Baycrest
KOSCHITZKY CENTRE
for Innovations in Caregiving

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REFLECTIONS ON BEING A FAMILY CAREGIVER

The Experience and Impact of Being a Family Caregiver

Adapted from Dr. Adriana Shnall's webinar on April 5th, 2022



What does being a caregiver mean? How can family caregivers find ways to celebrate themselves on this journey?

In celebration of National Caregiver Day, April 5th, 2022, our webinar series host Dr. Adriana Shnall PhD, MSW, RSW steps into the featured speaker spotlight to reflect professionally, and personally, on the experience of caregiving herself. Adriana's talk helps participants to explore what being a caregiver means to them and find ways to celebrate ourselves as we go through this journey together.

Family caregivers

- The term family caregivers is used to describe any family, friends, or neighbours who provide help to someone living with a health issue or who needs some help with their day-to-day life
- The help can vary greatly and can include transportation, picking up groceries, personal care, managing finances, attending medical appointments, and emotional support



Value of family caregiving in Canada

- As of 2018 there are over **7.8 million**family caregivers in Canada
- 1 in 4 Canadians over the age of 15 are caregivers
- Caregivers provide **5.7 billion hours** of care which is the equivalent of **$97.1 billion** in unpaid care
- Canadian caregivers provide the equivalent of the work of **2.8 million** full-time employee

While family caregivers do not provide care to save the government money, their efforts significantly benefit the health care system.



- Caregivers provide **80% of all care** to older adults in the community
- Without family caregivers many older adults could not remain at home in the community
- Caregivers provide **30% of all care** to older adults in institutions, like long-term care
- 44% of caregivers between the ages of 45 and 64 care for both a parent and children

Although caregiving is difficult, many people derive pleasure and meaning from caregiving

Caregiver Burnout

Commonly, caregivers can suffer from the effects of the work they do, which shows up as burnout

Caregiver burnout occurs when caregivers reach a state of emotional, physical, or mental exhaustion, and can impact mental and physical health, work, and relationships

Signs of burnout

- Becoming quick to anger, getting easily frustrated or "losing it"
- Forgetting things sometimes
- Feeling anxious or depressed
- Feeling hopeless or helpless
- No longer being interested in the things that used to give you pleasure

Additional negative effects of caregiving

- An increase in metabolic illness (like diabetes, high blood pressure, and higher cholesterol – this one is more so in men) could be a side effect of caregiving
- Social isolation is another potential side effect of caregiving. This was an even bigger problem during the pandemic as many caregivers providing care at home were isolated from their supports
- In Canada, the top stressor for caregivers is finances (both for those caring for people at home and in long-term care)
- Caregiving can create discord in families through disagreements around care
- Caregivers of people with dementia are at a 600% increased risk of developing dementia themselves. For more information on this topic, please refer to the handout on Brain Health, from the April 27 2022 webinar

Though government financial supports for caregivers are limited, only 8% of caregivers apply for and access the available tax credits in Canada

Caregiving experiences are affected by:

Time

- Caregiving varies by intensity, with some people providing 24/7 care and others providing far less or increasing care over time
- The amount of time that someone provides care for can vary significantly
- The longer you have been providing care, the more likely you are to experience caregiver burnout

Culture

- Culture influences our beliefs and thoughts about caregiving

Disease Progression

- The stage at which you enter caregiving can influence the experience of caregiving

Relationship

- The type of relationship you have with the care recipient also influences the experience

Location

- Whether someone lives at home, in an institution, or if care is provided from another province or country (long distance caregiving); these situations can all come with their own challenges and feelings of guilt
- Caregiving does not stop when someone moves into an institution, it just shifts and changes

The more roles (employee, parent, etc) a caregiver has, the more stress they are likely to perceive as a caregiver



How to 'muddle' through caregiving:

- We do not always recognize ourselves as caregivers and this can negatively impact us
- Recognize that you need help – until you can recognize yourself as a caregiver it is difficult to find and accept help
- Self-care is crucial for managing our emotional, psychological, physical, and social well being
- For some, self-care can become a burden and those with the greatest needs may not have the necessary support or resources to self-care
- While we need self-care, we also need community
- A community of care is a very important form of self-care and can be small or large and can benefit all involved
- You can join one that already exists like a religious institution, community centre, or an interest-based group

What can members of a community of care do for caregivers?

- Communicate regularly and be able to identify when professional support is needed
- Offer to do something concrete like getting their child from school or walk their dog
- Specific things that can be done for a caregiver:
    - help with respite
    - take their family member for a walk in a wheelchair
    - help with paperwork
    - pick-up or return books to the library
    - take their car for an oil change
    - change their tires
    - go to the post office for them
    - pick-up their prescriptions
    - drop off dry-cleaning
    - do their shopping
    - teach them how to shop online
    - rake leaves
    - clean the fridge
    - remember their birthday and important days
    - take pets to the vet
    - invite them to social gatherings even if they are likely to say no
    - bring them their favourite coffee or snack
    - bake a cake
    - create a music playlist
- Help caregivers understand that rest is a priority, ease their guilt (for example, by telling them that they do not need to visit the nursing home every day), and empathize and validate their experiences



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