

Meet the woman who wants to cure brain cancer

Heather 00:00

[Your Complex Brain theme music] This is Your Complex Brain, a podcast all about the brain, the diseases that impact it, and the path to finding cures. I'm your host, Heather Sherman, and I have the great pleasure of working alongside the team at the Krembil Brain Institute in Toronto, Canada, a leader in brain research and patient care. In each episode, we'll take you behind the scenes into our clinics and our research labs to meet the game changers of the future, and we'll empower you with the latest research to help you take charge of your own health. You'll also hear directly from patients who are living with brain disease and the care teams who support them. Join us on a journey to unravel the mystery of your complex brain. [theme music continues then fades out]

Rick 01:01

[delicate electronic music] I love talking about my wife, but where do I start? She was amazing. She was a firecracker. She was a big personality. So, when Ally entered the room, everybody knew it. But she was just such a breath of fresh air when she came into the room. Yeah, she was incredible. [music continues] So, we were up at our cottage, big family annual weekend we do in January, and there was probably 20-something of us, you know, cousins and little ones, and everything. And we're there for the weekend. And the one night, she had been having some headaches and stuff. But, you know, there was a lot going on. She was finishing her Master's, we had a two year-old, we were trying to have another baby, she was tired, and we didn't really think much of it. [light electronic music] She had gone to bed early one night and in the middle of the night, I felt her kind of shaking, and I thought she was nudging me, and she was having a grand mal seizure. I flipped the lights on and, you know, horrific, and, you know, Emmett was watching from his crib, and not sure what was going on. I didn't know what was going on. And, it turns out she had a large brain tumour and had emergency surgery. And then, even after that, they couldn't stop the seizures, and so she was in a coma for about a week and a half, and then woke up one day, and had no clue what was going on. And, yeah, we thought we were going to lose her at the time. And we didn't, God bless her. And it was a rough go, obviously. And she had partial paralysis at the time but worked her ass off in rehab and got back to normal, so to speak. But the pathology had come back that she had incurable brain cancer. She had astrocytoma. And so, that was the new beginning of a new life for us, you know, trying to navigate forward from there. [music continues] You know, she didn't stop living. It was incredible to watch. She lived another 20 months, and we did some traveling, and we just spent every day together, and it was pretty magical. It was really lucky in that respect. I never saw her cry. I think I did, one night. She woke up from a dream and was afraid just for Emmett and I, and that was the only time in almost two years that I'd seen her shed a tear over it. You know, she was just like, "I just want people to know what I'm going through so I can help others. I want to document my journey and just share it with others, as many as possible." It was pretty incredible to see. She inspired so many people. [music fades out] I see her in Emmett every single day. Like, he's got her zany, comedic nature, and it's amazing... really amazing. He'll be seven in July, and what a remarkable kid. I mean, he's so funny, just like Ally. He's my whole world, right? Ally

and he were my whole world, and she's always with us, [light electronic music fades back in] so, yeah, I'm blessed. We were in the Dominican last week and just had an incredible time, and we had hired a photographer to do some group photos and family photos, and when it was Emmett and my turn to get up on this platform, suddenly a rainbow popped down behind us. Sorry. I'm gonna get a little teary, but I always look for signs. Since Ally passed, stuff like that happens all the time where, you know, family photos, "There's Mommy." And Emmett said it, too, when he saw the pictures, "There's Mommy. She got in the photo. She's photo bombed us." So yeah, that's pretty remarkable. Our lives and our world are filled with clichés about, "Oh, you've got to live every day," and you know, but I truly believe that. I try to live that every day. Ally inspired that in me, in us, because you never know. We had a perfect life. Cancer came out of nowhere. So don't wait to tell your kid, your partner, or your family, or anybody how much you love them, and just laugh every day, enjoy every day. Too many people waste time just stressing over, you know, mundane things and I know my Ally would give anything to have, you know, just another afternoon hanging around with us. So don't waste it. You've got to live every day and enjoy life. You know, there's too much negative stuff out there, so just enjoy the positives, and make every day your best day. [music continues then fades out]

