

SERVICE PROVIDER GUIDE TO UNDERSTANDING THE IMPACT OF CAREGIVING

As a service provider who deals directly with caregivers, you are in a unique position to help recognize, respond and refer to the needs of caregivers. To help you do this, this guide provides you knowledge about the factors which contribute to caregiver burden, stress, burnout and abusive behaviours and where you can find help for caregivers.

WHO IS A CAREGIVER?

A caregiver provides assistance to a family member or friend living with a disability, illness, or aging.

The Alberta Caregivers Association reports that more than half a million Albertans are caregivers. These individuals provide essential assistance to family members and friends who are aging or living with a disability and/or illness. Caregivers provide 80 per cent of the care required by older adults in the community. This contribution is estimated at \$25 billion annually in unpaid care savings to the Canadian health system.

SCENARIO:

Clara provides day-to-day care for her 87 year-old husband Jim, who suffered a stroke six years ago. Jim is sensitive to light and noise so he spends all of his time in the basement. He sleeps in a basement bedroom, has access to a bathroom with a shower and has a small microwave to warm his food, but he often forgets how to use it.

Jim cannot climb the stairs without assistance, and has lost his ability to speak clearly. He does not wish to be seen in public and is completely dependent on Clara for his daily needs and social life. Jim needs Clara to help him shower, shave and dress. Some days Jim insists on staying in bed to watch TV.

Clara gets Jim up and settled for the day by leaving him with a sandwich or lunch to heat up in the microwave. By 9 a.m. most mornings, Clara is off for a coffee at the neighbourhood coffee shop. Clara enjoys listening to the news about friends and feels she deserves this break just to stay sane. At 11 a.m., Clara starts her volunteer shift at the animal shelter until around 2 p.m. The staff treats her like gold and always shows their appreciation. At 2 p.m., Clara runs errands,

Caring for an elderly family member or friend can have a profound impact on a caregiver's mental, physical, social and financial well-being. Caregivers are more likely to have depression, experience severe stress and be socially isolated. More than one third of caregivers report extra expenses due to their caregiving responsibilities, and two-thirds spend more than \$100 per month of their own funds on caregiving.

There is also a connection between caregiving and elder abuse. Caregivers may engage in behaviours that appear abusive, including becoming irritable or yelling at their care recipient. These behaviours could indicate abuse is happening and/or may be a sign the caregiver is burning out.

WHAT IS CAREGIVER BURDEN?

It is the accumulation of all the tasks and responsibilities that caregivers do to fulfill their caregiving role. Burden is connected to, but not always correlated with caregiver stress.

gets daily groceries and returns home by around 3 p.m. Jim is usually excited to hear Clara's stories about her day.

Summary:

- Clara's life is full of many tasks and responsibilities as a caregiver. Currently it appears she is able to balance Jim's care needs while taking time to look after her own health and social well-being.
- Given that Jim cannot climb the stairs and may not be able to heat his food, it appears Clara is unknowingly neglecting Jim.
- As Jim's health changes, Clara may struggle to see friends or volunteer. Depending on her ability to cope with the demands of her role, she may either give up activities that keep her well or may continue to neglect Jim.
- Acknowledging Clara's experience could open the door for future conversations. "Do you recognize by leaving Jim alone you are putting him at risk? A lot of people in your situation find they start to feel stressed or frustrated. These feelings are normal. There are resources that can help you and help keep Jim safe."

WHAT IS CAREGIVER STRESS?

A caregiver's perception of how difficult their role is. Some caregivers with a relatively light burden (few responsibilities) may have very high stress because they do not have adequate coping techniques.

WHAT IS CAREGIVER BURNOUT?

Caregiver burnout is a state of physical, emotional and mental exhaustion that may be accompanied by a change in attitude. Those experiencing caregiver burnout may experience fatigue, guilt, stress, anxiety, depression and anger.

SCENARIO:

Diana has been helping her mother, Pearl, for a couple of years. At first it was pretty straightforward. Diana would pick Pearl up once or twice a week for medical appointments or to run errands. Both Pearl and Diana enjoyed spending time together.

Six months ago, Pearl fell and broke her wrist. Pearl required 24-hour care and Diana spent weeks sleeping on her mother's couch. Diana could hardly leave because Pearl needed help with basic things like standing up, bathing, dressing, attending the bathroom, and preparing meals. Diana and her husband, Toby, had planned a vacation about a month after Pearl's fall, but Diana decided to cancel the trip because she could not leave Pearl alone.

Even after Pearl's wrist healed, Diana spent almost every day helping Pearl. Pearl was weak and continued to struggle with getting up on her own, bathing herself and she needed assistance with house cleaning. Pearl was very demanding and often was not happy with the way Diana did things. With all of the demands on her time, Diana decided to leave her volunteer placement at a seniors centre and often cancelled plans with friends. She started to feel resentful at how much caregiving was intruding on her life.

It all came to a head when Pearl dropped her cup of coffee all over herself and the kitchen floor. Diana had just cleaned the floor and now coffee and a shattered mug were everywhere. This was the last straw for Diana. She started yelling at Pearl, berating her for being so careless. Afterwards, Diana felt awful. She acknowledged she had been feeling very stressed, but believed she should have been able to handle anything.

