Cancer Assist Podcast\_ Winemaker and Seow

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**SPEAKERS**

Dr. Bill Evans, Narrator, Dr. Hsien Seow, Dr. Sammy Winemaker

**Narrator** 00:01

You're listening to the Cancer Assist Podcast, wherever you are, in your experience, we are here to provide help and hope as you navigate cancer prevention, treatment and care hosted by Dr. Bill Evans, and brought to you by the Cancer Assistance Program. Help when you really need it.

**Dr. Bill Evans** 00:17

Welcome to the Cancer Assist Show. I'm Dr. Bill Evans, and I'm here today with two guests. And we're going to talk about a book that's about to be launched. And this is going to be a really interesting conversation. So I think you'll enjoy it. As you know, if you've listened to previous podcast for the Cancer Assistance Program. The program here in Hamilton provides a variety of services for cancer patients, including free rides, free equipment, loans, nutritional supports, and a variety of other services that patients need. And one of the other things patients need is inflammation. And that's really the focus of our conversation today with our two guests. So I'm delighted to welcome back to our studio because she's been here before actually, exactly a year ago, Dr. Sammy Winemaker who's an associate clinical professor in the Department of Family Medicine in the Division of palliative care at McMaster. So welcome back. Sammy,

**Dr. Sammy Winemaker** 01:07

Thank you so much for having me back.

**Dr. Bill Evans** 01:09

Delighted to have you and also welcoming back, it was back when we were on the radio show. Hsien Seow is the Canada Research Chair in palliative care and health system innovation. It's quite a mouthful. And a professor in the department of oncology, who has a lot of research in palliative care. And I think that this is an interesting duel here, because we've got a lot of clinical strength and a lot of research strength. And he came together to create this book, I think it's just amazing, I congratulate you on doing it. I've read a lot of it, scan some parts of it. But what impressed me was how it got started. You've been laboring away trying to educate physicians and being a physician. I know we're very hard to educate. But you can kind of have this light bulb moment. And I think it sort of came to Sammy, after you'd had a bit of a downer experience with a particular patient you describe in the book and visited this gentleman who had some lung disease and interstitial fibrosis, he was deteriorating. And he was really looking to have made of medical assistance and dying. And you came in sort of late to the game and could have done more for him. Had you had the time. And he just felt very frustrated with it. So he came and had a cup of coffee with CNN. And you're both a bit down at that point. So maybe pick up the story how this then evolved into a book.

**Dr. Sammy Winemaker** 02:38

Sure. Yeah. So you're you're taking me back to a dark time bill. Well, that's exactly what happened, I had come home from yet another home visit and met the same type of patient who was very much in the dark, about their illness and where they were at in their illness and not knowing what their options were. They were told by their specialists, there's nothing more we can do for you. And so this particular person thought that the only option they had was to go for medical assistance in dying, which certainly in Canada was an option for him. But it really saddened and frustrated me because what he didn't know is that long before that, he could have had more information about what the natural storyline of his illness was going to look like so that he could prepare ahead, so that he could get the right medications, he needed to feel less breathless. And perhaps if that had happened, he would have seen some silver linings to living out the rest of his illness. So he was just, he represented most of my patients who very much feel like I wish I had known more. And so Sienna and I have been trying to, you know, change the healthcare system from within. We've been trying to move the dial and teaching doctors, nurses, any health care providers that we all have a stake in providing realistic and honest information to patients and families, but felt that things were not changing fast enough. And so this one day, we had coffee, this conversation was a game changer for both of us.

**Dr. Bill Evans** 04:34

And you've done a lot of research and I'm sure it's impacted how palliative care is organized, delivered and so on in Canada and abroad. But you've had a sense of frustration as well, I think.

**Dr. Hsien Seow** 04:46

Yeah, because thanks for having me on the show, Bill. Yeah. The you know, the meeting that we were having and it was a coffee shop here in Hamilton. It was about a research project that Sammy and I were involved in which was creating education for primary care We're a family, physicians, people in the community working in the community. And we were trying to operationalize what a palliative care approach means. So not just the medical parts, but really showing the tips and the best practices of how you can really do this in their clinical practices. And doing it early. And that was what our research project is. It's a randomized trial across Canada, it's shown, you know, showing some promising results. But what Sammy asked me was, was the light bulb moment, she said, you know, again, if we do this right, with family physicians, and you know, their teams, what about the specialists? We're still missing the cardiologists, the oncologists all the ologists. And then at the real light, Bob was when she said, and what about the patients and families? Because they deserve this information, too. And what in what education do we have? What messages do we have for them, and that's when we really realized that is the biggest gap is that, you know, we have been spending years and years on educating clinicians, but a lot of the ways that we we do it, there is a patient facing version of this, you know, sort of like a ready to wear version. And I don't think there's been as much research and attention spent on that. And they're the most important that the listeners are the most important people who needs information. So that drove us on this whole journey,

**Dr. Bill Evans** 06:14

right. And you talk in the introduction about activating patients. And I guess that image is a very good one, because I think a lot of patients are rather passive. And they're kind of just told you're going to have this treatment, you're going to come back in this date, etc. And really, the whole book is about activating patients and, and you use the expression to Dr. Winemaker about acting as a medical interpreter, because patients don't really seem to get it, what's happening to them around them where they are in their journey and so on.

**Dr. Sammy Winemaker** 06:49

Yeah, so patients, I think, put full trust in the medical system, that the medical system has got them 100%. And so they start on this journey, just prepared to go with the flow. And that information will come to them in a timely manner and when they need it. And we know that there's efforts for that to happen, but it's imperfect. And so if a patient and family just bubble around, almost like I envision like a boat, without an anchor, just like floating wherever the weather takes them, they are really operating behind the eight ball doing themselves a disservice. Because on the other side of the equation, we have this uncomfortable healthcare system that is busy and tries to be efficient, and is not very forthright, and asking patients and families what's on their mind, and if they have questions, unless the patient and family initiate those questions. So we have on one side, the health care providers that aren't eliciting questions from the patients and families. And on the other side, we have patients and families being very polite, and in quotations, good patients and families and being passive. And then we have in between them a vortex we have a lack of communication flow. And this creates anxiety, as patients journey through their illness, really feeling as they get deeper into the story, that they are more and more feeling unclear and anxious and fearful that they don't really understand what's happening. Even when information comes to patients and families. Like sound bites, for example, a patient and family might be told, we're going to increase your lasix today, which is your water pill. And the patient and family received that information. But they don't necessarily understand the meaning behind that which could mean your illness has changed. It's entered into a different chapter. And we're needing higher doses of your medication. So do you want to talk about about that? So that's the interpreter part that there even if there is information flowing, the meaning behind it, the subtleties, the between the lines information is going past everyone.

