

The Rise of Stroke in Young Adults

SUMMARY KEYWORDS

stroke, patients, life, brain, stroke prevention, population, recovering, stroke patients, recovery, study, research, outcomes, people, clinic, team, learn, support, young, nurse practitioner

Tim 00:00

[electronic music plays] [siren wails] When a Code Stroke is called, especially when it's two o'clock in the morning, your adrenaline is pumping. You have to act fast. [music continues]

Heather 00:11

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. [music fades out]

Heather 01:02

[clock ticking] There are more than 50,000 new strokes every year in Canada. That's one about every 10 minutes. [gentle music plays] Stroke is the leading cause of disability in Canada, and the third leading cause of death. The medical after-effects of a stroke can be mild or severe, depending on where in the brain the stroke occurred, the amount of damage, and how quickly you receive medical attention. But for the one quarter of Canadians under 65 who are currently living with stroke, the consequences of surviving can often be just as devastating. Only about half of young stroke survivors are able to return to work. 80% report living with some level of depression, anxiety, or extreme fatigue. Relationships are often impacted, too. But with the right supports, there can also be hope, acceptance, and a chance to rebuild their lives in a new and more meaningful way. In today's episode, you'll hear from Dr. Aleksandra Pikula, a pioneer in the field of stroke in young adults, and two of her patients, Marianne Fedunkiw, and La Croix Calloo. [music fades out]

La Croix 02:23

My name is La Croix Calloo. I was 22 years old when I had an ischemic stroke. I remember bursting into tears. Immediately I said, "I don't know how this could happen to me." I lost the ability to speak, I lost the ability to walk, I lost the ability to transfer any of my mind, or my thoughts in my head, to my mouth. So, I knew exactly what I wanted to say, 110%. However, getting my mouth to say what my brain thought was a little foggy. Just to say the least, it was the scariest moment in my life, and definitely my parent's life, because they had never experienced or knew anybody that had had a stroke so young. [thoughtful music plays] I pride myself ever since I was six years old to be able to draw, to be

able to create, to be able to make stories and memories through my art in any facet that it's in. That's the person that I am. And I wear my heart and my art on my sleeve and my skin. So, to not be able to do that was the most devastating moment in my life. And to say that I had a devastating moment at 22 is surreal. [music fades out] [upbeat electronic music plays] It doesn't seem like it should have happened to me. But in retrospect, I'm looking at it now and I'm glad it did. I know I sound absolutely nuts, but I'm glad because it made me who I am now. And I could have never transformed if it wasn't for my doctors. Dr. Pikula, an angel walking on planet Earth. And Dr. Pagnoux at Mount Sinai Hospital. Like, they are with my parents on the throne of greatness. Yes, it's a traumatic experience. Yes, it's heartbreaking. Yes, it's nerve wracking because a lot of people do not recover from strokes. And a lot of people do not get back all their skills. I don't want to say I was one of the lucky ones, and the blessed individuals to do that. But through hard work, determination, and a little stubbornness, I definitely did it. I didn't think I would, but I did. [music fades out]

Heather 04:40

[music plays] What an incredible and inspiring story. Dr. Aleksandra Pikula is a stroke neurologist, a clinician investigator and Director of Stroke Research with Krembil Brain Institute at UHN. She is also the founder and director of the largest stroke in young adults program in Canada, and she's leading a study looking at the lived experience of this population, and the lifestyle interventions that may help them reclaim their lives. Thank you so much for joining us today.

Dr Pikula 04:41

Thank you. [music fades out]

Heather 05:14

As we heard in the intro, you've had a very accomplished career. So, what interested you in neurology in the first place, and specifically in working with stroke patients?

Dr Pikula 05:23

Well, that's always somehow a difficult question. And it relates really to some deep personal feelings or experiences. So, without going into too many details, I want to say that at the time when I was making this important decision, choosing, you know, which career I'm going to pursue, I had already been exposed to a lot of collateral suffering of my family members and friends with migraine, epilepsy, and even dementia. So, recognizing how brain controls everything we do on daily basis and realizing that such a loss of control even for seconds or minutes, not to say permanently, was quite devastating. So, it really made me want to learn and understand underlying processes, biology, how to diagnose, prevent, and treat those conditions that could cause such a loss. You know, when you look at the neurological conditions, stroke is probably one of the most dramatic neurological conditions in which one can see those sudden losses, but also sudden recovery of function within minutes and hours. So, the acuteness of it was, at the same time, very challenging and frightening. So, I felt I could help advance the field, and I really enjoyed every day I was spending on neurology floors, or, you know, with stroke patients.

