

Your Complex Brain - Season 3 Episode 7 - What Women Need to Know About Stroke Prevention & Recovery

Dr Patrice Lindsay 00:02

[Your Complex Brain theme music] One of the things we've been learning is what happens during, you know, your early years onset and then our timing have an impact on your risk for stroke and heart disease later in life, and nobody ever tells anybody about that. We're appreciating more and more how important it is to educate everybody across the system and, you know, women themselves. For example, if you have high blood pressure in pregnancy, that changes your 5- and 10-year risk of having a heart disease or stroke. [music continues]

Heather 00:32

[music continues] 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 research labs to meet the game-changers of the future. We'll empower you with the latest research to help you take charge of your own health. You'll also hear from people who are living with brain disease, as well as their loved ones 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]

[epic electronic music] Today's topic is a personal one for me and for many of you listening right now. That's because there are several women in my life who have experienced the heartbreaking impacts of stroke. A stroke happens when there is a sudden blockage of blood flow to the brain or bleeding in the brain, which can result in symptoms such as numbness or weakness, trouble speaking, confusion, or dizziness. The type of symptoms one might experience depends largely on the type of stroke, and the area of the brain affected. But one thing is clear – despite the many advances in stroke care over the past 30 years, it's women who often suffer the most.

Today, we're going to talk about why women are more susceptible to stroke, what the risk factors are, and what women need more of to help them recover, not only from the medical condition, but the impacts to their careers, their mental health and their families, as well. Here's the story of one woman's inspiring journey to recovery.

Shruti Kothari 02:40

[bubbly electronic music] My name is Shruti Kothari. It's actually pronounced Shroo-thee Kothari, but no one calls me that except for my parents when I'm in trouble, so Shruti is really my name now, and I am a

34-year-old actress and stroke survivor. My friends and family would describe me as outgoing, an extrovert, very social, very friendly. Some people have described me as being intimidating. I don't see it, myself. [chuckles] I think of myself as being very friendly and very approachable and, let me put it this way, when I was a kid, my favourite thing to do was to find the shyest person in the room and bring them out of their shell. So, that's me.

[music continues] I think energy is just so important and, especially when you're going through a recovery of any kind, your energy and your attitude is just so paramount to recovery, and how you approach things is as important as what the actual thing you're approaching is, in my opinion.

On March 7th of 2020—this was about a week before the pandemic exploded in North America—it was a beautiful, sunny day and I was in my apartment in the annex with my partner at the time, and we had some visitors, our old neighbours. We had been living in Stratford for the previous two years, so our old neighbours had come to visit us with their new baby, and we were trying to figure out where to go for brunch and I was holding their baby and, all of a sudden, I felt my left side go a little numb, and so I thought, "This is odd," so I handed the baby back to his mother and I decided to go out onto our balcony just to get a bit of air. I thought I'd stretch it out. [music continues] And, when I went out onto the balcony, I was doing a sun salutation. I was doing a bit of yoga, trying to get some air in, and I fell over because I lost sensation on my left side. And then, my partner came out to the balcony and he said, "Are you okay or are you just being Shruti?" I told him I couldn't feel my left side and he picked me up and took me into the apartment.

You know, they called the paramedics and, by the time they got there, I was, you know, fine. I was making jokes and, you know, trying not to make a big deal of things, you know, hoping to still go for brunch on this beautiful day. And, the next thing I knew, I was in the back of an ambulance with my partner and I was telling him to call my parents, and then I asked him to e-mail a bunch of my friends to let them know what was going on because I knew that my family would need support if this was serious.

[music continues] I, of course, at the time, didn't know how serious it was. I didn't know that, at that moment, I would not be seeing him again for many, many, many months. The way my partner described it, it was like a TV show, you know, where he was running alongside the gurney with the doctors and stuff and, apparently, by the time my parents got there, I had been prepped for surgery. I don't remember any of this at all, but they had apparently been told to say goodbye to me just in case. I can't even imagine what that must be like for a parent to hear that and to have to do that. Of course, my mother didn't say goodbye. She said, "I'll see you soon," so ever the optimist. You know, the apple doesn't fall far from the tree. [music fades out]

[gentle electronic music] And then, I went in for surgery. It was a long procedure, I understand, where they had to remove half of my skull to alleviate the swelling of my brain. I still don't know what the

source of the bleed was, in terms of why it happened. They have absolutely no idea because I was, and am, a very healthy, very fit young adult. But, I think it just goes to show that, with things like stroke, anyone could be a victim to it. It really just strikes. You know, that's why they call a stroke. It strikes anywhere, anyone, at any time, which is really frightening.