Heather 06:53

[wistful electronic music] Rick Arkell is an old high-school friend of mine. Hearing Rick talk about losing his beloved wife, Ally, to brain cancer at only 35 is heartbreaking, but sadly, not uncommon. There are more than 120 different types of brain tumours, of which a third are cancerous. Glioblastoma is the most common and most aggressive malignant form of brain tumour. Glioblastoma strikes suddenly, without warning, often in the prime of life. It's a devastating diagnosis for patients and their loved ones. But innovative new research such as a blood test to detect and diagnose brain cancer could be revolutionary in the field. [music fades out]

Heather 07:51

[Your Complex Brain theme music] In today's episode, we want to introduce you to Dr. Gelareh Zadeh, a neurosurgeon and scientist on a mission to cure brain cancer. Growing up in Iran, Dr. Zadeh immigrated to Canada with her family in her senior year of high school. She struggled with adapting to a new culture, a language barrier, and freezing Manitoba winters. That resilience has served her well. Throughout her career, Dr. Zadeh has often been the only woman in the operating room or conference auditorium. The first female to become Chair of Neurosurgery at The University of Toronto, Dr. Zadeh has risen to become a powerhouse in the field of skull base surgery and brain cancer research. Now, she's set her sights on advancing research to better diagnose and treat brain cancer, with a goal of improving the quality of life and long-term outcomes, for patients. Dr. Zadeh, who is Medical Director of Krembil Brain Institute, Head of Neurosurgery at UHN, and a Senior Scientist at Princess Margaret Cancer Centre, believes that through investment in research and innovation, we could see a breakthrough in brain cancer treatment in our lifetime. And we are so thrilled to have her here today on the podcast. [music fades out] Dr. Zadeh, you've been treating patients with glioblastoma, and other types of brain cancer, for more than 20 years. So, what's changed in that time in terms of treatment options?

Dr. Zadeh 09:25

So that's a really good question, Heather. It's something I ask myself, and review, on a fairly regular basis, and I think you can divide it into, technology's advanced significantly with respect to how we can detect a tumour, imaging, which MR imaging is one of the key changes that has happened. The ability to see tumours better on imaging in the OR (operating room) has changed significantly, and some of it is really just the optical technology that's improved. Moving towards more minimally invasive endoscopic surgery, improvement in optical imaging has added a great degree of improvement. And then, on the scientific side, it's the biology that's changed how we view tumours. We understand the molecular biology better, that although, previously, under the microscope, two or three different tumour types were categorized under one, that they are now distinct, based on specific genetic patterns that are altered, so genes that are lost, or genes that are mutated, changed in some way, biologically, makes a difference in how we understand the brain tumours that we deal with. The last piece of it would be, I think, as a whole field and medicine, in general, we've come to really appreciate the value and recognition of the quality outcomes for patients, and what are some of the metrics of success that are defined by patients rather than by the healthcare providers. And that, I think, is an area that would dramatically change over the next 10 years or so, so patient-driven priorities that you would want to set your standards, based on what's important to the quality of the outcome for patients' experiences.

Heather 11:33

Well, I know patients are always the focus of your work. Let's talk about prevalence. So, how common is brain cancer?

Dr. Zadeh 11:39

Brain cancer, compared to other very well-recognized cancers such as breast cancer, lung cancer, prostate cancer, is not as common. The challenge is that brain cancer affects, considerably, longevity, and also, it affects the function of individuals. And so, your life is shortened significantly more in comparison to other cancers. So, the impact of it on the individual and the society is much larger than other cancer types because, fortunately, other cancer types, you do tend to be able to get to a point where you live with the cancer for much longer, but the majority of the malignant cancerous growths in the brain, you do not. And I think the lower numbers and lower percentages contribute to the fact that the recognition for needing to put funding towards research on brain cancer is, as a consequence, lesser than other main cancers. The desire to explore pharmaceutical treatments or new targeted therapies in brain cancer becomes challenging because the population that would be able to enroll in clinical trials or benefit from it, from a pharmaceutical perspective, is less. And so, I think we need to raise awareness of its major impact on people: loved ones, patients, and caregivers, that despite the prevailing rates being lower, its impact is actually felt moreso due to reducing longevity significantly and impacting the functionality of the individual. And the average length of survival from the time of diagnosis, unfortunately, still remains around 18 to 24 months, so a significant impact and the diagnosis happens 60s, mid-50s range, so a considerable impact on the individual, again, their family and loved ones, when your longevity is suddenly reduced to such a dramatic extent. [gentle electronic music]

