



In-Depth Brief on Priorities and Recommendations Related to Caregivers

Appendix

Example 4:

J. is an unpaid caregiver to her mother who she resides with at her condo in Toronto. Her mother was diagnosed with Alzheimer's disease four years ago. J. gets 20 hours of respite a month plus 3.5 hours of personal care a week for her mother from what was formerly the Community Care Access Centre (CCAC). J. describes her situation here:

Presently, mom only leaves her condo every three months to see her "favourite doctor" and it's a challenge at times convincing her to go. In the past, mom would stay over at one of my siblings' homes. However, the visits eventually ceased as mom's behavior would escalate resulting in unpleasant times for both mom and my siblings. These behaviors continued for about 2-3 weeks when she returned to her condo before she settled, causing me to be physically, emotionally and mentally exhausted.

Temporarily removing mom from her place of security and placing her in unfamiliar surroundings for respite only to risk destabilizing behavior upon her return to her condo, provides no benefits to mom or myself and therefore not an ideal option. Providing mom with respite in familiar surroundings, her condo, by my siblings is a more viable solution to alleviate the anxieties/unpleasantness that mom experiences when away from her condo. Such an arrangement also reduces caregiver exhaustion/stress.

Unpaid family caregivers need meaningful time away from caregiving to decompress. Utilizing five hours or more a week of respite does not provide the meaningful mental, physical and emotional relief caregivers need. Also, being dependent on family members, adult children or friends' homes to stay for extended relief is not always feasible. The government needs to provide unpaid caregivers with vouchers or accounts at hotels so caregivers can schedule some days away when they need respite. Such extended time away from caregiving would revitalize caregivers, reduce caregivers' stress, and enhance the care they provide to the care recipient. This will benefit both the caregiver and care recipient in both the short and long term. In simple terms, if the government does not begin to use a person-centered approach to provide caregivers with the appropriate

relief they need from caregiving, we will be the next healthcare crisis. This time away needs to be in addition to the 20 hours respite currently available to me to really help me continue to manage my caregiving role.

What this example shows:

- Out-of-home respite can create more problems than it solves when it is disorienting for the care recipient.
- Sometimes, true respite means “getting away” but even overnight hotel stays may not be affordable for a caregiver; creative options like vouchers for hotels might be considered.

Example 5:

S.’s story:

At the suggestion of CCAC, we applied for the direct funding program operated by a charity called the Centre for Independent Living Inc. and funded by the Toronto area Local Health Integration Network (LHIN). We were at first advised that we were perfect candidates because we already had a live-in caregiver who we were now struggling to pay. My wife clearly qualified owing to disabilities related to living with Multiple Sclerosis for over 20 years.

The process to qualify was a nightmare and included detailed descriptions of the exact nature of the help required which robbed my wife of dignity, two three hour interviews which I, as the primary family caregiver was not allowed to attend, all of which took more than a year only to result in being denied funding. The reason given was that my wife lacked the capacity to instruct and manage an employee owing to some minor dementia and that a family caregiver's ability to do so was irrelevant as this ran contrary to their philosophy of independent living.

This left me frustrated and confused because I was not permitted to assist my wife with the process. It appeared that my support for my wife was not being valued.

What this example shows:

- Barriers to accessing respite or in-home support can be formidable. The caregiver must often be seen as the co-client in situations where self-directed funding is being considered but where the care recipient is dependent to a great degree on the caregiver.
- There must be reasonable expectations on what sort of obligations a caregiver receiving self-directed funds must fulfil while still ensuring that there are accountability mechanisms in place for the disbursement of those funds.

Example 6:

Heidi is a young, active, busy girl who has a diagnosis of autism and a developmental disability. She is impulsive, often putting her safety and well-being at risk, and therefore requires constant supervision. Her mother is currently dealing with some serious health concerns and her grandmother has taken over the care of Heidi for an indefinite period. Prior to Wesway's involvement, Grandma was overwhelmed in her new caregiving role. She was requesting out-of-home respite but it was difficult to find safe environments in the community for Heidi. Grandma approached Wesway for help.

Heidi began by having regular respite at the Wesway Respite Home. The success of Wesway's Respite Home is the environment and the relationships. The home is centrally located in a quiet residential neighbourhood. It is bright, spacious, and very home-like with a barrier-free design. The services are personalized to suit the strengths, needs and preferences of the individuals and families served. The staff team is small, so they get to know the individuals very well. Although Grandma preferred that Heidi was supported in an out-of-home way, the reality of using such a service was daunting.

Wesway started slowly with a respite worker supporting Heidi at the Respite Home for three hours, twice a week. The respite worker arrived at the home before Heidi to ensure that the environment was safe and conducive to Heidi's needs. The two of them would enjoy a meal and home-based activities. This proved to be a great segue to overnight stays at the Respite Home. Heidi has recently begun to stay for a few overnights in a row, giving Grandma the solid break she needs. Grandma is very pleased with this option. She is now able to rest and "recharge her batteries" while staying in her own home. These breaks enable Grandma to continue in her caregiving role until Heidi's mother is well enough to resume the daily care of her daughter.

What this example shows:

1. A range of respite supports, including out-of-home options need to be available to caregivers.
2. Some caregivers need a break but do not want to leave their own homes to get this break.
3. Out-of-home respite options work best if they are conducive to the wants and needs of those who use them. They must be welcoming, safe, supportive, flexible and home-like.

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