[music continues] So, my mom had told me that the step-by-step process was basically that I had to be weaned off of the trach and the g-tube—my feeding tube—before I could go to the-- it was a low-intensity rehab place, which was the Bickle Centre, and then I would go to a high-intensity rehab place, which was TRI on University. Something that I remember is, I'm evidently a talker, so the scariest thing was thinking that I might not have my speech. [music fades out] I might have aphasia, and I'm so fortunate to not have any of that. That was not the part of my brain that was affected at all.

[glitchy electronic music] For me, it was my motor recovery and, because I'm such a talker, because I'm an actress, if I had lost my speech, I would have lost my sense of identity completely, and that would have been devastating. So, I'm incredibly fortunate and incredibly grateful to not have those problems. I know a lot of stroke survivors do struggle with aphasia, and I can't even imagine how difficult that must be. So, I was very fortunate to get my speech back fairly quickly and I remember working on my mouth muscles with my mom. She would call me every hour and make sure that I did my exercises. She was amazing. She really, really was. So, I'm very, very fortunate. [music fades out]

[gentle electronic music] This horrible thing happened, but I am an eternal optimist and I just don't believe that this is the end for me, so to speak. I'm not surprised that I am making such a good recovery because I refuse anything but. I appreciate every moment that I've been given. My parents will always say, "You know, Shruti, you're looking for that magic bullet and that magic bullet doesn't exist, unfortunately," which is true, and that is something I have to keep in mind. But, even that being said, I will leave no stone unturned until I find something that is going to help me.

[music continues] I am very fortunate in that we worked a lot on my core strength when I was at TRI, because I had none whatsoever. I could barely sit up in my wheelchair, and now I am walking. I'm walking with a cane and with some braces around my ankles, but I'm walking, which is miraculous, really – nothing short of miraculous. My left arm is still quite paralyzed. I've been told that this is the last thing that comes back, usually. I'm not sure why that is, but I am working really hard to get it back because we live in a two-handed world, and it's very difficult, not having both of your hands. Something as simple as tying your hair up – I'm a young woman and I like my long hair. I'd like to be able to tie my hair up. I'd like to be able to wash my own hair. [music fades out]

[laidback electronic music] I was definitely the 30-year-old who said, "A stroke can't touch me." Healthy, I had never broken a toe in my life. I really thought it was invincible, and far from it. So, I think it's important that we all recognize that and realize that life is fragile, and I think that a stroke can happen to

anyone at any time, any age, any circumstances of health. It could just happen to anyone, which is terrifying, but people need to know that.

[music continues] Honestly, in terms of what I've learned. I'm still trying to figure that out, [chuckles] but I just think that we can't take our health for granted. That is just something that's become so apparent to me because it's not always in our control. I encourage people to loosen the reins a bit and understand that life is going to take you up and down and you've got to learn to ride the wave. I remember, at New Year's Eve of 2020, thinking, "This is going to be the year for me where I'm going to travel, I'm going to go somewhere with my partner, we're going to maybe get married, we'll see." You know, there was infinite possibilities for 2020. And then, of course, [laughs] we all know what happened. [sighs resignedly] Yeah.

[music crossfades to bubbly electronic music] So, I feel like the same person, but I am inherently different because of my experience. I used to be the most carefree person you've ever met – the most carefree person. Don't tell my mom this, but I was the person who, at a stop light in my car, I would pull out my ukulele and start playing – not the safest thing to do but, you know, I was truly carefree and I just lived every moment like it was my last. That's really how I lived my life, which I'm grateful for, but I am not carefree anymore. I am very careful, which I'll be perfectly honest, I miss that carefree person.