Heather 11:42

Well, I know you're a physician, and you deal with patients every day, but it has to be challenging on a personal level, having difficult conversations. So, what keeps you going? What motivates you?

Dr. Zadeh 13:59

A few things motivate me, which is to help the individual before me to come to terms with the diagnosis and help them recognize how this disease is going to impact every aspect of their life. Of course, I do what I can, as best as I can, to remove the tumour completely, surgically, to give the person the best outcome. But another component of what I think is my responsibility is have the patient come to terms and accept the diagnosis. Not that you ever fully accept it, nor should you, because it is a really devastating diagnosis. However, to be able to get them to a place as soon as possible, and each individual goes at a different rate, so that they can enjoy the time that's remaining for them. It's a very clear human reaction to go into denial at the time of this diagnosis, and then to be faced with the harsh reality that it will limit your life in a significant way with, really, very little realistic hope, at this point, to change it. So that's my number one goal. Second, though, my number one goal and motivator is to really explore - without any setback in negative outcomes or negative results - explore, "What can we do to understand the tumour biology better? How can we improve therapeutics? What new therapeutics can we identify? Are there things we can deliver during surgery into the tumour to prevent it from coming back? Are there opportunities for targeted therapeutics, which is biological treatments that we have, based on our laboratory research?" and, "Are there ways that we can use more non-invasive, less aggressive procedures to detect, diagnose, and then use as follow-up, tools for the patients. So, in other words, using blood tests to be able to diagnose, blood tests to be able to detect recurrence sooner, etc.?" So that would be a second major focus motivator for us to keep working on this area.

Heather 16:27

Well, that's a perfect segue that leads us right into your research. So, you mentioned a blood test to diagnose brain cancer. Can you tell us more about that?

Dr. Zadeh 16:36

Yeah. So, one of the advantages of working at a powerhouse such as ours, the Krembil Brain Institute, together with the Princess Margaret Research Institute, is we can merge the expertise of the two worlds. And so, in doing brain tumour clinical care, brain tumour research, and having partners such as Dr. De Carvalho, who comes up with innovations in being able to advance the forefront of cancer. We were able to really take this to the next level, which is merge his discoveries of plasma detection for all other cancer types, with the work that we do to see whether we can, in fact, use that same innovative technology in a new way for brain tumours and detect whether an individual has a brain tumour, and then, are we able to, in fact, distinguish, discriminate, diagnose accurately the type of brain tumour they have, and also look for those genetic alterations that I mentioned, that are important for distinguishing one brain tumour type from the other, using that plasma? Because there's a lot of skepticism, whether we get enough DNA from the tumour, genetic material from the tumour shed into the blood, that could allow us to make that detection. And, in fact, using approximately 500 cases, we were able to demonstrate that we can, very reliably, with very good accuracy, detect brain tumours, distinguish what subtype, and look for some of the molecular signatures. [pulsing electronic music] And so, that was a really, very rewarding collaboration, most importantly, very promising to be able to transform how we care for our patients, and potentially move away from having to do biopsies for very deep-seated tumours, avoid an invasive surgery in order to make a diagnosis and when, next, we look to apply this technology, is to see, "Can we use this to be able to detect recurrence of a tumour when it comes back sooner than what we see on the MRI?"

Heather 18:54

Wow. And is this blood test available, currently?