Dr Pikula 05:31

So, here you are.

Dr Pikula 05:51

Yes! [chuckling]

Heather 06:47

Today, we're talking about some of the unique challenges faced by younger stroke patients. But first, I'm curious, why *is* stroke on the rise in this population? And what kind of an increase are you seeing?

Dr Pikula 06:58

Yeah, it's quite dramatic, actually. And I find it's very important to talk about this all. The stroke prevalence is on the rise for younger adults, period, and mostly for those that are younger than 50s. And what we have seen in the past 10 years, there is a relative change of roughly 30 to 40% in the risk of stroke in this population. And what's even more frightening is that in the millennials population who live in urban settings, it's even higher. The question is why, because that's the only way we can prevent or perhaps do something about it. So, it's not entirely clear, but more association studies are showing that there is a link between our stressful urban lifestyle and a dramatic increase in prevalence of what we call traditional stroke risk factors, such as high blood pressure, diabetes, obesity, even metabolic syndrome, and of course, you know, in the millennial population, we have to also consider the increased use of drugs and alcohol. So, you know, there is definitely a link, and hence we do see more strokes within this population. So, you know, going back to your question, it's really going to pan out to be a lifestyle. [electronic music plays]

Heather 08:13

I've heard you say in the past that stroke is becoming a 'lifestyle disease' among this population. So, is that what you mean?

Dr Pikula 08:21

Yeah, yeah, definitely. I mean, you know, we treat stroke as an acute event. But this is a chronic disease. And when we talk about, you know, the cause, we have to talk about lifestyle. It's really what leads to that stroke that becomes important. So, yes, the way we live, the way we treat our body, you know, our brain, it's panning out to essentially speak to us in the form of having or not having the illness of any kind, including stroke. [music fades out]

Heather 08:54

What are some of the distinct challenges that these patients face in their recovery?

Dr Pikula 08:59

The challenges for young survivors are multifold. First of all, stroke is a life changing experience for anyone, you know, regardless of age, or sex, or gender. However, for young adults who do experience stroke, they do most of the time have good physical recovery. They can talk and walk. But there are a lot of invisible deficits. They are substantial. Those can really affect the ability to transition back to their professional and personal roles. And when we talk about those, it's really translating to being able to earn a living again, care for young children or elderly parents, and essentially, you know, have those life satisfactions that were pre-existing before this dramatic event. If you want to talk about statistics, we

can say that roughly 50% of young stroke survivors will not return to work, and about 25 will require modification of their workplace. It's even more dramatic that about 80% will have some sort of psychosocial complaints in the form of depression, anxiety, fatigue, and 50-70% will have sleep disturbances. And talking about more objective issues, it's 30-40% of all would have some cognitive dysfunction. So, we're really talking about a lot of invisible disabilities, that in general, you know, people don't think when talking about stroke.

Heather 10:31

So, you're saying that these younger stroke patients, they may recover more quickly medically, but it's returning to life, returning to their world, that's the biggest challenge for them.

Dr Pikula 10:42

Exactly, exactly. So, you know, they do have a good what we say physical outcome, you know. They can talk, they can move, they can participate in conversations. But that's not good enough for a younger population. And when we compare, you know, the quality of life between younger and elderly, the perception of quality of life is quite different. A young population is looking for quality of life that's determined by life satisfaction, while elderly population looks at the quality of life such as being able to talk and walk, and spending time with families and grandchildren. So, the perspective of quality of life across different age group is quite different.

Heather 11:25

Well, let's talk about your new study. And you're looking at stroke in young adults. So, what are you investigating specifically, in this study?

Dr Pikula 11:32

Several years ago, literally in the stroke clinic hallways, we were discussing among, you know, all our health care professionals that spend time together in the clinics, how we're seeing more and more young patients who had stroke. And more so, we noticed that they're looking for more. You know, they just didn't want that sort of a pat on the back, you know, "You're doing great, you're walking and talking, here is your prescription, go back to your family physician." They really were looking for more longer support. And, you know, we just realized how we don't know how to provide that. We did not even-- could not realize, actually -- how much we're missing in understanding their needs, and their lived experience. So, with that in mind, we felt that we're not able to move the field forward in terms of providing better care for post-stroke interventions. And as such, you know, I felt it's important to maybe start from a small, you know, pilot study. And I assembled a large team of clinicians and research scientists at the U of T, including Dr. Katherine Sheehan, she's a UHN child psychiatrist. And we, we share a lot of patients together, and we always discuss those issues. But the two specific aims that we try to accomplish with this study was to understand the health-related quality of life of these patients, with a focus on psychosocial and occupational functioning of young stroke survivors. And really to also understand and determine the patient's preferred preferences and needs regarding post-stroke intervention. And you know, having that in mind, we want to focus on the patient, not on only the healthcare system needs. And you know, here we are now, finishing the study, and finally having a little bit more advanced results to share. [music plays]

Heather 13:25

It's exciting.

