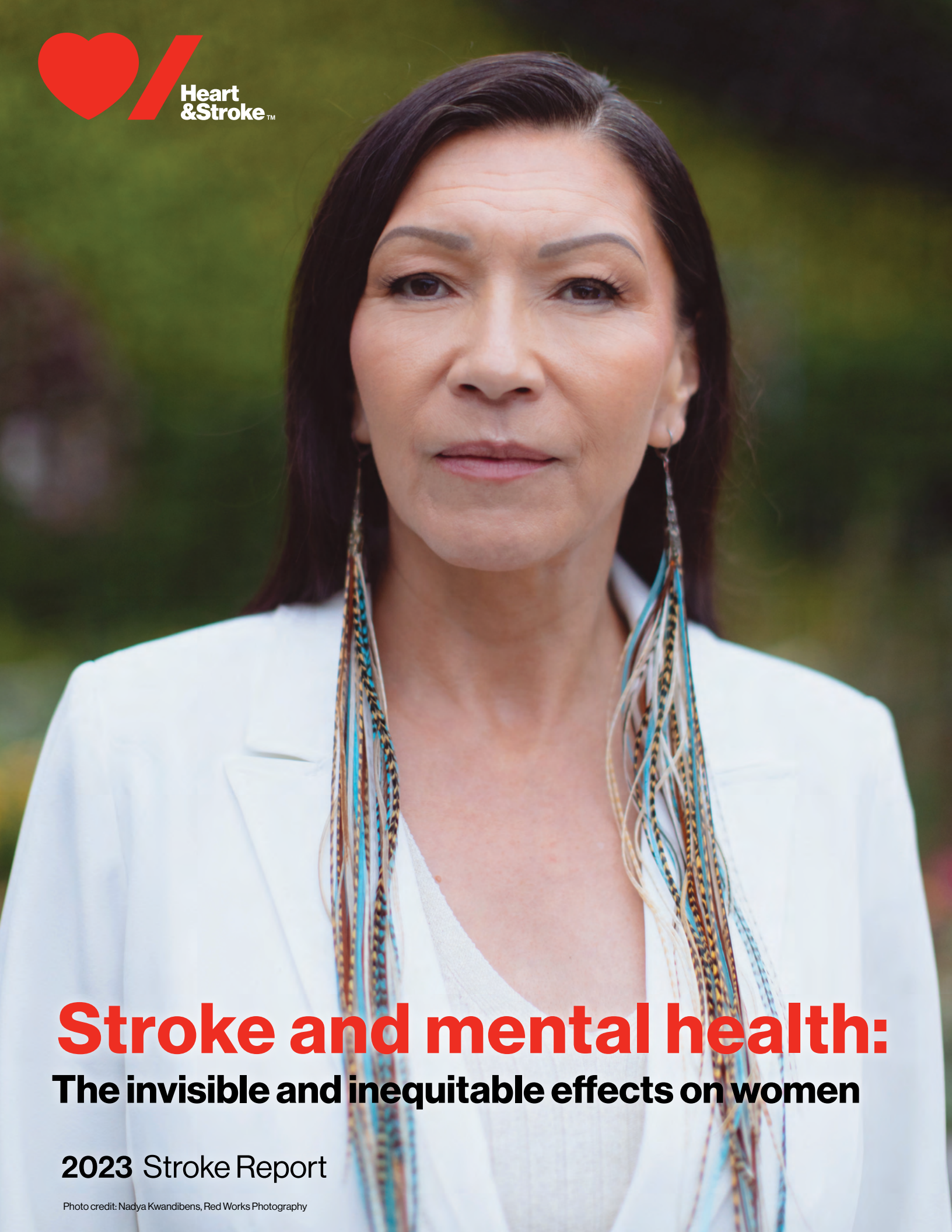


Heart &Stroke™

Stroke and mental health:

The invisible and inequitable effects on women

2023 Stroke Report

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The burden of stroke on women

The impact of stroke across the country — and around the world — is enormous and it is growing. Stroke is on the rise in Canada due to the aging population and younger people having strokes. At the same time, improved awareness and better treatment and care mean many more people are surviving stroke.

