

From Voices to Action: A Women-Centred Toolkit for Parenting After Stroke

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Disclosure Statement

There are no conflicts of interest to declare.

A Critical Gap in Post-Stroke Support for Women

- Younger women are at an increased risk of stroke compared to their male counterparts.
- Women ≤ 35 have approximately a 44% higher stroke risk than men and account for nearly 60% of stroke deaths globally.
- Stroke education rarely addresses how women navigate recovery while continuing their roles as mothers and caregivers.
- Parenting roles are often disrupted → school routines, caregiving responsibilities, emotional presence.
- Current stroke recovery models are largely generic.

Standard Stroke Education Covers:	But Rarely Addresses:
Mobility	Parenting roles
Speech	Caregiving and household expectations
Medication	Financial stress
Prevention	Reproductive health

- No existing comprehensive, interactive resource.

What Women Told Us: Lived Experience Findings

Research Article

Younger adult women who had a stroke or at high stroke risk: Exploration of their experiences and needs

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Based on a previous qualitative study of younger adult women with stroke or high stroke risk (n=11).

Parenting - "Not the same mother as before"

Professional identity disruption

Fear & anxiety of recurrence

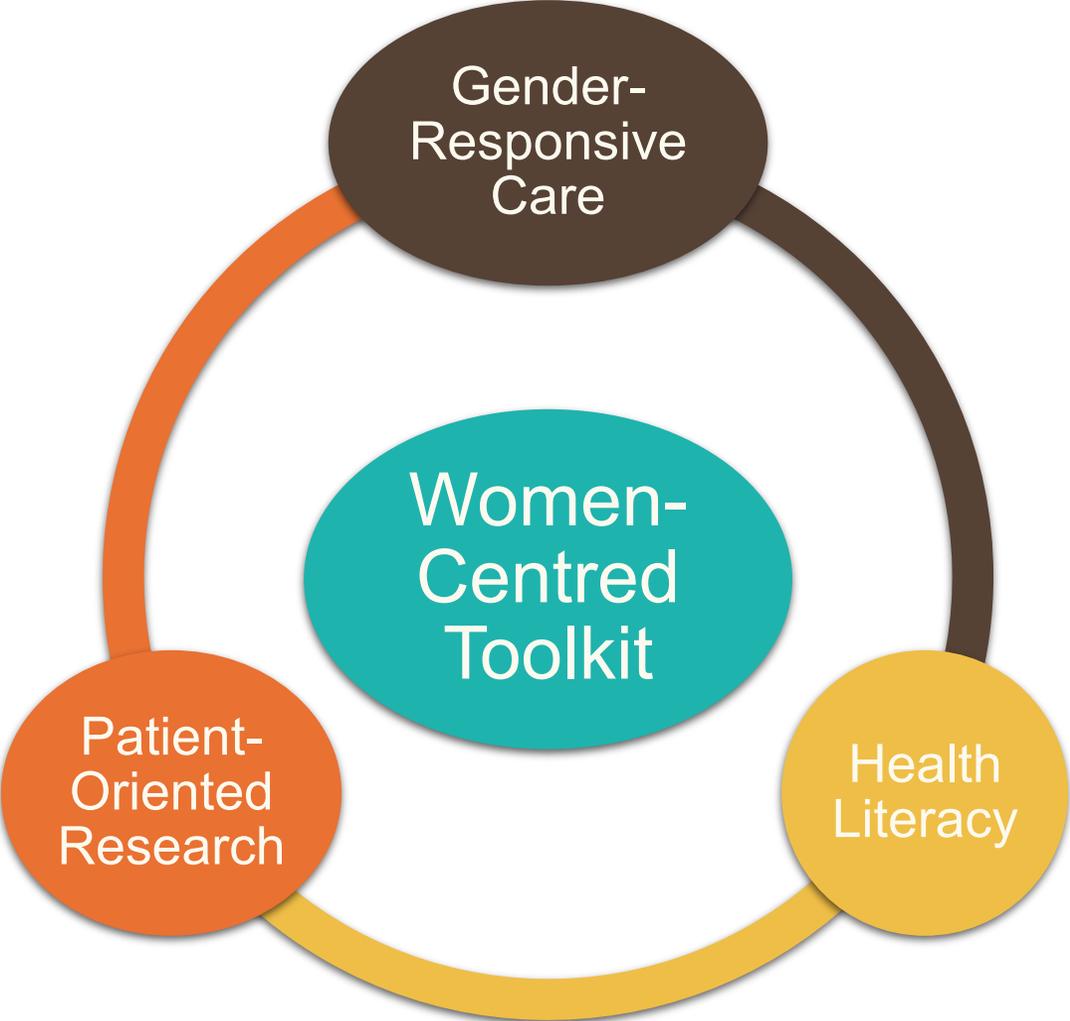
Gendered expectations & guilt around self-care