**Dr. Bill Evans** 09:32

Right. And it's perfectly understandable how this has occurred, right? Because it seems to me, medicines become more complicated. There's a lot of pressure on the system, particularly post COVID Because we seem to have fewer health care workers, limited time. So it's kind of how how quickly can I process people? So on the medical side, there's not as much opportunity to listen to them. Find out what the patient's thinking, how they're perceiving their illness, what level of information they want, et cetera. And you mentioned the good patient. And I think that's a very real thing too, because in my own experience, as an oncologist, I think patients have always been kind of polite and accepting of what you offered, if you've presented it in a reasonable way to them. And not asking too many questions, and not wanting to upset the doctor, because that might mean that, oh, they might stop my treatment, you know, or change my treatment, or they won't be so engaged and looking after me, as I'd like them to be. So they're kind of tentative to be more assertive about asking for things. So it's an interesting dynamic that's been created, and you're trying to break it up, and you started something called the Waiting Room Revolution. Revolution is a good word for this, because it really would require a major shift in how both patients and professionals in the healthcare system engage in providing care, right, it's, it's really a big change. And that's what you map out in this book.

**Dr. Hsien Seow** 11:07

Yeah, the Waiting Room Revolution was a name we came up with for sort of, it's a movement, it's more than our podcasts. It's more than this book, it's this change in the idea of, you know, how active patients and families in need to be to really own their health care and to take charge of their journey. And I think, as you said, medicine has evolved so much, the world has gotten more busy and complicated. And, you know, Google, everyone, you know, Google's their diagnosis, there's so much information. I mean, the idea that we don't have the answers is just mind boggling. But really, what Sammy was saying that it's the meaning making behind it, and what all of that means for you, the person. So the real, you know, innovation and excitement about this was it wasn't only identifying the problems of the system of the, you know, the complex system that we live in. It was trying to come up with the solutions. And but when at that point, we really had to think through all the times that people said, Why didn't someone tell us that sooner, and then also reflect on the stories where we thought people had a better experience and compare what was different about those who had a better journey felt more prepared more at peace with things more accepting, and their families weren't so overwhelmed. And that's where we came up with the seven keys for having a better illness experience. And it was really about the earlier you start, you know, as soon as you get a life changing diagnosis and understanding what that means for the you know, the rest of your story and your life. And that doesn't always mean that it's going to go straight down. There's lots of options for hope, and treatment. But those all have to be in the context of what is truthful information of what's happening to me and what this means for me and my family. And not only putting blind trust, in that there's always going to be a cure, or there's always something in the cupboard.

**Dr. Bill Evans** 12:53

Well, let's dive into the seven keys that you've laid out. And they all have interesting names, it seems to me, I'll just name them for our listeners, walk to roads, that's when we're going to delve into a little more depth. Zoom out. Know your style, customize your order. Just want to say something about the ripple effects. Expect to expect ripple effects, connect the dots and invite yourself. So there's the seven keys, but you describe the first one walking two roads is kind of the linchpin for, for all the other keys. What do you mean by that? And how is it the linchpin and what are the two roads?

**Dr. Sammy Winemaker** 13:32

Good question. Well, currently, what tends to happen is naturally we want to be hopeful. Patients want to be hopeful families want to be hopeful healthcare providers want to be hopeful. So as humans, we tend to take on a positive type of attitude when someone gets a serious illness. We become their cheerleaders, their friends and families become their cheerleaders. And they might say things like, Oh, come on, don't lose hope. You have to, you know, stiff upper lip, keep your chin up. Oh, don't, don't worry, don't go there. You know, you're gonna beat this. We're gonna fight this together. And we take on this culture of what can be toxic positivity, where everyone is rah rah writing. And what happens is a person and families hope get stuck in an unrealistic stage of the illness in their mind. And walking to roads means that we can definitely have hope along the entire illness journey. But the focus of the hope at the beginning of an illness will change over time as the illness unfolds at the beginning of person And might hope for that it was wrong, that the doctors wrong, they got the wrong information. And I'm not the I'm not the person with the cancer. But as time goes on, they can maintain a level of hope. But it shifts, it can become hope for treatment, hope the treatment works, and then maybe hope for that I'll feel as good as possible hope that my family does well. Hope that in the end, I'm comfortable. So they can still be hopeful, but it needs to evolve. And the only way it can do that is if they walk two roads. So the other road is seeking and accessing honest, realistic, truthful grounding information at the same time that they're being hopeful. So they can hope for the best. While planning for the rest, they can hope for the best while entertaining, well, what if this doesn't work out, hope for the best, or ask themselves, what if. And so it's the most protective way for everyone to interact together, because we can just like it says, We can walk those two roads, we can maintain hope, but also infuse a hefty dose of reality into the situation so that the person feels grounded the entire illness journey. If people so research does show that people who get information for better or worse, do better, they feel better, they feel like their boat suddenly has an anchor, and they can then adjust. Perhaps be sad, disappointed, but move forward, you cannot move forward if you get stuck in only hope, without the reality simultaneously. So walking to roads means a patient and family and health care system learns how to balance both of both of these things, both being hopeful and truthful, at the same time.

**Dr. Bill Evans** 17:13

Got it? You mentioned the research. So I'll maybe just direct this to UCN. I guess from my own experience, I would say I can't see this being applied to all patients like there are patients who? And maybe maybe it's because I didn't communicate with them appropriately. But it didn't seem that they wanted the information or or in fact, the some of them actively rejected it and said, You know, I'm the kind of person who you do you do what you do doctor, you know, best kind of thing. So when you present it semi it sounds like it's a universal thing. But is it really? And what are physicians to take away from it?