[music continues] I am sad a lot of the time, and I'm not used to being sad. I'm not used to being a sad person. I remember in high school, I used to romanticize sadness so much because I was this young person who wanted to be an actor and who wanted all these dramatic things to happen and I thought sadness was so romantic, and now that I am living it, it ain't so romantic. I am still very optimistic about my future so, you know, it's up to me to make sure I make the most of this second chance at life. [music fades out]

Heather 13:13

[Your Complex Brain theme music] Dr Aleksandra Pikula is a Stroke Neurologist and Clinician Investigator at UHN's Krembil Brain Institute, as well as an Associate Professor of Medicine at the University of Toronto. Dr Pikula is also the newly appointed Jay and Sari Sonshine Chair in Stroke Prevention and Cerebrovascular Brain Health at UHN. She is Founder and Director of the largest multidisciplinary stroke in young adults program in Canada.

[music continues] Dr Patrice Lindsay is Director of Health Systems Change at Canada's Heart and Stroke Foundation and a leading expert in stroke care and patient advocacy. Dr Lindsay received her nursing degree from Western University and completed a PhD in Health Services Research at the University of Toronto. She received the Queen Elizabeth II Diamond Jubilee Medal for her efforts to improve stroke care and outcomes in Canada.

Dr Pikula, Dr Lindsay, thank you so much for being here today.

Dr Aleksandra Pikula 14:24

Good morning, Heather. It's so lovely to be here. Thanks for inviting me.

Dr Patrice Lindsay 14:24

Good morning, Heather. I think it's awesome that we're having this conversation today. [music fades out]

Heather 14:28

It's a really important topic and we have tons to cover both on the prevention side. We're also going to talk about the recovery side of stroke. So, Dr Lindsay, why don't we start with you? Can you put into perspective for us, what is the real stroke risk for women today and what's really changed in the past 10, 20 years, even?

Dr Patrice Lindsay 14:47

More women than men die of stroke, although the numbers of people having stroke aren't different between the sexes – that women tend to have a harder time of it after their stroke for some of the risk factors that they experience. Even though men may experience risk factors such as atrial fibrillation more than women, women have worse outcomes with those conditions.

What we've seen over the last several years is access to some of the treatments or therapies that are normal for some of the risk-factor management are being provided less often to women than men. There are disparities. At the same time, women wear a whole bunch of hats that are different than men's. They are mothers, daughters, care providers, and so that adds an extra burden both on their physical health and their emotional mental health. Women tend to put everybody else before themselves. One of the things I often tell women is, they don't stop and take a few minutes for themselves, they won't be able to be that person to everybody else.

Dr Aleksandra Pikula 15:52

We need to start from the outcomes and evidence-based knowledge that stroke is definitely a leading cause for premature death in women, and also draw the attention that it's taking twice as many lives as breast cancer. So, we know that women do have high risk for stroke, in recent reports, globally, but also

that the risk of stroke in young women—less than 45—is emerging as much higher than in men, and that's seen also in Canada.

Another very important piece is that traditional risks are emerging among women, such as high blood pressure, diabetes, obesity, and those are the sort of very important aspects of health care sort of designs that we need to focus on how women will be taking better care of themselves, given that their social roles in the preventive sort of space to be able to work on reducing the risk for stroke. And, I think it's also important to add to this already quite complex story the complexity of life stages of women such as childbearing, which we call reproductive life stage, and then menopausal/post-menopausal life stage, which is non-reproductive life stage, and address them differently with the lens of the roles that are gender based, that, again, you know, becomes very complex when we talk about prevention and outcomes of stroke.

Dr Patrice Lindsay 17:30

Dr Pikula makes some good points around the life stages. One of the things we've been learning is what happens during, you know, your early years onset and then our timing pregnancy and any complications have an impact on your risk for stroke and heart disease later in life, and nobody ever tells anybody about that. So, there's some big education gaps that we're appreciating more and more how important it is to educate everybody across the system and, you know, women themselves. For example, if you have high blood pressure in pregnancy, that changes your 5- and 10- year risk of having a heart disease or stroke and nobody ever tells you that.

