received her MD from Yale University School of Medicine, completed her internship and residency in internal medicine at Dartmouth-Hitchcock Medical Center, and joined the faculty of Dartmouth-Hitchcock Medical Center in 2007. She has completed bioethics training courses at the Kennedy Institute of Ethics, Georgetown University, and Harvard University. In 2013 she earned a Masters of Science from The Dartmouth Institute with a focus on research methods.

Dr. Ryder was inducted into the Academy of Master Educators at Geisel School of Medicine at Dartmouth in 2016. She is a fellow of the American College of Physicians and the Society of Hospital Medicine. Dr. Ryder is involved in research on include feedback, assessment, and evaluation in medical education as well as predicting survival after in-hospital CPR.

Registering Your Advance Directive with the Vermont Advance Directive Registry

egistering your advance directive is an easy way to give your care providers and the hospital immediate access to your health care decisions.

The Vermont Advance Directive Registry (VADR) is an online database that stores copies of completed advance directive forms. There is no fee for Vermont residents who choose to register their advance directive with the Vermont Advance Directive Registry.

To register an advance directive, simply complete the Registration Agreement, attach a copy of your advance directive document to the registration agreement and mail or fax the forms to:

Vermont Advance Directive Registry (VADR)
PO Box 2789
Westfield, NJ 07091-2789 5.
FAX to: 908- 654-1919

Within about two weeks after sending in your documents, you will receive a confirmation letter with a username and password from the Vermont Advance Directive Registry. This letter will contain a wallet ID card with your registration ID number and stickers for your driver's license.

For more information about registering advance directives visit www.vtethicsnetwork.org or call us at (802)828-2909.

VERMONT DEPARTMENT OF HEALTH Vermont Advance Directive Registry REGISTRATION AGREEMENT VERMONT DEPARTMENT OF HEALTH SOURCE CODE: 53101301				Registry Use Only Received: Confirmed:	
Read the Registration Policy, and complete this Regist date the form. Attach either a copy of your advance directive, or option physical location of your advance directive so that it can a Registrations MUST include a completed and signer directive document. Westfield Ave., PO Box 2789 Westfield, Nu 07091-2789 OR FAX to: 998-684-919 For forms, or additional information visit:					