Samuel Harrington discusses 'At Peace'

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[00:00:36] Good evening. I'm Stesha Brandon. I'm the literature and humanities program manager here at The Seattle Public Library. Welcome to this evening's program with Samuel Harrington and Marion Gwen we are presenting tonight's program in partnership with Elliott Bay Book Company and we're grateful to our authors series sponsor Gary Kunis and to the Seattle Times for generous promotional support of library programs. Finally we are grateful to The Seattle Public Library Foundation. Private gifts to the foundation from thousands of donors helped the library provide free programs and services that touched the lives of everyone in our community. So the library foundation donors here with us tonight we say thank you very much for your support. Now without further ado please help me welcome Karen Madea Allman from Elliott Bay Book Company who will introduce tonight's program.

[00:01:36] Good evening. I'm so glad that we have such a turn turnout for this program. Very important Pergram to me personally and then that you're all here tonight is a testament to that as well says Sam Harrington our author. Tonight is an honors graduate from Harvard College and the University of Wisconsin Medical School. He practiced internal medicine and gastroenterology for more than 30 years in Washington D.C. and served on the board of trustees of simply Memorial Hospital. A member of the Johns Hopkins Health System and he and also the former Hospice Care of D.C.. His writing on end of life care has appeared in The Washington Post and other places.

[00:02:24] As a clinician in private practice Sam served a wide range of patients from the indigent to those working at the highest levels of government and as a medical staff leader he worked to improve quality and advance patient safety. He's here to speak to us today about his first book at peace. Choosing a good death after a long life. This is an essential book thoughtful readable impractical. You'll appreciate his candor and his compassion for his patients and first parents whose lives and deaths are very much a part of this story. I hope you'll read this book and I also hope that reading it will help you have the important conversations with physicians caregivers and with your family members.

[00:03:11] Often we try to make crucial decisions for ourselves and our loved ones without the support and information we need. This book is an important step toward helping us become better informed.

[00:03:23] He appears tonight in conversation with former Seattle Times book editor Marianne Quinn who continues to freelance for the Times Newsday L.A. Times and other media.

[00:03:36] She is a board member of the National Book Critics Circle and she served as a judge for the 2017 Pulitzer Prize in Fiction. And this year she will receive a Shehri proud literary Champions Award for Service to the liberal literary community.

[00:03:52] And I'm so excited that she's agreed to help with a conversation on this program. She's also someone who's had experience with some of the issues about which Dr. Harrington writes. So we'll begin with an onstage Q and A and then we'll invite audience to also ask some questions and we'll follow what the book signing at the table and we have copies of at piece for sale.

[00:04:21] So with that thank you very much and please welcome Sam Harrington and Marion Gwyn OK let's do the mike can everybody hear me.

[00:04:38] All right OK. It's great to be here as Karen mentioned.

[00:04:44] I've had experiences that this book really helped me understand even in retrospect and I'm very happy to have Sam here to talk to them about.

[00:04:55] He told me to call him Sam not doctor here. That's what we're going to do.

[00:05:01] So I've read the book and one thing that really interested me about it was how it's it as a lot of your professional experience but it's very personal as well because you used your dad's experience as sort of a central narrative thread throughout the book. So I wanted to ask you how was that. How was it to write about your dad in this context.

[00:05:27] Before I get into that I want to thank the Seattle Public Library. I want to thank Karen Allman thank Karen Allman and The Elliott Bay Book Company.

[00:05:41] And I want to thank Mary Ann Gwinn because I have trained for this moment by doing colonoscopies for 35 years and she is going to protect you from me and me from you.

[00:05:56] So I I wrote the book. I've been thinking about writing a book for some years but it didn't really crystallize into a book proposal until a conversation I had with my father when he was 88. And at that point I realized that I was going to write a book that incorporated my appreciation for him and my experience with him and I will say that in about the year 2000 I had reviewed his advance directive which appears in the book and we discussed it so we had a very long practical relationship about end of life issues but it wasn't until about twenty five years before he died which is now 2010. I guess that it really crystallized in the form of as a result of this conversation and the conversation surrounded an aortic aneurism that had been followed through a variety of scans and now it reached the point that it had to be dealt with because of the concern of rupture and of course a ruptured aneurism in your abdomen would be fatal. And he had witnessed this happen to one of his clients and so he had some understanding of that type of problem. And I was outlining a course of action whether it could would be major surgery which I thought was risky at the age of 88 for him even though he appeared to be in perfect health or whether he did a temporary procedure or a kind of cardiac catheterization outpatient procedure which would buy him several years of life and he furled up his brow and squinted at me and he asked me Sam why would I want to fix something that is going to carry me away the way that I want to go.