**Dr. Hsien Seow** 17:53

Yeah, so, I mean, it's a really great question, Bill. You know, I think the whole gist is that we want to, we want to invite patients, we should offer information and opportunities all throughout the illness, so that they can be invited to be in the know, you know, and when there are versus being in the dark. And I would say the what I have learned over the many years, you know, working with clinicians is there's this idea that, you know, they didn't want to make patients sad, so that one patient who said, you know, keep you know, I'd rather not know. And I don't want to make them sad and disappointed. So I will just, you know, hold that information and wait for them to ask. But as Sammy was saying, like, they're waiting for you to bring it up. So what I would say is we are not forcing information on people, we are offering them the opportunity to learn as much as we do as like healthcare insiders, right as interpreters. So that's the reality. The real gist of this book is that after all these years, we want to let people know how to leech out the best care without the labels and without waiting to be invited, they can invite themselves. And the reality is, as patients, they don't come alone, if they don't want to know, they're the kind of person who prefers to keep their head in the sand or so to speak. someone in their family who came with them probably is desperate for this information, and they're being locked out. And so I think we're really just pulling up the veil to say there is information if and when you're ready. And I also want to say that this idea of denial, what people really don't want to know, is is very rare, like you know, we call it the big D It's very rare to meet someone who really, truly doesn't understand. In fact, the more that you feel a pushback of this is scary. Let's shut this down. The more it seems that there's emotions behind that to unpack, maybe not at this appointment, and maybe it's not with a doctor, maybe it's really to unpack with their family. But why is there such a strong emotion that they can't even talk about something that really might happen? I mean, we talk about, you know, all kinds of possibilities all the time. So I think there's an emotional part, not only medical knowledge, where it's very rare to meet someone who really truly doesn't understand that everyone at some point will get illnesses that might you know, shorten their life.

**Dr. Bill Evans** 19:59

Okay. that. So the research really shows that the vast majority of people need to be invited in and and to be provided the information as opposed to what we're perhaps doing as healthcare professionals is not giving it to them, because we think we're protecting them. Is that a fair summary?

**Dr. Sammy Winemaker** 20:17

Absolutely. I mean, I had an example yesterday, where I went to see a person and their partner. And, of course, like I do in every visit, I asked people if for permission to speak openly, and honestly, and usually everyone looks at me, why would you do it any other way? And I say, Okay, I'm just checking and, and along those lines, is it okay, if I just speak straight, Frank? And without any sugar? And they say, of course, we wouldn't have it any other way. And look surprised. And so I will then go on, at some point to say, does your mind ever wander into the future? And wonder, you know, what's going to happen? And some people will say, yes, and some people will say, No. And I will ask, Is that something you want to talk about today? And to your point, Bill, some people will say, No, I don't want to know. And so and some, like yesterday, that one person said, no, she was the person with the illness. But her partner said, Yes, he was nodding, yes, there's a lot of non verbal communication that happens in people's homes. So in any one family, you can have a mixture of people's readiness to go there. But when people say no to me, I have to tell you, I don't just leave it at that. That would be very easy. If I said, Do you want to know more information about the future? And the person said, No, I'm sort of a day to day kind of person, I'll just take it as it comes. And, you know, no, thank you. I've come to the point of taking it a couple steps further, but not to dishonor someone's decision, because they have a right to the amount of information and when they want it. But I will share with them having cared for 1000s of people in similar situations, that my experience has been that people who have more information are first of all, surprised that it's not as scary and upsetting as they think. And secondly, do better. They can plan, they can be proactive, they won't get stuck from crisis to crisis, like jumping from puddle to puddle. Patients do better when they have more information. So I'll just leave that with you. I say to the person, and then they really have informed decision making about saying yes or no to the invitation to know more. I tell them, you know, if you do know, these are the benefits. If we don't talk about it, these are the pitfalls. And then if they say no, I'm good with that. And if the partner wants to know more, we might go into the other room. But we have a responsibility in the healthcare system, to continue to invite people to know the big picture of their illness, where they're at in that illness, and what's going to happen, instead of staying in the weeds of the illness and talking about the day to day stuff and the busyness of ordering treatments and results and how they're doing on this that the other thing, we will miss the forest and patients at the end are tangled and what we don't do contributes to their suffering. So so that's how I would answer your question.

**Dr. Bill Evans** 23:49

Well, it's also a nice transition into the second key and the zooming out. Because what you say in the book is if you just focus on the smallest details, you never get the big picture, right. And as physicians, we often focus on the results of this test, your blood work shows this your a CT scan shows that rather than where you are in the whole journey, and patients never get really a clear picture what the whole journey looks like. And hence any understanding of where they are on that trajectory. And it can be very confusing. You say in the book that on the one hand, you can never really know what a person's prognosis looks like, because everybody's an individual. But on the other hand, we do have cumulative knowledge about the natural history of, of diseases and so at least you can paint that picture with the natural history of the patient deviates from either either doing much better, much worse well, so be it but you can least create a broad picture of how you know people with chronic obstructive airways disease do or when you're in congestive heart failure, what it's likely to happen or when you're on stage for lung cancer. So it is possible to do that in a reasonable way. And I think that's what you're saying that patients should know that big picture.

**Dr. Sammy Winemaker** 25:12

They should be invited. Invited? Yeah.

**Dr. Bill Evans** 25:16

Well, that's gonna be a really important part. Because I guess as I read the book, I was thinking that you were almost prescribing this for everyone. But that piece about the invitation, which is really the last key, right, is, invite yourself. The patient should take some initiative to, I guess, signal, how much they want to know.

