

**A Guide to the
Promising Practices and Indicators
for
Caregiver Education and Support Programs**

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Introduction

Many people across Ontario voluntarily provide health and social care to family and friends, and it is anticipated that with Ontario's aging population, the demand for this kind of caregiving will grow, while the capacity of these people to provide care is projected to decrease.¹ The care that caregivers provide includes assistance with the activities of daily living (such as eating, dressing, toileting), as well as with instrumental activities of daily living (such as shopping, transportation, recreation, and financial support). The burden of providing this care can result in stress, depression, emotional strain,² loneliness, decline in physical health, and financial losses.^{3,4}

Many people voluntarily providing health and social care do not use education and support programs,^{5,6} though these resources are designed to provide information, knowledge, coping strategies, skills and competencies to help them deal with and address the multiple and competing demands and stresses associated with their efforts.³

Echo: Improving Women's Health in Ontario funded this study to determine the current promising practice programs and tools that provide education and support to family members and friends who care for others and to create recommendations for cost-effective education support priorities for a range of people across Ontario.

During the research project, an iterative dialogue between the research team and steering committee led to consensus on five draft promising practices and 15 draft promising practice indicators. These were identified based on consistency between what the literature says is effective and what is currently being exercised in practice.

From a jurisdictional review of caregiver education and support programs in Ontario and across Canada, we selected 8 programs that each put several of the draft promising practice indicators into action. We should emphasize that there are certainly many other programs that are currently being offered, which also illustrate several of these promising practice indicators, and we cite these 8 programs as examples only. Please refer to Table 1 below for a summary of each program.

We subjected the draft promising practices and indicators to strict scrutiny after meetings with caregivers and program facilitators in focus groups and interviews. The number of indicators increased, from 15 to 20, and were rearranged and realigned to reflect caregivers' perspectives on what they require in order to meet their education and support needs. Please refer to Table 2 for a list of the promising practices and indicators, and the identified programs that address each one.

Using the promising practices and indicators

We believe that these indicators can be put into action right away by organizations who currently deliver caregiver education and support programs, and by those who are working to develop new programs or improve existing ones. The caregiver commentaries and the examples provide some ideas about how organizations can use the indicators within existing programs.

One additional important note: based on our review of current programs, we believe that it would be challenging for a single organization to provide a program that meets all of the indicators. Nonetheless, caregivers indicated to us that any program hoping to meet their support and education needs should at least identify partner programs to fill gaps in their own programs, and help caregivers link effectively and seamlessly to those partner programs.

Table 1. Example caregiver education and support programs

#	Name	Organization	Description
1	First Link	Alzheimer Societies, Ontario	A progressive, multi-component education program to reduce social effects for caregivers of individuals with Alzheimer’s disease and related dementias. The program takes a dialogue-based approach to education and support, which is focused on individual needs and stage of disease.
2	Reitman CARERS program	Mount Sinai Hospital, Toronto	A multi-component, evidence-based program offering unique, tailored skill-building interventions aimed at providing caregivers the tools and support to manage the day-to-day care of an individual with dementia at home.
3	Canadian Caregiver Support Group	CancerChat Canada	Online, interactive group chats for individuals with a diagnosis of cancer and their caregivers, facilitated by professional psychosocial oncology counsellors. It provides a safe place to discuss personal topics and gain emotional support.
4	COMPASS	Alberta Caregivers Association	A multicomponent, 8-module workshop offered to any individual who self-identifies as a caregiver, equipping them with the tools they need to care for themselves and cope with the emotional side of the caregiving role.
5	Rebound and Reconnect	VHA Home Care, Toronto	A short-term program targeted to vulnerable and marginalized caregivers, aiming to connect individuals within their community by offering caregiver relief while the individual attends a community activity/program of their choice.
6	Caregiver Support Program	The Friends, Parry Sound & Muskoka, Ontario	An individual and group education program that aims to prevent caregiver burnout, alleviate stress, and increase safety in the home by focusing on important issues such as self-care, stress and elder abuse. The program also supports caregivers with system navigation, placing a strong emphasis on cross-referrals to other programs and resources.
7	Education Series and Support groups	VON, Yarmouth, Nova Scotia	A multi-component program offering two education series and a monthly support group. The program aims to build knowledge and skills, and facilitate sharing struggles and good news stories. The first series focuses on self-care issues including stress, communication, and dealing with emotions. The second series specifically deals with Alzheimer’s disease education.
8	You and Your Aging Parent	City of Ottawa and Family Services, Ontario	A three-part education and support series offered to those caring for, or who anticipate caring for, an aging family member or friend, which focuses on preparing individuals for the aging process by providing information on safety adaptations in the home, community resources, and how to plan ahead.