[00:08:03] And I sort of reared back and I realized that that he had a vision of what he wanted. He wanted to die quickly. He without the ability decisively.

[00:08:19] Of course that's not how it played out because he did actually have the temporary procedure but he was quite sincere in his question and that informed me and my sisters about all future questions and problems as we worked through issues. I will say that he did have the temporary Presutti procedure. He lived five more years. The three of those were wonderful years.

[00:08:46] Two of them were not so wonderful and after he passed away then I was able to write the book I think the goal that you and your dad both shared was to have a good death as the subtitle of the book expresses what to you is a good death well his vision to me was not a good death to die of a ruptured aneurism required him to decline emergency surgery take palliative pain medicines for a very painful condition and then pass away with it within a few hours or a day at the most but for him the appeal of that was he was in control in the sense that he was sane. Do not do this. I am in charge. Give me pain medicine. Let me go. But that doesn't define a good death for most people or everybody.

[00:09:49] And yet the attributes of what we consider a good death if you study the literature if you ask patients what they think are the attributes of a good death have been well characterized and I sort of condense them down for this talk to five attributes. The most important is in fact control. That means the patient calls some of the shots they control as much as they can or their family controls. That makes the decisions based on what the patient has indicated they want.

[00:10:26] The second is comfort. Most people want to be comfortable. The third attribute of a good death is closure.

[00:10:35] That is the opportunity to reconcile with family and friends and the fourth is affirmation which is a way of condensing the concept that the patient is validated that their values are honored during the process and that the fifth is trust. Being in an environment that they find comfortable with caregivers that they trust so that that that really defines a good death.

[00:11:06] But I think it's really more instructive to look at the reverse of those characteristics to look where the OB for us.

[00:11:14] Because if you flipped control you have helplessness if you flipped comfort you have pain the opposite of closure would be isolation the opposite of affirmation would be denial and the opposite of trust would be distrust or frustration. And I think those five characteristics to define what it's like to die in an intensive care unit.

[00:11:44] One thing that came home to me is you talked about these issues is as you say there's a lot of philosophy and just the way you look at life in these considerations and you make the point in the book that Americans are by nature kind of a hopeful people and that strain of hope and we can make this work really works against us in a situation like this.

[00:12:13] Yes and we were not only hopeful but we we believe we're exceptional and we are also subject to a lot of media images of youth and healthy patients receiving chemotherapy and where and media images about how supplements will make a big difference and a lot of people don't make think that they're going to live forever quite honestly. My father was of course a member of what's come to be known as the greatest generation and they have lived through a variety of trials. My generation the boomer generation which the leading edge of boomers are 70 for the trailing Nyjer 52.

[00:13:05] We are much more optimistic and and have huge expectations in the American health care system which are probably I mean are definitely overblown and we have to. I wrote the book because I think we sort of need a reality check as to the progress that's being made. Yes progress has been made but it's quite incremental the cures for the great scourges of our time are not just over the horizon and try to hold on for a cure is for every cancer for congestive heart failure or chronic obstructive lung disease.

[00:13:44] These aren't going to happen during my lifetime.

[00:13:50] I just turned 66 and I of course want to believe that I'm going to be healthy for at least the next 20 years and hopefully more you make the point in the book that really anyone over 65 should start thinking about these issues even if you do have you hopefully have you know a life expectancy of 79 which I guess is the national average. So at what point should we really start seriously thinking about these things.

[00:14:23] Well I think we should start thinking about them much sooner than we want. But I'm going to sort of turn the question into When do we think that when should we recognize that we're old because everybody else is.

[00:14:39] I mean I'm not old but I can see some old people there and I am in fact 66 so we are clumped by the CDC into a large demographic everybody over 65 up to 105 is considered old by CDC standards.

[00:14:58] And there's some truth to that.