In fact, new data reveal that more than 920,000 people in Canada are now living with the effects of stroke, which include mental health conditions such as anxiety and depression. Although these are less visible than physical effects, they are no less devastating. **And unfortunately women are hit the hardest.**

Stroke can happen to anyone, at any age and at any time. But women are disproportionately affected by stroke. While stroke can happen at all ages and life stages, women are more at risk at three key times in their lives:

- Stroke in pregnant women is three times higher than in women who are not pregnant.
- Women are at higher risk after menopause.
- Women are at higher risk when they are elderly.

Gaps in understanding and awareness around these elevated risks mean women do not always get timely care for stroke.

As age is a risk factor for stroke and on average women live longer than men, elderly women have the most strokes — and their strokes are more severe. At the same time, stroke rates are increasing among younger women in Canada. Furthermore, women who experience stroke are at higher risk of dying than men — in 2019, 32% more women died of stroke than men. And when women survive stroke, their outcomes are worse — including the toll on their mental health throughout their recovery journey. Many women do not get the support they need.



More than **920,000** Canadians are living with the **effects of stroke.**

"The gender inequity starts with the difference that older women are most affected by stroke. They are also more likely to be single or widowed because they live longer than men, or if they have a partner, that partner will be older and less able to help them, whereas when the situation is reversed, women are more likely to be caregivers," says Dr. Mark Bayley, Program Medical Director at UHN-Toronto Rehabilitation Institute and a Heart & Stroke funded researcher who is part of a team exploring methods to improve women's participation in stroke recovery research.



Women are disproportionately affected by **stroke.**

Many factors can affect women's health including geography, race, and ethnicity. Women who live with lower socioeconomic status are more susceptible to stroke and heart conditions than those with higher incomes. Women in general earn less than men which can profoundly affect their ability to access and afford post-stroke recovery services — and the gender pay gap is worse for racialized women, Indigenous women and women with disabilities. Full-time employment is more likely to include access to extended health benefits yet, according to a Statistics Canada report, in 2021 68% of women aged 20 to 54 were employed full time compared with 81% of men. And there are disparities between population groups, as Indigenous and immigrant women have lower rates of employment.

"We have revolutionized stroke care in Canada over the past several decades, but recovery services have not kept pace," says Dr. Patrice Lindsay, Director, Health Systems, Heart & Stroke. "We need to improve support after stroke including more mental health services, and we need to ensure women have equitable access and their voices are heard."



I was a new mom and suffering from a brain injury and I was just so tired. Navigating services was really, really hard and for me to ask for help took a lot. I was feeling beat down, defeated and could not advocate for myself.

— Megan Snook, living with stroke



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— Dr. Mark Bayley, Heart & Stroke funded researcher

Stroke recovery – mind and body

A stroke happens when blood stops flowing to any part of the brain, damaging brain cells. The brain is the control centre of the body; it manages everything we do, from how our organs function to how we think and move. Every person who experiences stroke experiences it differently. It can impact everything from the physical ability to do daily tasks and activities, to communication and social interaction, mood and emotion.

Excluded from rehabilitation

The goal of rehabilitation after stroke is to help people recover abilities and regain as much independence and quality of life as possible. Yet of the stroke patients who leave inpatient acute hospital care in Canada, only about 16% go directly to in-patient rehabilitation, and only 19% go within the first month after leaving hospital. Fewer women than men participate in stroke rehabilitation.



Women have **fewer** opportunities to participate in stroke **rehabilitation** than men.

The reasons for this are likely multiple. For starters, women continue to be under-represented in clinical stroke research trials, including those focused on stroke rehabilitation. A systematic review of stroke rehabilitation literature revealed that 57% of the patients included in rehabilitation studies were male and only 43% were female. When women are included, researchers don't always analyze the data by sex and gender — and as a result, approaches to care and treatment do not equally apply to women. This includes existing research examining mental health post-stroke.

