**Patient-Centered Care for a Better Treatment Journey**

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**SPEAKERS**

Victoria Chambers, Angela Djuric-Paulin, Dr. Bill Evans

**Dr. Bill Evans** 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.

**Dr. Bill Evans** 00:14

Help when you really need it.

**Dr. Bill Evans** 00:17

Well, welcome to the cancer says podcast with your host, Dr. Bill Evans. Today we're going to talk about patient centered care and resources for patient particularly informational resources with our two guests, Angela Gerrish, Pollan and Victoria chambers. Welcome ladies. Just before I start the conversation with you, I did want to remind our listeners at the Cancer Assist Podcast is brought to you by the Cancer Assistance Program based here in Hamilton, Ontario. The Cancer Assistance Program provides a variety of free services to cancer patients, including free rides, equipment, loans, nutritional incontinence supplies amongst a whole lot of other supports for cancer patients. And these podcasts are made possible by donations from individuals in our community, with the hope that you as you learn more about cancer and its causes current best treatment approaches, and the supports that are available in our community, it will make the challenge of dealing with cancer just a little easier. So we're gonna start with you Angela about patient centered care. Now, as an oncologist, I would have said, through the years that I practiced and saw patients in the clinic, I practice patient centered care, what's this business of patient centered care? How is it different than what maybe doctors think it is? What are the dimensions of patient care, centered care that we're considering now that had been overlooked in the past?

**Angela Djuric-Paulin** 01:38

Thanks for the opportunity to explain what patient centered care is. So a part of the role that we have within the Regional Cancer Program and Ontario Health was looking at how do we really truly bring the patient to the center of care, we talk about patient centered care. And as you said, Everybody makes the assumption we're doing it. But there's so many different avenues and streams where we need to look at so part of that is looking at the symptom management of a patient. So coming in for treatment, and the focus of the clinical team is the the assessment the treatment, how to get patients best possible care. But along that line, we look at the stream of their symptoms, and how are they managing those symptoms, and, you know, are they able to manage day to day and function was good quality of life while they are receiving their treatment. Another component of that is looking at their psychosocial opportunities and supports and services available. So as we think about the emotional support, so again, symptoms support, emotional support, nutritional support, family support. And then another stream comes with the education component, so ensuring that there is resources that will support individuals and their families across the journey. So do they have the patient education material that helps them to go back and re review the information they received in a clinical visit? Was there an opportunity if they needed to call somebody can can they go back to a document, an information sheet that will allow them to know who they need to call what information is important. And so it's really putting the focus on almost like a hub and spoke model. So the patient's at the center of the care. And then there's so many different areas and aspects of that care, that go beyond the clinical treatments, you know, the medications, the radiation, a patient showing up for their chemo appointment or taking their chemo medications orally at home, what supports and services do they need for that component. So

**Dr. Bill Evans** 03:44

it's a lot broader than what most clinicians have time for in a busy clinic visit. And let's face it, usually the patient's seeing the doctor for a few minutes. So touching on all those different aspects would be extraordinarily hard while trying to manage the complexities of modern cancer treatment. Right? Its care has become so much more challenging to deliver. So I think the technical aspects are probably managed very well, but less awareness of how the patient's actually coping with the illness, how the caregiver is coping with the illness what, what the symptoms are and how they've been changing over time. So all of that's tremendously important. And then how well they understand their disease. And, and one of the previous podcasts we did when we're talking about the book, what's it called, it's planned for the plan for the best hope for the best plan for the rest of their we got it. It really was patient having a good understanding of the illness, so that they're much more prepared to make appropriate decisions for their own care. And so, Victoria, you run the patient Resource Center, and we'll call it a library because maybe that's makes it clear to people exactly We what's happening? So resourcing people with evidence based information is really rather important so that they can make good decisions with their doctors, right?

