MICA
Mental Illness
Caregivers Association

ARAFMI
you are not alone

The Path Forward

Supporting caregivers planning for when they are gone

June 2026

Message for caregivers caring for persons living with mental illness and/or substance use disorder

There are no easy answers but let's begin with the notion that for many of us, caring for a loved one with a mental illness is a life long journey. A journey that begins with the onset of the illness and continues as we work together doing whatever is possible to ensure positive treatment outcomes and recovery.

As caregivers, we struggle with a range of emotions – such as fear, grief, desperation as well as hope and the courage to go forward despite the many challenges we face.

In most cases we do what we can to better understand the illness that has had a lasting and profound impact on our family member. Although important, we soon learn that it is not only about the diagnosis but is also about what has changed for you and your family member.

Your family member is now on a different path that has significant and certainly unexpected obstacles – both painful and life altering.

You remember your family member as she or he was before the illness and your first response is to do whatever it takes to support him or her in achieving their potential while allowing them to choose their own way.

It may take some time but most of us come to realize there is no easy fix and with that realization there is often a sense of hopelessness. As difficult as it may seem, it is also a turning point that compels us as caregivers to reflect on what is important and focus on the possibilities not the illness. This is not to suggest that you avoid the obstacles but rather you develop the confidence together to overcome the inevitable challenges ahead.

We are not alone. When we share stories and experiences others deepen their knowledge, try different strategies and become more confident in their actions. By connecting with others who are searching to find solutions we are more likely to provide for the appropriate support to our family members while personally staying strong and healthy.

So - what next

Focus on planning for 'when I am gone' in a manner that engages mental illness caregivers in both identifying challenges and developing solutions that have a lasting and positive impact on the quality of life of persons living with mental illness and their caregivers.

For all concerned, given the complexity of the challenges as well as the range and scope of potential solutions, going forward should be based on addressing concerns one family at a time – and eventually when ready as caregivers coming together as a community in helping shape and strengthen the support systems impacting our loved ones.

In closing, sharing our lived experiences, our concerns, our successes and disappointments with others is also the first step in developing a sense of belonging – a sense of belonging to a community prepared to support each other. The result is the shared strength and confidence to support our family member as she or he continues along the path to recovery – a journey that allows them to realize their potential in their own way in a context that has changed supported by relationships that remain the same.

Supporting caregivers planning for when they are gone - a call to action

Background

What keeps caregivers up at night ….

"The number of people who are chronically homeless, meaning homeless for long periods or over recurrent episodes, continues to rise"

"Homeless population could surge over the next decade without substantial investments in affordable housing"

"Renter households live in housing that is unaffordable, unsuitable or inadequate. Social assistance rates remain far below market rents - the waiting list of rent-geared-to-income housing continues to grow".

The question of 'what will happen to the people we care for when we can no longer care for them?" has long been an issue of concern for families and other caregivers of people experiencing mental health and/or substance use challenges – and it's an issue of concern not only for families and other caregivers in Canada, but also for those in Australia. Mental Illness Caregivers Association (MICA) and ARAFMI (the peak body for unpaid carers of people experiencing mental ill-health in Queensland, Australia) have embarked on a collaborative effort in order to map out and develop solutions aimed at addressing this pressing concern.

The risk

"Caregivers told us – "who will replace me" - I am my family members "go to person" who cares for and understands him, provides direction, protects his housing and knows how to keep him from slipping into psychosis and hospitalization. Herein lies my greatest fear about the future for my son without me."

In many cases, the caregiver is the only source of supports and without a plan in place now our most vulnerable are at risk of increased 911 calls, visits to ER, hospitalizations, substance abuse, isolation and loneliness, food insecurity, homelessness, contact with the law, arrest, and incarceration in the future. The challenges are significant: as the current mental illness caregiver community ages, it is becoming increasingly more urgent to plan for "when they are gone."

A call to action

"Hospitals are facing emergency department closures and staff shortages - the number of persons with mental health concerns visiting emergency rooms continues to increase significantly - with many calls being urgent at the time of contact with patients."

"The number of homeless people on streets has risen – mental health-care systems need dramatic reform before things will get any better."