Gender roles and expectations that society places on women also play a role. Dr. Lee-Anne Greer is a psychologist in Prince Edward Island who works with stroke patients. In her 17 years of practice she has seen women discharge themselves early from rehabilitation because their children need them but has not witnessed similar behaviour in men. This means these women are also missing out on access to mental health therapy if is provided as part of in-patient rehabilitation.

Dr. Bayley suggests an age bias might factor into older women being excluded as they are more likely to live alone without a caregiver to help them participate in rehabilitation. Additionally, women experiencing stroke may be frailer than men, meaning they are older, less physically active and more prone to exhaustion.

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This exclusion takes a toll on women's physical and mental health as they recover.

Mental and physical connection

The mental and emotional aspect of stroke recovery is as important as — and connected with — the physical gains. It all works together and is interdependent.

Women are less likely to return to their homes after a stroke than men — especially older women, and in fact almost twice as many women as men go to long-term care instead. Research has shown that women are 60% less likely to regain independence in their daily activities after a stroke compared to men. Not surprisingly, as a result, women report worse quality of life after stroke. Poor quality of life affects mental well-being and vice versa.

"I wish that mental health and physical health were not seen as a dichotomy. The emotional and psychological aspects of recovery should be a standard part of rehabilitation," says Dr. Treena Blake, a hospital-based neuropsychologist in Vancouver.

Depression is common after stroke and there are two significant predictors. The first is a history of pre-stroke depression, and the second is functional dependence — which means requiring help with activities of daily living such as eating, personal hygiene, dressing and being able to move around independently.

Given that about 60% of people who have had a stroke are left with some stroke-related functional limitations and more than 40% are left with moderate to severe disability, requiring more intense rehabilitation and support in the community, many are at risk of depression. For women this risk is higher still, as they experience more activity limitations after stroke. In fact, when women have a stroke, they have lower overall levels of both mental and physical well-being.

"The severity of functional limitations after stroke has been identified as one of several risk factors for depression, so anyone dealing with this is at higher risk," says Dr. Gayla Tennen, a psychiatrist at Sunnybrook Health Centre in Toronto who works closely with people who have had a stroke.

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At the same time, post-stroke depression can adversely impact functional gains and outcomes, according to Dr. Bayley. "If you experience post-stroke depression, then your chance of becoming independent is lower and your chance of returning home is reduced and your chance of dying increases."

Dr. Abe Snaiderman, Director of the Neuropsychiatry Clinic at UHN-Toronto Rehabilitation Institute, points out that both stroke and depression are neurological issues. "It is the same circuitry, it's the same brain." He also underscores that the physical and mental aspects of recovery cannot be separated. Stroke can damage the areas of the brain associated with emotional regulation and result in mood issues, on top of the psychological and social consequences of suddenly developing physical and cognitive deficits. Dr. Snaiderman further stresses that if a person with stroke is depressed, they would find it very challenging to successfully carry on with a rehabilitation process and enjoy a good quality of life.

Many of the physical effects of stroke are apparent, but other effects that are cognitive, mood- or communication-related can be harder to recognize. These "invisible" deficits can be ignored or misunderstood, leaving those experiencing them feeling frustrated and isolated. Fears around stigmatization can pose additional challenges.

Janet's story

Not alone, but isolated

Janet Millen had retired from teaching and was running a youth theatre company when she had a stroke at 58. Fortunately, she had a lot of support, including a strong marriage, a close relationship with her young adult sons, and many friends – mostly retired teachers who actively supported her recovery.

But her change in role as the heart of her family after her stroke was difficult to accept, as was losing her role with the theatre company. She can feel isolated due to aphasia — a language problem that affects the ability to talk with and understand others and read and write. Janet's aphasia is mild and often goes undetected, but she cannot follow and participate in conversations with more than one person at a time and finds most people speak too quickly. She sometimes struggles to find the right words. She often has to step back from social situations or walk away from family conversations. "People don't really understand what aphasia is. Even my very good friends still don't get it."