Dr Pikula 13:26

Mm-hmm!

Heather 13:27

So, how many patients have you interviewed so far, and what are you learning from them in terms of their lived experience?

Dr Pikula 13:33

The study was accomplished through validated surveys and in-person interviews. Most of it was done virtually given the restrictions we had to go through. We included roughly 100 patients, and we did about 20-25 follow-up interviews. So, what we learned is that this is population that is desperately looking for a wholesome, or if you wish, holistic approach to their recovery and stroke prevention. They're more educated and looking for long-term follow-ups. And as you may know or may not, the usual follow-up timeframe for stroke patients, any stroke patients, is 90 days post-rehab. After that, they're usually sent back to their family physicians. So, this population is really expressively looking for, you know, beyond years of follow-ups. And we do that, nowadays, with the young stroke population. They're looking for mental health services that are personalized, not generic, and not based on the prescriptions of antidepressants. They need easy access to online and virtual professionals, cardiac and exercise programs, innovative art therapies, music therapies for stroke recovery, everything that is not offered through the current healthcare system. And for obvious reasons, you know, because we were treating all comers through our existing rehab and recovery protocols. So, they're really trying to take the charge, and they're looking for essentially self-management programs. However, truly what we're seeing is that as a stroke community, we're requiring to invest in this work. And we have to ensure that our intervention will consider those patient-reported outcomes. And in order to improve the lives, not only the stroke outcomes in terms of physical improvement of patients with stroke. So, a lot of work to do, together, is in front of us.

Heather 15:38

Well, I know a lot of your research also focuses on gender differences in stroke. So, I'm just curious, why are younger women in particular at a higher risk than young men?

Dr Pikula 15:47

Yeah, you're right. I mean, in last decade we're doing a lot of research on sex and gender differences in stroke risk management and outcomes. And through our research, we learned that the burden of stroke risks such as, you know, the risks that I already mentioned, like obesity, metabolic syndrome, diabetes, high blood pressure, has much more profound effect on stroke risk in women compared to men. And that effect is increasing risk in middle-aged woman by 30-40%. So, the reasons seem to be hormonal influence, or rather loss of protective effect of estrogen on vascular health. But at the same time, there is also accumulation of risk factors at the same age. So, the two together work in synergy. And as such, they do cause increased risk for stroke in pre- and peri-menopausal age. And it's important to be aware of that because there is a lot we can do. And there is a lot we can work on in prevention, you know, first

of all, education. And again, it goes back to the lifestyle interventions that we mentioned before that we could, as a provider, really work hard with our patients. [music plays] Even in primary stroke prevention, when one should focus on educating young women on maintaining healthy weight and healthy blood pressure, just to start with.

Marianne 17:20

My name is Marianne Fedunki, and I had my first stroke at the age of 34. I woke up one morning, having had an excruciating headache in the middle of the night. My ability to grip was thrown off. It took me three dedicated tries to pick up a t-shirt. But then I turned the corner, bumped into my husband, who looked at me with horror in his eyes, and he says, "Oh, my God. I think you've had a stroke." And when I tried to speak, my words were garbled, that I was trying to express to him, would come out, "Blah-de-blah-blah-blah." And I knew inside my head what I wanted to say, but what was coming out was nonsense or gibberish. At which point he said, "Get dressed, I'm taking you to emergency." I had no risk factors, no high blood pressure, no high cholesterol, no diabetes, none of that. No visible indication that I would fall victim to a stroke. [music fades out] I recovered from that particular stroke, and all was quiet for 15 years until I noticed that I was having chest pains like an elephant was standing on my chest. I had an angiogram done at Toronto Western Hospital and they found that two of my three coronary arteries were entirely blocked. When they put the schematic diagram on my chest in the angio suite, I actually cried. And one of the residents said, "Why are you crying?" and I said, "I thought I was healthy." So, I had a coronary artery bypass graft, a quadruple one, and then I was recovering from that when in 2016 while in Oxford, England, where I had done my postdoctoral fellowship, I had three other strokes. And this time they included a hemorrhagic, or bleeding stroke. I was very interested to hear about Dr. Pikula's study because I do think there's a lost population of people who have strokes. [music plays] If you're in your 20s, 30s, 40s, 50s, you know, your main earning years, your career building years, your family building years. What are the losses that those people face if they have a stroke? And how can they get their lives back on track to being happy, productive people again? I wanted to be part of Dr. Pikula's study because I wanted to add my voice to the group of us who are younger people who are living after a stroke, so that we could all help people understand the challenges that younger people face when they're recovering from stroke, as well as allowing people to understand, both our families and our healthcare team, so that they know what our needs are. And I think part of it is being brave enough to be honest, to be able to express ourselves about what we're sad having lost. Because there's always a loss. Strokes chip away at an individual, but most of me is still here. So, I wanted people to understand that, although we've had this stroke journey, that's just one part of our life story. And to let the community know how they might help us reach our full potential after a stroke. [music fades out]