Dr. Zadeh 18:58

So, the blood test is currently available as a research tool. However, we apply that in a translational manner when we think it could help shape some of our decision-making for patients. In order for it to become a clinical tool, there are a number of steps that need to be taken, which is what we're pursuing. We need to demonstrate in a prospective manner [music fades out] to new patients coming through, that we are able to accurately diagnose the brain tumours, using this technique. The next is to then have this done by a different group so that it's not specific to just our lab. And then, the third is to actually disseminate this knowledge, advocate for it, and allow it to be integrated into clinical practice. So, its comparable situation is we identified that if you analyzed a particular brain tumour type, which is called meningiomas - it's the most common type of brain tumour where we get, in fact. The majority are benign, managed by surgery - but there's a proportion of them that do not respond favorably to surgery because they come back, and they have a high recurrence rate. And so, how can we tell if one person's meningioma is going to come back, versus another person? And why does that matter, because if it comes back early, you would potentially consider intervening with radiation. But if it shows that it's not going to come back for a long time, then you would avoid radiation. So, we investigated this and found that there is a particular genetic alteration - we refer to it as methylation signatures - that can tell whether a meningioma is going to come back fast, within a five-year period, or not at all, or just at a slower rate. That was similar to the blood test, revolutionary in how we approach patients, and through prospective confirmation and validation of our results, and dissemination and advocacy, we now have reached a place, from its original publication in 2017, to a point where it's a test used commonly in our day-to-day practice, and we review methylation results for meningiomas at our Tumour Board every Monday. So, the blood tests will have to go through a similar process, similar type of timelines, but it's possible. I think it just -- if we can speed up the process, of course, it's fantastic. It's very rewarding to see that, when you work on a project with a view to understand the tumour, with a view to then come up with a tool that helps us change how we manage the patients for the better, and then see that, in fact, there is an interest and an adoption of your results, is really very rewarding and, most importantly, to see, over the years, that we've evolved in how we manage patients in that regard. But absolutely an amazing feeling to know that all of the hard work to become a neurosurgeon, do a PhD, do research, actually does pay off for a good reason. And so, it is really quite exciting. And I think that's what motivates trainees to pursue a similar education path, to see the value in it, to see the reward, and to know that you are part of a bigger vision and a bigger direction to change a field and move it towards something more impactful and, potentially, leave a small mark on how we can manage patients in general. [gentle electronic music]

Dr. Nassiri 22:50

My name is Dr. Farshad Nassiri. I'm a senior neurosurgery resident at the University of Toronto and at the Krembil Brain Institute. I've finished my PhD under Dr. Gelareh Zadeh. My interests are in brain tumour surgery and skull base surgery. [music continues] When I was growing up, I'd always thought that I wanted to be a scientist, wanted to be a microbiologist, but I had some personal family history where some of my family members were affected by brain tumours, and so I always, kind of, growing

up, came back to the idea of potentially going into medicine, and potentially working in either the brain space or the tumour space. My cousin who's my first cousin, Ramin, is about 20, 25 years older than me, had a - what I now know to be a - diffuse intrinsic pontine glioma when he was a child. And we lived in Iran, originally, and my cousin actually flew from Iran to the United States and Canada to get different opinions, and eventually actually had surgery in Canada for his diffuse intrinsic pontine glioma, which is a very devastating disease for children. It's a brain tumour in a devastating area of the brain. He's had, you know, very difficult brain tumour surgery by excellent surgeons and, by all accounts, had an excellent outcome, but just by the fact that he had a brain tumour, he was severely affected and even as a child, growing up, I could see the effects on him. [music continues then fades out]