We believe the question of "what will happen to the people we care for when we can no longer care for them?" can be solved through:

- a caregiver-focused approach funded by the provincial and/or federal government with the mandate resources and means to assist caregivers planning for when they are gone.
- a process that results in the establishment of an independent organization that will see to the development of a sustainable plans now and support their implementation when the caregiver is gone.

A call to action

"A plan that ensures the person, they care for has continued access to safe and safe and secure housing including community and personal supports as well as access to arrangements in place that provide for legal,
financial and property management supports"

An organization responsible for:

- supporting both the development of a sustainable plan now and its implementation when the caregiver is gone or no longer able to provide the required supports
- through diligent research and analysis, exploring a range of options that both address the unique concerns of each caregiver as well as concerns common to all caregivers - continued access to safe and secure housing as well as community, personal, legal, financial and property management supports when they are gone
- having links to organization(s) positioned to provide personal and community supports from access to wellness checks, social and community connections, leisure and recreation programs, psychoeducation, system navigation
  to the implementation of contingency plans in place for the family members in response to any change in both the housing needs and the required mental health and/or physical health supports.

Our response – a tool kit

A project focused on the development of a tool kit that invites caregivers to share their stories, supporting caregivers' efforts in planning for when they are gone, raising awareness and involving others that share our concerns.

Caregivers want …
"To share their stories and a plan based on their stories that ensures a safe place to live and continued mental and physical well-being for those they are for"

A survey – it's all about caregiver engagement

To get things started we invited caregivers to share their stories – stories that assisted us in identifying potential gaps in supports when the caregiver is gone (including continued access to safe and secure housing, personal and community supports, as well as trusted legal, financial and property management supports) and efforts focused on addressing these gaps

Our invitation included a survey. We asked questions about the types of support they currently provide for the person they care for and at what cost and finally, whether they already have plans in place for the future.

It's about caregiver engagement

A detailed summary of what we heard and an analysis of findings is presented at the ARAFMI Future Planning for Mental Health Carers Project - Stage One Report March 2026

The survey completed by carers and caregivers in Queensland and Canada showed many similarities and some interesting differences in the patterns of care and support provided to family members or friends experiencing mental health challenges.

What we heard

In total, 66 carers in Queensland and Canada provided a valid response to the survey [23 from Queensland and 43 from Canada]. Even though the numbers of responses are relatively small, the results are consistent with findings of other research conducted into the scope of mental health caring roles giving confidence in the validity of these findings:

- Mental health caregivers provide high levels of emotional and practical support as well as covering significant essential living costs and financial support for a range of other costs for the person they care for
- Caregivers (and the person they care for) are ill-prepared for the future – they want
  - help to put plans in place for the future
  - support for a range of planning needs
  - support to implement future care plans
  - supports in place that foster trusting long-term relationships.
- There are a range of issues that need to be addressed if families and carers are to have confidence that the people they care about will continue to be well-supported into the future including:
  - the large majority of families and carers do not have a plan in place and are seeking support to both develop and implement a plan.
  - everyday emotional and practical supports are the hardest to replace
  - continuity and trust matter more than service type
  - advocacy is essential for people with complex mental health needs and cannot be assumed or replaced by generic supports
  - planning the future support of someone experiencing serious mental illness can be expensive, complicated and resource intensive.

Our response – a tool kit

"It's more than planning …

When families do not plan ahead for the care of a loved one, the consequences can unfold quickly and painfully.

Familiarity matters deeply. Whoever is intended to serve as a future caregiver should be meaningfully included in the loved one's day-to-day life well before any transition occurs. When that groundwork is laid, the change feels natural rather than abrupt or frightening.

Without this planning, we far too often see vulnerable individuals end up in shelters or without stable housing. Mental health challenges tend to worsen over time in these circumstances, eventually requiring a higher level of care, which becomes even more difficult for family members to step in and help".

A planning guide

As mental illness caregivers age, it becomes increasingly more urgent to plan for "when they are gone". They want a plan that ensures a safe place to live and continued mental and physical well-being for those they care for.

Therefore, MICA developed a planning guide in consultation with subject matter experts and caregivers - our intent was to keep it simple while still addressing the various complex challenges that could arise in the future for providing personal and community support, trusted legal contacts, financial and property management options and so on.

It's about caregiver empowerment

The following summary of what we heard highlights what caregivers indicated planning needs to address as well as feedback from subject matter experts when asked what advice they would offer caregivers in support of their future planning efforts.