Dr Aleksandra Pikula 18:08

And that's also important because, you know, the effect of high blood pressure specifically, and diabetes, which also can happen during the pregnancy, has much higher risk of having a stroke during transitional years for women than compared to men of the same age in their fifties, for example. And, that risk could be higher by 20 to 30% for women with high blood pressure compared to men with high blood pressure. So, those are also, you know, teaching points that women need to know that. You know, the best tool they can have at home, it's probably a blood pressure cuff, as early as age 30, 35, 40, to make sure they know their numbers and be able to act on those numbers on time. [music fades out]

Heather 18:53

That's definitely something else that no one ever tells you about, thinking about the early stages of when to consider prevention. Dr Lindsay, you are, you know, a big part of the Heart and Stroke Foundation, and the recent campaign focused on women and stroke awareness assessment action. I was reading, as part of the campaign, that just over 10% of women in Canada can only name, you know, maybe one of the risk factors that are specific to women for conditions of the heart and stroke, both of which are the leading causes of death for women. So, why don't we just backtrack a little bit and talk

about what are those risk factors? We talked about a few of them, but what are some of the ones that women may not realize are risk factors at the different stages?

Dr Patrice Lindsay 19:35

So, we break down our risk factors into kind of different groupings. So, there's those non-modifiable which are sex, family history, medical history, age, ethnicity, generational trauma; those are ones you can't change, but people don't always realize, you know, the cumulative effect of those. We're starting to make it more known about the socioeconomic and personal circumstances and how they impact, so women who are in lower socioeconomic status, who don't have access to safe environments, who can't even go out for a walk during the day or are in remote geography so they don't have the access to care. So, those are all risk factors.

There's also the traditional modified weight, unhealthy weight, lack of exercise, smoking—smoking is a huge one—diet, you know, alcohol, and drug use. And, diet, we're changing the way we talk about this. It's really important because people may be in circumstances that prevent them from having that healthy diet. It's not that they don't want to; it's just that, you know, I've travelled around many remote communities where an apple costs ridiculous amounts of money and people can't afford to have those fresh fruits and vegetables.

Heather 20:47

Mm-hmm.

Dr Patrice Lindsay 20:47

So, we have to teach them how to accommodate with what they do have. And then, there's the medical risk factors. Which I'm sure Dr Pikula can talk more about – you know, the traditional ones that have been mentioned – diabetes, high blood pressure, high cholesterol, obesity, atrial fibrillation. And, all of those, we're realizing, impact women and men differently and impact their outcomes differently.

Dr Aleksandra Pikula 21:07

Yeah, I agree. I mean, and this is a critical piece, you know, really educating people, making them aware of the risk factors, specifically women, and how they can be addressed with really sort of small steps over time to develop the lifestyle around your health that can address those modifiable risk factors.

But, it's also important to be aware of what's called female-specific risk factors that, unfortunately, not all can be modifiable, but once that can be modifiable, so adverse pregnancy outcomes, you know,

someone who has recurrent pregnancy losses or high blood pressure during pregnancy, or diabetes during pregnancy, or pre-term delivery, or perhaps they have also endometriosis or polycystic ovarian syndrome – those are metabolic states that can actually increase the risk for stroke and cardiovascular risk, in general, for women, and essentially, during those early stages of women's life, which they're still young during pregnancy, you know, to really take them seriously moving forward to prevent the early onset of those modifiable, traditional risks such as high blood pressure, diabetes, obesity, metabolic syndrome and high cholesterol.

They definitely can be addressed by lifestyle changes, but again, you know the earlier, the better, because the effect of those traditional risks that we sometimes control with medications already do certain damage to the vascular, you know, system and sometimes, it's not as easy to treat them at a later age.

Heather 23:02

Mm-hmm.

Dr Aleksandra Pikula 23:02

And, just to kind of go back to Dr Lindsay's comment about lifestyle prevention strategies, I mean, there are many and, you know, even though we teach our patients about diet and exercise and weight maintenance, smoking cessation, I think that, overall, the medical, clinical environment is not ready to do that properly. It's important to understand that, in medical schools, we don't learn how to do that. It's not enough to say, "Eat more veggies," or, "Exercise more." We have to enter the space to be able to coach people on how and why, and I think that's where we are globally now. We know what to do, but the question is, "How do we do this at a larger scale for our patients?" specifically for those that do have maybe limited access as well as perhaps are also among the lower social-economic societies. So, you know, it's quite complex, but it's important to start talking about this.