Janet has experienced depression and grief during her recovery. "After years of constant struggle with frustration, low self-esteem and mild depression, I realized that poor communication is part of my life."



It has been 16 years since her stroke. She has good days and bad days but she is mostly doing very well, and she has written a book about her stroke experience. "Now that I have had a stroke, I am not the woman I was, but in a woman's life there are the things you can do and there are the things you cannot change. We can all learn and grow, despite the circumstances. Growth is always an option in making life more meaningful. You need to just carry on through the things you care about, find the things that are important and meaningful."

Lisa's story

Healing at home and finding balance

Lisa Meeches had a stroke in 2016 while attending a powwow with her husband and young daughter at Siksika First Nation in Alberta. Emergency first responders took her by ambulance to Foothills Medical Centre where she received world class, life-saving acute stroke care.

Lisa's business partner, Kyle Irving, flew to Calgary immediately with Lisa's two sons and one of her spiritual advisors. Kyle knew that Lisa had to return home as soon as possible to Long Plain First Nation in Manitoba to recover. It wasn't easy, but he made it happen.

"I wasn't going to take no for an answer, that's for sure," Kyle says. "Lisa has such a strong connection to the land. I just knew that she needed to be home and that the people who could help her get better were all there too — her Elders and the spiritual people she has relied on her whole life," he adds.

"I needed to be on my traditional territory, surrounded by my traditional items and my Elders to heal," says Lisa. "There is trauma with experiencing stroke, and there is trauma from past generations for Indigenous people, and Indigenous women leaving us way too soon and the discovery of little bodies across the nation. There is an emotional and mental impact to all of this and it takes a toll on our health."

Lisa drew strength in her recovery from many sources. She was motivated by her desire to brush her daughter's long hair and to dance powwow again. She was determined to return to her rewarding career as a film and television producer. She has accomplished all that. She was inspired by watching Paralympic athletes and by interacting with other stroke survivors in the rehabilitation program she attended, most of whom were much older than she was.

She also credits her team of health professionals, her family, her community and her Elders, as well as spiritual advisors across Turtle Island who participated in a long prayer chain for her recovery. "I really believe in prayer — everyday is a sign from the Creator," says Lisa, "And nobody gave up on me. I had such a great cheerleading team."

Lisa continues to see an Indigenous therapist and would like to see more discussion about mental and emotional health when it comes to stroke recovery. She urges other women who have experienced stroke to check in with themselves, to have the tenacity to stop and rest, find balance and say no when they need to.

"I have learned to live every day to the fullest. I delegate more," she says. "I really take care of myself and surround myself with positive people and spend time with family and friends. I've also learned not to engage in fights I know I won't win."



Women are more at risk of depression and anxiety

"Women have worse outcomes and health related quality of life after stroke, and depression is a contributing factor," says Dr. Tennen. Depression or cognitive changes post-stroke are common — studies show this happens to 30% to 60% of people in the first year after their event.

And women are at even greater risk. The Canadian Community Health Survey reveals that women have higher levels of mood disorders than men, and this is more marked in the 18 – 34 age group. More women than men perceive their mental health to be poor or fair. According to the Centre for Addiction and Mental Health (CAMH), women have higher rates of mood and anxiety disorders than men — which puts them at greater risk of developing depression after stroke. The findings from a study that considered a sex and gender-based analysis of depressive symptoms post-stroke reveal that women are 20%–70% more likely to experience post-stroke depression than men and some studies show that women are more likely to experience post-stroke anxiety than men.

Many emotional reactions can be experienced after a major health event such as a stroke, ranging from sadness to anxiety and clinical depression and others. Early recognition and intervention is important to make sure people are best supported in all aspects of their recovery.

Ages and life stages

Depending on their age and their life stage, women can face different challenges that affect their mental health as they recover from stroke. Elderly women are particularly over-burdened by stroke, representing a large proportion of the total population with stroke and they are missing out on access to treatment, care, and rehabilitation.



