

## **Episode 8 – Dr. Deborah Waldrop: End-of-Life Care for Our Nation’s Elderly In Their Own Words**

[00:00:00] This is Deborah. I have the privilege of interviewing Dr. Kenneth Herman. Thank you very much for being with us and for your willingness to share your story with us to make a really great fun. It's a pleasure. It's a good thing if you could just start by telling us the story of your illness and how you came to know what was happening to you when I presumed that I had a problem with my gallbladder.

[00:00:23] A lot of very old people have problems with their galbladder and mine was producing the gas made me think that I was the next one of those to be attacked by gas and things of that sort.

[00:00:36] So they wanted to meet with my doctor and he confirmed that I had a very healthy galbladder which was good to know.

[00:00:47] They they have the symptoms gas and things of that sort. Harrisonburg No. So you get further testing and the testing resulted in my now having mass growing near my pancreas and then further testing each other as mass might not be the gallbladder but it might be other organs. So we pursued research into her body. So we met with other service providers in the V.A. hospital. And found through all of that testing that consistent pattern of symptoms like this indicated that I had something usually wrong with my pancreas and eventually found that I had stage 4 pancreatic cancer so that it's silly to think which how it all unfolded. You wonder if you could tell us a little bit about the care that you received and what you thought was really helpful from a patient's perspective and a family's perspective when you needed. To. Now let me tell you that I'm a healthy KDKA and I've been to is my wife will tell you that into health foods and things of that sort. But I'm a healthy person. And Susan is too healthful linens and things of that sort. Now that's OK. And even a smoker like the one with tobacco. The V.A. has a reputation in the media especially of providing shoddy care and especially nowadays in the media of. Providing services.

[00:02:32] And consistently unpopular man. I didn't find that I found that my care was basically oriented toward maintaining that the hole they had in the help they wanted to preserve and the self-image ahead of me. And it had nothing to do with who I was. I was a veteran picking through the door. We did a good job. And there were times when of course there were some questions about that. But when we hear answers to questions we all like we tend to do that.

[00:03:08] Yeah because I'm thinking that they had to give us the really difficult news and I'm wondering if you can tell us how that was done. It sounds like it was done well, What elements did you think mattered?

[00:03:19] Well one of the things I did find was that it could be some example that at one point I noticed that the other patients on the floor to reach out was assigned receive something different in terms of care. I'm sure what that was but I didn't know that there was something different in the type or the quality of care as she and I talked with a couple of nurses who were there and a social worker who was there.

[00:03:49] And only because I wanted that clarified for me.

[00:03:53] And that was only because I find it interesting the type of care that was being given to me because it was all anticipated flurry of answers as we got it diagnosed with pancreatic cancer. That happened to me earlier today.

[00:04:13] So they came to confirm the fact that there was a difference in the quality or the type of

care that was being given to some being given to others. So you paid more attention to them and had a number of conclusions that came with that. First of all we're all being given bad news. That's why you were on that floor.

[00:04:35] You didn't really know it because nobody told you that you figured it out in a very brief period of time.

[00:04:43] You knew that you had a particular kind of cancer or a particular difference from those 230 of those you're going to be given you know a couple of things you knew that the people on that floor were all going to die.

[00:04:59] And interesting, they're all going to die and you watch them interacting with staff and the staff was consistently caring but more than half the staff was able it seemed to be able to identify in some way that you wouldn't really expect the health care team. And by that I mean patients seemed to be resolved not to get off the floor which is what one might think. You flee that kind of pain and then to some harm other resolving the issue they are unable to resolve. So I looked more and more what I found was that the doctors and the nurses frequently were responding to patients who dealt with some phantom care and sometimes very elderly care. And that was tough. It was tough for me but it was also tough and the other folks who were meeting up there with their little patient. Each day is different. You know you can't say you can't remember this particular disorder compounded by these other difficulties in his life and that perhaps he's going to get better because he's not. And it gets worse.

[00:06:24] And like any kind of medical condition is not predictable. You know it's kind of disconcerting. So I could do an interview with you today and tomorrow I can expect that you're not going to be sitting with me you'll be sitting with whatever has developed over that period of time. Because the same. And that presents some challenges real challenges.

[00:06:47] So in the light of bad news you might have seen this play when you were with other people who were experiencing bad news. And is the third part of this this is an educator what do you think. Important elements. We'll start with our profession social workers the kind of people you interacted with. What's important for social workers to be able to bring to this kind of influence.