[00:15:01] And authors write about young old 66 middle old 75 old old 85 but old age really is a combination of several things.

[00:15:15] It's a combination of numerical age our performance status which is medical speak for our ability to take care of ourselves and our disease status and disease generally Progress's.

[00:15:30] So if if your disease is moving from stage one to stage four and your performance status is declining and your age is advancing at some point these lines are going to converge and that is the zone where we should think hard about what decisions we make when assessing the risk benefit ratio for any proposed treatment.

[00:15:56] And I'd like to give three examples because I find it easier to deal with something concrete than sweeping arc of disease into sweeping arc of performance status.

[00:16:10] If a patient came into my office this is not medical advice just for the record. But if a patient came into my office and they were 65 and they had stage 4 cancer that was not responding to chemotherapy I would call I would think of that person as old if a 75 year old person came into my office and they had stage 2 congestive heart failure but they were unable to feed dress themselves or bathe themselves because of any number of problems accumulated. I would think of them as old if an 85 year old person came into my office and they appeared to be in perfect health but they were unable to get up off the floor by themselves if they slipped and fell. I would advise them they were frail and old and that we had to think long and hard about whatever decisions they make.

[00:17:13] So you're sort of walking backward from the point that the person is presumably closest to death.

[00:17:21] Is that fair to say.

[00:17:23] I'm not sure that well the 65 year old person is all because their death is much closer because they have stage four cancer right.

[00:17:35] I'm trying to give an example at each age of where somebody just because you're 65 doesn't mean you're not old if you have some of these Ilma if you have a certain level of illness just because if you're 85 and look at the picture of health which my father did you might have an aneurism that's waiting to happen.

[00:18:00] So if you undergo aggressive treatment for something over here for another organ system is the first organ system or the vascular system in this case might rear its ugly head quite unexpectedly.

[00:18:19] Ages I mean old age being old is not purely numerical it's to take all these other factors into account.

[00:18:28] One thing I learned from reading your book was as you go along this path you're going to be interacting more and more with different doctors and I learn that you are likely to get a different kind of advice from somebody who is say an oncologists than you will from somebody who specializes in geriatric medicine. So could you talk a little bit about the different perspectives people would get from those two doctors and how they should take the different kinds of advice they're going to get.

[00:19:07] Well I I will get to that.

[00:19:12] Most people write a book like this are geriatricians or they are palliative care specialists or they are chaplains for a hospital or a hospice. I was a super sub specialist who did things to people.

[00:19:28] As a young physician but I sort of matured into a person who's said to myself I'm really not helping them. I should I should help them think about it as well as think about it myself. But we super specialists are trained to do things we are trained to use our techniques to prolong life if possible. And oncologists are trained to give chemotherapy and although there is a movement now for oncologists to get double boarded in chemo oncology and Palliative Medicine the vast majority of our ecologists are not double boarded in that way and most of them have a blindspot to discussing or many of them have a blindspot.

[00:20:16] I don't want to offend the oncologists in the audience. We have a round of applause for the oncologists. Most of them have a blindspot to discussing prognosis and and the end options or or the ability to say no to more therapy and so they tend to use terms like let's buy a little time with this. Well if this doesn't work we can try such and such and geriatricians on the other hand are trained in principle to help make slow medicine decisions and ideas.

[00:20:58] In my ideal would be that every every physician moves into that kind of perspective.

[00:21:06] In the book you talk about language that specialists to use that may really what they're saying is that the outlook isn't that good but they sort of cloak it in different terms. Could you talk a little bit about that. What they say versus what they mean.

[00:21:25] Well there is there is the let's buy a little time with this. The the cardiologist will try and adjust the potassium or the let's get a little fluid off you'll feel a lot better. The pulmonologist will soft pedal the need to increase oxygen treatment. It's very difficult for us to say this isn't going to work. It's easier for us to say let's give it a try. And many of the adjustments we make are not very not really helping patients. They're just kind of moving them into the into the next visit or you know let's adjust your potassium pill but then we'll have to bring you back to check your potassium level. So we'll see you in a week kind of thing and if you find yourself in a cycle of seeing a physician and not actually making progress that's another sign that you have sort of entered what I consider the old age zone where you should be rethinking how aggressive you ought to be.