Heather 24:11

Yeah, and I know it's a big focus of your work, Dr Pikula, especially as the Jay and Sari Sonshine Chair in Stroke Prevention and Cerebrovascular Brain Health at UHN. It's part of what you're trying to implement. Tell us a little bit more about your research and your work in this area.

Dr Aleksandra Pikula 24:23

The work that's actually emerging from people with lived experience, and this is what patients are asking for – essentially, we're implementing the new model of care that was informed by research done through patient-reported outcomes, where we learned that, even for those that had stroke that

recovered really well, there is a lot of invisible stigma and invisible need for more than only pharmacological approach to their stroke prevention.

So, they're asking, essentially, the health care provider to teach them how to take care of themselves. And, as a health care space, we are not ready for that. So, we developed the model of care where we're going to have group visits, let's say 6 to 8 patients together, and the patient will lead the visit with the health care provider in the background to guide with the knowledge.

Heather 25:24

And, there's also the support element there, as well.

Dr Aleksandra Pikula 25:27

Exactly. So, it's really important that peer support is really necessary because when a person has a stroke, they usually come to our clinic at 90 days. You know, we make sure all the numbers look good or they're on appropriate medications and they're pretty much gone from our clinic back to family physicians and they're not ready for the complexity of this care. So, we said, "Okay, let's see if we can start working on implementation of lifestyle medicine approach as an evidence-based medical discipline. So, yeah, there are some good points that we're learning from it, but it's going to take a couple of years really to be able to speak about the success stories from this work.

Heather 26:14

That's great, but as you mentioned, this is coming from what patients are asking for. So, can we talk a little bit more about the patient journey, post-stroke? We talked a little bit about, you know, what happens to women when they have a stroke and why the number of strokes seem to be increasing, but how does it actually impact their life and lifestyle after the stroke? Dr Lindsay?

Dr Patrice Lindsay 26:34

[light electronic music] What we find is those women tend to go into in-patient rehabilitation, even though there's not a big difference in the numbers between men and women on who needs or would benefit from rehabilitation, women tend to be more hesitant to go in. We also find that there may be biases in the system in terms of women getting access to in-patient rehab. Part of the reasoning for that is they feel this pressure as a caregiver—and in their other, you know, gender-assigned roles—to hurry up back to the family, that they can't take time for themselves, that the world will fall apart if they're not back on their feet, so they tend to push the recovery too fast a lot of the time.

It was mentioned earlier the concept of stigma. Having a stroke does bring a stigma. Whether you have physical limitations that are obvious to other people or not, there's still the stigma, especially if it happens at a younger age. We know some very distressing statistics that, when a man has a stroke, the women are there to take care of them – spouse, children, others. When women have a stroke, there's a higher divorce rate, and there's been some really great research about this where, when the woman in a relationship has a stroke, there's a higher divorce rate because, unfortunately, men aren't really wired to be caregivers and caretakers and so, rather than trying to play that role, they often will choose to dissolve the relationship. So, those are really challenges for women and those fears and wanting to get back to normal or not feel-- you know, women are already marginalized a lot of the time, are not getting equal pay, and all those other issues in society, so they feel they need to get back on their feet and be as competitive and show that they're okay sooner than later. [music fades out]

But, like anybody who has a stroke, you need time to let your body heal. You've had a major health insult to your body. Even if you have milder strokes, so you don't have a lot of, you know, weakness or other limitations or challenges afterwards, it takes time for your body to just recover. Things like post-stroke fatigue, which are more of the invisible signs, you know, a bit of a brain fog or cognitive issues that may be mild or less obvious, they really can slow you down or frustrate you. There's also the mental health aspects and the challenges that that brings.

But, it's really important that anybody having a stroke, including women, to have that rehabilitation, to give their bodies time to heal, to do what they can in those early days when the opportunity to have some rehabilitation actually accelerates your recovery, to not miss those windows because it will catch up to you later.

Heather 29:13

Especially the mental health aspects, as you mentioned, I know there's a lot of research being done in that area. Is there anything else you can mention about how important it is to focus on your mental health, post-stroke for women?

