

# JO-ANNE'S STROKE STORY

October 2024

"Hmmm... why am I making so many typos on this document? That's not like me. What's going on? Is there something wrong with this keyboard?"

And that's how Jo-Anne quietly entered the realm of a puzzling and debilitating stroke that ravaged the entire left side of her body, on March 2, 2023.

"I WAS AT HOME ON MY COMPUTER WHEN THE SILENT ASSASSIN STRUCK AND CHANGED MY LIFE FOREVER".

She alerted her husband and told him that the fingers on her left hand were numb, and she was making typos. Despite her plight, not to mention her husband's plea to call 911, her commitment to her work never wavered, "I've got to finish what I'm doing first". But when her arm went limp and a crushing paralysis set in on her entire left side, there was no denying something was seriously wrong and 911 was called. Within minutes, paramedics were at the door, taking her to the frenetic sanctity of The Ottawa Hospital - Civic Campus' emergency department.



The Civic Campus' Stroke Team led by Dr. Dar Dowlatshahi was waiting for Jo-Anne as the ambulance pulled up and immediately went to work to diagnose and stabilize her. Realizing that Jo-Anne was still in the midst of a stroke, a brain hemorrhage, Dr. Dowlatshahi sought her permission to take a trial drug that would possibly more quickly stop the bleeding. Fortunately, she was experiencing no cognitive deficit and was "with-it". However, it would be a 50-50 chance that she would actually receive the trial drug and not a placebo, the clotting agent normally used in such an emergency. Permission was granted and the bleeding ended quickly saving Jo-Anne from further long-term brain damage, but she will not learn which drug was administered for a couple of years when the drug trial ends.

"Dr. Dowlatshahi and his entire team were incredible... I've never seen such a magnificent blend of medical proficiency and bedside manner like that," she said. "My confidence was buoyed as they made me feel like they were in control and could overcome any medical challenge that they faced... and they did!"

Following her hospital stay, Jo-Anne started outpatient stroke rehabilitation at Elizabeth Bruyère. Rehabilitation, she admitted, was a humbling experience. "I had to learn everything all over again—how to walk, how to use my hands and all while under the curse of stifling fatigue... one of the byproducts of a brain hemorrhage". She recounted how impactful the physiotherapists and occupational therapists at Bruyère were, "You become so attached to the people that help you rebuild".

## QUESTION AND ANSWER

## How has having a stroke changed your life?

After experiencing the stroke, life shifted dramatically for Jo-Anne. The stroke prompted a deep reflection on mortality and legacy, particularly in her relationship with her children. Conversations with her children now often include practical advice. She organized her Will, driven by a desire to ensure her loved ones were prepared.

The stroke came suddenly and without warning, a reminder of how unpredictable life can be. "A stroke is not something you feel pain with. It just happens." Despite its sudden onset, it brought about a profound shift in her perspective. She became more cognizant of the smaller things. Now, she focuses on the little joys—making people smile with small gestures—and when appropriate, learning to say "no" more easily.

She has found herself travelling more while partaking more often in arts, sports and entertainment pursuits. "We've always been well-travelled, but I think we're doing more of it now." Though she now prioritizes rest—going to bed earlier and ensuring time to recover—so she feels more in tune with the moments that matter.

A critical part of her recovery involved the support of the Elisabeth Bruyère's

exceptional and first-class rehabilitation team, including her formidable occupational therapist, who played a pivotal role in guiding her return to work. Initially, her healthcare team advised against rushing the process, but Jo-Anne was eager to return to work after just a few months. Her occupational therapist successfully intervened and encouraged a more gradual approach. Together they devised a 12-week back-to-work schedule, a structured transition that was crucial in ensuring her successful return to work.

Grateful for the support from her NSERC colleagues and leaders who stepped in during her absence, she did notice the challenges of returning to a work environment and recognized that she was not as efficient as she was before.

### How are you living your life differently?

Jo-Anne lives her life quite differently now. "I have no feeling on my entire left side," she explained, with a split running from the top of her head down through her face and body all the way to her feet. "It's like when you go to the dentist and they freeze your mouth for a cavity—you know that numb, heavy feeling? That's how my entire left side feels". This loss of sensation has brought unique challenges, physically, mentally and emotionally. She can move her left side, thanks to rehabilitation and has strength, but the sensory loss has had a profound impact. "I don't know hot from cold, so if I'm eating something and there's food left on my left side, my husband has to wipe it away. During allergy season, he has to wipe my nose because I can't feel if it's running." There are also more subtle challenges—drooling that she can't control, a heavy eyelid, and difficulty placing her left

foot on the ground.

At work, she's adapted with tools like Dragon Software for speech, which helps her overcome issues with typing. "Sometimes I make mistakes because I don't have the tactile feedback in my brain that I've pressed a button all the way down not to mention the ongoing numbness in my fingers." While her right hand is faster, dictating has become an effective workaround.

Her daily life now revolves around accommodations and finding new ways to enjoy old passions, like baking and spending time with family. Her resilience shines through, though she acknowledges that living with an invisible disability can be frustrating for both her and those around her. "To friends, relatives, and even my husband and kids, I look absolutely normal. But inside, the sensory loss, the cognitive fatigue—those deficits are huge."

And it is these deficits that now place pressure on her ability to nurture and enjoy her relationships and intimate moments with the ones she loves the most, her husband and two boys. Better sleep and rest habits have helped in this regard as has a better understanding of, and ability to avoid, the things that trigger her frustrations... concepts and techniques that the Bruyère rehabilitation team has counselled her on.

Despite these struggles, she remains determined that the stroke isn't going to keep her down. Jo-Anne has adapted and found ways to enjoy her life, even if she must do things differently.

### What three things would you tell a person that has just had a stroke?

Firstly, Jo-Anne acknowledged the importance of open and two-way communication with her family and loved ones on issues ranging from day to day living to those relating to intimacy. "Your family must be aware of your struggles and especially your triggers so that they can be patient and even empathetic as you proceed on your post-stroke journey of recovery. With respect to the sensitive topic of intimacy, you and your partner may have to reimagine your post-stroke physical interactions as "things" have changed. The first step will be frank yet loving two-way communication."

Her second piece of advice was, "Don't be afraid of dying but you MUST live in the moment and continue planning for the future." Reflecting on her own predicament, she emphasized that living in the now is about embracing life to the fullest and such a strategy will help both in the short- and long-term especially if it includes a robust physical exercise regime paired with a healthy diet and overseen by regular check-ups with her GP. "Since my stroke, I work out 5 days out of 7 at a local gym and carefully control my food intake and it has really made a difference in my physical strength, emotional and mental outlook!"



Her third piece of advice was deeply personal: "You've got to hug your kids and tell them you LOVE them." She shared how the stroke has made her even more aware of the importance of family, and how burdensome it can be to reflect on everything she's gone through. "It may have been my day of infamy, but it was also a day during which I redefined my love and respect for my husband whose instincts and persistence saved my life."



JO-ANNE'S JOURNEY IS FAR FROM OVER, BUT HER STRENGTH, HUMOUR, AND TENACITY ARE A TESTAMENT TO WHAT IT MEANS TO SURVIVE—AND THRIVE—AFTER A STROKE.

# Thank you, Jo-Anne, for sharing your story!