**Victoria Chambers** 05:12

Oh, it definitely is. I mean, that is just one of the questions that I get. There's just so don't show wide variety of questions that people have. I get people coming into the library who have first been diagnosed and are looking for information, you know, they've never heard of this particular type of cancer before. And then also people who perhaps might have a second occurrence, or someone who has been coming in for years, but looking for information, like we, previous person that you've interviewed, one of the child life specialists that we have. So people are looking for information about talking to their children about cancer. Also, caregiving as you touched upon Dr. Evans, so we provide resources such as we have a full lending library. So that means lots of books, CDs, DVDs, on not only particular types of cancer, but things surrounding caregiving. Talking to children, we have children's storybooks, another popular topic is people are wondering what they should be eating while undergoing treatments, or nutrition. books or recipe books are very, very popular. I try and keep that collection up to date. I'm always looking for the latest publication. But I'm also adding new books such as the one you just mentioned, hoped for the best current topics, obviously, around cancer.

**Dr. Bill Evans** 06:37

So quite a wide variety of media in order to meet the various needs. But I guess one of the challenges is people come with different levels of we'll call it health literacy, or maybe just depending on their educational background, some people would expect very sophisticated information, some people wouldn't really know what a cancer is to start with. And I must be one of the challenges to meet them where they are in their ability to understand and based on what medication they have, and and, you know, prior experiences. How do you how do you manage that piece?

**Victoria Chambers** 07:14

Definitely. It's coincidentally, October is Health Literacy Month. So it's fortunate that you mentioned it. We're fortunate to live in such a day and age where I'll give an example. I had a patient come in and she had trouble with reading her reading level of literacy levels. And so she admitted that to me, and I found some information, a video about leukemia for her online and she was able to listen to it in our library, we have three public access computers, in addition to all the books and resources. So I was able to play the video for her and she was better able to understand her diagnosis, the possible treatments. I also have been asked numerous times for resources in other languages, Korean just being the latest example. And so I access all the various websites, I make phone calls. Fortunately, there are a number of, of resources in other languages these days. So we're very lucky to have those

**Dr. Bill Evans** 08:17

really thought about that. But as soon as you say it, it's so obvious, isn't it that we're such a pluralistic society that you've got to deal with people from all sorts of nations and immigrants to the to the areas who may have the different language in which to provide the information. And so that makes your job a tad more complicated. I think

**Victoria Chambers** 08:38

it does. But once you've been asked, you know about a certain language, I've kind of put together a bookmark my favorites, and there's, you know, a number of different sources. So it's wonderful to have that at my fingertips. And then like, oh, you know, I do have this lung cancer information in Chinese here. You got her Mandarin or you know,

**Dr. Bill Evans** 08:52

excellent. Great to know. And, Angela, your role is regional. So as we're talking about person centered care. There's multiple other institutions in our region. And so, how do you how are you trying to evolve patient centered care and Branford and St. Catharines and Burlington a Joe Brant and those other organizations are part of the regional network?

**Angela Djuric-Paulin** 09:18

Thanks. Great, great question. And we're always looking for that opportunity. We work very closely with our our partners within our regional programs. So as you mentioned, we've got branch St. Joseph Brant, Brent community, Walker cancer family, as well as the German ski Cancer Center. We have what we call a person centered care collaborative program. And we meet every other month with our regional managers, the directors, our patient, family advisors are a part of that committee as well as our psychosocial team. And within the program, we discuss key key areas where we'd like to see advancements. So as we're working on education development, our patients are flowing through each of these areas, some may start at one of the cancer programs and end up at another facility. And we want to make sure that the education resources are available at both consistently. Symptom Management is one key area that we've worked very closely with our regional partners to develop and enhance, and sharing education that's developed, we may develop it at one site, do some testing and trialing. And then we work with our regional partners to then spread that information across. We also look to see where there's opportunities to enhance as part of the patient education component, a lot of education is developed in house. So as Victoria was saying a lot of the information a validated we have information, the in house education resources are critical to ensure that they are easy to read, they are understandable. They provide direction and to support us with that work we use up the keys information is from our health care providers. And then we engage with our patients and families to review the information and let us know, were they able to understand it was it easy to read, if they had no knowledge of this illness or subject, would they now be able to manage their cell their symptoms, would they be able to manage knowing who to call or when they needed to seek additional medical information. So we're really fortunate that we have this program, and we've are looking to develop a pilot where we can standardize it across the cancer program, and hopefully across actually the whole organization of Hamilton Health Sciences. So it's a it's a very new pilot, and we're excited it is at the Cancer Program. We have nine patients and family advisors who are supporting this work and Victoria myself, as well as a sandy and Lisa, two of the librarians are kind of CO leading this work. But the drivers really are patients and family advisors.