**Dr. Hsien Seow** 25:39

Yeah, I think what we found is the whole story is that, you know, the passive patient and family don't do as well as ones who are in the know, they, you know, if they're passive, they end up to be in the dark, if they're all trusting and sort of get go along, they know they're very at risk of, you know, all these things happening around them without any control. But the more information they have, the more they can be proactive and plan, hoping for the best, but planning for the rest, and take charge of the story. And the things that are important to them, again, not just with the medical system, you know, 90% of their time, is their life outside of the hospital of which they have the most interest of making sure that time is well spent in exactly all the ways that they want. And so zooming out is really this idea of the big picture of the illness. And I think we sort of make the analogy of it's like you're in a car, and you're in the backseat, and we want you to be in the front seat. Because if you're in the front seat you you have information like where you're going, you have a roadmap of what to expect, you know, every road trip might take a little bit different times because there are pitstops, or detours. But you have a sense of where you're going and how roughly where you're headed so that you can enjoy the whole ride, not just this is where I'm ending. In some people, I feel like if you're in the dark, you don't even know you this is a ride that you could be, you know, enjoying like a train ride across the country. And only when you're there, you're like, oh, how come no one told me that I was supposed to be enjoying the train ride and looking out and enjoying the view the whole time. So zooming out is this idea of every illness, every cancer has a beginning, middle, late and end stage. And we often start to reveal what to expect only at the end stage the weeks days before someone passes away. But some now we know with all these treatments. So this whole journey of cancer there's, there's so many twists and turns in the middle chapters, that late chapters, there's extending things. So it's really important to understand the storyline, not just the timeline, people think the timeline is this magic number, and it's an expiry date, it's a countdown, that's kind of scary, I totally get that. But if they understood the storyline of what they should expect in each of these chapters, it actually gives them a lot of relief. Because they can know that they are in a stable part, they can spend more on the hoping rather than the planning, you know, and not so worried so much about is it getting worse because they actually know what to expect what to look for. And they can be more in the present. So these chapters in the storyline are another piece. It's not only about the amount of time.

**Dr. Bill Evans** 28:04

Not, I don't think we actually have said the name of your book, although you said it an answer to a question hope for the best plan for the rest. And that's really the the walking to roads. And maybe in addition to the seven keys, we should tell the listeners how some of the chapters are structured, because it's quite interesting that you have real stories of real people, I presume these are actually from your personal experience, the names change and all that but the real people who have been either in the dark, or in the know when you contrast them in each of the chapters, and then you have something called conversation starters or which are really like prompts for patients or individuals or read this book, what you might say to your doctor, or what the conversation you might have with your family as you go through the journey. So I thought this is really helpful, how you've organized and maybe little elaborate on how you came to provide the stories and so on.

**Dr. Hsien Seow** 29:01

Yeah, I'll take this from Bill, if it's okay. The you know, with every chapter, we sort of explained the key like walking through it this hope for the best plan for the rest. And what we realized was it was really important to explain, why does this not happen already? There is this assumption, by healthcare systems implicit or explicit by patients and families to have, you know, that, that if you hope, if you force over the first key walk through roads, so the idea is, you know, if I start planning in the future, I'm sort of, you know, enticing it to happen, and that I'm betraying, you know, all the good wishes of people around me. But the reality and then we talked about, but the reality is hoping and planning can coexist, and doing so makes for a better, you know, outcomes for patients and families. So, then we tell a story about someone who was in the dark who didn't follow that and a real story of someone who's in the know of what the benefits are, and then we explain how to enact the key we don't just explain the key But we give every chapter three action steps of things they can do right away, to bring this key into their life. And, and do it right away because we don't want to wait. I mean, that's the idea that information is power. And it for not just for the person who eats it, but for everyone around them, it can increase their, their their quality of life, their satisfaction. And so we really tried to make it as practical as possible, because this is a how to book is isn't a memoir, it was really a Patient and Family Guide, so that they could get the best experience from day one, by having the most information as much as they want and at the right stage, but knowing that there is information to be had.

**Dr. Bill Evans** 30:43

So, as you said, it's very practical. And amongst those practical things, you have these conversation starters, as we were talking about zooming out and getting the big picture, like just quoting one here helped me understand the average timeline for someone with my illness. How long do people typically live with this illness? Very practical. And if patients ask those questions of their doctors, maybe the doctors need a little training about how to answer them. But they could describe a more effectively, what is the usual history of heart failure? What can you expect along the way of treatment and the ups and downs of it, and so on, and what timelines might went on. And I thought it was really interesting to that end of each of your chapters, you had this summary, the three key bullets that are the summary of the content that the readers gone through. So very, very practical. And then this moving on in the Keys is one called Know your style. And I guess another interesting feature of your book is that you're always start with a quote. So this one is the leopard never changes its spots. So you, we all have our individual styles, and how we deal with bad news, or how much information we want those sorts of things. And tell me a little bit more about your thinking. And in this particular chapter of knowing your style.

**Dr. Sammy Winemaker** 32:01

Yeah, well, it comes from a place of realizing that all of us have been through difficult times in our past, you probably can't find one person that's just had a completely smooth sailing life, whether they have, you know, been through a breakup of a relationship, or the end of a career or, you know, have been in trouble of some sort, you know, everyone's had their challenges. And as people, we have moved through those challenges in very individual and unique ways. We all have different personality styles, we all have characteristics about us that are unique to us. We have coping mechanisms that serve us well. And we have coping mechanisms that don't serve us well. This key is about harnessing all that information that we can know about ourselves by reflecting on how we have performed in the past, when we have gotten into difficult situations. And the reason for doing that is because if we acknowledge that, you know, maybe I'm the kind of person that puts blindfolds on, I'm not but I'm just pretending, you know, or I'm the kind of person that avoids conflict, or I'm the kind of person who doesn't like a lot of information. That chapter describes how those traits will serve you well, or not well as you move through a serious illness. And so it just allows someone to be more self aware about themselves. And the family members can do the same exercise, so that you can almost mix and match. If I'm the kind of person who's not very organized, then perhaps my daughter is very organized. And so I'm going to saddle up with her for that one. If I tend to avoid information. Well, my best friend is a Super Seeker of information. So bring her into my inner crew. So we shout out in that chapter. What are some of the qualities that fair? Well, and you may not have them all yourself. So you are to create a crew around you of your inner circle so that you have many of the qualities that will help you get through this biggest challenge perhaps of your life. So I think in healthcare, we don't really do that service we don't know are people at that level? Now family doctors who have had a longer term relationship with their patients and families might have a sense of The person's style and be able to warn them. You know, don't forget, last time we ran into trouble together, you started drinking heavily. So we're in another challenging situation. So let's talk about that. Or I know you surely surely you last time we ran into trouble, you actually hunkered down and you faced it straight on. So I have no doubt you're going to face this one straight on. So we can just use all of this personal style information to help change the experience of the illness, even though we can't change the illness itself.