[00:22:42] Well I believe we say in the book that if you hear that language consistently and you keep getting that advice you should consult with somebody whose orientation is more.

[00:22:53] I do. I do. I feel that if if you're seeing an oncologist and they won't give you they won't talk prognosis with you. You should either seek another oncologist or talk with a geriatrician or somebody who will discuss prognosis. And many doctors are loathe to discuss prognosis cetera because of the fear of destroying hope which is a double Hope is a double edged sword.

[00:23:27] I mean there's there's hope for a variety of things we want. We all want to hope for a high quality longer life but we don't want false hope. And I think false hope is a very cruel tool to move patients out of the office.

[00:23:44] Let me talk about prognosis for a second. When my mother was diagnosed at age 82 with lung cancer she had pneumonia and while visiting my sisters she was coughing. It was clear she had pneumonia. She was treated as the pneumonia cleared subsequent x rays showed it was the result of a cancer. Then subsequent tests all done in relatively relatively rapid succession showed that it was metastasized it was described as stage 4 cancer and that's when I got to come and visit with her and discuss her prognosis because I think that's the right thing to do.

[00:24:30] And her median life expectancy based on her cancer was 10 months. So we had a very difficult conversation where I tried to explain my father was there and my mother was there and I tried to explain you know there's a 10 month median survival and I said she looked at me sort of puzzled and I said Well that means that if there were 100 people in your apartment it would be very crowded. But in 10 months half of them would be gone.

[00:25:04] We just don't really know which half and she looked at me and she asked me if I Sam. Am I going to die. And I said yes but we don't know when.

[00:25:20] And then there was a long silent pause. And there was a sort of figuratively some hand wringing and then she and my father started to make plans based on what I'd said. Well you know my daughter was getting married in four months. So now we're focused on getting my mother to the wedding and then we'll see what happens. So the decision was made to have enough chemotherapy to slow the progress of the disease but not cause a complication. Which is of course art. No doctor can cut it that fine. But that's the discussion point and we got lucky and she did in fact make it to the wedding and then she went home and passed away at about the nine month mark and I in my own mind when I told her that she had a median survival of 10 months I really didn't expect her to make it because she was 82. She was frail and she wasn't going to tolerate very aggressive treatments.

[00:26:33] I just want to emphasize in the book that you make really clear that that a reason to really think hard about this stuff is that if you wind up in an ICU and that's where you end your life it's probably going to be very uncomfortable and painful and not and hard on everybody. So one of the points of the book is to try to get ahead of this. So that's that's not the end point.

[00:27:02] Am I correct in that.

[00:27:05] Yes.

[00:27:07] If you if we survey of elderly patients 80 to 90 percent of elderly patients would prefer to die at home express an interest in dying at home as quietly as possible. But the majority of elderly patients still die in institutions. Maybe 60 percent 40 percent in hospitals 20 percent in acute care nursing homes 20 percent in acute care nursing homes. And my point is that it's fundamental to it that if you want to die at home you have to at some point have to say no to hospitalization. And the question is when can you come to that point when can a person come to that decision making point. Because doctors aren't going to make that decision for you. There they are not inclined to say OK it's time to go home and die. They are going there are inclined to treat the path of least resistance is to treat the family expectation is to treat. And we all want to live.

[00:28:17] We don't want to face that decision. But it's fundamental that we have to.

[00:28:22] So in my father's case he he was prepared he was he was trying to make himself prepared to say no to emergency surgery. Well comparatively few people have an opportunity to decline emergency surgery but some people will have an opportunity to decline a pacemaker for congestive heart failure. Some people will have an opportunity to decline. He might die now that dialysis for kidney failure. Some people will. Many people will have an opportunity to decline a fourth or fifth course of chemotherapy. And most of us if we're lucky enough to live to old age will have an opportunity or two or three opportunities to decline antibiotics for the types of infection that afflict elderly people with chronic illnesses. So I say it's fundamental to know when you're going to say no to medical treatment if you and when to say no to hospitalization if you want to actually get home and have a more peaceful death.

[00:29:38] My experience with these issues and probably most people their first experience with these issues was my parents specifically my mother who died at 95 and right up to the pretty much the month that she was diagnosed with pancreatic cancer she was determined that she was going to stay in her house forever.