Heather 21:13

Well, we just heard from one of your patients, Marianne, about her stroke journey. So how are the lifestyle interventions in your study helping Marianne adjust to her new life?

Dr Pikula 21:23

I mean, she's an amazing motivation story, I want to say. You know, she recovered well before we started our study, but was definitely a driving force, as many similar patients of her age and experience. So, what we have learned is that through this multidisciplinary approach within our clinic, you know,

through cardiac rehab, psychiatry, ongoing allied health support, you know, doing the different lifestyle medicine surveys, and questionnaires, and following up on that, while giving small interventions of what to do, we have proven that through her experience and the experience of other patients, this is the model that could work. So, we are yet to develop the full intervention, and this is really based on funding that we're hopeful to get. But what we also learned through our experience with Marianne is, the only way to help our patients is not to throw everything at once at them. You know, really allow them to take small steps at a time, and to continue to be available for them beyond those 90 days that I mentioned. So, I've been following Marianne for many years now, and many other, you know, young stroke survivors. [music plays] And just the benefit of those long and prolonged follow-ups, and checking in every three to six months, helps a lot.

Tim 22:55

I'm Tim Stewart, I'm a nurse practitioner with the stroke team at Toronto Western Hospital. I originally came to the stroke team back in 2013 after a long career in the emergency department. [siren wails] When a Code Stroke is called, especially when it's two o'clock in the morning, and your pager goes off. [pager beeps] Your adrenaline is pumping. [heartbeat whooshing] You have to act fast. So, initially we'll get a call from the paramedics, and they will let us know their stroke is coming in. From there, we call the emergency department, who then is starting to prepare for the stroke. [heartbeat monitor beeps] As soon as that patient arrives, we're called immediately. We ask a few questions, organize imaging for that patient, and whisk them off to the CT scanner. The CT scan techs will get the patient on the table for the scan. The stroke neurologist will look at the imaging as soon as it's up. And the nurse practitioner, if at home, will even be coming into hospital to administer clot busting drugs to that patient. The nurse practitioner is the team lead for a Code Stroke, and it's kind of like a Formula One race pit crew, where everybody has a role and a responsibility to make sure everything is done. The stroke team has been super great to work with. And although we have a close-knit team of stroke neurologists and nurse practitioners, the team is so much bigger than that, because it involves everybody trying to do their best for our patient. From the paramedics, to the emergency nurses, to the neurology team, to the residents that spend their time learning on our floors, to the interventional radiologists, and all our allied health team, including nurses, physiotherapists, occupational therapists, speech and language therapists, as well as social workers. What I love about my job is really the amount of time I get to spend with patients. So, in the emergency department, you quickly ran from bed to bed, but in stroke, you see them throughout their hospitalization. You get time to get to know them and their families, you get to see them over the long-term, and see how well they've been doing. So, it's very gratifying to actually see the outcome of all the hard work that they've done. And that you sort of appreciate that you've hopefully add a little part to that. [music fades out]

Heather 25:36

That was Tim Stewart, a nurse practitioner in the stroke unit. So, what is it like to work as part of this leading stroke team at Krembil Brain Institute?

Dr Pikula 25:44

Well, it's amazing. We are very cohesive, and we learn from each other. We bounce back ideas to each other, we share, you know, good and bad. [chuckles] And we talk a lot about our patients, you know, as I said. This study also developed in, you know, clinical ways, and this is the way we advance the field.