**Dr. Hsien Seow** 35:38

And Bill, you know, the reason why I know your style is so important for your listeners, patients and families, in many ways it could have been the first key and this is why everybody's experience is different is because we're all unique individuals, it can, you know, there's so much anxiety, anxiety and stress when you're in these, you know, situations and decision points, that you're hoping that the patient, the person with the illness changes who they are, or you're just so frustrated, why don't they just do this, you know, some people take a long time to make decisions, and you're like, why can't they just make a decision. But if you really reflect and go, Well, this is the kind of person they've always been, you know, it just helps to, you know, check yourself that we're actually honoring who that person is, if we respect their wishes, we this helps us to think about their plans ahead of time. So we know what they would do in a situation like that, even if it's not what I would do, it's what they would do. And this is how they've always lived their life, this is what bring them brings them joy, then we can at least not, you know, we can still go through the journey, but be more supportive. And rather than fighting against people's nature. So this is just as important for knowing yourself, the patient, but knowing yourself, the family, and then how you work together as a team.

**Dr. Sammy Winemaker** 36:51

That's where the leopard doesn't change its spots, like people stay the same. This isn't about changing people, this is just about knowing yourself. So these kinds of traits we talked about, they stay constant through a person's life, I mean, we can change a little bit. Anyway, I was going to talk about how some people might not change at all. But you know, we can you know nip and tuck a little bit. But the leopard doesn't change its spots you are who you are, who you are, by what the age seven or something, Show me the child and I'll show you the man whatever that saying is.

**Dr. Bill Evans** 37:25

And of course, you're talking about the patient. But then as you refer to the inner crew, that group of people that are closest to you, they also don't change their spots, and they may have different attributes that may be complimentary, and hence the idea of kind of mixing and matching and finding the person who's well organized and keep you getting to your appointments and so on the person who likes collecting information can ask all the tough questions and and do the Googling and what have you so they have better understanding and provide you with that information as necessary. So, like this has been great. Let's take a brief break to hear a word from the Cancer Assistance Program and we'll be right back with Dr. Sammy winemaker and Dr. CNC out in a few minutes to talk further about this wonderful book. Hope for the best plan for the rest.

**Narrator** 38:13

We'd like to take a moment to thank our generous supporters, button Family Fund and Becca creative studio who helped make the cancer assist podcast possible. The Cancer Assistance Program is as busy as ever providing essential support to patients and their families. We remain committed to providing free services for patients in our community, including transportation and equipment loans, personal care and comfort items, parking and practical education. These services are made possible by the generosity of our donors through one time gifts, monthly donations, third party fundraising, corporate sponsorships and volunteer opportunities. Visit cancer assist.ca to see how you can make a difference in the lives of cancer patients and their families.

**Dr. Bill Evans** 38:57

So we're back with Dr. Sammy winemaker and doctors in Seattle talking about their new book, hope for the best plan for the rest, which is launching in a few days at the public library here in Hamilton. We'll talk more about how you can get this book at the end of the program. But we were talking before the break about your inner crew. And that assumes that you have a family friends around you to support you. But of course we know there are individuals who are living alone, maybe rather isolated. They're also homeless people get illnesses too. And they don't have an inner crew. So how do we help them in a system that seems fragmented and frankly, a bit broken? Yeah, it's

**Dr. Hsien Seow** 39:37

a really great question Bill about equity and access. And the reality is even people we call it an inner crew and not family because even people who are living on the streets, they have a street family, they they have people that they trust. It is rare to find someone who's really a hermit and isolated on some remote island. We live in communities and so If you're the kind of person who doesn't have a lot of support around you, maybe your kids live far away or you don't have kids, then that's all the more reason why you need to hope for the best and plan for the rest early on. Because the more time you have, that is giving you the opportunity to tap into community resources, like the cancer assist program, and, or Good Shepherd, or other, or, you know, other services in the community faith groups that are there to, you know, to support you and communities have come up. And we've seen this and COVID, where it's the communities, it's the families that have risen up to fill in the gaps, and we were always going to have an imperfect health care system. And so you still have to live and for today, you're going to tap into the things around you. And there are groups for different immigrant groups, or LGBTQ plus. So there are so many community services, but knowing that this is who you are. And these are, this is what you start with the assets that you start with, and nobody has nothing, okay, so we all have something. And we all make choices of how we want to surround ourselves with and who we want to let in. But if your story and how you want it to play out, involves more people in connection, then start to make those plans now and start to look for those resources early. And the cancer assist program is a perfect example. Because there are so many things that you just didn't know you didn't know. And so don't wait. That's why we don't want people to be at the end and then go well, everything is falling apart. I'm overwhelmed now to look for supports, sometimes that's too late.

**Dr. Bill Evans** 41:37

That's a really good message for people to hear. And thank you for that. Thank you for the plug for the Cancer Assistance Program, too. But no, it's in reality. People don't know what they don't know when by signaling what they have and what they need. Others can direct them to the things that exist out there, that would be helpful. And that's partly what this program is about to we've talked to people and in the various supportive roles in this community to try and heighten awareness of the public of the resources that are available to them. Well, this is going back to your book, then. I think your fourth key was called customize your order, which is an interesting title. But it starts off with a quote from Aristotle, knowing yourself is the beginning of all wisdom. It's a good quote. And so it has to do with tailoring your care plan. And what do you mean by that? How does one get to tailor the care plan? Some people would just say, well, the doctors said I should do this. And I I just do it because they think it's the right thing for me to do. I don't know, what's the answer?