Dr. Nassiri 24:27

[gentle electronic music] One of the most interesting research projects that I've worked on is the development of a blood test to diagnose brain tumours. Typically speaking, patients are diagnosed with brain tumours by an MRI and, once you have an MRI scan that shows that you might have a brain tumour, you know, the standard clinical pathway to diagnose a patient would be to do an operation and to get a piece of the tumour, give that tumour to the pathologist who can look at the tumour under the microscope, and officially give you a diagnosis of what your brain tumour is. That's a lot of work. You have to go through an MRI scan, you then have to have a very invasive brain tumour operation, and sometimes it's, for example, in the case of my cousin, that tumour is in a very, very difficult location to do surgery, and sometimes you can be left with effects from the operation. And so, if there's a way to really diagnose the tumours and, you know, the specific diagnosis of that tumour without having to do a brain operation, then that could have really impactful changes for patients. [music fades out] Patients who have brain tumours and brain cancers are doubly vulnerable so, you know, the brain is the organ that makes you you. It makes you uniquely the person who you are. And, unfortunately, we have not been able to make significant progress in terms of the amount of research and the treatment options that are available for patients with brain tumours. [gentle electronic music] I think it was, you know, particularly exciting for me, working on this project, to be able to maybe change the dial a little bit for patients with brain tumours, bring in an advancement that might have real clinical impact for patients, not just research. In fact, that actually has a translation to a difference in outcome for patients. So, it was really exciting for me to be a part of this journey, and certainly a lot of exciting work that we have planned moving forward, as well. Dr. Zadeh is really an incredibly patient, supportive, all-around inspiring supervisor. She's really the epitome of Academia with a capital A and, beyond that, she's really just thoughtful, and an incredibly kind person. I feel very fortunate to have her as my mentor, and I'm eternally indebted to her for the countless opportunities that she's provided me. I think, you know, all things considered, that is probably the number one thing that drives her. She wants to see patients with brain cancers be cured, or at least be treated in a better way than they are now. And I think that is, you know, the absolute best way to describe her. [music continues then fades out]

Heather 27:11

You mentioned trainees. I know that mentorship is a big focus of yours and a big priority of yours. How important is it to you?

Dr. Zadeh 27:18

I think mentorship is like friendship. Mentorship really is a form of partnership where there are two people, the mentor and mentee, that have responsibilities towards each other for an outcome that's positive for both. The mentor benefits from knowing that they've taken somebody and launched them towards a career path that that mentee wanted and wished for. The mentee's responsibility is to be sure that they're open to accepting direction, perspectives, from another person who they trust. It's really rewarding, in particular, for when our neurosurgery residents come through. You see them as a medical student. You think they have the right combination of skills and ambition to become a neurosurgery resident. You then watch them grow and develop and support them to become independent and go off and do what you've envisioned they can do. And they do beyond that. And then, you know, that's even more rewarding.

Heather 28:21

I know one of your mentors was Dr. Fred Gentili, a neurosurgeon who became a patient after a diagnosis of glioblastoma. Tell us about him.

Dr. Zadeh 28:31

Well, [pauses sadly] he was just an incredible person. Fred Gentili was really a unique person. He was a master surgeon. He was committed to caring for his patients beyond really anybody that I knew. He would work long hours, and he had this very unique ability to be accepting of everybody, whether it was the patient, whether it was family members, whether it was a trainee, or a colleague, and he really did it with no bias. And a best example of it is, when I was a medical student, and in residence afterwards, my interest in skull base surgery-- at that time for a female to go into skull base surgery was really very rare, and most people would have tried to discourage me, but quite the opposite. Without ever talking about this as being a factor, he provided me with support, and trained me, and did so without ever making me feel like there's something different, a challenge, a bias, and he was there. He accepted who I was, as I was, and we worked super well together. If I needed to run a case by him, if I needed to run an issue by him, if I needed to just vent about something, he'd be available, so I do definitely miss him.

Heather 30:06

[gentle electronic music] Well, I wanted to mention, I mean, Dr. Gentili was also a big advocate of research, particularly after his diagnosis. So, we're just going to take a moment to listen to a clip from a tribute video recently. [music continues]

Dr. Gentili 30:21

I was operating on a patient with a brain tumour, and I realized that, when I was under the microscope, that my left side was not quite working 100%, and sure enough, the MRI scan showed up these two lumps in the right side of my brain. Can you imagine? Somehow you think that you're so special, but you're not. It doesn't matter that I'm a surgeon, that I'm neurosurgeon. I'm a patient. The final solution to my problem is going to be not surgery. It's going to be research funding, molecular biology, looking under the microscope to check the cells, see whatever, so that's so important. [music continues then fades out]