[00:30:00] She was going to take care of herself. She was going to mow the lawn. She was an extremely smart stubborn person. So my sister and I kind of went along with that because like as you know these things are hard to bring up so suddenly she was diagnosed and we were kind of thrown into this whirlwind of what are we going to do.

[00:30:24] You know first it was like what we're going to try to get her home care with and she got too sick and she went to the hospital.

[00:30:31] And then people started talking about hospice and I said hospice great. Where is it. Let's let's go there. But I learned during that experience. And was greatly eliminated by reading your book that hospice is actually many different things and I was hoping that you would talk about that.

[00:30:55] Well going into hospice means different things to different people in different contexts it's the same term and it frequently gets confused.

[00:31:05] There's the philosophical aspect of going into hospice. There's the physical aspect whether hospice care comes to you in your home or you go into a hospice freestanding hospice or you go into a hospice hospice bed in a hospital and there's the sort of regulatory aspect of going into hospice. Oh you're not qualified for hospice nurse might say because you are you're not sick enough. Well I think of most of the time however going into hospice means accepting the philosophy doing it at home and and satisfying most of the regulatory requirements based on your physical status. And when my mother went into hospice that is to say when we signed her up which was about a month before she traveled to my daughter's wedding I felt great relief because some of the hospice benefits are transportable meaning when she moved when she went from Milwaukee Wisconsin to Washington D.C. for the wedding. I knew that if minor things came up I could get I could get some hospice equipment to the hotel or I could take her to my hospital and get her into a hospice bed and not have to worry about losing her losing control and having too many tests done and having her swept up into the medical system. And so I felt good about it. Now my father didn't like hospice at all because they don't do anything. He thought they just show up once a week and talk about dying which didn't appeal to him. I mean he was ready.

[00:32:57] He knew better than my mom every time. But you know why do we have to talk about it.

[00:33:03] You know once a week let's make it once a month. Why do they have oxygen here. That kind of thing you know. Why my pain Faarax. So OK that you're not paying for oxygen. They are looking ahead. She has lung cancer she's likely to get short of breath if they have oxygen in the house. It might spare a call to 911 when she gets short of breath. Let's put it in the other room. Let's just let's let's deal with this. Let them be the pros and we'll listen to what they say. But they also I feel that hospice is an alternative system that protects our loved ones from being swept up into test and the test and treat standard of care. And of course they bring narcotics into the house so that if a painful condition arises they can get at least a dose of narcotics and a call to the hospice nurse before you have to call 911. And hopefully don't have to call 911 in the case of lung cancer that frequently metastasizes to the brain. Seizures are a very frightening symptom to occur the first time in a family. And of course that would be a 911 call. But under hospice circumstance you'll have and I convulse since in the House INSTRUCTIONS TO to administer them. Hopefully things calm down you can call the hospice nurse and again hopefully prevent a trip to the hospital for this very unappealing symptom development. So I think that it's I feel like when my father got into hospice which turned out to be seven months before he died I felt it was quite an accomplishment because he was still able to get up and around. He was still going to the the Metropolitan Opera broadcasts on Saturday and he would go with a caregiver. And I knew that if he had a problem in the theater the theater owner would call 911 but the caregiver would call the hospice nurse and we would have us try and coordinate to protect him when the ambulance came.

[00:35:24] When you were talking about regulations I mean one aspect of hospice that is going to influence a lot of people is the way Medicare pays for hospice. Can you talk a little bit about that.

[00:35:37] Well I don't I don't feel expert in that I was quite comfortable as a physician skirting some of the rules if a patient wanted to be signed into hospice and I read that it was the right thing to do. I didn't worry about that. They met every requirement that that Medicare required.

[00:36:02] But many physicians do feel that they don't do feel that where they feel they can't sign people in early. I mean when I say early I'm talking about I think you're going to live less than a year. I'm going to sign you into hospice. But some physicians won't sign you in unless they think you're going to die within three months because it's an imperfect science to predict where the six month life expectancy is and many hospices won't take you unless you satisfy all the requirements. But we fund. So my father was originally rejected from the first hospice we applied to.

[00:36:42] I kind of blew a gasket with with respect to talking to the nurse manager who was dealing with him who was a family friend.

