From Lived Experience to System Change

What Families Need Researchers to Know



NS Moms: Turning Experience into Action

- **Who we are —** Mothers of youth and young adults with serious mental illness — some lost to suicide, some still being supported today.
- **What we seek —** A compassionate, collaborative mental health and addictions system where families are respected as part of the care team.
- **Not about privacy or autonomy —** Severe depression, bipolar disorder, schizophrenia and psychosis can impair a person's ability to recognize they are ill.
- **Why consent breaks down —** Symptoms can make a person suspicious of, or angered by, those trying to help — preventing them from sharing vital information.



Meeting with Government and Health Leaders

1. **Goal**
   Shift legislation, policy, culture and practice through direct engagement with decision makers.

2. **A clear, focused message**
   Amend an outdated law that excludes families from care, treatment and recovery.

3. **Solutions, not just problems**
   Every ask backed by research and evidence.

4. **Common ground**
   Government, clinicians, regulators and faculties share our goals: better care, lives saved.

5. **Nimble and assertive**
   Ready on timelines, prepared whenever an opportunity to be heard arose.





Building Relationships, Staying Accountable

Trust first
Private, secure ways to contribute and one-on-one meetings that lower resistance.

Common ground
The shared professional desire to provide the best care and save lives.

Accountability
Clear timelines and follow-through, while naming gaps where we see them.

Sustainability
A manageable pace and small wins celebrated, so relationships last.

Lived Experience as Evidence



In March 2025, ten NS Moms shared their stories about care failures in a roundtable with health care professionals, government leaders, psychiatrists, and lawyers.

This was a springboard to achieving a legislative change to the Personal Health Information Act (PHIA).

Our First Legislative Win

The milestone
On Oct. 23, 2025, in the Fall Sitting of the NS Legislature, NS Moms won our first amendment to the Personal Health Information Act.

Clause 38(1)(d)
A custodian may disclose personal health information without the individual's consent to any person if the custodian believes, on reasonable grounds, that disclosure will avert or minimize a significant danger to the health or safety of any person or class of persons.

Key achievement
Removal of the word "~~**imminent**~~."

Why it matters
Families can be involved before a crisis turns critical.



Next Step: Collaborating to Change the Culture

- We work alongside clinicians, regulators, educators and government so families are recognized as partners on the care team.
- That means public education about consent and circles of care, trauma-informed training, and real supports for families.
- The greatest threat to this work is not opposition; it is collective burnout.



The Experience of the Caregiver

- Ambiguous loss
- Emotionally overwhelming
- Continuous state of high alert
- An unknown territory
- Stigmatizing
- Highly confusing
- Lonely
- Exhausting
- Guilt inducing
- Depressing
- Completely time consuming
- Financially draining
- Lifelong commitment
- Traumatizing



Only a Mother's Love Endures Schizophrenia

> Caregiving often calls us to lean into a love we didn't know possible.