**Dr. Bill Evans** 12:05

And there is a patient and family advisory committee have Cancer Center did the other sites also have so called P facts with patients providing input to the processes and each of the other sites the

**Angela Djuric-Paulin** 12:18

other sites do. However, they're not fully oncology focused, where's the patient family advisory council at the Children's Cancer Center is very oncology focused. And with that, we also have a few P fac members who are a part of different committees, from Walker family Cancer Center participating in regional programs and supports. Were looking to see how we engage more broadly with our community partners to expand so that it's not just a smaller, isolated group of our patient family advisors. So you know, we work closely with our patients, our community partners, but we need to figure out how to better engage with our community partners. So that's kind of one of our key initiatives moving forward this coming year.

**Dr. Bill Evans** 13:09

But to me, it's it's music to my ears because it's it's great to have a cancer center, like the Juravinski has a lot of expertise and so on. But if patients are being seen in other institutions around our region, and don't have access to the same levels of supports, of information and so on, seems to be having almost a two tiered system. And what you're obviously striving to do is to make sure everybody who goes because not all patients are going to come to the Juravinski and they may have their surgery done and and Joe Brenton that's all they needed and be followed by a medical college, their surgeon there and don't need any any time at the Juravinski so to speak, but they need to have the same kinds of sports and in education and psychosocial supports. What one of the challenges I recall was an implementing symptom assessment, so called E SAS, which stood for the Edmonton symptom assessment, scale or system officially published as the system. I think you're calling it Your voice matters now which symptoms

**Angela Djuric-Paulin** 14:11

are your symptoms? matters? Yeah,

**Dr. Bill Evans** 14:14

yes, yeah. It's I think that was more understandable to patients than ESA. It was a challenge, I think to get patients to routinely complete them and maybe a bit of a challenge for doctors to look at them to and how is that ongoing? Because it seems to me, I can just say, I'll confess that as among college, I was really surprised to see the level of psychological distress and lung cancer patients that I did not appreciate. Through my years of practice. I really didn't and I just say this I love for physicians to take it much more seriously because they might be surprised. Patients often put on a better face in the clinic than what they're feeling and acting at home right and they don't want their doctor is to feel that the treatments not working. So they sound upbeat when maybe they're severely depressed. And we could be doing more to help them. So are you making gains on getting patients to complete them? Or is that still the challenge

**Angela Djuric-Paulin** 15:21

it's still a challenge, we have our ebb and flows where we seem to be really gaining momentum there. And then like everything, unexpected things happen within healthcare systems and teams, most recently with the pandemic. So, within our Regional Cancer Program across prior to the pandemic, we were seeing 70 to 75% of our patients completing their symptom screening assessment prior to coming into their clinic, the pandemic came into our world and things had to change. And so access to the equipment was something that was a concern for infection control. So the onsite devices were shut down. And patients weren't able to access that information Ontario Health was instrumental during that time and created what was called a home channel. And it was a link that allowed patients to complete it from their own personal devices, a cell phone with data, you would be able to open up the link and be able to go directly to the symptom screening assessment. Now you're using your own device. And again, education communication, getting that information out across both the clinical teams as well as our regional partners, patients and families. So we did see a gain and momentum shortly after the implementation of the new link. And then as with everything, some more challenges along the way, new electronic health record put in place to enhance access and communication across the program. Clinicians are rightly needed to focus on being able to manage that system, treat patients. And so now we are back into a point where we are stable with that. And that ability, everybody's comfortable with the new system. And we are really looking at how do we strategize to engage with the patients and families to start making sure that's a part of the process. And it's really important that it's seen as a part of a check in process. So a patient is coming to a clinical visit. They're not only bringing their health card, they're bringing their medications, and they're completing their symptom assessment. It's a great tool that allows the communication and the language to be consistent. So if a patient is talking about how they're feeling around their their appetite, or they're being not nauseated, having difficulty with shortness of breath, their clinical team is using the same language, the patient is using the same language. And now you're ensuring that everybody is really communicating effectively, it's a great opportunity to see any changes and small changes, to be able to trend for the clinical team, and to be able to add interventions earlier. And that is really the most important component of doing it. It's, you know, patients will say I have no symptoms, and I'm doing great, why am I doing this every single time. But the minute that there is a change, the healthcare team is able to see it and and have a further conversation around it. And there's so many things in such a short period of time that the clinical team is accomplishing with the patient and family, you know, talking about their treatment, answering any questions that they may have planning the next steps of their care, it allows the opportunity to to focus in and say, wait a sec, I noticed that you mentioned you're really tired, you, you know your score has changed. Let's talk about that. What can we do to support what information? Is there an opportunity that, you know, we can give you some tools that will assist and help you so it really is an opportunity to allow the patient to focus in on what's important to them for that, that that appointment and that time, while the clinician is also focusing in on what's important to move the patient through their care. And