Dr Patrice Lindsay 29:23

[upbeat electronic music] Absolutely. So, we did a big campaign around this last fall and the number of women I spoke to about their mental health and their stories were phenomenal. It is a major issue. Women tend to talk about their feelings more and acknowledge their emotions more, but they also tend to have higher rates of anxiety and depression in the general population. So then, when you add the stroke on to that, reducing more depression and anxiety and other mental health issues with women following stroke. But, we do find that women, although they're used to talk about their feelings more, again, will hide that, or hold on, or not share it for fear of the stigma or repercussions that may have on them.

So, we're really trying to push and encourage everyone with stroke, and especially women, to acknowledge that these are normal things. Depression in mental health could be caused just by virtue of where in your brain a stroke happened, whether it impacted areas in your brain that control emotions, or just, it's a major life event and it's normal to have these feelings, and the sooner and more you talk about them, the less impact they will have down the road. [music fades out]

Dr Aleksandra Pikula 30:35

We just recently completed a study that we looked into this for the younger population under 65, and we have observed similar things that Dr Lindsay was just mentioning, but more often, women, compared to men, were unable to return to work, and that has really a huge impact on many things in the working population. Even when the physical disability is minimal or not present, they don't go back to work at year one or year five.

But, it's important to also mention that, you know, we observed that women report significantly worse depression scores, emotional dyscontrol, stigma, as mentioned before, fatigue, sleep, and they also have significantly worse ability to participate in social roles or being satisfied with social roles because those roles have changed after a stroke. Their life has changed. They need to adopt the roles around what has happened with stroke, and now we're exploring the idea of how to parent a child, regardless of their age, after a stroke because women don't have guides on that. It's not only their mental state; it's also, you know, "How do I communicate to my children about the stroke that has happened?" and how my children will learn to communicate with me because I'm now a little bit different person and I need to learn how to establish a new parental role.

It's a very complex matter, you know, for women because they are providers for everyone, and, as Dr Lindsay said at the beginning, you know, they don't spend enough time taking care of themselves, and that's very important for the health care system to embrace, to have options that are beyond, you know, standard care of practice, which usually lingers around through transitional care for perhaps six months after a stroke, not longer, because we don't have a system in place that can embrace that.

Heather 32:45

And so, how do we help them? How do we help women learn to advocate for themselves, particularly in the area of stroke prevention?

Dr Aleksandra Pikula 32:54

Yeah, it's hard. It is hard because we have to develop the model of care that can support that. You know, there are a lot of groups looking into how to do better education, awareness of symptoms, you know,

how to manage certain symptoms, teaching them to take time with tasks. You know, we're also translating the knowledge that is coming from science and from patients with lived experience into the models of care, but it's going to take some time.

And, I mean, talking about lifestyle medicine approaches, there are numerous approaches. The question is, who can deliver that message? And, I think it's important to always go back to basics, small steps, increments. It's essentially making sure, you know, the sleep is addressed, you know, the diet is addressed, the person knows their numbers. It's not about rushing through because they're looking into establishing a sustainable lifestyle for better brain care in order to have better brain health. So, it takes time.

Dr Patrice Lindsay 34:03

And, I think that's where we've, at Heart and Stroke, really been able to kind of step up and support and work closely with the medical community with Dr Pikula and others, is we have that kind of mass audience, so we've been working really hard over the last several years to-- and especially, this year we've just launched a new campaign around prevention and risk factors for women to reach those broader communities. And, it's really about better education – things that we never talked about with women, let alone young women before. You know, we're really pushing that during your pregnancy years and your reproductive years, we have to start this conversation much earlier, on the mental health side, building space and making space for women to come together on our online communities, you know, helping bring groups together to have those conversations with others.

One of the big challenges is we just don't know what questions to ask, what we want to talk about. So, we've been creating tools around how to talk to your doctor and hear your questions and, you know, hear the numbers you should know, and it's talk to your doctor, but also talk to your local pharmacist. You hear that it takes a village...

Heather 35:14

Yep.

Dr Patrice Lindsay 35:14

...This is going to take a village.

Heather 35:15

And, you mentioned to me once that, in a lot of your conversations with the women that you meet when you're travelling, you know, across Canada and across the world, is that you feel like you are often giving them permission to ask these questions and to advocate for them.