**Dr. Sammy Winemaker** 42:40

Well, okay, the analogy I think about is when, for example, someone belongs or goes to a private school. And when someone goes to a private school, they might have to wear a school uniform. And so everyone has to wear the school uniform. But as I'm driving down the street, and I see all the private school people going to school, you can see that they have nipped and tucked and individualized, they're very standard uniform, and so that it can help identify their personality and who they are and differentiate them. When I apply that analogy to the healthcare system, I think at the health care system as a conveyor belt of standard care of best practice that we've decided in the health care system, it's meant to be efficient, and to help the majority of people. And so, as a medical system, we're more comfortable with people who step on to the conveyor belt and just go, it's easier to take care of someone who just gets on the conveyor belt and says, yes, yes, yes. To everything that's offered or not offered to them. So what we want people to understand, in, in this key called customize your order, is that although you cannot demand everything that you want, you can't say I insist on this, and I and I insist on that and, and I'm you know, I, I am not going to, you know, leave the hospital like you. There's only so much you can do. It's not a carte blanche. But what we want people to do in this key is to reflect on again themselves, what they value, what's important to them. What gives them meaning, almost like their Terms of Reference, or their resume or curriculum vitae, like what are the most important things about me that I need to bring forward in my healthcare journey, and let the healthcare providers know about me, the things that At, or the most important, like, I might say, Dr. Evans, I want you to know, as your new patient with cancer, that as we go through this journey together, it's really important for me to maintain my sense of independence. So if anything we decide together is going to chip away at that just can we keep that in mind as we're deciding together. Or they might say, Dr. Evans as your new cancer patient, I want you to know that it's important to me to spend as much time at home, I want to be with my family. So as we move along, if there's anything about this journey that's going to take me away from my family, or someone might say, it's important for me to stay mentally clear. And so if anything, is going to cause my mental sharpness to be dolt, then so these are that nipping and tucking of the school uniform that we want people to bring forward and to also think about what they would be willing to trade off. So we're all of these things are important, I might be willing to trade off, you know, an extra three months of life for being able to be at home, I'm going to favor quality of life instead of quantity of life. So we're teaching people to take stock of what they value, what they want to hold on to, and the things that they're willing to trade off as they go through their journey, and to make sure they share that with their inner crew, and their healthcare providers and not wait to be asked. So you can get on the conveyor belt, but you're allowed to press pause once in a while.

**Dr. Bill Evans** 46:47

So this is a variation on personalized medicine cept. It's personalized care, we talk a lot about personalized medicine, because we're making more and more decisions for treatments based on molecular abnormalities. And it may be called lung cancer, but you have this genetic change or mutation, you have a different one. And then the treatments are different. So as a personalized medicine, you're talking about personalizing the care, which is a beautiful extension of what we're doing and and weds together sort of science with values, right to, to really change how we think about it from the patient perspective, we've got to get physicians to think about it that way as well, because there are those trade offs. The fifth line of chemotherapy for lung cancer versus better quality of life.

**Dr. Sammy Winemaker** 47:35

Yeah, no, I love that. We do warn people that the more you want to customize your order, the more you might be met with some pushback from the system. It's not easy, especially when the medical and healthcare system likes efficiency, and likes standardization, and likes the conveyor belt. So we're not in sync that way. But we are encouraging people to persist, because if enough people begin to respectfully demand that they can make these kinds of decisions, even if the healthcare provider thinks it's the wrong or bad decision. Generally, it might be still something we have to live with, that the patient has chosen. So I meet lots of people who customize their order currently. And they often tell me, you know, I feel like my team is mad at me that the medical team is mad at me. And every time I go, they tried to convince me to take this androgen deprivation therapy for my prostate cancer, they say it could actually cure my or extend my prostate cancer for many, many years. But I'm choosing not to do it because I don't want to be on that therapy. i It's not something I ever was part of the way I live my life i i only use very natural products, and it makes me feel a certain way. And I've made a decision, an informed decision not to go on it. So it's about people making decisions, but making sure that they have all the information they need to make their individual decision, whether we in healthcare think it's a good one or not. Our responsibility is just to make sure that they have the info they need to customize their order to make a truly informed decision and then we have to live with it. But we shouldn't do is just cut them off. Because the patient I'm talking about felt that he was no longer invited to be followed at, for example, this particular cancer center and because he wouldn't agree to the treatment, so we can't withhold or take away support and care for a patient just because they don't want what we have to offer them. They still need us wrapped around them.

**Dr. Bill Evans** 50:00

Right, you had some great expressions later in the book about how you should communicate, you touched on one of them respectfully assert of like the one gently fierce, and then just persist. And I think that's what a lot of patients are very hesitant to do, you know, because of just what you describe the feel like the team is going to be opposed to their ideas and, and that they're going to be treated differently label. This is a difficult patient. And, you know, like the

**Dr. Sammy Winemaker** 50:33

Seinfeld episode with Elaine, she went to the doctor. And she was convinced they wrote something about her in the chart. And she was obsessed with, you know, seeing what they wrote, like difficult patients.

**Dr. Hsien Seow** 50:45

I mean, the truth is, you know, we can't control what people's impressions of us are. But customizing your order is exactly what Sammy said, thinking about your values, goals. But then the other key part is to bring it forward. And the more that you can we coach, patients in the book with a little prompts to say, Doc, this is who I am, this is what you need to know about me, to provide me the most personalized care, this is important to me. And that can include things like your culture, your religion, your beliefs, your spiritual practices, that's all ways that we can, you know, try to improve upon the health inequity we have in our system is by making those explicit and bringing that forward. Because the more the health care team knows about who you are in what's important to you, the more that they can feel like they're honoring what it is that you want, and you're making informed consent, which is really what they want, they want to make sure that you have the full information. So you can make the best choices. Of course, they want to extend your life and the quality of your life. But at the end of the day, we all make choices about what we're willing to do to do that, you know, I know I'm supposed to be exercising seven times a day, and I'm fighting to do one hour a week. But you know, that's a choice. And I'm making, but we all make different choices. But I think we need to let our healthcare team know who we are as people and put the humanity back in health care. And that's missing. And that's the onus on that is also on the patients and families to bring that forward to help your team learn about you. And what's important to you.