[00:07:13] Well I think first all we talk about things in social work education like strength orientation. We talked about the introduction of trauma in your life experience. We talk of a types of services we want to be able to provide. And we try as subsidies of bringing into play a whole host of skills learning and other professions like a quick introduction of massage and to being able to talk and push. Of some of these things. Because we get so that we forget to do that kind of stuff and realize oh we're really important it is but the one I mentioned is this idea of trauma. You know the University of Buffalo is putting emphasis on trauma whatever it is. And old people like me find the introduction to things so dense and sorry but sometimes embarrassed because it's not new. It's something we've been doing since we came here. And if it is no then you should really read your old textbooks and grade school because you've forgotten a number of things or maybe these are. Not.

[00:08:28] In any of the others in terms of strength orientation I mean that's been a play in social work education now since the 1980s. I guess early 80s. So

[00:08:40] is that a surprise but it's something that we're finally opening your eyes and realizing we have done our reading above us and it does help us to orient ourselves toward the possibilities of the social worker that I guess is one of the most important things we can do with the terminally ill is to introduce them to their clients to their potential. Everybody says when they find a terminally ill Oh

I'm so sorry.

[00:09:10] I will be very well off the second feeling better than dying for Kearsley and that's okay to get to that point.

[00:09:19] Being able to say it really is okay is just part of life. And we say those words too but only in death and dying courses and things like that because we're afraid of it. And personally I don't see any reason to be afraid of that. I mean that's cool. You had the science disclaimer forms before you're going to take this. I think it's a reasonable sort of thing to do with something you don't really lust after if you do then maybe you do need a social worker or some kind of help.

[00:09:51] Let me add to that that consistency that I talked about earlier that was lacking when I was introduced to particular's and that was really disconcerting to me that lack of consistency should everybody have a right to but the privilege perhaps of receiving quality care and the same kind of care regardless of what their title might and I've found that services often over the years is for me but for others and frequently depended upon what this person is telling me.

[00:10:33] I mean it really bothers me in a profession that is supposed to attack elitism and it doesn't seem just as if I were around or are going to be around a lot longer. Perhaps they could read longitudinal studies as thing would produce. I'm sure some major questions are we have to answer and we couldn't get away without answering and playing the kangaroo jargon game.

[00:11:02] We do because everybody know you make a really good jargon and I think that that leads me to thinking about the medical providers. I'm wondering if you can talk about physician addressed what was happening with you did they put it in mind which was understandable was clear to you. Can you tell us a little bit about how your physicians responded to that position.

[00:11:23] They talked to me as though I were an expert in cancer and pancreatic cancer etc. etc.. Well I was not I was not an expert in any form of cancer. The only ones I knew something about were cancers that were unforgiving but groups on the DA list of Unforgiven sins against veterans of the cancers that causes for it that would readily provide that veterans which was an area of specialty for me with providing veterans services because of their exposure to Agent Orange.

[00:12:04] But not the other forms of cancer. Well first of all I found the cancers and cancers and cancer. The other over. I found that it is insurance and getting disability payments and the third is this rather silly game of verbiage that we each engage in our way. That was the doctors themselves.

[00:12:27] Well they don't doubt their sincerity. I don't doubt they are concerned about their patients so any of that is just entering my field of vision.

[00:12:39] We're a bunch of fellows and women who didn't seem to readily respond to the patients who did not quickly respond in an acceptable manner. And based upon entering the manner it is on the list of.

[00:12:59] Items of protocol for the V.A. So stated somewhat differently than it sounds like you would want them to be in the moment with him. You would want them to respond to you individually and truly find out what's the priority for you and what's most pressing for you. Is that accurate.

[00:13:16] I think that's accurate. They think it's a very valid point. Yes. Is it an urge to leave here when we're arriving. Who's from hospice and home care and whatever else is that long title or agency. When she arrived here this morning to talk of a care she seemed to thank you.

[00:13:40] They realize that I had not been really introduced your service it's all really quite sure of doing or that she was there to provide care and she was a good person and clearly knew that she was doing.

[00:13:53] So can you say more about what is important for a nurse to be able to bring to the equation we get a nurse and a professional has to bring with them themselves. I think that's the element that we're often forgetting. Now we do talk about it and all of these professional education programs doing that empathy caring for years between what we do and what we can do what we should be doing doing the tough things about being able to understand what a patient or client is dealing with.

[00:14:30] And how to bring that into a professional relationship with a client. We don't often talk about it enough in my opinion that this the key change in the number of folks and a variety of topics that seem to get around to empathy because empathy and relationship are the key to change so we can talk about any of the rest of this stuff none of them would be under relevant with healthy productive focused relationship. It just won't work. Nothing.

[00:15:03] So that was my concern with home health care. I couldn't agree more that empathy is at the core of all of that. It's so important.

[00:15:14] You know the kind of thing where you should be sitting with the guy Saddam Hussein or somebody and attempting to deal with the oppression of the Kurds in northern Iraq because they didn't like each other.