Dr Patrice Lindsay 35:26

Yeah. I think women, especially, have felt that they're always in that kind of secondary role of are not taken seriously, you know, but we've heard so many stories about women going to the emergency department with signs and symptoms of stroke or heart attack, and maybe having those interpreted, on the first instance, as anxiety or other things or, you know, related to reproduction. So, it's really important, the messages that I give on this. First of all, you have to be a self-advocate. Unfortunately, that's true. You know your body best. If you know something is different and wrong, be the noisy, squeaky wheel. And, sometimes, we need to do that. We don't like doing it, but we need to do it to get attention and to be heard and to get the care we need early so that, whatever is happening begins with stroke or some serious risk factors, they don't escalate to a point where it is a major crisis.

But, women tend to be shy about pushing back. I had one woman tell me she was in her physician's office, told her story, and basically wasn't believed until her son, who came to the next appointment, said, "Yeah, I've noticed this and that about my mother." "Oh, okay. Well, we'll look into that."

Heather 36:36

Oh, wow.

Dr Patrice Lindsay 36:36

Women shouldn't have to have their husband or son. or other partners be their voice. Their voice should be good enough and should be heard just as loud. [music fades out]

Heather 36:45

I know Dr Lindsay, you started your career in the nursing field, and you've now become one of the leading advocates for systems change, both in stroke care and stroke research. You're also a stroke survivor, yourself, so I wondered if, you know, you could tell us how that impacts the advocacy that you do today and also, what's your number-one piece of advice to leave women with who are listening today?

Dr Patrice Lindsay 37:08

So, unfortunately, at the time that I had my stroke, I also was in that situation and being a woman who basically got brushed off, in spite of having all the FAST signs. My stroke was kind of disregarded in the emergency department by a particular physician, and it took two or three physicians and follow-ups over the week before I got properly diagnosed and treated, and I was brushed off as having stress and overwhelm because of things going on in my personal life. And so, that taught me, and, you know, I was in the middle of my PhD studying stroke as one of the conditions in my quality of care dissertation, so poor doctors didn't realize who they were dealing with.

Heather 37:46

[chuckles] Who they were dealing with, yeah.

Dr Patrice Lindsay 37:48

So, that came back to haunt them, but I knew enough to self-advocate for myself, and that's what others don't know, right? And women don't realize you can push back and that you have to kind of be that voice. So, as I said earlier, be the squeaky wheel when you need to push to be heard, and it's okay to do that because you know yourself best. And, those are the things I've carried with me. That's been my primary motivation for the last 24 years now, since my stroke, is to really teach people that it's not okay not to be heard, and to work with our health care system to understand the urgency, the importance that sex, gender, ethnicity... You shouldn't see those things as influencing-- we shouldn't have those systemic biases in our health care system. We need to treat people with their signs and symptoms in front of you and don't let those other things cloud your judgement.

Heather 38:51

Dr Pikula, Dr Lindsay mentioned the FAST, so could you remind us once again, because we haven't talked about it in this episode, what does FAST stand for? What are the signs and symptoms to look out for? And, also, what is your one last piece of advice to women who are listening today?

Dr Aleksandra Pikula 39:07

FAST is, essentially, recognizing the symptoms of stroke, so it stands for Face, so one side of the face is drooping. That's F. A – arm or leg weakness, but stands for arms. S – speech, any speech difficulty. And, Time. It's time to call 911. So, essentially, if anyone has face, arm, or speech deficits or weakness, it's time to call 911.

So, it's really important to be aware of this. Women are less aware of stroke symptoms and we need to teach them through public health, through Heart and Stroke, through Canadian Stroke Consortium, through any modalities of social media. It's important to raise that awareness. And, as Dr Lindsay said, you know, access to care is something that women are challenged because sometimes their symptoms

are dismissed and those symptoms that are usually dismissed are the ones that are added to FAST. When we say B-FAST, it's essentially B for balance and eyes. It's a blurred vision or loss of vision. And those are less common symptoms of stroke, but somehow do happen more often in women. And, because of those symptoms, sometimes women have to be really strong advocates for themselves for the care that they need to receive, because sometimes those symptoms can be dismissed in the emergency room, and there are studies around that.