Summary:

- Like many caregivers, it appears Diana and Pearl did not have a plan in place to prepare for Pearl's changing needs. If Diana and her mother had information on community and health services it may have helped alleviate stress for Diana, as well as, provided Pearl autonomy with her choices.
- Caregiving can be challenging and overwhelming at times. Caregivers with high levels of stress may find they are "not acting like themselves" or experiencing anger at "small things". These are signs that a caregiver may be burning out.
- Diana has given up her holiday and is spending more time caring than she used to, but it is possible she may not recognize she is experiencing caregiver stress. Providing a self-assessment tool could help Diana take a step back and provide an opportunity to connect to services and supports for them both.

WHAT IS ELDER ABUSE?

Elder abuse is any action or inaction by self or others that jeopardizes the health or well-being of an older adult. Elder abuse refers to a pattern of behaviour rather than a one-time event. Like other types of family violence, it is often committed by a family member,

and often occurs for the purpose of gaining power and control over the person. Elder abuse can take several forms including financial, emotional, physical, sexual, medication abuse and neglect.

SCENARIO:

Ben, a divorced father of two adult children, is the oldest of four siblings. Ben has been the only sibling to step up and help care for his elderly father, Mike. Ben's mother, who handled all of the finances, passed away a couple of years ago so Ben was added to his father's accounts for the sake of ease. Mike's health has been declining over the past six months so Ben took early retirement from a part-time job to meet his father's caregiving needs. Ben has been struggling financially ever since and is frustrated by the lack of support from other family members. He has kept his own apartment but finds fuel, rent, groceries, insurance and occasionally assisting his children has eaten away at his savings.

Ben asked his father to help pay his rent for a couple of months, until he was able to pay off some bills. Mike agreed because Ben is the only family member helping him and without his help, Mike fears he could not manage alone. However, once Ben had access to the bank account he started using his father's money to cover fuel costs when running errands and now regularly uses money to cover his own expenses without his father's consent.

Mike feels overwhelmed with any legal paperwork, like developing a power of attorney. Ben's siblings

have started to ask questions about his finances but Ben told his father to keep their agreement secret to spare him embarrassment. Ben has refused to let anyone see his father's bank account records; after all, if a stranger were hired to provide care they would need to be paid. Ben feels entitled to some money and believes his family should be grateful he is caring for their father.

Summary:

- In this scenario, Mike is experiencing financial and emotional abuse because Ben, his son, has been taking money from him without his consent for some time.
- A sense of entitlement is a factor often identified in financial abuse of older adults. Ben feels unsupported by his siblings and has been providing the majority of the care for his father for a number of years, which has impacted his financial well-being.
- Consider providing caregivers information on personal directives, powers of attorney, and community resources which support preventative measures. A discussion and agreement between Ben, Mike and perhaps other family members could have prevented this situation from becoming abuse.
- In this story, both Mike and Ben could benefit from being connected to local elder abuse resources for support.

SEVEN TIPS FOR SUPPORTING CAREGIVERS

Here are some tips to engage and support the caregivers you meet in your practice:

1. Acknowledge Them

In our patient-centred system, it's easy to focus entirely on the patient. One caregiver described her experience as "My name's now 'How's your mother?'" Asking the caregiver how they are doing tells them they matter too.

2. Address Their Experience

Guilt, anger, resentment, sadness and frustration are all common emotions for caregivers. Many caregivers are reluctant to admit they are experiencing challenging and conflicting emotions and, as a result, don't seek help until they are burning out. It is important to normalize those emotions and encourage them to ask for help. You may want to consider the following response:

"You seem to be managing well, but a lot of people in your situation find they start to feel stressed or frustrated. These feelings are normal. If you start to feel this way, let me know and I can help you find resources."

3. Help Them Recognize Stress

Caregivers can become so focused on their care recipient that they don't recognize they have high levels of stress. Self-assessments, such as the American Medical Association self-assessment (available at http://www.healthinaging.org/files/documents/caregiver_self_assessment.pdf) can help. If you are using a self-assessment, be sure to encourage the caregiver to discuss the results and next steps with you.

4. Look for Signs of Burnout

- Lacks energy
- Frequently sick
- Always exhausted
- Neglects needs
- Life dominated by caregiving, little time for social connections
- Difficulty relaxing when help is available
- Acts impatient or irritable with their care recipient
- Appears overwhelmed, helpless or hopeless

5. Encourage Self-Care

Help caregivers recognize they may not have to do everything themselves. Ask them what they are doing for themselves and encourage them to access respite and other caregiver supports.

6. Work with Caregivers

Caregivers spend a lot of time with the care recipient and likely know more about their needs than anyone else. Listen to what they say and include them in care planning.

7. Provide Referrals

Navigating the system can be hard. Caregivers often don't know who they should talk to or what resources they should ask for. Don't assume they are aware of services; sometimes caregivers are unfamiliar with common programs like home care. You don't need to know everything that's available, but help them connect to someone who can help. Here are some key resources to help them connect:

- Alberta Caregivers Association www.albertacaregivers.org
- Alberta Seniors www.seniors.alberta.ca
- Health Link for access to home care, respite and case management www.albertahealthservices.ca
- Local information and distress lines (for example: 211 in Edmonton) www.ab.211.ca
- Local FCSS offices www.fcssaa.org
- Seniors outreach workers at local seniors' centres www.seniors.alberta.ca
- Family Violence info line www.humanservices.alberta.ca or call 310-1818
- Disease and disability-specific organizations (for example: the Alzheimer's Society)