

Everyone Has Their Story By Andrew MacPherson
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I work in politics. I live and I breathe politics. And politics, let me tell you, can really, really suck. Perhaps this is obvious or implied and it seems on a daily, hourly, and minute by minute basis we're deluged with negative news about politics. The issue of healthcare, of course, is no exception. And perhaps it's an issue where this is even more pronounced. Why? Because health care is politics that is literally on our body. It's the government on us, close to us, near us, even in some cases in us.

This creates immense political and personal challenges. So why the hell do I work in politics? For one simple reason, contrary to what we've come to believe, on a large scale [00:01:00] politics is perhaps the best vehicle to improve people's lives, and improve their care. And this fact is exponential, for those living with serious advance illness and facing the end of life.

Take Linda. Linda is a working Mom, her son not yet out of high school. Linda is caring for her parents, both of whom are suffering from Alzheimer's and have less than a year to live. Take Phil. Phil is a physician in practice for over 30 years in Johnson's City, Tennessee but still Phil could not have imagined how hard it was to have that conversation with his terminally ill wife at her bedside holding her hand. Take Johnny. Johnny is son of a mother and father with two terrible diseases: cancer, mother with cancer and a father also with Alzheimer's and Johnny saw the importance of thinking about your own care options [00:02:00] when you are sound body and mind as he did with his parents. And finally take Ted or Teddy as many of us know him. Teddy lived and worked after being diagnosed with terminal brain cancer. Wanting to leave his mark on those he dedicated his entire life to serve. His mantra while still working and dying: "Aren't I lucky?"

So what do each of these individuals have in common? Why are their stories unique but also common to us all? Linda, Phil, Johnny and Teddy are all members of United State Congress, United State House or United State rep or United State Senate. It's true actually; politicians are humans too, I know it's hard to believe. But this notion that politicians regardless of their legislative body in which they serve, Federal [00:03:00], State or Local have personal end-of-life stories that cut through the political toxicity and challenges we face as a country. It's this notion that I found in the halls of congress can be the most powerful and can change the lives of millions of Americans.

I have a story too. To me this is issue is deeply personal, it's my mom. This was taken from Facebook yesterday without permission.. though this is a big film, right, so my mom has cared for hundreds of individuals in hospice for the past 35 years. She is the "heart" side of my brain. My dad is, was a physician and a pathologist on the left tier and a scientist, he is the technical side of my brain. This led to some very interesting dinner conversations, growing up. I called them conversations now — they were arguments about death [00:04:00] — is these two opposing viewpoints of a dying patient, not a patient my mom would teach me, but a person. Seeing the person honors their dignity and their quality of life, not just their medical care. My dad on the other hand taught me just how much could be done, the miracle of modern medicine and how far medicine could actually extend life. It's my parents, right handed, left handed; science and spirituality; life and death that lead me to palliative and hospice care the idea of alleviating suffering through health and human care. And the idea that if we redesign our health care system, redesign those built-in incentives that we can achieve the promise of palliative care and hospice care and that care could always be responsive to one's goals, values and wishes for all people, not just those who are dying [00:05:00].

Unfortunately in America, we do not receive the best end-of-life care possibly. Well, we have different terms for it. I call it “The big gap.” On the left is what people want and on the right is what we typically get. We want to have our care coordinated in the home as the primary setting yet too often where we cycle, in and out of the hospital, study after study shows that our healthcare system still prioritizes volume over value of care. Don’t we all want our health professionals to communicate with one another? Especially when we’re seriously ill? Next we wanna have our pain managed and receive comfort care yet many people who are dying receive unwanted, ineffective treatments. Another study showed that 89% of individuals said that their healthcare providers should talk about end-of-life care. Only 17% of those talks actually happen [00:06:00] and 90% of physicians, if you think of physicians in this room, ever brought this up. Ninety percent. Next they wanna be at home with their family and loved ones yet all too often, and typically we die in the hospital. Sometimes even in pain and isolation. Studies performed right here in California asked “Where do you wanna die?” 70% of individuals want to die at home, 68% in California did not. This is the big gap. And finally the seriously ill as BJ was saying earlier, they don’t wanna be a burden on their loved ones. This is sort of a shocking notion to me. But study after study after study shows that it’s the number one issue that people think about when they’re dying. Yet we know that high medical costs at the end of life can impoverish families and it costs our nation hundreds of billions of dollars and unnecessary spending. This is the gap that we must close [00:07:00].

Finally, Darmith Alice teaches us that there are geographic disparities as well in the United States. And that there are best and worst places to die in this country. Why is it that 71% of individuals in Ogden, Utah, die in hospice? Yet 31% do in Manhattan? A full 40-point spread. Why is it that ICU deaths in Cedar Rapids, Iowa are almost four times that of Los Angeles? Again, we must close these gaps in order to honor individual’s dignity and to ensure that they get the best care possible.