Psychological safety in women-centred spaces

Healthcare system: Women report feeling unseen, unheard, and overlooked

Our Goal: Supporting Life After Stroke

To co-design, validate, and evaluate the feasibility and acceptability of a women-centred educational toolkit that supports parenting, recovery, and brain health after stroke.



Methods: Integrative, Iterative, Multi-Phase Co-Design

Working groups comprise of **6 persons with lived experience (PLEX)** of diverse cultural, ethnic, & socioeconomic backgrounds, all stroke survivors and mothers to children aged 5-20 years.

Team met bi-weekly for 3 months for content development.

**Co-Design
(Phase 0)**

**Readability Assessment
(Phase 1)**

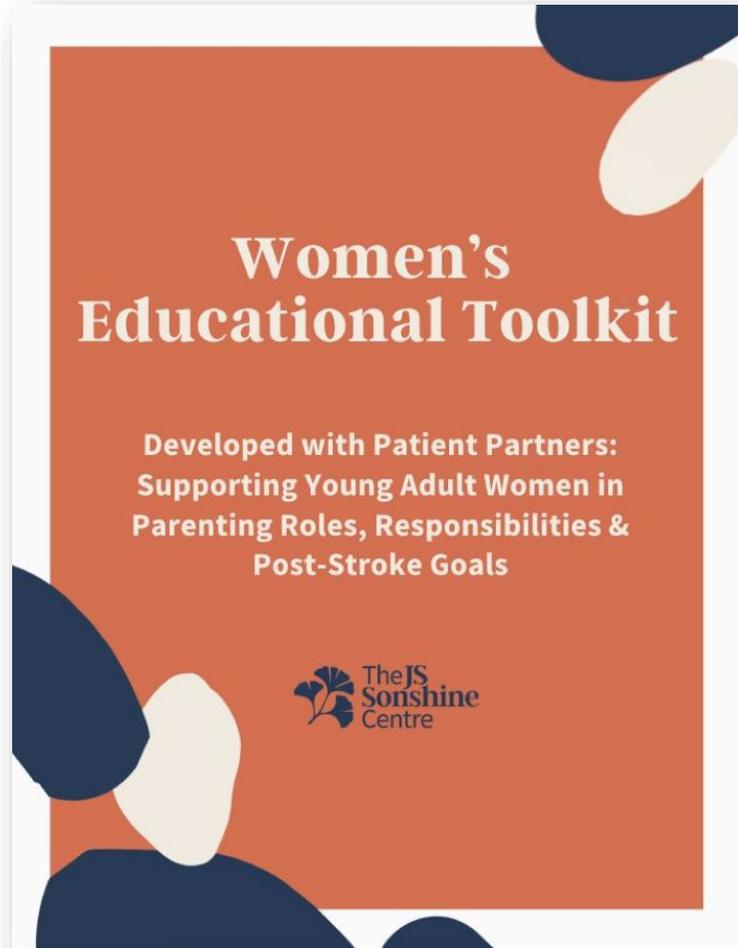
**Suitability,
Understandability, &
Actionability Assessment
(Phase 2)**

**Perception Assessment
(Phase 3)**

Suitability Assessment (SAM): assesses content, literacy, demand, and graphics.
Understandability and Actionability (PEMAT): assess content clarity, word choice, layout, and actionability.

