

OUR CONVERSATION – ONE FAMILY’S STORY

MICA: We now invite you to share your story in your own words. Let’s start with you telling us about the person you care for

Caregiver: The person I care for is 35 living with mental illness for over 15 years (schizophrenia and anxiety), living at home, no recent hospitalizations. Living with symptoms that include disorganized thinking, paranoia, delusions, hearing voices, anxiety, fear.

MICA: What does your caring role mean to you?

Caregiver: Where to start? To be honest, we have rarely taken the time to reflect on what care we do to support our family member – the last 20 years or so we simply just did what was required. But here goes!

For us, it began with making the 911 when our family member was in crisis. We were there in the emergency room and when admitted we assisted our family member in understanding the need for a mental health assessment, the diagnosis and the treatment plan. It was also about being there to address concerns and offer support including visits to the hospital and consults with health care professionals.

We were there to support our family member on discharge and help them integrate back into the community by developing goals and accessing the proper supports and services.

Caregiver: We soon learned that wasn’t the end of our role. We continue to provide day to day supports from being a good listener, to providing words of encouragement and if required, someone ready to advocate access to treatment. We are there to assist our family member in ensuring continued access to mental health programs and services including arranging appointments and ensuring compliance with any follow-up actions. We are also there to monitor self-care from good hygiene practices to regular visits to health care professionals – medical doctors, dentists, optometrists and so on.

MICA: Has it been more than a caring role – what challenges has your family faced along the way?

Caregiver: Our family member was involved in an incident that required contact with the law and we found ourselves supporting our family member in working through the judicial system. If contact with law was not enough, over the years, we have also paid out credit card debt on more than one occasion.

OUR CONVERSATION – ONE FAMILY’S STORY

MICA: What other supports do you provide?

Caregiver: For us, over the years it is also about: providing for safe and secure housing including property management as well as access to services such telephone, internet and utilities (water and hydro) as well financial and legal services from accounting advice to managing their RDSP to filing their annual tax return. Being there to celebrate special occasions from birthdays to holidays and whatever else can be done to address the loneliness and isolation faced by our family member.

MICA: The support you provide is at what cost?

Caregiver: My best estimate of the cost we have assumed over the years follows:

- Visits to the ER and hospital stays – cost estimate based on \$40 an hour for up to 60 hours monthly for 3 months on each occasion - 3 months at **\$7,200** – two hospitalizations for a total cost of **\$14,400**
- Contact with the law and paying out credit card debt - **\$10,000** (one time cost) – credit card debt - **\$5,000** (one time cost)
- Day to day on-going supports – cost estimate based on \$40 an hour for up to 30 hours monthly - **\$1,200** monthly and on an annual basis is **\$14,400**
- Psychology and other related services as required - Up to **\$5,000** annually
- Providing for a safe and secure place to live: Housing – **\$12, 000** annually; Utilities and other services – **\$4800** annually; Food security – **\$9,600**; Legal and financial supports – **\$2000** annually; Property management supports – **\$6000** annually

MICA: One last question – what would your plan for when you are gone need to include?

Caregiver: My plan would include arrangements to support our family with the following:

Visits to the ER and hospitalization - assisting my family member to prepare an emergency response plan and in an emergency assisting my family member in understanding need for a mental health assessment, the diagnosis, and the treatment plan.

Contact with the Law - support to divert my family member from the justice system toward the mental health court and services in the community.

Day to day supports - someone being there to address concerns and offer support including wellness checks, social and community connections, leisure and recreation programs, psychoeducation, system navigation.

Annual legal and financial review - assisting my family member in accessing and understanding provisions of caregiver estate instructions including financial arrangements in place to fund both current and long-term expenses while ensuring the appropriate controls are in place.

Annual property management review - assisting my family member in accessing property management services – both routine and emergency services as well as the periodic appraisal of the home. And, if necessary, manage the sale of the home and arranging for alternative living arrangements

Sharing your story by telling us what your plan would include – one family’s response!

**WHAT TYPES OF SUPPORT DOES YOUR LOVED ONE CURRENTLY RELY ON YOU TO PROVIDE?
AT WHAT COST?**

| Supports | At What cost (Annually) | Contribution in-kind | Out of pocket expense |
|---|------------------------------------|--|----------------------------------|
| <input type="checkbox"/> Day to day on-going supports | \$14,400 | (30 hours monthly at \$40 an hour - \$1,200 monthly, \$14,400 annually) | |
| <input type="checkbox"/> Psychology and other related services | \$5,000 | | ✓ |
| <input type="checkbox"/> Providing for a safe and secure place to live | | | |
| <input type="checkbox"/> Housing | \$12,000 | | ✓ |
| <input type="checkbox"/> Utilities and other services | \$4,800 | | ✓ |
| <input type="checkbox"/> Property management | \$8,400 | | ✓ |
| <input type="checkbox"/> Food Security | \$9,600 | | ✓ |
| <input type="checkbox"/> Legal and financial services – out of pocket expense | \$2,000 | | ✓ |

**WHAT WOULD YOUR PLAN FOR WHEN YOU ARE GONE NEED TO INCLUDE?
WHAT ARE THE GAPS AND AT WHAT COST?**

| Supports When I am Gone – My Plan Includes | The GAPS - At What cost (annually) |
|---|---|
| <input type="checkbox"/> Day to day on-going supports | \$14,400 (GAP) |
| <input type="checkbox"/> Psychology and other related services | \$5,000 (GAP) |
| <input type="checkbox"/> Providing for a safe and secure place to live | |
| <input type="checkbox"/> Housing – \$12,000 | \$25,200 Source of funds – estate, ODSP, RDSP, OAS |
| <input type="checkbox"/> Utilities and other services - \$4,800 | |
| <input type="checkbox"/> Property management - \$8400 | |
| <input type="checkbox"/> Food Security | \$9,600 (GAP) |
| <input type="checkbox"/> Legal and financial services – out of pocket expense | \$2,000 (GAP) |
| <p style="text-align: center;">“What is the one key support for your loved one that you feel will be absent when you are gone?”</p> <p style="text-align: center;">Personal supports – day to day on-going supports and continued access to psychology and other related services</p> | |