Dr. Zadeh 31:23

I think really having a more in-depth understanding of the biological drivers, finding ways to detect brain cancer earlier, to me, are essential. I think diagnosing it earlier, finding the biomarker that would tell us we're going to develop a brain cancer, much like a mammogram for breast cancer, the PSA for prostate cancer is an absolute necessity because right now, by the time somebody presents to the emergency department with the scan of a tumour that we know is a glioblastoma, unfortunately, it's too late. And I think the shift that we need to happen is to know, "What is that one test that's going to tell us that you're at risk of developing brain cancer?" and, if that level goes higher than a certain value, you need to start getting imaging done, biopsy intervention. Because we do know that, if we're able to intervene when the tumour is smaller, we're able to resect it, intervene sooner, the outcome is better. And so, how do we get there for every patient? That would be really the golden ticket to transform how we manage brain cancer patients.

Heather 32:48

What makes Krembil Brain Institute unique in terms of how we're able to treat brain diseases, such as brain cancer?

Dr. Zadeh 32:54

What's very unique about the Krembil Brain Institute is the intersection of caring for patients with research in each of the areas and having a strong team that is so specialized. From our emergency physicians to our neurosurgeons, from our primary care nursing to our specialized nurse care, from our allied health to our specialists who do functional mapping recordings of brain activity, everybody really within the team has a full range of specialties that can come together and care for the patient, think of the most burning questions, clinically, and then be able to tackle these questions one by one, together. And so, we divide our specialty teams, based on the tumour types that we have. There are a range of brain tumours with various genetic alterations. Our teams are designed and created in response to those specialty types because each brain tumour type requires a different approach, so we have a very dedicated brain metastases clinic, we have a very dedicated pituitary tumour clinic, dedicated skull base clinic, dedicated meningioma clinic, and in each of these areas, we have unique technologies that are designed to best treat the tumours and, obviously, the patients, as a result. For example, our Gamma Knife treats a high volume of acoustic schwannomas. We have the laser interstitial thermal therapy, which is the LITT, in short, and it's very specialized for brain tumour surgery, minimally invasive surgery that converts an open operation to a catheter-guided surgery. [gentle electronic music]

Heather 34:47

So how does it do that, exactly?

Dr. Zadeh 34:49

So, the LITT is a technology where you use a probe that's the size of a pen. It's inserted through an image-guided technique to the center of the tumour. Through that same probe, laser is delivered, and it destroys the tissue. That destroyed tissue is then suctioned out through the same probe, removing the tumour, the debris, the dead cells, and really, essentially, taking care of removal of the tumour. With this technology, we can reach areas of the brain that we previously wouldn't have been able to, and it converts an open operation where the brain has to be exposed, the brain has to be dissected to reach

some of these areas where the tumour sits, to a closed operation, minimally invasive, with no brain exposure, no dissection needed. And essentially, you can convert it into a day-type procedure.

Heather 35:45

That's incredible.

Dr. Zadeh 35:46

It really is a revolutionary technique. [music fades out] We also have additional advantage at the Krembil Brain Institute, where we have one of the largest brain tumour banks in all of North America. We have accumulated and stored, banked, collected tumour from over 5,000 patients. This has served as a platform for multiple research projects within our institution, and outside, placing us in positions where we can collaborate, learn from other researchers, and also have that guide some of the discoveries that we've made, such as the plasma biomarkers, and very few other institutions can do this.

Heather 36:31

Could we see, based on all of these advancements, in our lifetime, personalized medicine for brain cancer?

Dr. Zadeh 36:37

Absolutely. I think we actually are. What I said about our methylation predictive modeling for meningiomas, that is precisely personalized medicine. Each person's tumour is analyzed. Each decision is made, based on those results, so I would say that it's here, and it's going to increase and become more and more reality for all brain tumour types and for every patient. So, absolutely, I think that is possible for brain cancers at the Krembil.

Heather 37:09

You've come up against a lot of barriers in your life, too, in your career. I mean, you talked about some of the supports and some of the mentorship, but how have those experiences, especially as a woman in neurosurgery for so many years, how have those carried you through to this moment?