**Dr. Bill Evans** 19:24

are the this is a blunt question. But are the doctors and nurses taking note of the the use is scores all the time? Or are we still challenged a bit in terms of how they use that information? So

**Angela Djuric-Paulin** 19:41

they're like everything with a system. There's challenges with the new electronic health record, one of the benefits is that the your symptom assessment has been built into one of the flow sheets that the nurses go through. So if a patient actually hasn't completed it as a part of the assessment And then the conversation, the nurses will go through that. Not every clinical encounter will have a nurse with the patient. So there's the opportunity for the physicians to then further engage and reviewing and seeing if it's been completed, if it hasn't been completed, again, being mindful of the time and the period of going through because clinicians are great at doing their assessments and looking at, at, at the end discussing symptoms, it's a perfect opportunity for the clinicians to provide a bit of education. So the patients are aware, and the importance and the value for the next time that they come into their their clinical appointment. So it really is a constant conversation. It's not one one and done. It is every time you're coming into the clinic visit, asking, checking, validating, and really reconstructing a patient and really showing them how important it is. So it's asking, appreciating and acknowledging. And I think those are the three key things if all of the healthcare team remembers to do, it will engage with the patients and their families, you ask about it, you acknowledge it, and you discuss it. So I

**Dr. Bill Evans** 21:12

think it's terribly important. And I that's why I'm sort of belaboring this point in for his listeners, particularly for your patients, it's, it's so important to complete that assessment each time because those little changes can dictate how your your therapy might need to be adjusted, or other things introduced that would help you along that journey. So I know that there's a certain fatigue that happens when you've been doing it for a while. And it's just something we want to see the culture change within the cancer center so that it's just part of the regular rhythm of doing things so that we can do the best job for the patients and back to being patient centered, right. So you mentioned how COVID, in the pandemic impacted, I'm sure it's impacted the delivery of information resources, because I imagine people weren't coming into the library to get hard copies of it printouts or books or whatever. So how did you adapt Victoria, to the provision of information resources during the pandemic?

**Victoria Chambers** 22:16

Well, luckily, I was proud, I'm proud to say that we were only close for a couple of months, and then we reopen the library. So I just undertook a lot of infection control measures. So any books that were borrowed, we made sure to sanitize them for putting them back on the shelf, there was a bit of a quarantine period like of a day or two and then wiping them down and putting them back paper resources, we had the rule if you know they were picked up, then please take them or recycle them, you know, don't put them back down. We whereas normally, we would encourage people to sit down linger, perhaps spend some time we just had an in and out policy, we were limited to, you know two people at a time, that sort of thing. Luckily, that's over with but during COVID, I did receive more emails, I would say phone calls. And for the most part, I would say 85% I see people in person. But during COVID Yes, there were more email requests, as well as telephone calls. And luckily, in this day and age, I'm able to forward a lot of information online, definitely. For the most part, people do have an email address that I'm able to forward the the information,

**Angela Djuric-Paulin** 23:27

I was going to say we should talk about the QR codes that we developed to support patients. So that was something that during the pandemic, and we continue to use, we developed QR codes to make it easier and accessible for patients. So they didn't need to, you know, type in a full length, they would be able to if they had access to a device, they could just scan a QR code, it would bring them up to information on the library, it would bring them up into information around survivorship. If there was discussion or request for palliative care, all of the resources that were available, identified by the communities. You know, so we weren't again, just looking in the Hamilton area, we were looking at our all of our partners so out to Niagara to our Burlington area, support some resources. And they became one of our staples. And now as we develop all of our patient education materials, we ensure that we've not only have the link, so it's accessible to patients, but we have included a QR code to make it easier. And not all patients we appreciate not all patients are, you know, technologically able to do it. They don't have the devices, but with the support so they can get paper or they've got the paper with these access codes that their family members. You know, it could be a grandchild of a sibling. Yes. Who would be able to help and support and then you know, that broadens that knowledge base because, you know, I've got this information but I Don't know how to access it, you're asking one of your family members. Now you're engaging in further conversation and education and knowledge spreading. So across. So anyone talked about the library QR codes that were developed. And