[00:36:51] So I got away with it and we introduced we started interviewing other hospices and we found one that would take him based not on the diagnosis of geriatric failure to thrive which is medical speak for saying that he was dying of old age and that diagnosis required him to be housebound and he couldn't go to the Metropolitan Opera broadcast. Under those circumstances. But the second hospice said Well you know he's got a chronic lymphoma.

[00:37:24] It's not really it's not really active. They're not doing anything about it.

[00:37:28] But we'll use that as the main diagnosis. And they kind of slip them in. And that was fine. He did in fact pass away in seven months which is close enough for government work.

[00:37:40] What is the difference or is there a difference between Poliakov care and hospice care or are they the same thing.

[00:37:47] Palliative care is is what is done in hospice. So hospice care is limited to palliative care and but palliative care is its own subspecialty and can be invoked and should be invoked before hospice care is invoked. So if you fail to get into a hospice you probably should consult with a palliative physician. They still can get paid under Medicare and and get the benefits of their palliative expertise and then they might help you segue into a hospice at the earliest possible opportunity. But palliative care is the practice of alleviating symptoms without trying to prolong life or without worrying about the underlying diagnosis.

[00:38:42] Interesting when you finish this book can you thought about the people your readers. What are a couple of things that you hope readers will take away from it.

[00:38:59] There are only two things that I mean the two basic things are if you want to die at home you have to know you have to think about when you're going to say no to hospitalization and embrace hospice as a means of taking control of that which you can control.

[00:39:20] Nobody can control that the end of their life in the fullest sense. But if you don't take control you are ceding that we're ceding control to two doctors most of whom are well intentioned or all of whom are well-intentioned but who will also continue to treat longer than you might want them to.

[00:39:45] So think about when to say no to hospitalization embrace hospice care.

[00:39:57] We have time for questions. I think what we'll do is we'll all call on folks and say the question and then Sam will repeat the question so we'll make sure that everybody hears it. So do you do you want to go first.

[00:40:18] Right. You want to sum up that. So I think the question is or or the statement for discussion is that doctors are obliged to tell patients more and to tell them about more options and care including palliative care and hospice care. And I agree with that position. I think I think doctors don't do a good enough job discussing prognosis discussing disease trajectory. Where the heck is this disease going.

[00:40:52] And and yet I also believe that it's patients are obliged to either ask those questions or tell doctors what they want. So both sides need to communicate better. But I agree that doctors should should feel obliged to discuss things more.

[00:41:15] The problem is a problems a systemic problem is that doctors don't get paid very much for discussing things.

[00:41:24] I got paid for doing procedures. It was easier for me at the beginning of my career and for to schedule a procedure than to sit down and talk to the patient about why I thought they shouldn't have the procedure or.

[00:41:42] So that's the point the question is.

[00:41:47] Am I familiar with the concept of medical aid in dying formerly known as physician assisted suicide which is available on six states and the District of Columbia.

[00:41:59] If the Republicans get out of the way for the District of Columbia that's an aside. Yes I am. And I touch on that in the book I believe in my perspective on medical aid in dying has sort of three components.

[00:42:18] Intellectually I think that where it is available people should study it and consider it as a as one end of life decision to consider.

[00:42:34] Professionally as a physician who had taken an oath to do no harm. I find it difficult for me to reconcile and I am glad that I have never I have not actually had to face that decision professionally. Personally if my father had had medical aid in dying available to him and he did not. He lived in Wisconsin but if he was certified to have less than six months to live which is one of the stipulations of the statute and if he was medically mentally competent and if he was physically capable of self administering the lethal dose I would I personally would have felt that I was cheated out of some quality time with him. I would have respected his decision but I would have felt that there was an impulsiveness or a prematurity to that decision. So I'm conflicted professionally and personally but on an intellectual basis if it's available to a patient they should definitely study the issues surrounding it.

[00:43:55] Now on the other hand if my father had been suffering from severe pain then I would have had a whole new level of conflict because I would have felt that I wanted to help him personally.

[00:44:12] The question is is there euthanasia available to in another country.

[00:44:19] I don't I know that euthanasia is possible in Holland but I really don't know anything more than that. On the subject of euthanasia I don't I don't know that it's being considered. The question was Is it being considered in other countries.