Dr. Zadeh 37:25

My answer evolves. I think, if you view every challenge as surmountable, and every problem having a solution that needs you to figure it out, then I enjoy that, and so I think that's what motivated me to move through my career in life, figuring out how to get over a barrier, or how to find and navigate my way through a challenging situation. I think that, somehow, must motivate me because I enjoy doing it, and in the process of doing that, I've learned something. I learn about people. I learn about the environment. I learn about myself as to how I can, you know, expand my perspectives. [upbeat electronic music]

Heather 38:18

The title of this episode is "Meet the Woman Who Wants to Solve Brain Cancer". So, ultimately, what's your hope, in terms of what you want to accomplish in your career, that you haven't already? [music continues]

Dr. Zadeh 38:30

My hope, really, is that the work that I do, on an individual level, helps people, whether it's with removing the tumour or, as I said earlier, coming to terms with their diagnosis. My hope is that the skill sets that I've acquired, I've reached that moment where my skill sets are probably at the best that they would be able to perform intricate surgery, that I can sustain this for as much as possible. I hope that I inspire others to do what I do and continue in the pattern and manner that I like to conduct myself, doing neurosurgery, caring for patients, doing research. And I hope that the research we do does transform how we approach our patients, and that there will be some memory of that so that, after I'm no longer in the field, there will be a continuation of what we've contributed to the field. [music fades out]

Heather 39:42

And, finally, what's your message to people who may be listening right now who might be struggling with brain cancer themselves, or have a family member who is?

Dr. Zadeh 39:49

I think the best approach or the best message, I would say, is to not hesitate to seek information and to not hesitate to talk about your experiences, and the fears and challenges that you face because, unless they're known and voiced, it's always difficult to know how this diagnosis and the disease affects each individual. And so, I think, on a personalization of medical therapy, how you travel through this journey needs to be individualized to the person because each of us have different wishes, and, sometimes, that's challenging, and I think I've really learned that from watching Fred go through his diagnosis and get to the end of his journey. His resiliency is, of course, noteworthy, but highlighting to me that what he wanted was really very unique to him, as it is for every patient. And also, nobody knows how they're going to react until you're faced with the diagnosis, not even your loved ones,. You really don't know how you're going to react until you're faced with the reality of it. I also would like for people to know that we are working on better understanding the disease, coming up with better treatments, and that we are moving the field forward, and there are ways that you can help contribute to this advance. And so, you can turn the experience into impact that it will leave on the field for yourself and for others.

Heather 41:45

[upbeat electronic music] Thank you for your honesty, and for the work that you do. And we wish you all the best.

Dr. Zadeh 41:46

Thank you very much. This has been a wonderful experience. [music continues]

Rick 42:00

I always worry that people are going to forget. I don't want her memory to be forgotten. You get into your lives and time passes, and she was such an incredible spirit, and I know it lives on in the people that we know and love. I want people to remember how strong she was. I want people to remember what kind of mom she was, what kind of friend she was, and [voice breaks] just remember her laugh.

[chuckles tearfully] She had this infectious giggle, and [chuckles] yeah, just a zest for life, and she was unforgettable. [music continues then fades out]

Heather 42:58

[Your Complex Brain theme music] Special thanks to Dr. Gelareh Zadeh and Dr. Farshad Nassiri for bringing their expertise to today's episode, and to Rick Arkell for sharing Ally's journey with us. [music continues]

Heather 43:21

If you'd like to hear more about Ally and Rick's story, head to our website at uhn.ca/krembil and click on the show notes for today's episode.

Heather 43:31

This episode of Your Complex Brain was produced by Jessica Schmidt. Executive Producers are Tobin Dalrymple with Pilgrim Podcasting and Carly McPherson, with production assistance from Dr. Amy Ma, Twayne Pereira, and Suzanne Wice. If you enjoyed what you heard, tell your family and friends, and leave us a rating and review on your favourite podcast listening app. Thanks for listening. We'll be back in two weeks with another exciting episode. Have a great day. [music fades out]