**Dr. Bill Evans** 25:10

maybe just even for those who don't know what a QR code is, it's those funny little squares with a black and white patterns on them that seem kind of random, that you put your phone to, and, and, and then up pops a link. And you click on that and you get taken to resources we're finding

**Angela Djuric-Paulin** 25:29

in a number of situations, through the Cancer Assistance Program, also on the hospital board that among a lot of people don't know what they are, and therefore we're not getting them as involved. So a little bit of education around QR codes is going to be necessary. I'm sure they're definitely the way of the future. But we got to bring everybody along with ours, because that was a concern that we had. So we literally right above it, provide directions, and with an explanation, what is a QR code? And how do I access this, again, because not everybody's comfortable using them. And we took the opportunity, we are really fortunate that we get some Co Op students periodically within the Patient Family Resource Center, the library, and we did take the opportunity to have our Co Op students support patients coming in with the symptom screening, because we developed a QR code there, as well as the patient education library information. So having our Co Op students educate patients spend time because they have the time to you know, meet and greet patients as they were coming in, talk a little bit about the symptom screening the library, and how to access a QR code, how to link into the hospital Wi Fi, if they didn't have date data, because the hospital put in free Wi Fi during the period of time or COVID, they still have free Wi Fi for guests. So not everybody has, you know data on their phone that they can use. So showing them how to access their data, and then link into the hospital systems data. So then they can pull up information. So again, it was looking at all of the steps that would be required. It's great to say, please do.

**Angela Djuric-Paulin** 27:12

But we needed to remember that not everybody is comfortable with technology. So how do we help and support and educate so that we can get patients comfortable and their family members comfortable with using it. And again, very much paper based still I know we talked about trying to get away from paper. But Victoria and I also appreciate how important paper is for our patients and families. So with the resource, they may do it electronically, but they like to have that piece of paper in hand.

**Dr. Bill Evans** 27:42

I understand perfectly. I'm one of those people. But it's it's really fortunate we have the technology because I don't really know how we might have got through the pandemic were it not for the various technologies that have been enablers, to continue to provide supports and educational materials, et cetera, et cetera. It really was fortunate that and can't forget, zoom, all the things that we've had to help us get through the pandemic. Like we're going to take a brief break now. And we'll be back to talk some more with Angela and Victoria about more of the supportive care measures that are available at the Juravinski and through the Regional Cancer Program. And we'll be right back.

**Dr. Bill Evans** 28:28

We'd like to take a moment to thank our generous supporters, button Family Fund and Benka creative studio who helped make the cancer assist podcast possible.

**Dr. Bill Evans** 28:36

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**Dr. Bill Evans** 29:10

Welcome back. We're talking to Angela Gerrish pollen and to Victoria chambers about various supports in our community. And at the Juravinski Cancer Center that really revolve around patient patient or person centered care, the educational support the symptom, assessment and support for the various symptoms cancer patients can have. And if we're doing it really well, I guess we'd have a lot of satisfied patients. And one thing we need to know is what are the patients think and how do we get that feedback? I know a lot of of centers have I guess all the Regional Cancer Centers have patient and family advisory committee so we get some direct feedback from a limited number of people then we're also trying to serve a patient population with satisfaction surveys and together there's a new survey tool that's been recovered from Ontario Health to measure patient satisfaction. Maybe you could tell us a bit about those things, Angela?