[upbeat electronic music] I also want to add that it's important for the scientific society and scientific space to embrace the culture of an ethnicity and race when we're talking about intersexual aspects of gender, because that's where the biases are really very strong and access to care is even worse. The culture that the woman brings to a clinical space, it's different if they come from different parts of the world and we have to be educated to understand and embrace that in the clinical space.

When we talk about prevention, we always talk about the Mediterranean diet. Well, the Mediterranean diet, for certain, cultural groups mean nothing. You know, people come with different dietary habits that we have to learn about, and there are many healthy dietary habits elsewhere in the world that we should be able to adopt when we are doing sort of advice on lifestyle changes – how to prepare food, you know, for women that are usually providers around them, taking care of their families, and learning what's healthy, not only for women, but for their community, for their families, for their children. Teach them what stroke means. You know, what are the risks?

I mean, it's as Dr Lindsay said; it takes a village. You know, there are a lot of partners that have to be at the table for us to be able to do that. We're doing small steps and the increments of those small steps will have a powerful result, but we just have to continue advocating all this. [music fades out]

Heather 42:32

You know, we're also seeing a lot of momentum in the field of stroke, in terms of research and care, and a lot of change in advocacy actually happening on the front lines, especially on the Heart and Stroke Foundation and through a lot of the work that Dr Pikula is doing at UHN, as well. So, what is happening that you are most proud of right now in terms of the work that you both have done? Dr Lindsay?

Dr Patrice Lindsay 42:53

So, at Heart and Stroke, we've launched dedicated research competitions with considerable amounts of funding investment on women's heart and brain health. So, traditionally, that hasn't been the case, so we've got very specific funds dedicated to diving into the research, answering a lot of those questions that we don't know the answers to about women. Do they respond to certain treatments the same way men do? Because we know more men than women participate in the research that we know now. So, that's been a major piece.

A second piece for us has been the big awareness campaigns – the public awareness campaigns we've been doing, the education. And then, the third part is our provincial teams have been on the ground every day at the provincial level where we know health care is funded and organized, really trying to bring that message to the decision makers, to the health system planners and organizers, to increase attention, knowledge, education around women's heart and brain health to build that capacity in, to build clinics that are women-focused clinics, to do some of the work that Dr Pikula is talking about with those very specific redesign of care.

Dr Aleksandra Pikula 44:10

In addition to that, I think there is more momentum in terms of funding women's health research and science here in Canada, as well as in the United States, and that's very positive. But, locally, you know, in our space here, we're doing a lot of studies that will address long-term sex- and gender-based differences in what we call physical and psychosocial and environmental aspects of health outcomes and quality of life after stroke, and also looking into how to examine the sex- and gender-based differences in the utilization of rehabilitation services, including access to support occupational goals and return to work, looking, you know, into long-term models of care that will incorporate lifestyle changes, behavioural changes that are more geared towards women's needs to really understand what can work for the woman, but also for her family and for her community. And, hopefully, we'll bring that to the community and having what we talk about, you know, living community labs, where people will learn from each other, hopefully from these models of care that will embrace women as a core component of the society.

Heather 45:32

[gentle electronic music] Well, thank you both for the work that you both do to move the needle forward in this area and improve stroke prevention and care for everyone. Thank you so much for being here today.

Dr Patrice Lindsay 45:41

Thank you for covering this story.

Dr Aleksandra Pikula 45:40

Thank you, Heather, for having us. [music fades out]

Heather 45:43

[Your Complex Brain theme music] Thank you to Dr Aleksandra Pikula and Dr Patrice Lindsay for joining me on the podcast today and to Shruti Kothari for sharing her story. If you'd like to hear more about Shruti's story, head to our website, uhn.ca/krembil and click on the show notes for today's episode.

[music continues] This episode of Your Complex Brain was produced by Jessica Schmidt. Dr. Amy Ma is our executive producer. Thanks also to Kim Perry, Meagan Anderi, Sara Yuan, Liz Chapman, and Lorna Gilfedder for their production assistance.

If you enjoyed this episode of Your Complex Brain, please tell your family and friends, and don't forget to leave a rating and review on your favourite podcast listening app. We'll be back in two weeks with another exciting episode. Have a great day. [music continues then ends]