[00:44:37] And I don't have the answer.

[00:44:41] What are my thoughts about C.P.R. when Myf mother went into hospice of course she became a Do Not Resuscitate patient after she passed away. My father wouldn't let her wear the bracelet. He kept it in his wallet which of course is a mistake. But there are some things we have to put up with. After she passed away he started wearing her bracelet. I said Dad you need to register if you're serious about this you have to register.

[00:45:15] So he registered as a Do Not Resuscitate patient and because at that time this is about five years before his death. He started with one of his mantras which was you know I'd like to wake up dead. And that's shorthand for saying you know I don't want to be resuscitated. So CPR is what we do to people who have. If we find that they've woken up dead if we find them collapsed on the floor we start CPR. Well my attitude is this is not medical advice but this is is that if a hundred patients over the age of 85 collapsed and their heart stopped and we started CPR 82 of them would not come back. 18 of them would make it to the intensive care unit of which 13 would die before they left the hospital. And all of those 13 would likely have broken ribs and a bruised heart.

[00:46:33] And of the five that were discharged three would be neurologically altered and two would be close to normal. And for me that wasn't.

[00:46:45] I would. I was glad that my father had made the decision for me so I didn't have to wake him up slap him awake and say OK we've got to get sensible here dad.

[00:46:57] You need to register for this.

[00:47:01] The question is what kind of directives do doctors have to respond to legally and I'm not a lawyer but I think that's a very sophisticated question because doctors generally follow patients requests but doctors are not required to give care that they deem medically futile. And this is a very difficult area because medical futility is extremely difficult to define.

[00:47:40] I have my own definition but in answer to your question my understanding is doctors are not required to give care that they deem to be medically futile although it is very hard sometimes to have that conversation and tell patients this is going to prove to be futile.

[00:48:04] But I would like to define medical futility as I see it and it is a retrospective definition that I think we can understand. If we were to reflect on the last treatment that our loved one received or that they endured or that they suffered and if we look back on that treatment and we say I wish I had not done that to my mother. I wish I had not done that to my father. We have defined futile treatment and the trick is to try and predict that in advance and avoid it.

[00:48:41] So I'm sorry I lost track. The question is about lifestyle genes genetic makeup versus healthy lifestyle. Predicting the presence or absence of chronic diseases I don't I personally don't believe that supplements do very much if anything at all.

[00:49:08] I think that a healthy lifestyle is much better than an unhealthy lifestyle.

[00:49:13] I think that a healthy lifestyle largely includes limiting calories and limiting and eliminating tobacco products and other toxins. And I believe that jete genetics are really that genes are responsible for the most long lived people that we observe but that my oldest patient died at 107 and I saw him quite regularly. But my take on chronic illness is if we are lucky enough to live to be old if we are lucky enough to live to be 85 or 90 80 percent of us will be suffering some disability from chronic illness. During the last year of our life. So I think that we have not. Medical science has not cured chronic illnesses we have we have cured many acute illnesses was just the survival to later. So more people will have chronic illnesses. And as we improve the treatment of chronic illnesses we will have even more people dying of what's called senescence which is the medical term for dying of old age and there you go.

[00:50:41] So the question is are the statement is that the title of the book is choosing a good death and that if a patient has the opportunity to take advantage of medical aid in dying that I should embrace that process.

[00:50:58] And I tried to say that on an intellectual level I do and that I've framed the rest up as emotional and and or professional ambivalence.

[00:51:11] Yes indeed. If my father had that opportunity and he chose to exercise his option I would have had to live with that because of my belief in in autonomy. But again personally I would have felt a little bit cheated on the subject on the other hand. I think it was very important. It was very important to my father to have a dignified death. He did not want to be dependent on people and yet he was. But that's that's the reality of the situation. I respect people who don't want to be dependent on others. And if that's how they define dignity and they meet the stipulations I could live with that.

[00:52:05] So the question is are there other counseling services or professional services that help families cope with this kind of decision making and in particular when not all the family members are on the same page.

[00:52:20] And I I myself don't know of any particular services. I I'm I'm sure that if we crowd sourced it there would be services like that but I don't know exactly how to find them.