Assess the readability of the toolkit.
Metrics include: **sentence length, word complexity, percentage of complex words, and syllable per word.**

Think aloud method: participants verbalize thoughts while reviewing the toolkit. Focus groups had audio recordings and field notes for qualitative analysis.



Navigating Stroke Recovery

- Practical guidance for understanding symptoms, preventing recurrence, and rebuilding daily routines.

Mental Health

- Support for anxiety, trauma, identity shifts, and emotional recovery.

Relationships & Reproductive Health

- Addressing intimacy, shifting family dynamics, and women's reproductive health across the lifespan.

Menopause & Stroke Symptoms

- Understanding how hormonal transitions intersect with stroke symptoms and recovery.

Caring for Children

- Helping mothers explain stroke to their children and adapt parenting roles realistically.

Managing Finances

- Navigating financial strain, work transitions, and system-level supports.

Modules derived inductively from thematic analysis of co-design sessions and prioritized by participants.

FINDING THE RIGHT EXPERTS

Consult A Neurologist Specializing in Stroke Recovery

1. Specialized Care

Stroke survivors need long-term care for recovery. Follow-up with a neurologist is essential. Neurologists specialize in nervous system disorders and provide ongoing support to help you regain function and manage any symptoms you might experience post-stroke.

2. Self-Advocacy

Advocate for yourself by seeking a neurologist who specializes in women's stroke care. Women may experience different symptoms and recovery patterns, so finding a specialist who understands these nuances can significantly improve your recovery process.

Neurologists monitor conditions, offer recovery advice, and develop treatment plans, which may include:

- Prescriptions for blood-thinning medications.
- Referrals to surgery.
- Referrals to occupational, physical, speech, and/or respiratory therapy.

Their expertise helps prevent future strokes. The care team may also include psychologists and rehabilitation specialists. Neurologists should ensure comprehensive care, monitor progress, and adjust treatments as needed.



MENOPAUSE AFTER STROKE

Menopause is a natural part of aging that marks the end of a woman's reproductive years. For women who have experienced a stroke, navigating menopause can present additional challenges, as the hormonal changes of menopause may interact with stroke recovery in unique ways. Understanding what to expect and how to manage symptoms can help one feel empowered during this transition.

Common Symptoms

1. Hot Flashes and Night Sweats

- Sudden feelings of intense warmth or sweating, often during the night, can disrupt sleep patterns.
- Sleep disturbances may increase fatigue, making recovery more challenging.



TIP: Use lightweight bedding and maintain a cool bedroom environment to improve sleep quality. Consult your doctor if symptoms are severe, as there may be treatments to manage hot flashes.

2. Cognitive and Memory Changes

- Many women experience "brain fog" during menopause, which includes difficulty concentrating or memory lapses.
- These cognitive shifts may overlap with cognitive changes caused by a stroke, making it harder to differentiate between the two.

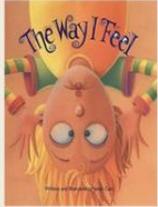


Tip: Keep track of any cognitive concerns and discuss them with your healthcare provider, who can help determine if these are related to menopause, stroke, or both.

Health and Wellness Programs Available Through Employers in Ontario

	Description	How to Access
Employee Assistance Program (EAP)	Confidential counselling and support services for employees and their families.	Contact HR or check the employee website for EAP details. Find your organization's EAP provider here (federal agencies).
Fitness Programs	Corporate memberships at a commercial gym and access to fitness classes.	Inquire with HR regarding employee benefits and whether they provide discounted memberships to gyms / fitness classes.
Mental Health Resources	Mental health services including counselling, therapy, and peer support groups.	Access through the company's intranet or employee wellness portal.
Stress Management Workshops	Provides workshops on stress management, mindfulness, and resilience training.	Sign up through HR announcements or the employee wellness platform.
Nutritional Counselling	Connects employees with registered dietitians for personalized nutritional advice.	Check the employee wellness platform or contact HR for available services.
Physical Therapy and Rehabilitation	Physiotherapy services through an external or internal clinic; supports recovery and overall health.	Inquire with HR or check the health benefits section of the employee portal.