[00:15:28] The Kurds are Saddam Hussein's people any doctor at the V.A. hospital in Buffalo with whom I had a disagreement bring a brief encounter in the hall. It was a kind of fellow that would say Oh Debbie can play hear me. Yeah yeah you're doing well.

[00:15:53] Well how well am I doing.

[00:15:55] Oh just fine fine that I'm doing fairly well in the recent tests. You know if you talk about it if they find bang bang and you want to beat them over the head with them.

[00:16:07] You know you want them to be. No they are saying the same thing. Yes yes yes. You want them to be straightforward. Yes exactly.

[00:16:18] That care whether he he told me it was going to live for a week or a day or a year or whatever I just care that he told me what he knew. Mean that's it.

[00:16:33] That's a very important message and I think my last question for you is just that. Is there anything else that's really really important that you want us to take away from listening to you about your honesty honesty straight forward.

[00:16:51] These people understand those people that are dealing with end of life issues all understand that there's something wrong. And secondly they need information to be able to process that which they don't understand and none of us understand. End of life issues because of her of doesn't want to. We don't want to deal with this. The last thing literally a list of things we want to deal with. So it's this doctor who is talking with me at the V.A. was pretty clear that he was uncomfortable in talking with me smile the you know sounds like verbal and verbal and he made that pretty clear and he made it very clear that it irritated me because you know my own selfish sort of way. He's a physician hired help and we deal with end of life care specifically this type of cancer

right here and that maybe it would behoove him to respond to my direct question what's wrong with me. And is it going to kill him. And if you don't know. Tell me you he couldn't do that because we've been conditioned not to do. You hear the room lapsed into silence.

[00:18:13] You know with the identified client comes with this to erupt into disgust. We've been talking about your condition your situation now. Tell you what we've been saying rather than.

[00:18:31] So we had this discussion. He and I this doctor and I have about this this and he eventually said he came over to my way of thinking you know life would be fine so I'm leaving this facility. And the doctor is being friendly and smiling. And it was still I'm comfortable with him and for me that there are some things that were so often resolved and he didn't when he really had the resources to do anything but I figured if I'd like to have resolve so evening I'm sitting in the most part they have at the V.A. and see but for now I'm smoking my pipe which is something I knew I shouldn't do it and part of the reason I did it is that I have oppositional disorder a think that I do things as opposed to because I get sick and I do. That's the way it is moving west. So I was doing that and I felt much more comfortable coming through the walkway. This park is this physician and he saw me and I waved and he came over and said things for an hour or so and we chatted. He said By the way you know that Qype you really should be aware that smoking a pipe. Smoking the pipe. Oh never mind he said as he and we both laughed it off he went being reassured of the fact that he told a patient what he was obligated to tell them that you shouldn't smoke and then he gave me an offer a mini lecture for some somewhere.

[00:20:22] Thank you so much for telling us about your experience. It's really helpful.

[00:20:28] I hope we shan't give other people that listen to any of this stuff. I mean there's ramblings. The ability to do something they don't think they have right now and what they have is a handful of attempting to understand what their duty is and what their obligation is and therefore what they do and those really are profoundly different casts. And knowing that we had the opportunity to do with them as we wish those three tests can be one of the most important lessons we draw from life nor are we willing to change ourselves because it's death and dying issue is something isolated to disease. Is isolated to nothing. I think it's a vision both as an overall process that we call death and dying or something else that you know what I mean focusing and that gives us a rare opportunity if we don't see it of being able to actually effect major change in micro level with individuals who are having problems and being in discussion are having difficulties ending a relationship or having difficulty and being a living arrangement or any other kind of relationship with people. We have the obligation to pursue that. I think a healthy sort of way in such a way that we're not producing the end of something or producing something and then it doesn't become so on the wrist it's all that new thing that we produce is probably more valuable than that which from which it came. So I think that if you think about it it might justify your taking the time to hear something very profound some thought to because it's very important to us.

[00:22:25] And I think it's important to bring into preparing professionals to be able to be present with him me just given bad news or someone without their helping prepare for those things to be authentic to be honest to be true.

[00:22:41] And what does it give us. It gives us something which is. He's going to do things that are fun or if we do we're in the same path can be sad or something we do. We do things that are fun for us. We do things that are vying for us we do things that are self-fulfilling for us there was a consistent use for us. We're given with their own needs and if we realize how consistently available that makes our selves to others then they help us that are helping profession if it helps us in terms of understanding how that can assist the abused kid or the scary new social worker during that field or. The Freydon new nurse assistant. See here is very obvious I think that is readily available and that's

been a frustration for me for decades. So we're getting. Why would we pass this opportunity to really learn how to impact the lives of others in such a way that they want those to pass over. I don't know why I.

[00:23:51] Think the question you've been given as a gift to be able to come and spend some time with you and I thank you for that. Thank you for the chance to teach others things. Thank you. Thanks for coming to New.