But, you know, we learn a lot from our team. They're critical in our acute and stroke prevention care. And I cannot say more, I think we're quite unique, actually, across Canada to have such a model where we have now five nurse practitioners as a part of the neurovascular team.

Heather 26:24

What's the ultimate goal of this research for you? What do you hope to achieve, long-term?

Dr Pikula 26:29

Well, every researcher's ultimate goal is, you know, to improve patients' health or disease outcomes. So, for us in the Stroke in Young Adults program here at Toronto Western, the ultimate goal is to develop multidisciplinary and innovative interventions that are based on what we just talked about. And really, it's to move forward the stroke prevention model that will continue to improve stroke recovery, as well. But I think the ultimate goal for the research is also to spearhead that further beyond the walls of the UHN, and really continue providing community education at a higher level. You know, without supporting the community and educating the community about stroke, I think it's impossible to elevate the awareness of the risks, but also of what we are doing and what we can offer. I think that here at UHN, we're at the forefront of such a stroke prevention model, and it's in development. The Secondary Stroke Prevention Clinic is moving forward to the model of lifestyle medicine, as well. And as I said, we're moving the envelope forward in the sense that, while perhaps, depending on our funding and institutional and community support, together I'm sure we'll get there. [music plays]

Heather 27:55

Well, I wanted to ask you, too, how rewarding is it for you personally to see one of your patients like Marianne recovering and getting her life back on track?

Dr Pikula 28:02

Well, that's the whole point, eh? [chuckles] That reward is priceless. I mean, to see patients like Marianne claiming her life purpose, having a smile on her face, and you know, learning how and what else she likes, other than what she used to do before she had a stroke, is amazing. And, as I said, it truly takes a village of many of us to do so. But the patient is the key. I mean, they have to participate. They have to be motivated. They have to be hopeful, and they have to believe, with our help in the background. So, it's absolutely rewarding. [music fades out]

Heather 28:38

Well, before we let you go, I know obviously stroke education is a big priority for you and for your team. So, can you remind us, what are the signs of a stroke? And how important is it to seek help right away?

Dr Pikula 28:50

Well, right to the point, you know, I think this is probably the most important part of why we're talking. It's to educate people about the signs of stroke. We use an acronym FAST, F-A-S-T. So "F" stands for face. And I always tell my patients, if you notice a droop of your own face, or an uneven smile on a person's face, this is a warning sign of strokes. So, seek attention immediately. "A" stands for arms, any arm numbness or weakness of a person, or someone you are with. This is a warning sign, as well. "S" stands for speech. So, ask the person to speak. If you notice any slurred speech or trouble expressing

their thoughts, this is, again, a really important sign of stroke. And then "T" is for time. If someone is experiencing stroke symptoms of what I've just mentioned, it's really time to act FAST. And I always say, 9-1-1 is the only way you're gonna get-- you're gonna get on time, and you're gonna get appropriate stroke care that is well established here in Toronto. And we can help immediately if that would happen. So, remember FAST, act fast.

Heather 30:11

[music plays] Well, thank you so much for joining us today. I really enjoyed talking with you, and I wish you the best of luck in your research.

Dr Pikula 30:18

Thanks very much for inviting me, and I'll share whatever we learn. [music plays]

Marianne 30:27

I'm not just a stroke sufferer, I'm many things. I'm a writer, I'm a PhD graduate, a historian, a former journalist. I'm somebody's wife, I'm somebody's aunt. I'm still all of those things. [music plays]

La Croix 30:43

I want people to know that it's okay being vulnerable. It's okay to not be okay. Hello, my name is La Croix Calloo, and I had a stroke. No, that does not define me. It is a part of my story, but it's not my whole story. It's not. [music fades out]

Heather 31:18

[Your Complex Brain theme music plays] Thanks so much for joining us on this episode of Your Complex Brain. And a big thank you to Dr. Aleksandra Pikula, Marianne Fedunski, La Croix Calloo, and Tim Stewart for participating in today's episode. If you'd like to hear more from Marianne and La Croix about their stroke journeys, head to our website UHN.ca/Krembil, and check out the links in today's show notes. This episode of Your Complex Brain was produced by Jessica Schmidt. Executive Producers are Tobin Dalrymple with Pilgrim Podcasting and Carley 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 favorite podcast listening app. Thanks for listening. We'll be back in two weeks with another exciting episode. Have a great day! [music fades out]