



TO YOUR HEALTH



Carleton-Willard Out-Patient Clinic

100 Old Billerica Road, Bedford MA 01730



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Changes in End-of-Life Care: An Interview with Barbara Chenoweth, NP

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This is an interview with Carleton-Willard's former Clinic Administrator/ Barbara Chenoweth, NP. She discusses the changes she has seen in health care during her extensive career, focusing on the development of end-of-life care and where she sees it going in the future.

Q: How long have you been working in health care and what drew you to working with people at the end of life?

A: 50 years from nursing school to semi-retirement. I was a nurse in Appalachia before going to graduate school and worked as a discharge planner. I helped people get the services they needed to go back home. Many of them would be dying at home and this led to my interest in end-of-life issues. Because I was interested in people with serious diagnoses and the emotional dimension of illness, I decided to attend graduate school at the University of Michigan to become a psychiatric nurse. Then I worked in geriatric mental health and helped people cope with chronic disease and terminal illness.

There wasn't much written in the mid-1970's about end-of-life, but I read the works of Elizabeth Kübler-Ross, Cicely Saunders and Sherwin Nuland. And I learned from the first-hand experiences of the founder of an Ann Arbor Hospice.

Years later, as the Director of Nursing at Sherrill House in Jamaica Plain, I was aware that we did not identify the time when a person began to actively die nor were we trained in ways to explain to Residents or families about the dying process. When hospice was involved, it was assumed that the hospice staff would discuss this difficult topic. Our chaplain at Sherrill House,

Rev. Judy Krumme, developed an end-of-life program and we began to learn how to have these conversations. From this program grew the goal that no one should die alone.

Q: In your career, what changes have you seen in how end-of-life issues are managed?

A: Now we're better at helping people manage pain and other physical and emotional symptoms that can arise at the end of life. Communication has also improved. Now more doctors and nurses are comfortable talking with people and letting them know that they have a serious illness. However this may not be the case for every condition. For example, 93% of cancer patients are told their diagnosis. Yet even though dementia is a fatal disease, only 45% of people with Alzheimer's Disease are told their diagnosis according to unpublished data from the Medicare Current Beneficiary Survey for 2008-2010 and Medicare claims data. This may be due to the fact that it's easier to predict the trajectory of cancer than for other chronic diseases such as dementia, heart or kidney failure. It's important for health care providers to say, *"You've got heart disease and we don't know how much time you've got left. If there are people you want to see and conversations you want to have, do it now."*

Q: What do you see are barriers preventing people from good end of life care?

A: People may want to talk about death but they are often afraid to bring up the topic. We all think about death, but putting it into words can be scary. Some people may wait for their health care providers to raise the topic. There's certainly much more education for nurses and doctors than there used to be, but we still have a ways to go in learning how to talk about this complex and difficult subject.

continued



**Q: How did you develop the ability to talk with people frankly about illness?**

A: In part it was due to my education in Psychiatric Nursing with its emphasis on listening. Other important experiences were the end-of-life trainings at Upaya Zen Center and the Harvard Palliative Care education. This study led to certification as a Palliative Care Nurse Practitioner. In addition, I wanted to change the indirect ways that we have communicated difficult information in the past. I feel strongly that it's important to try to speak directly to a person if they want to know what is happening to them.

Q: How have people reacted to hearing the truth about their terminal illness?

A: I've learned that some people want to talk about it and other people prefer to avoid the topic. In general, most people welcome the opportunity to talk about what's going to happen and their families are grateful to know what to expect.

Q: What would you consider a good death or a bad death?

A: Whether a death is "good" or "bad" is very individual. It depends on what a person really wants. Some people may want to be awake as long as possible and others are more concerned about having their pain managed even if it means they will be less awake and alert. As caregivers we hope that a person's death is peaceful, that their wishes have been respected and that they're not alone when they die.

Q: Where do you see end-of-life care going in the future?

A: In the future, I think people will discuss their wishes for end of life care sooner. People want control over their lives, and they realize more and more that they can have a say in where and how they die. As a culture we are moving towards greater openness in the discussion of end of life issues. This opens the door for all of us to more freely talk about our hopes and fears for the end of our lives. It will also be an impetus for developing more formal programs addressing the needs of the dying, such as we have at CWV.

Q: How has working with the dying informed how you live?

A: It's definitely made me appreciate how fragile life is, how quickly things change, how quickly it can be over. It's a gift, and has helped me to do and say things that I may not have because of this awareness. We have to do the things we want to do while we can. We don't have endless time, and we're caught in that reality.

BEDFORD DRUG PICK-UP

**The Bedford Police will pick-up
expired and unused medications on:**

Friday, November 13, 2015

**You can drop off any prescription
unused/expired medication at the Clinic
between 8:30 am and 12 noon.**

**Unfortunately, we can only accept the
medicines during these times and on the
date of pick-up.**

Drivers Wellness Lecture

"Ways to Stay Driving Longer and Safer"

Wednesday November 4th

10:30 am —11:30 am

Auditorium Center

**Kristen Dixon Keilty is an occupational
therapist and a certified driving instructor
and has been running the**

**Keys to Independence
driver assessment program at
Emerson Hospital since 2012.**

**Please join Kristen for a brief lecture and
discussion on topics of driver
wellness.**