**Angela Djuric-Paulin** 30:08

Sure, absolutely. There's a patient feedback survey tool, it's called Your voice matters. It aligns with the your symptoms matters tool. So it's it is also done on the web based platform. And patients are able to provide feedback around their clinical appointments, their wait times, understanding the next steps, what were family involved, where it family engaged enough to be involved. And that's every 30 days. So when they're coming in for their appointments, every 30 days, they would be asked to complete this, it takes between three to five minutes. There's 14 questions. And it's an opportunity for them to share their feedback to let us know and let the clinical teams know how they're doing. Everybody strives to do their best, but as we know, there's always opportunity where we can improve. And it will allow teams to see where we do need to improve. Sometimes it's around our you know, wait times check in times. Sometimes, you know, especially during the pandemic, family members were limited so there wasn't as much engagement and inclusion there. And we're working really hard to get back to where we were before. And you know, things do change. But maybe there's an area where we need to focus a little more on our regional partners are involved with the Your voice matters. A two verse sites, the Joseph Brant site and Branford general site weren't using the Your voice matters. However, they will be launching it this fall. So all of our regional partners will be using this program and it's just a great opportunity doesn't take too much time. And it it just lets our clinical teams and our allied health know so you know, our our clerks, our healthcare aides, our dieticians know how things are going within the program.

**Dr. Bill Evans** 32:09

So how is the information from the surveys sort of distributed to staff who gets to see it? You mentioned a lot of frontline staff there that sometimes it's just management looks at us and berries that are so much it sounds like it's widely distributed such

**Angela Djuric-Paulin** 32:24

an important question. So a couple of really important pieces of information for both your symptoms matters and your voice matters, the information is all confidential. The Your Symptoms Matter information does go into the patient's electronic charts. So the information is is put right into the patient's chart. So the clinical teams have access to that information. It is all kept private and confidential. There's no concerns with privacy areas and issues around that Your Voice Matters is a bit different that information does not go to the patient chart, that information goes directly to Ontario health. And Ontario health then keeps that data very private, and brings it back to each of the the cancer programs. And it's called aggregate debt. So the information there is just if there's a question, so your wait time, you know, Were you satisfied with your wait time? Yes, no. And 100 people answer that question, that information would come back as a score, there would be no information as to what patient will leave that information. Absolutely none. And I think that's really important. And I know it's a concern, especially in this day and age was everything out there electronically, social media. And sometimes people are hesitant to complete that information for fear that the you know, if they were unsatisfied with the wait time, and they they may fear that this may go back to their clinical team. Now the clinical team knows that they were they were upset about the wait time. And the fear of it may impact the relationship or the care they received. So it's really important to stress, the information does not come back directly to the clinical team and that in any format that they would be able to say oh, so and so created that information. And it's just a way of knowing how you're doing. The symptom management, though, is different because that is a part of your care. And it's important for your health care team to know and understand how you are feeling and how you're doing

**Dr. Bill Evans** 34:32

right. Makes perfect sense. Thanks very reassuring that the information that is captured in the patient satisfaction surveys is anonymized and you're not identified. That's the, as you said aggregate data that's coming back to the center so they can see how in a general sense how the center is performing. Late times are becoming long which they're measuring anyway they'll know but that the patient's complaining then adds further weight so got to do something to you prove the problem. Victoria, we, we, there's something that you mentioned, I think about a Pathfinders series, which I gather sort of very specific to patients needs. Maybe you can kind of fill that out. So it's a little more understandable. least to me, of course.

**Victoria Chambers** 35:19

So Pathfinders are sort of like information guides. They're topic specific guides for reliable resources. They kind of act as a starting point for your information finding journey. So the Pathfinders that we have, I have over 40 of them, they are accessible on the Patient Family Resource Center webpage, which is accessible via the Hamilton Health Sciences website. And so, some Pathfinders are about different types of cancers. So breast cancer, colorectal cancer, head neck cancer. Other topics include things like cancer during the holidays, and how to manage genetics and cancer, sleep issues, sex, intimacy and cancer returning to work or life after cancer. So what they are the print guides that are available in the library at the Juravinski. The front page mentions books that we have on our shelves, and then the opposite side has reliable websites. So everyone's heard of Dr. Google going in and just typing a few keywords, but then some of the results can be alarming. You don't know if they're credible, if they're reliable current. So using these guides, these Pathfinders that we've created, you know, you're getting the most reliable information, the most current information, just a few to name a few, I would recommend if anything I'm gonna leave the listeners with is if you're, you know, diagnosed and you're looking for information, I would say, find the credible association or organization, if you've been diagnosed with ovarian cancer, go to ovarian cancer, Canada, if it's lung cancer, lung cancer, Canada. And those are the kinds of websites that are available on these Pathfinders now, hopefully has heard of the Canadian Cancer Society. And that's another one that I would recommend, you know, as well, just going there and just starting with a reliable source, and then maybe extending your search from there, but not just typing it into Google.