What we heard – from caregivers

- What's at risk?

"Who will replace me? I am my family members "go to person" who cares for and understands him, provides direction, protects his housing and knows how to keep him from slipping into psychosis and hospitalization. Herein lies my greatest fear about the future for my son without me."

"Continued access to personal and community care is critical to my family member's mental and physical well-being."

A safe place to live - will depend on whether contacts are in place and are contacted on regular basis to provide for the necessary legal, financial and property management supports."

- Future planning needs to address the following:
  - **Gaps in personal and community supports** – caregivers presently address the requirements for mental health, physical health and emotional supports. Their concerns were around how to ensure that personal and community supports will adequately meet these needs.
  - **Legal, financial and property management supports** – making arrangements that will ensure continued access to trusted legal, financial and property management supports
  - **Implementation** – making arrangements that will ensure supports are in place to implement their plans

What we heard – from subject matter experts

Based on one family's story we asked subject matter experts to consider what advice they would offer caregivers from their perspective as a lawyer, financial planner, property manager and case manager (social worker) as it relates to:

- estate and legal planning
- financial planning
- property management
- personal and community support.

- Planning also needs to:
  - **Integration** – assist caregivers in understanding the links between personal, community, legal, financial and property management supports – for example, the link between personal and community supports and the financial and property management arrangements in place that provide for a safe place for the persons they care for to live.
  - **Coordination and collaboration** - provide for a coordinated and collaborative approach to supporting the implementation of their plans – for example, mental illness service providers and subject matter experts working together in both the implementation of the plan and responding to the needs of the person they care for from on-going support to being there in the event of a crisis/ emergency.

What we learned – an environmental scan

Governments worldwide are increasingly recognizing the need to support individuals living with mental illness who lose their family caregivers due to aging, illness, or death. Jurisdictions such as Australia, the United Kingdom, Japan, and the Nordic countries have developed structured approaches that prioritize early future planning, individualized funding, and integrated housing and mental health services. These models are typically rooted in recovery-oriented and rights-based frameworks that align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). A common feature among successful models is their ability to transition individuals smoothly into community-based living arrangements while preserving autonomy and access to ongoing support.

Key elements of effective systems include individualized budgets (e.g., Australia's NDIS), supported decision-making alternatives to guardianship (e.g., Canada and Sweden), and automatic service triggers when caregiver loss occurs (e.g., UK's local authority duties and the U.S. Adult Protective Services). These jurisdictions also emphasize the importance of cross-sector collaboration between health, housing, and legal services. The integration of proactive contingency planning, such as Japan's "life-long support plans," further enhances the ability of service systems to respond promptly and appropriately when caregiving responsibilities shift.

In contrast, Ontario's mental health system, while relatively strong in community-based supports like Assertive Community Treatment (ACT) and case management services, often lacks the coordination and future planning mechanisms seen in other jurisdictions. There are limited tools or requirements for caregivers and professionals to plan proactively for the transition of care. Moreover, there is no standardized system to identify or automatically support individuals whose caregiver has become incapacitated or has passed away. Guardianship arrangements are available but often complex and resource-intensive to establish, and individualized funding options remain limited for those with serious mental illness.

To address these gaps, Ontario could benefit from introducing a province-wide future planning initiative, supported decision-making frameworks, and a trigger-based notification system to initiate care transitions when caregiver loss occurs. Enhancing coordination between healthcare, housing, and legal systems will also be critical. By adopting a more proactive and integrated approach—modelled on international best practices—Ontario has an opportunity to ensure continuity of care, protect the rights of individuals with mental illness, and reduce the long-term burden on emergency and institutional services.

Core components of support

Our call to action is about exploring program, service and system changes. Our efforts going forward will focus on ensuring the changes provide for core components of support.

- **Caregiver Engagement** – use the 'power of caregivers' stories' to support the urgent need for caregivers caring for persons living with mental illness and/or substance use disorder to plan for when they are gone – a need that becomes more pressing as the caregivers age.
- **Caregiver Empowerment** - through planning while keeping it simple and understanding that the tool kit also needs to address some of the challenges in more detail from
providing for personal and community supports, as well as trusted legal, financial and property management supports.
- **Partnership development and outreach** - building partnerships all the while raising awareness as to the significance of the issue at hand and empower caregivers in the ongoing support of the person they care for based on fostering integration and collaboration.
- **Integration and collaboration** - partner organizations positioned to explore a range of options that both address the unique concerns of each caregiver as well as concerns common to all caregivers.
- **Evaluation and continuous improvement** - an evaluation framework to monitor outcomes, impact and overall operational efficiency.