**Dr. Bill Evans** 52:15

I guess I also feel that the onus would be on the professionals to draw that out of their patients or notable families too. And I don't think that's that's the missing piece. You know, it's partly because of the conveyor belt and the speed and the efficiency all the things you've been talking about.

**Dr. Sammy Winemaker** 52:28

And, and often people will say, you know, we just don't have the time to do that we are always in a crunch and healthcare. Some students when they come and see a home visit with me will say to me afterwards, Dr. Winemaker, how will they call me Sammy, but how can you expect everyone in healthcare to spend 60 or 90 minutes? And I say, Well, I've got an answer for everything, Bill. But I do say, you know, the reason why I have to spend this much time is because no one's done it. And so if we, again, chip away, or the nice way of saying invite these types of conversations just a little bit at a time over an illness journey, it never has to derail the appointment, or take that long. So I'm cleaning up, they should have

**Dr. Bill Evans** 53:17

been done earlier, in small little chunks along the way. And that wouldn't have been necessary for you to have the 90 minutes with a patient at the end necessarily. All right, well, there's there's more keys we have to get through here. So let's move on to anticipating ripple effects. And this is really sort of parallel effects going on amongst others around you. As you go along your journey as a patient. And particularly focusing on caregivers and one of the statistics in your book that actually surprised me. I had no idea. One in four Canadians are currently caregivers. And that almost half will be a caregiver at some time. That's, that's extraordinary. I hadn't really hadn't thought about it. And it shows how much I guess we transfer from healthcare system onto people outside of it, that piece of people closest to patients a lot of care delivery, don't we? So what are some of those ripple effects that you talked about in the book?

**Dr. Sammy Winemaker** 54:17

Well, this is about shining light on the people around the patient with the illness, the person with the illness, so they get the spotlight, but we need to broaden that light to see who's in the shadows. And unless you're living your life completely on your own. Usually there's a couple people if not more, that are experiencing your illness in parallel to you. So it's almost like a team sport when you have a serious progressive, life limiting illness. That there are people around you who are involved in your story want to help you but they're also having their own illness experiences vicariously so So if I get an illness, my husband's going to have my illness experience, but his own experience as he moves through my journey. And so the ripple effect is when someone has a diagnosis, like when you drop a rock in the water and you look at the concentric rings, the there are people in your life who are going to be affected by this illness. And we need to just be honest and frank about that at the beginning and not wait for these people to suffer in silence. They often will describe feeling invisible, they are treated like they are just lovely chauffeurs that have brought the patient to the clinic. They are a massive source of Intel, the inner crew or the family or friends, they can tell bring forward to the visits information that would be important for the healthcare system to know about, about how things are going outside of the healthcare system. And they also have their own storyline going on so should be encouraged to check in with their health care provider. Because often the key to people staying at home and being as well as possible for as long as possible at home, rests on the shoulders of their untrained unprofessional care team also called their family or chosen family when I do home visits, and don't get me started on the fact that we don't expose doctors in their training to home visits, you can't believe what families are shouldering at home. And so they truly are part of the unit of care. And it's just a fact. And again, we do not want to shine light on them when they're already in a crisis at the deeper stages of an illness. So this is about acknowledging who's in your inner circle, how this is going to affect them. And just preparing again earlier on for their parallel journey.

**Dr. Bill Evans** 57:06

Know it resonates with me, it's been a more recent learning experience. As a physician, and oncologist in my career, you know, you spend a few minutes relative, relatively speaking in the clinic room seeing someone and hearing how things are going and often you get a rosy picture because patients want to tell you what's going on right doc? Then I went on to the body that reviews new drugs and part of the decision making process for new drugs is to get input from patients about the lived experience of their disease. It was actually very eye opening to hear how burdensome it was to live with these diseases and the impacts on families and so on. And as I say it was eye opening to me and I think physicians as a group don't have a real appreciation of the burdens carried by both the patient protecting the patient, but also those around. And there's a real risk of burnout amongst a family members. And you list in the book, the signs of burnout, the irritability, insomnia, loss of appetite, loss of weight, lack of compassion, a variety of different things of the constant stress of trying to care for someone who's, who's ill. And I guess part of the solution to that is just as it takes a village to raise a child, he talks about a village to provide care for someone who's ill is you described it in the book, I think there's all you know, really wise comments about being alert to you know, yourself if you're a care provider. But even for the care person who's being cared for to be a bit observant, it's more responsibility for them, I guess. They're the one with the burden of the illness, but still they have see in their spouse or in their daughter, son whatever, that there may be struggling a lot and have to give some that are direct them to some help or to signal that they need to back off and take some rest or look after themselves better etc.

**Dr. Sammy Winemaker** 59:10

and natural style of caregivers is to put their own needs aside, and to dive into caring for the one with the illness. And then the person with the illness will see that struggle in their family and their care provider. And it will contribute to their feelings of being a burden on their family. So we get this dynamic happening and we end and we end up with more than one patient quite frankly. So it is really important to keep our informal care team as healthy as possible for themselves as survivors if the person ends up passing away, but also because they are enacting all the care at home. So if you're in the hospital and you say Send someone home with a medication regimen that requires, you know, start, you know home hydration and give this medication every two hours. And, you know, we want to give suppositories so that they have a bowel movement every day. We don't appreciate that when the person gets home, it is the untrained family that is managing all of those things. And they didn't interview to be a caregiver, they became a caregiver because of circumstances, and they weren't aware of what it was going to entail or change over time, their role. So they may still also be trying to work. They're also doing daycare for their grandkids. They they keep everything on their plate and add the person's illness and their caregiver role onto the plate without knowing they need to clear the plate to become this role as a caregiver, or sometimes say, I don't think I'm that person. I love you. And I mean, your inner crew. And but I'm not that primary caregiver. So we need to find someone else.