Policy and politics do offer solutions to close this gap. So first, policy. In the past several years, dozens of bills have been introduced in Congress to improve the lives of those with advanced illness and facing end-of-life care. More than ever before [00:08:00] it’s my great privilege to work with many of us folks in the room and across the country on this legislation. Some of them had even progressed and already become law. Yes, we’re making progress and yes there’s hope. For example, Medicare now places a value on advanced care plan on advanced care planning by paying positions in health professionals for a conversation about end-of-life wishes. Advocates fought for decades for this simple policy’s solution. Yet politically charged issue one would think that the death panels are indeed dead. My part in this legislation has been introduced to deploy new models of care similar to hospice but upstream from hospice for those with advanced illness. Imagine getting supportive palliative care from an interdisciplinary team in the home setting months, if not years, before hospice eligibility. Payors in the commercial marketplace [00:09:00] and Medicare advantage marketplaces are experimenting and investing in this kind of care. Medicare itself should be next. The Medicare choices model which is referenced earlier shows promise by allowing for curative and comfort care to be offered at the same time. But this model only applies to those who are currently hospice-eligible. We must go upstream from hospice. Hospice is the original person-centered care model. My part of the legislation was to introduce to train our workforce and palliative care. We need more palliative care soldiers in this country. Let’s invest in our workforce to ensure that health professionals not just in hospice and palliative care, but all health professionals have basic training in end-of-life care. Shouldn’t that be the norm?

[Crowd Applauding]

And finally, my part as legislation [00:10:00] pass the senate unanimously just a few short weeks ago that would improve and pave for better care coordination for those with multiple

chronic conditions. This legislation included a seminal study that looks at longitudinal care planning for those at the end of life. This is just a sample of the bipartisan, bipartisan progress we've made. Yes, we're making progress and yes there is hope.

Now politics. Yes politics could suck. But in this case politics can be a bolt of solution and inspiration. You've heard the phrase that all politics are local. Well, in healthcare all politics are personal. And how do we navigate the complicated politics of advanced illness and end-of-life care? We use personal stories as our guiding beacon [00:11:00]. Just one year ago, the senate, special committee on aging held a bipartisan hearing led by Senator Sheldon Whitehouse, a democrat from Rhode Island, and Susan Collins, Senator Susan Collins, a Republican from Maine. A guy by the name of Dr. Atul Gawande, maybe you've heard of him, was the lead witness at the hearing. The hearing was about end-of-life policy. Guess what? Within moments, it was clear this hearing wasn't about policy. This hearing became about stories. There is not a dry eye in that committee room, including members of Congress, including me, I'm a cryer. I even think I saw Atul get a little misty. Yes, even the committees in Congress. We have the opportunity to humanize the issue of end-of-life care. Many of the members who support this legislation do so not for political reasons, but because of their stories. Tory's story. My story [00:12:00]. Your stories. Our stories. But it's more complicated than that when it comes to politics. If personal stories are our guide, our green light across the bay, our key to unlock that conversation, then managing the process -- the political process -- is the strategy. Process is the roadmap for success. We have many tools in our tool belts. Law makers deal all sorts of pressure and want to create change from constituent outcry to big donors from their own political aspirations to putting political points on the board. Law makers have problems that need to be addressed and the best possible end-of-life care can be a solution to solve those problems. One of these is fiscal in nature, it was touched on earlier. The problem of high unsustainable costs in the Medicare program largely attributed to too many expensive tests being ordered and a growing [00:13:00] baby-boomer population. We know the Medicare trust fund will be insolvent, for example, by 2029. We know that approximately 5% of Medicare beneficiaries account for almost 40% of the costs of Medicare. Many of them at the end of life. We also know that Medicare spending in the last year of life has doubled over the past 15 years. Addressing costs at the end of life is the unspoken, the quietly whispered issue in end-of-life care. Politically cost at the end of life are the third realm. Lowering cost must mean rationing, right? It must mean that the government is taking something away. No. It makes no difference to me, no difference to Congress, no difference to Medicare, what you want in terms of your treatment... or none at all. You do you! When done right, when [00:14:00] care is provided in accordance with one's goals, values and wishes, when care takes into account the conversation, supports the family, is provided in a home setting and avoid the unnecessary crisis care in the hospital, guess what? It saved money. And more often than not, when more care is provided in the home setting or the appropriate setting, costs are still lower. That's the care that my mom wants, I think it might be the care that my dad wants, we're still talking about it. So maybe, just maybe, quality advanced illness in end-of-life care is the solution to this sustainability of our cherished public program, like Medicare. Not just for now but for generations to come. Yet serious challenges do still remain. When asked does the affordable care act allow a government panel to make decisions about end-of-life care for people on Medicare? [00:15:00] A full 60% said yes or I don't know. See I don't know is 5%. Indeed the death panels are still alive. And this is our challenge. So that's where you come in. It's your stories that will be the engine that will drive politics for better advanced onus and end-of-life care that will kill that death panel, that will normalize the conversation in politics and well beyond. It's your stories that will break this lodgin' that will neutralize the toxicity. Keep talking, keep sharing, and keep telling because if you do, if we do, we will have better end-of-life in this country and politics might just suck a whole lot less. Thank you.

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