A service/program delivery model (system navigation, partnerships, integration, coordination, collaboration)

Exploring the possibilities around a service/program delivery model that provides for the core components of support.

Going forward our efforts will focus on exploring a a two-tiered approach as follows:

- Tier one - An organization with the mandate resources and means to assist caregivers in the development of a sustainable plan now and support its implementation when the caregiver is gone
- Tier two - Partner organizations - supporting the implementation of caregiver plans through integration and collaboration and service coordination

- Tier one - An organization with the mandate resources and means to assist caregivers in the development of a sustainable plan now and support its implementation when the caregiver is gone.
    - Service offerings: caregiver empowerment and engagement, governance and leadership, partnership development and community outreach, evaluation and continuous improvement.
- Tier two - Partner organizations - supporting the implementation of caregiver plans through integration and collaboration.
    - Service offerings – a care plan (coordination and system navigation); a legal and financial plan (coordination of planning and the resulting legal and financial arrangements); a property management plan (coordination of planning and the resulting property management arrangements).

The Path Forward

A Caregiver Future Planning Pilot Project –
access to caregiver planning supports including a coordinated, integrated and collaboration approach to the implementation of their plans when they are gone.

"Caregivers worry about what will happen to the person they support when they are gone – they shouldn't have to face future planning alone."

- **A Caregiver Future Planning Pilot Project that explores how caregivers can be supported based on the following:**
  - a caregiver-focused approach supported by an organization with the mandate, authority, and resources to assist caregivers develop sustainable care, housing, legal, financial, and property management plans for their loved ones.
  - exploring partnerships with community organizations and others that share our concerns in support of a coordinated, collaborative and integrated approach to the implementation of their plans when they are gone.

An Action Plan

Caregiver and community engagement

"One community and caregiver at a time."

"A pilot project in the Ottawa region - although healthcare is provincial, municipalities such as Ottawa absorb many of the consequences when caregiving arrangements collapse. Investing earlier in supporting caregivers in their future planning efforts is a cost-effective way to prevent crises before they occur."

Caregivers are often the only source of supports and without a plan in place now our most vulnerable are at risk of increased 911 calls, visits to ER, hospitalizations, substance abuse, isolation and loneliness, food insecurity, homelessness, contact with the law, arrest, and incarceration in the future. The challenges are significant: as the current mental illness caregiver community ages, it is becoming increasingly more urgent to plan for "when they are gone."

When caregiver networks collapse, municipal systems frequently become the first point of contact bearing costs such as those associated with paramedic and police services, emergency shelter usage, supportive housing costs, public health expenditures and so on.

Although healthcare is provincial, municipalities such as Ottawa absorb many of the consequences when caregiving arrangements collapse. A modest investment in supporting caregiver future planning efforts is a cost-effective way to provide for continuity of care while both improving long-term outcomes and, in many cases, preventing crises before they occur. Running a pilot will allow for the proper analysis of the cost and socio/health benefits, prior to any launch at the provincial level.

Next Steps

Caregiver and community engagement

"One community and caregiver at a time."

"Going forward should be based on addressing concerns one family at a time – and eventually when ready - as caregivers coming together as a community in helping shape and strengthen the support systems impacting their loved ones."

Caregiver engagement

- **A workbook – a planning guide**

- Continue development of a workbook in consultation with the caregiver community to be used as a guide in planning for the future needs of those they care for living with mental illness and/or substance use disorder – a range of supports that include emotional, practical, mental and physical health and for some legal, financial and housing supports.

- **Outreach – Did we get it right?**

- Share a progress report and a draft planning guide with caregivers and others that provided a letter in support of the proposed 'caregiver future planning pilot project' for review and comment.

Community engagement

- **Host a Workshop – Setting things in motion**

- The workshop will include establishing links with similar initiatives and involve participants from community organizations/agencies and others that share MICA's concerns regarding the need to support caregiver future planning efforts focused on ensuring those they care for have continued access to personal and community supports as well as safe and secure housing