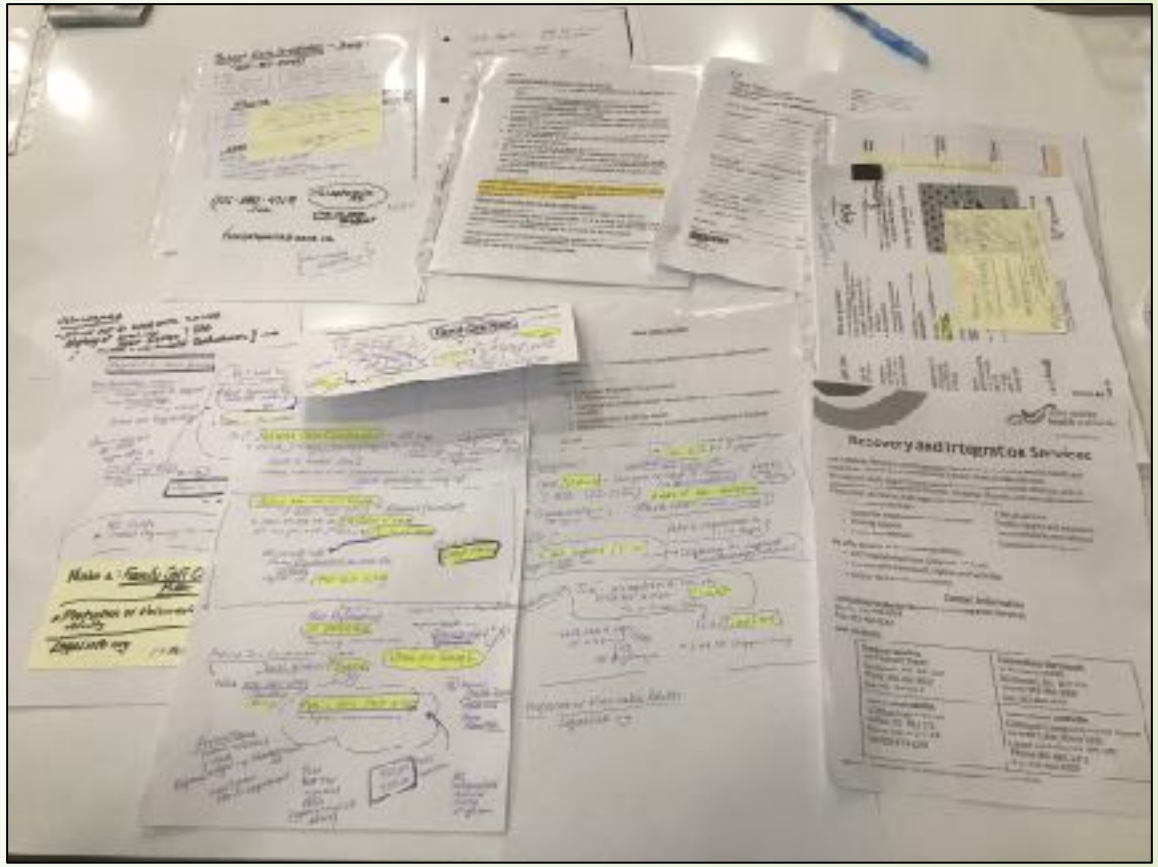
TIA WALKER

The Invisible Partner

01 A patient's recovery and their caregiver's wellbeing are **inextricably linked**.

02 Collateral information is **vital** to diagnosis and the patient story.

03 Trauma results when clinicians shut a family's information out — rigid views of privacy and confidentiality **deepen** it.



An early photo of the mountain of information that contributed to my first piece of collateral information.

What the Research Says

Evidence-based research shows better clinical outcomes for people with serious mental illness when family caregivers are meaningfully included in care and treatment:

Reduced relapse and hospitalization

Longer time between relapses

Shorter inpatient stays

Improved treatment adherence

Better symptom management and prevention of suicide

All are a result of the protective and supportive factors that families provide in a caregiving role.



What Prevents Mental Health Professionals from Working with Family Caregivers?

Barriers

- Heavy caseloads, and in some cases no fee for service to interact with family caregivers
- Family blaming, or believing the family is toxic
- Feeling unequipped to deal with complex family relationships and behaviours
- Not understanding legislation or policy well enough to answer families' questions confidently
- Hearing a patient does not want information shared with family, and not exploring why
- Not understanding the benefits of including families

Solutions

- Recognizing that most families want the best for their loved one, and may need support, education and kindness to flourish in the role
- Clear boundaries, with conversation centred on medically relevant topics
- In-depth training on policy and legislation, with a subject matter expert at every location
- Asking the patient why they don't want information shared, and what can be shared versus what cannot

What Researchers Can Do Better

Involve families from the start

Set research questions with caregivers, not just about them.

Treat lived experience as evidence

Family knowledge is data, and it belongs in the findings.

Measure what matters to families

Caregiver burden, access and continuity, alongside clinical outcomes.

Share results in plain language

Come back to the families who helped and take their input on the changes.

Translate evidence into policy

Carry research through to decision-makers.

Partnership with families makes research stronger and faster to apply.



Questions Researchers Can Ask

- What matters most to family caregivers?
- What makes care easier?
- What creates unnecessary suffering?
- What services change lives of those with SMI?
- What could have been prevented?



Research Changes Lives ONLY when it Changes Systems…

Shift culture and daily practice

Real change happens in everyday clinical routines, not in reports.

"We have pretty good symptomatic treatments for psychosis. The trick is, and this is borne out of research, if people go for long times untreated or accumulate multiple episodes, it becomes treatment resistant over time."

~ Dr. Jason Morrison, Clinical Director, NS Early Psychosis Program

Equip caregivers as partners

Fully resource families to take their place on the care team. This could help to prevent multiple psychotic episodes.

If You Remember One Thing from Today…

Families often know something is wrong long before the system does

Earlier listening → **Earlier support** → **Earlier intervention**

More chances for recovery ◆ Lives saved

Research is how we make it happen — WITH families, not about them