**Dr. Bill Evans** 37:16

Good advice. How many people are can you estimate of all cancer patients how many want that depth of information because some people are really hungry for information and others say, Doc, you You're, you're the educated person, you tell me what the best treatment is, and don't want to go searching for more information, you have any idea of what the distribution is of patients, but that's so

**Victoria Chambers** 37:41

true. But I would say I see the people who want the information, right, the people I think, who are not stepping into the library, the ones that being said, I've had a few people come in and just want the basics, perhaps they'll just leave with the Pathfinder, or one or two documents. And then I have the people who want 10 books on the subject and every single, you know, flyer that I have and then some they don't, you know, they might pass on to family members or something like that. So I would say for the most part, um, you know, 90% of the people who come in to the library want everything they can get their hands on about the topic, I also get just we spoke about caregiving earlier, I will get a lot of spouses, as well or, you know, siblings, parents who want information. So sometimes it's not necessarily the patient who wants the information, but it's a caregiver or a loved one who wants that information. And they're there the reader in the family, let's say I've joked with a number of wives just and I kind of can relate to them. And I say on the reader in the family and my husband, so you know, and so it's generally I get the readers who come in are the people the information, Houghton's, for lack of a better word?

**Dr. Bill Evans** 38:45

Well, the caregivers are often forgotten in the whole process in terms of their needs, some of which is information so they have a better understanding of what their spouse is going through where their partner is going through. But also they have specific needs because they're, they're burdened with an emotional burden to care for someone in the home, particularly if a person is not doing well and has a lot of physical and emotional needs themselves. So then the caregiver gets a burden passed on to them. So there must be in the patient and Resource Center, there must be sort of special information needs for caregivers, I would hope

**Victoria Chambers** 39:22

I do have an entire shelf. So the way that the library is organized, obviously our book collection organized by topic. And definitely we have a lot of caregiving books for for caregivers who come in, as well as I have a number of shelves, and I have an entire shelf dedicated to caregiving. So obviously the I have a caregiving Pathfinder, so they'll mention the websites that you could visit the books that are available to be borrowed, as well as things like there's the Ontario caregiver organization so I have their brochure. Other organizations for example, you know, Leukemia Lymphoma Society of Canada, myeloma, Canada, they have their own special Perfect kind of caregiver guides that I provide in print, if people are not able to go to the website and access them electronically

**Dr. Bill Evans** 40:07

sounds like you're very well resourced for caregivers. So maybe, maybe it's more an issue of making caregivers aware that within the patient Resource Center, there's a place for them as well to access to their needs. So that's great. And then you're launching into something Angeline gather a patient education series that's being planned or in motion. So where are you in that? And let's talk about that for a minute.

**Angela Djuric-Paulin** 40:34

Yeah, so we're going to be collaborating with the psychosocial oncology team, Dr. Karen Zang is taking the lead on this, and developing some patient education series that will be available online for some of the key topics, so nutritional support, psychosocial oncology. And so it will be a pilot, once it rolls out, we're hoping that it will be in place January, February. And with that work, our collaboration is ensuring that we have adequate resources within the Patient Family Resource Center at the Library, to support patients who are attending these sessions. And so that there's if they've got more questions, they're looking for more information, they'll be able to come into the library and find that so it'll be a great topic. And Dr. Sang would be a great person to have on the podcast to talk a little bit more about this. And we're very excited to be collaborating with her.

**Dr. Bill Evans** 41:32

So is she doing it with a group of patients? Or is it something she's preparing to, like a podcast or webinar? How is it going to work?

**Angela Djuric-Paulin** 41:42

Right now, it would be patients who are interested would sign up to participate in the session, it will be done most likely by zoom, I believe right now, unless the platform changes, and so that it will, you know, a larger audience, and there's, you know, with every resource, you have to look at ways to expand and be able to have as much information available to as many people as possible. So this is a way for key items and common topics that people patients, families are interested in to get at least some foundational information out. And then from there, you know, additional questions, and spending more time being able to answer those questions and support patients, but it's almost like starting a foundational conversation and providing direction. And that's that key, you know, what else? Where else do I go? What other information do I need? What are my gaps, where, you know, who can I talk to, and so, the collaboration with our the, our education department, as well as the psychosocial oncology team made great sense because it starts the conversation gives initial information, and then anything else that people are looking for, we'll be able to support with?

