

For the record, my name is Erik Fromme. In 2002 I became Oregon's first fellowship trained palliative care physician and I am now the medical director for the palliative care service at OHSU. I've been asked to testify on behalf of SB 608 by the American Cancer Society Cancer Action Network.

One of the best things that could come from this bill is that Oregonians could begin to learn what palliative care is. A survey done in 2010 found that only 32% of people in Oregon reported knowing what palliative care is. A bigger problem for my field is that a lot of people, and unfortunately a lot of health professionals, think palliative care is about dying, but this is not the case. Do I take care of very sick people, many of whom die? Yes I do, but so does every health professional that I work with in the Knight Cancer Institute. But palliative care is not about dying it is about living, for as long as you can as best as you can. Palliative care is about quality of life. It's a problem that people don't know what palliative care is, because they need to know what it is in order to ask for it. One of my patients who I will talk more about came to me after reading an article in the New Yorker by Atul Gawande called Letting Go. She had to convince her surgeon to refer her to me because she was not dying, indeed she would live for 2 more years, but he went along because he had operated on her 13 times, and he wasn't sure #14 would be a good idea. She commented that had she not read that article, she would never have even known to ask, and regretted that she hadn't come to see me years earlier because of the significant improvements I was able to make in controlling her pain, fatigue, and insomnia. In 2008 colleagues at Harvard stunned the world when they found that patients with metastatic lung cancer lived 2-3 months longer when they were referred to palliative care early in their treatment. But why is that so shocking? All they proved is that it's hard to live when your pain and your anxiety are out of control and your family is scared to death and the quality of your life is not there.

I suspect many people here are aware of Dr. Gawande's book that is currently #1 on the NY Times Best Seller list, Being Mortal. If you haven't read the book, I highly recommend it for any human being, or perhaps watching the Frontline video about his work on PBS.org. I am astounded by how many people are aware of Dr. Gawande's work right now but I do not think it is coincidental.

On Saturday, Dr. Atul Gawande addressed the Academy of Hospice and Palliative Medicine and he was asked what most surprised him about palliative care. He replied “why aren’t people listening to you?” As I was leaving the lecture hall, I passed a handwritten note that said “do you we really need a surgeon to tell us what we do matters?” and my answer is that clearly we do, because his book is reaching people in a way that no one from my field ever has—what we really needed was for Dr. Gawande to tell everyone outside our field why what we do matters. And what we do in palliative care really matters. We needed someone to help us think and talk openly about how perilous it has become to grow old and frail and die in this country, that this is not somebody else’s problem this becomes our parents’ problem, then it becomes our problem, then we become our kids’ problem. We needed him to show us what we were missing – that a health care system that is focused on curing diseases, prolonging life, and protecting vulnerable elders is simply not enough when the diseases can’t be cured or strip us of things that we lived our entire lives taking for granted – our eyesight, our ability to drive, our ability to eat a cookie, our ability to make it to the bathroom in time, our ability to speak. I have a patient whose brain tumor cost her the ability to make new memories – an experience she describes as ‘swimming through darkness’. She thought she was going to die but with radiation and chemotherapy her tumor has stopped growing, at least for the time being. And so she came to me because she wants to have meaning in her life, she used to run a non-profit organization and she wants to feel like she is accomplishing something with her life. And so I had her speak to the first year medical student class at OHSU about what it is like to live with a life threatening illness. She said that was good but I want more so my challenge is what is next?

The problem, as Dr. Gawande articulated it, is that we have developed a system that targets disease and prioritizes safety and using time and resources today to hopefully have more time in the future. In many situations that is good and that is right and don’t get me wrong it is valuable. But what is surpassingly rare in health care are systems that listen, that find out what is most important, and help you ensure that the things that are most important are at the center of your care.

Hospice care has been doing this work for over 40 years in the US and doing it well. There are over 50 hospices in this state and I have worked with many of them and I have not found a single bad hospice in the entire state. But the US is the only country that requires patients to have a <6 month prognosis and to give up curative treatments in order to get hospice care.

And so the field of palliative care has developed to reach patients who need to continue treatment and who are not terminally ill. And that development has been mostly a good thing – doctors like me did not exist in Oregon when I came here as an intern in 1994. The field has evolved rapidly and now there are health professionals – doctors, nurses, social workers, chaplains, psychologists with specialized training and focused experience – palliative care experts and this is a very good thing.

And this level of palliative care, expert palliative care, requires a team of professionals because no doctor, no nurse, no social worker alone can presume to answer when a young woman with a brain tumor asks “how do I have a life that matters”.

The problem with expert palliative care is that there are not and never will be enough of us to ensure that every Oregonian gets what they need.

And that is why this bill is important. It makes access to palliative care a measure of public health, and I can tell you it's not a measure that we are succeeding on. Remember when I said the development of expert palliative care mostly a good thing? Well one thing that is not so good is that increasingly, doctors think that palliative care is something that palliative care experts do. But when I was an intern, there were no palliative care experts and we all did it ourselves, without training, expertise, or much experience, but we all did it or it didn't happen. And so another important parts of SB 608 is that it says teaching primary palliative care IS public health. What is primary palliative care? That is palliative care practiced by primary care providers, by critical care nurses, by oncology social workers, by any health professional who takes the time to find out about the person who has the disease, who helps them to think about what is most

important, and who helps ensure that what is most important is kept at the center of their care.