[00:52:34] This in my in my own family dynamic this is where I would have turned it over to my older sister and she would have found something now. But but to

[00:52:48] Ok so you offer those services. Oh oh oh ok. Good luck with that.

[00:52:57] One second I want to in my own family.

[00:53:05] There were three sisters and myself and one of my sisters.

[00:53:12] Was perhaps more optimistic than the other three and one of them was more hopeful than the other three my older sister and I were kind of coldly pragmatic but we met we discussed and we came to the conclusion that unified family is much much more important or than exercising your personal opinion because a unified family and a doctor can make decisions with the patient and the end. And a family that is not unified causes lots of problems and doctors will have a very difficult time dealing with a fragmented family.

[00:54:07] Thank you very much. I hadn't thought of that. I did not avail. So the question is are the statement is that services do exist to help families make these decisions.

[00:54:19] They are referred to in general as death Doulos or death midwives. And it's a growing movement. And I was aware of that but couldn't think of it. It needed to be reminded.

[00:54:34] You.

[00:54:38] So the question is how should we discuss end of life issues with young adults whose biggest risk would probably be a traumatic injury that they would have to deal with. And then there would be the rare statistically less common problem related to a critical illness developing at a young age and I I would probably limit. I mean I this is outside of my this is outside of the context of the book so I really don't discuss this. I knew that this was beyond my. This question is beyond my level of expertise and I would be torn with it. But with respect to doing my best to answer the question I think every young adult should have should address the possibility of brain damage related to what do I want to do. What do I want my family to do if I become brain damaged as a result of a motor vehicle accident. And it is the responsibility of families to have that conversation. All these conversations are difficult and my point is that I do make I try to make in the book that there's no easy way to do it and you just have to blunder ahead because the alternative is worse is worse not to have some idea of what people want and get trapped in an excessive treatment. Then to blunder ahead and start the conversation or have the conversation so that we are. So the question from an oncology provider is how do we define a good death for a patient. And who wants to die in the hospital or who wants to be treated to the end and wants to die in the hospital.

[00:56:41] And my response is that I don't have a different response. I believe if a patient wants to fight to the end that is exactly what should happen and they should understand that they are going to die in the hospital. And I'm totally comfortable with that. Everybody has a especially young age. People should think about fighting if that's what they want. But at an old age I think the people need a reality check because they are not going to have the same they'll let me go. There's a chapter in the book called The median is the message. And that is a riff on a famous essay by Stephen Jay Gould who wrote that the median is not the message he wrote that because at age 42 he was diagnosed with at age 40 to a young person. He was diagnosed with a rare abdominal mesothelioma a cancer that was considered incurable at the time and the median life expectancy was eight months. And he being a scientist knew that some few people do live into the long tail of survival and he did indeed live for 17 or 19 years I'll have to go back and reread it and died roughly 60 after a second cancer or lung cancer. And he lived for two years after that. But if my father was diagnosed at age 85 with a healthy glioma in the abdomen I would have advised him that the median is the message that you are not going to.

[00:58:35] There's no way you're going to live 17 years like Stephen Jay Gould because if you survive more than eight months or two years you're going to. Something else is going to rear its ugly head in this. In your case and aneurism and you just have to deal with with that reality.

[00:58:54] But a young person I I would struggle with those decisions.

[00:59:00] I think I don't have I don't have good advice for your answer or your question. But I'll just say I'm reminded of Groucho Marx who said I plan to live forever or die trying. Well that's a valid perspective but it also means he's going to die in the hospital. The question is. Ron's the issue of acceptance and what are you accepting death or a spiritual life afterwards.

[00:59:37] I I don't address that in the book. I my attitude is that the acceptance is part of an understanding of the process and the goal from my parents was a natural death a death that was not medicalised that did not involve technology which was designed exclusively to prolong life and lower quality. I obviously dodge any in the book any religious or spiritual aspect because I am not a spirit.

I'm not a religious person as the minister I'm a person of goodwill and again my book really just deals with a reality check for people above a certain age well thank you so much.

[01:00:41] Very helpful.

[01:00:45] Thank you Marianne. Thank you so much Sam.

[01:00:51] This podcast was presented by The Seattle Public Library and Foundation and made possible by your contributions to The Seattle Public Library Foundation. Thanks for listening.