Women are hit the hardest by **depression** and **anxiety** post stroke.

"Many women in their 80s are still incredibly high functioning. Depression is not a normal part of aging — post-stroke anxiety and post-stroke depression have a significant negative impact on this age group," says Dr. Tennen.

Younger women are also at risk as both younger age and previous depression or anxiety are predictors of post-stroke anxiety.

"Younger women may be working or raising their children, or both, and they often have many roles and responsibilities. They may have difficulty managing these post stroke, and this can be emotionally challenging. Very few people their age, or in their social circles, can relate to having a stroke, and it's not uncommon for them to feel disconnected and isolated," says Dr. Tennen.

Gender roles play a role

The expectations placed on women are not only a barrier to participation in rehabilitation, they also affect women's mental health as they learn to cope with changes to their lives after a stroke, including their roles and relationships. Women do not always put their own health first, and they often play a greater caregiving role than men.

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Dr. Greer has witnessed a disparity in terms of roles and expectations for women. "I have seen when mothers have had a stroke, they can really struggle to take on all of the roles that they had before, and potentially be trying to get themselves back to work at the same time."

Helping women to recognize that focusing on their needs and directing compassion towards themselves is not indulgent or selfish is a significant component of Dr. Blake's work. "I try to help women understand that putting their own needs first during recovery is actually helping their family. Working towards greater independence can reduce the perceived burden and stress on the whole system. And they can usually get on board with this idea because it doesn't require a major shift in their thinking."

Megan's story

Challenges for a new mom

Megan Snook was about 30 weeks pregnant with her second baby in 2018 when she knew something wasn't right. She spent the next week seeking help for her concerns. She called her doctor. She went to the hospital but was sent home. Her blood pressure spiked, she had a severe headache and her vision became blurred. She went back to the hospital but was dismissed again. When she returned home again she had two strokes, which left her fully paralyzed on her left side and unable to see. She was taken from Campbell River, BC, to Victoria by ambulance, where she had an emergency caesarean and received treatment for her stroke.

Megan faced many challenges in her recovery. "I was a new mom and suffering from a brain injury and I was just so tired. I have post-stroke pain syndrome and it is just physically and mentally draining to have pain all the time."

Support options such as physical therapy, child care, caregiver leave, and financial assistance were difficult to find, harder to access and often insufficient. Her young age worked against her as she was expected to recover faster and was denied some services that were only available to seniors. "Navigating services was really, really hard and for me to ask for help took a lot," she says. I was feeling beat down, defeated and could not advocate for myself."

Megan and her family have moved to a farm in Saskatchewan, which has provided a healthier and more manageable lifestyle. They have dogs and cats and horses — which she refers to as her therapy.
"I am doing better out here. My mental health is better, my physical pain is better."



Gaps in screening and support

According to the Canadian Stroke Best Practice Recommendations (CSBPR), everyone who has experienced a stroke should be considered at risk for post-stroke mental health issues, which can occur at any stage of recovery. Yet screening is not happening as often as it should.

"When Heart & Stroke surveyed stroke prevention clinics across the country, we found that only 54% reported that they routinely screened for post-stroke depression," says Dr. Lindsay.

Dr. Tennen believes increasing awareness and resources around mental health after stroke could improve the situation. "I think physicians and other health care professionals work very hard to manage the physical aspects of stroke and recovery, but the systems and resources needed to screen patients and then to treat them, are often lacking. I think patients should be educated about emotional changes following stroke and they should also be screened. People often suffer in silence until they are asked the specific screening questions." When mood issues are routinely addressed, they become normalized and destigmatized.

If women are not being screened and identified, they cannot be referred to the services they need. Yet there are additional challenges even if screening takes place. "Screening is important, but it is also difficult because there are not a lot of resources available. You ask the questions and then you're kind of stuck," says Dr. Blake. Her rehabilitation centre integrates psychology across the healthcare teams, but she knows this is not the case for most programs.