Recommended Books for Discussing Parental Illness and Emotions

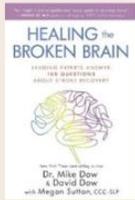


The Way I Feel

Author: Janan Cain

Description: This book teaches children to recognize and express their emotions in a positive way, building resilience and emotional intelligence. It covers a wide range of feelings with colorful illustrations and simple text.

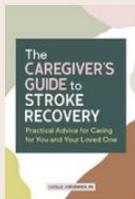
Recommended Books for Adolescents & Young Adults



Healing the Broken Brain: Leading Experts Answer 100 Questions About Stroke

Author: Mike and Peter Dow

Description: This book provides clear answers to common questions about stroke recovery, making it easier for young adults to understand what their parent is experiencing and how to support them.



A Caregiver's Guide to Stroke Recovery

Author: Lucille Jorgensen, RN

Description: A practical guide for caregivers, including adolescents and young adults, offering advice on how to support a loved one through stroke recovery while also taking care of their own emotional and physical well-being.

AGE-APPROPRIATE LANGUAGE FOR EXPLAINING STROKE

Age Group	Description	Example Explanation	Visual Aids
Young Children (2-6 years of age) 	Believe that the world around them is directly affected by their behaviours.	"Mommy had a boo-boo in her brain, and she needs to rest so it can get better." "Mommy's brain got hurt, but the doctors are fixing it."	
Older Children (7-12 years of age) 	Able to understand the concept of illness in more detail. Want to know what happens during stroke, causes, and symptoms.	"A stroke is when blood doesn't flow to part of the brain, and that part stops working for a while." "When someone has a stroke, it means their brain isn't getting enough blood, which makes it hard for them to do things they usually can."	

STROKE AFTER CHILDBIRTH - MENTAL HEALTH AND INFANT FEEDING CONSIDERATIONS

Recovering from a stroke after childbirth can be especially challenging. The postpartum period is a time of higher stroke risk due to blood pressure, clotting, and hormonal changes.

Emotional Wellbeing

- It's normal to feel guilt, sadness, or anxiety about parenting after stroke.
- Concerns about bonding or meeting expectations are common.
- Post-stroke and postpartum depression can overlap—early support helps.

Infant Feeding Options

Feeding should not add pressure during recovery. Options include:

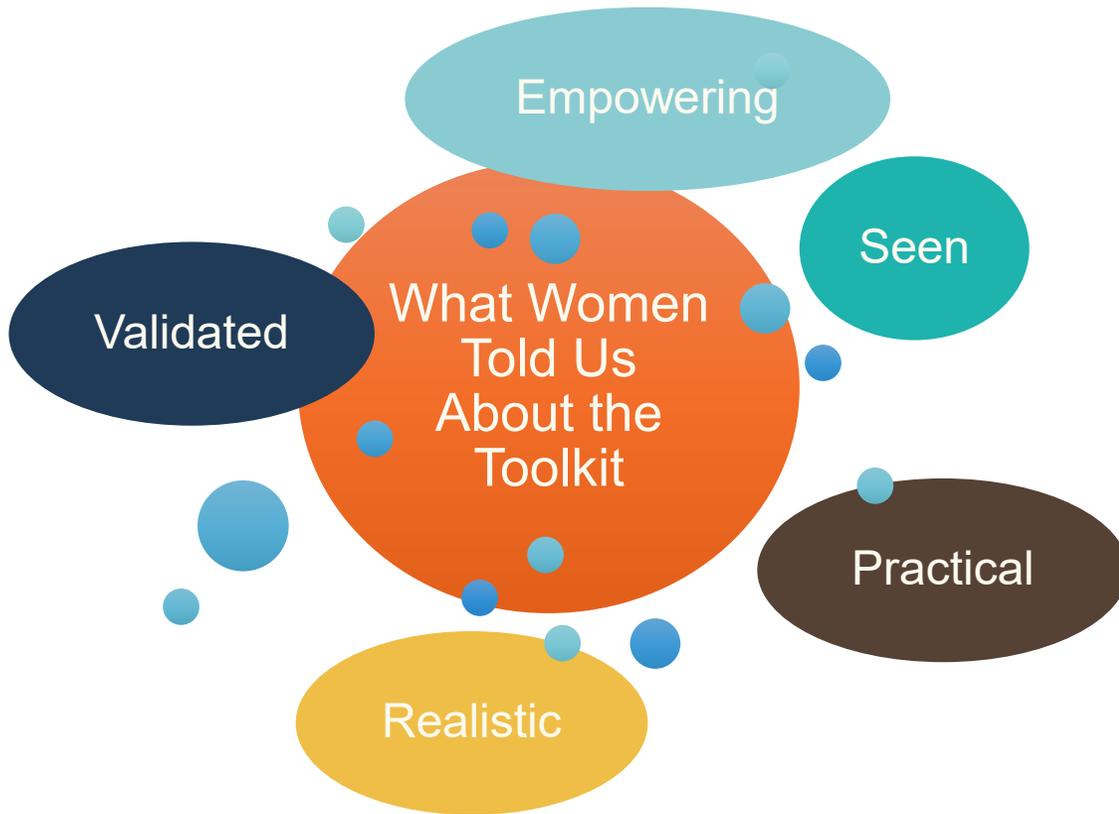
- Formula feeding to reduce strain.
- Pumping / partial pumping if manageable.
- Combination feeding for flexibility.
- Shared feeding with partners/family to allow rest.

What matters most is your health and your baby's nutrition. Feeding choices can be flexible and should be made with your healthcare team.

Quick Tips for Infant Feeding After Stroke

- Talk with your doctor or lactation consultant about safe options.
- Don't feel pressured to breastfeed if it increases stress or fatigue.
- Share feeding responsibilities. Partners and family can help.
- **Remember:** a fed baby and a recovering parent is what's most important.

Why This Toolkit Matters



For Women

- Practical tools for everyday post-stroke life.
- Increased confidence and self-advocacy amidst challenges.
- Reduced isolation through representation.

For Clinicians

- Structured entry points into gendered conversations.
- Supports person-centred care delivery.

For Health Systems

- Scalable educational model.
- Adaptable across settings.
- Aligns with World Health Organization (WHO) calls for gender equity in care.

From Research to Real-World Implementation

Launched on International Women's Day
March 8th, 2026

Scalability

- Continuously updated with feedback.
- Print, digital, audio versions planned.
- Micro-formats (brochures, cards).
- Local resources + globally applicable themes.

Where We're Going Next

- Community & clinical dissemination.
- Web-based & accessible adaptation.
- Translation & audio tailoring.
- Partnership invitations – ***Work with us!***

Access the toolkit:

her-brain.ca



Scan QR Code

Women's Educational Toolkit

A comprehensive guide co-designed with women and for women recovering from stroke.

This toolkit brings together practical information, lived experiences, resources, and evidence-based strategies to support recovery, independence, and long-term brain health.

[View Full Toolkit](#) [Download Full Toolkit \(PDF\)](#)

This is a free resource developed by the Jay & Sari Sonshine Centre.

A photograph of the 'Women's Educational Toolkit' booklet, which is white with blue and teal accents. The cover text includes 'Women's Educational Toolkit', 'Developed with Patient Partners: Supporting Young Adult Women in Parenting Roles, Responsibilities & Post-Stroke Goals', and 'The JS Sonshine Centre'.

“A stroke does not define the end of your life, and there are resources and support available to help you navigate this journey. Remember, you are not alone.”

- *Women's Educational Toolkit, page 9*

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Thank you for joining!

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