**Dr. Hsien Seow** 1:01:09

And that's the practical tips we offer in this chapter is about knowing the job description, having an explicit conversation of, you know, what jobs are you asking me to do, and am I the right person for it, and if not, let's find other people who would be willing to help that we just didn't think we needed to ask. And this will change over time. And it can ebb and flow. But it's where we run into challenges is when we never have that conversation. And all the tasks are by the primary caregiver, the spouse or the you know, the child. And there's never this opportunity to say you know what I need to step away. And the patient recognizing that this is a big, big job, if, especially if the illness sort of is getting deeper and deeper into the story, to allow them and encourage them to have the small sips of self care or breaks because that is what sustains people over the long term is being able to have just some moments to themselves, where they can, you know, run errands, but also just be away from that constant vigilance of being, you know, the perfect caregiver,

**Dr. Bill Evans** 1:02:11

really, really important points to make. And I'm sure there are listeners out there who are in that role right now and take heed, you know, don't get burned out, you're no good to the person you're trying to support. If you become ill yourself, it's really important for people to be aware of it. Your sixth key is called connect the dots. And see, I imagine this is probably a lot about you. Because you know, when you've studied a lot about the healthcare system organization, and how palliative care can be better, integrated, and so on. I think there's an assumption by patients until they get into the system or have their first illness that the things are coordinated and easy to navigate well, and it's far from it, isn't it? And it's it's actually an extraordinarily complex thing to move through a journey and in the healthcare system, because we should put quotes around system because it's a non system, frankly, trying to become a system that not doing a bang up job of it yet.

**Dr. Hsien Seow** 1:03:09

Yeah, I mean, I think it's the assumption, you're exactly right, the assumption is that everybody talks to each other, and we're all working as one unit. But in reality, all healthcare is different individual organizations and providers, you know, and all of them trying to figure out their role, but not knowing exactly who are all the players. And so connect the dots is really the flag that someone in your crew, either the patient or the family or a combination need to be have some role in keeping track of all the information so that whenever they get transitioned to another setting, or meet a new provider, they can give them the you know, the three page summary of what's happened, and, you know, make an continue to keep track of all the little changes that are happening. Because as we've been talking about the people in the home, the family, the patient, they know what's happening the most. And it's they have really important information and how to bring that forward. And so there's never going to be a perfect system where you have no role and in tracking information. And, and sharing that because you they are the glue, you are the glue your story, your life, the decisions, you are the glue that brings these pieces together. And so that's a key piece. I mean, in the book, I talk about tips of how they can do that. And it isn't just medical information. It's the the quality of life information. It's the how things are changing what you're noticing those gut feelings about, you know, there's something odd about this and that those are really important to bring forward as well.

**Dr. Bill Evans** 1:04:43

Which leads a bit too into the final key which is invite yourself. We've talked about it already a bit but it there's a lot of information that the caregiver could pick up family members could pick up the patient and pick up but if they don't invite themselves into the company especially with the healthcare system, healthcare professionals, and it's all for naught right. And so you have to be the squeaky wheel. As the chapter begins with it's the squeaky wheel gets the oil. And you have to raise those topics and, and we talked about that already a little bit. But it's hard for many patients to do that they're intimidated by the white coat, the professionals that the experts assume they should just be passive and accept what's being told to them and what's being done to them. And you really make a call out for patients to to be gently fierce and persist and so on. And and I guess the frustration you feel to my voice right now is, how do we do that, because he can tell people, You should do that. But it may not be in their character. And I think there's such a power imbalance between patients and their physicians and the health care team that it doesn't feel like an easy thing to do.

**Dr. Sammy Winemaker** 1:06:04

But they need to. And because as we said, at the very beginning, we've come full circle now that the passive patient will get nowhere and be, for lack of better words, spit out at the end of a journey, and not recognize themselves and be very scared. There is a huge power differential between healthcare provider patients and family and it is going to be uncomfortable for the first people who take us up on it, and decide they're going to move from the backseat of the car into the front seat or the passenger seat. They might be met with, as we said before, some resistance or discomfort from the healthcare system. But we are asking people to find their voice to to understand that no question is a bad question that whatever is on their mind is important. You know, being able to address these things is as important therapy for them as it is their medicine. So we're encouraging people to speak up. Those who speak up get more information, those who get more information will feel more grounded throughout their illness. And that's the bottom line. So that key is really important. But you're right, some people will not be able to do it. And so that's the whole point is to make sure that you have someone with you, who's going to have more hutzpah, let's just say or be able to be gently fierce or respectfully assertive. Again, the leopard doesn't change its spots. If you're if you don't tend to be that way, we just want you to realize that you need someone on your side who's going to be that way. It doesn't mean being rude. It doesn't mean being disrespectful. It means being respectfully assertive, or gently fierce.

**Dr. Bill Evans** 1:07:55

You know, this is probably a good place to stop that. But I want to say to the listeners, there's so much more in this book, it's worth the read to get all the practical stories of individuals are in the dark, and those who come out of the dark if you will, and and assert themselves in this gently fierce way. And there's more in the book too, about putting it all together. And there's a final chapter that speaks to the how the seven keys can be blended, how it's a bit of a mix and match. And also how various communities like marginalized communities, the LGBT community, and so on, and deal with an illness. And so there's much more here. And then there's a final two chapters that I'd like to have you come back and talk about, because it's really about end of life care. So we'll plan to do that again. But let's just wrap it up now and just say this has been a great conversation. I love listening to the two of you have so much to impart. And I really would encourage listeners to get this book and maybe a question how are they going to get this book? Where is it going to be available? How can they get a copy?

**Dr. Hsien Seow** 1:09:04

Yeah, it will be available in every bookstore across Canada around the world actually. And of course on your online books, however you get your books, it will be there in paperback in E copy and an audio book.

**Dr. Bill Evans** 1:09:16

Wow. So no excuses for not reading the book called hope for the best plan for the rest. Seven keys for navigating a life changing diagnosis by Dr. Sammy Winemaker and Dr. Hsien Seow. So great to have you too in the studio with us. Thank you so much. And I'm sure the listeners are really going to appreciate hearing this podcast but even more importantly, reading your book. All the best to the two of you.

**Dr. Sammy Winemaker** 1:09:40

Well, Bill, welcome to the Waiting Room Revolution. Thank you. Thanks for having us. My pleasure.

**Narrator** 1:09:50

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