Lack of services across the country

There are access challenges to mental health services across the country. According to Statistics Canada, in 2018 roughly 5.3 million people in Canada said they needed some help for their mental health in the previous year — and almost half said their needs were partially or completely unmet. The reasons

Lilli's story

Finding compassion and support

Lilli Law was a self-employed bookkeeper when she had a stroke in 2019 at age 46. She spent three months at G.F. Strong Rehabilitation Centre in Vancouver, which provides access to a comprehensive range of professionals to support both physical and mental recovery. Lilli says she was "insulated with support" at the rehabilitation centre. She did not realize how important it had been to have access to a psychologist until she was discharged. "I was treading in deep, dark waters and I consider myself very fortunate to have received this support. I know it is not an equal playing field for all people who experience stroke and not everyone receives that opportunity, but it should be a pillar of stroke recovery."



Ongoing counselling has not been an option because it is both scarce and expensive. However, Lilli has found support from several sources: her long-time family doctor, a UBC physiotherapy program, her partner and her strong circle of girlfriends, who supported her physically and mentally as she continued to recover. She also joined a support group for young stroke survivors, which she says was tremendous.

Her advice for other women who have experienced stroke: "Give yourself deep compassion. Don't look at the whole picture; do what you can handle and chisel away. Grab hold of your family and your best friends, pull them close — you will need them and they want to help. Find a support group; they will pull you into the community. Women especially want to try to do it all, but we don't have to."



Women who experience stroke are **not getting** the support they need for their **mental health** recovery.

for lack of support included that people did not know where to go, they were too busy or they could not afford to pay.

On Prince Edward Island where Dr. Greer works, mental health resources are limited unless people have comprehensive extended health benefits. And even that does not guarantee adequate support. "Many of the psychologists in private practice have long waiting lists similar to community mental health services — and add to that trying to find a therapist who actually understands stroke."

Dr. Blake, who works on the other side of the country in a major urban centre, Vancouver, identifies many of the same barriers. "You can be on a waitlist for a private psychologist for six to 12 months even if you can afford to pay."

Additionally, not all therapists or counsellors understand stroke and the deficits that can present such as cognitive changes or aphasia.

Getting support by staying connected

In addition to professional services to support mental health after a stroke, social networks including peer support groups can be an important enabler for women in their recovery. "Having opportunities to connect with others matches the way many women cope," says Dr. Greer.

Dr. Blake has observed that younger women often benefit from joining a young survivors' group in the community. "It is invaluable connecting with other women who know what it's like to be going through some of these role changes. Others may be further along in their recovery and this connection engenders hope."

What needs to be done?

Heart & Stroke is committed to working in partnership to ensure all women receive the care and support they need in their stroke recovery journey by:

- Providing health information for the general public as well as people who have experienced stroke and their caregivers. Visit heartandstroke.ca/stroke/recovery-and-support
- Expanding our peer support abilities. Heart & Stroke's Community of Survivors and Care Supporters' Community are two separate members-only Facebook groups: one for people who have experienced stroke or heart conditions and one for those who provide support or care to them. The groups offer social and emotional support in a safe, inclusive and respectful environment.
- Improving stroke systems of care by:
    - Advocating for better access to stroke rehabilitation and recovery, including more mental health services in communities.
    - Leading the Canadian Stroke Best Practice Recommendations and providing up to date evidence and practice recommendations on mental health following stroke. According to the recommendations, people who have experienced a stroke and families should be given information and education about the potential impact of stroke on their mood and they should be provided with the opportunity to talk about the impact of stroke on their lives at all stages of care.
    - Providing educational information and resources for people with stroke and health professionals.
    - Collaborating and partnering with other organizations to strengthen services for people with stroke.

Heart & Stroke's vision it to live in a world where all women receive the care they need when it comes to their heart and brain health. Working with partners from all sectors, Heart & Stroke will take an approach that considers health equity and Indigenous well-being and drives change in three key areas: Research, public awareness and education, and the healthcare journey.



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