**Dr. Bill Evans** 43:06

Well, it strikes me from this conversation that you have an awful lot of things going on. And a lot of great supports for for patients and, and the efforts to truly make care patient centered, are obvious. It's a challenge, because there are lots of things that tend to get in the way. And one of them being lack of time to do everything as well. And as thoroughly as you'd like for each and every every patient. But with a variety of resources, you're really having an impact. Maybe just in closing, what messages would you like to have our listeners hear about what you're doing? Or what what do you think really makes a difference? Or what should they be doing to maximize the benefits of all the resources that are are available through the Juravinski in the regional program?

**Angela Djuric-Paulin** 43:56

I think the first would be talking to their team if they're not aware of their symptom screening assessment, asking it for support on how to complete it engaging with the team, the fit their families, Austin, the Resource Center, to support them with doing that at each of their clinical appointments. The second would be really so that there's awareness of the resources and supports. And I think a lot of times the information is available, but not everybody is aware. And as you mentioned, there's so much to be done in such a short period of time. It's how do we get that information out? So Victoria and I are available in the Patient Family Resource Center Monday to Friday, nine to five. I'm usually there a little bit later. So sometimes people will pop in, but I'm there and being there to support and assist them with any of their questions. Victoria is phenomenal doing literature searches. And so if there's a question

**Victoria Chambers** 45:00

If we can't answer, then we will find that information. So we really just want people to be aware that we've got these resources. We've got the supports and services to come in and visit us. We're right at the front doors across from the lab at the Durban scandals. I mentioned that because I'm meant to ask you, where are you located? As you come in the front doors of the Juravinski Cancer Center, if you turn if you look to the right you see the lab, if you look to the left, you'll see our door is always open. And it's available for not only the devinsky Cancer Center patients, but our regional community partner patients. So should they want to call and ask for information, we can pull it so that they can come and pick it up, or there's information available online and Victoria will direct them to that area. But it's really it's the awareness so that you know we are here we are able to support and obtain the information and I'll pass it to Victoria chat. Oh, my final thought is just welcoming everyone to the library and hope they will seek us out. And I just wanted to mention, in addition to all the information, I would like everyone to know that it's a quiet and comfortable space. I have had all sorts of people come in people who are first diagnosed, just need a quiet minute to themselves to absorb kind of the shock of receiving the news. You know, parents will come in with little ones looking for the storybooks talk about cancer, I have some coloring books and crayons, you know, sometimes people are waiting for grandma to finish her appointment. I have people we have comfortable seating space, plugs, I've had people charging their phones, or they don't have a device they need a computer to use. So it's it's just more than just the books and the paper. I believe it's a welcoming atmosphere, I've had more than one person asked for cuttings with my plants. So I pride myself on my green thumb. And so I just find that it's sometimes it's, you know, the atmosphere, not only just the information, and sometimes a listening ear, I have no social work background, I don't claim to be, you know, have a medical background. But I think that I'm a good listener, and sometimes that sometimes what people need is the box of Kleenex in the center of the table and just a listening ear. And so I hope I can provide that. Well, there's been a lot of listening ears today to both of you. And I think the information has been amazing. And I hope people will truly access it, whether it's the symptom management piece in completing those, Your Symptoms Matter that you've emphasized, Angela, it's so important, and then all the resources that are available through the patient Resource Center and library. So as we close out today's podcast, I just like to remind our listeners that there are many podcasts available through the Cancer Assistance Program going to the program's website cancer assist.ca. So I think there's about 40 Plus podcasts there on different types of cancer on the supports that are available in our community. So avail yourself of those and thank you to our two guests. Angela Victoria, thank you so much for sharing all your knowledge about the efforts to make care in our region truly patient centered. Thank you so much. Thank you. Thank you for listening to the cancer assist podcast. Find more episodes, resources and information at cancer assist.ca or follow the Cancer Assistance Program on Facebook, Twitter, and Instagram.

**Dr. Bill Evans** 48:24

We'll see you next time.