Table 2. Promising practices, indicators and example programs

Promising Practices	Promising Practice Indicators	Example program							
		1	2	3	4	5	6	7	8
#1 Respond to the Unique Care Situation	1. Ask caregivers what they need; tailor services and content	✓	✓			✓	✓		
	2. Consider the relationship between the caregiver and care recipient	✓	✓						✓
	3. Include strategies to address family dynamics and roles	✓	✓				✓		
	4. Consider the influence of gender		✓		✓		✓		
	5. Recognize cultural influences		✓		✓	✓	✓	✓	
#2 Stimulate Caregiver Involvement and Interest	6. Foster networking among caregivers	✓	✓	✓	✓		✓	✓	
	7. Make connections to community services	✓	✓		✓	✓	✓		✓
	8. Offer online interactive program components			✓					
	9. Help caregivers apply knowledge and skills	✓	✓		✓				
#3 Address the Emotional Context of Providing Care	10. Reinforce that caregivers need to care for themselves	✓	✓		✓	✓			✓
	11. Recognize the different emotional stages of caregiving	✓	✓	✓	✓				
	12. Affirm caregiver competence and confidence	✓	✓				✓		
	13. Encourage caregivers to consider their positive experiences	✓			✓				✓
#4 Provide Relevant Information	14. Educate caregivers about how the system works				✓		✓		
	15. Provide practical strategies for caring	✓	✓					✓	✓
	16. Address informational needs over time	✓					✓		✓
#5 Enable Caregiver Participation	17. Arrange for respite if needed		✓			✓	✓	✓	
	18. Arrange for transportation if needed		✓				✓		
	19. Make the program convenient	✓	✓	✓	✓		✓		
	20. Provide a welcoming and comfortable atmosphere	✓	✓	✓		✓	✓		

Promising Practice #1

Respond to the Unique Care Situation

Caregivers are individuals who have unique needs, which go beyond their quest for basic information and greatly influence their capacity to be able to support the care recipient. Therefore, caregiver education and support programs must be able to respond to the unique care situation of each caregiver.

There are 5 promising practice indicators that provide further details of how programs can respond to unique care situations.

1. Ask caregivers what they need and tailor services and content accordingly

While research studies suggest that multi-component programs are the most effective, it is not enough to offer caregivers variety. To be effective, multi-component programs must tailor their resources to the care situation by directly asking individual caregivers what help they need. Programs should therefore include an assessment component (formal or informal) to determine the individual needs of caregivers, as well as the relevant background and circumstances of the individual. According to a program representative:

“Support is crucially important, but accurate support is what is necessary. From the outside we analyze and come to conclusions about what people need in terms of support and then provide that to them. Support is only support when it is experienced as support, and that can only be when it is developed and engaged in a joint process. In the main, our service resources are external to collaboration with the caregiver and they are provided ‘to’ them.”

What caregivers said

During a focus group, a caregiver discussed a program that was unable to meet her needs:

“There’s a disconnect between what you need and what they’re able to give you because you express your need and they’ll say, ‘oh yeah, that translates into three hours of [us] sending you something.’”

During a key informant interview, another caregiver described her experience having to advocate for her own needs rather than having them formally assessed, and she later discussed the need for program professionals to be more proactive in the process:

“As a care partner, I have never been offered education. I have had sort-of my needs assessed, but it has not been a formal assessment of my needs, or my husband’s needs as a care partner...[With the] CCAC I could ask for things that I knew were available, but they didn’t offer them. So I was expressing my own needs, rather than them assessing my needs. I think that one of the things that people in the role of care partner need is their needs assessed as well as the person they are caring for, because their needs are very important because they are the most formal caregiver.”

“If the professionals were assessing the needs of the caregiver, then they would know what things to point them to...they are not asking the right questions.”

Examples of this indicator in action

The *First Link* Program focuses on assessing “fit” by asking caregivers what their individual concerns are during a screening and intake process. Additionally, the *Rebound and Reconnect* program works with caregivers during a telephone intake process to determine their needs and develop an individual strategy for participation in the program. Further, the *Friends Caregiver Support Program* uses the RAI assessment tool* to formally assess what the needs of the caregiver are. This is particularly useful for caregivers who may have their own health needs. Similarly, the *Reitman CAREERS program* also completes a formal intake assessment. A program representative described this process:

* RAI, or Resident Assessment Inventory, is a standardized suite of 12 patient assessment tools tailored for use in different health care settings, that is, acute care, home care, long term care. The tools use a common language to assess patient functioning, needs, quality of life, preferences, strengths and weaknesses with an aim to improve continuity of care. The tools can also be used on multiple occasions to monitor an individual’s response to care and/or services. See www.interrai.org for more information.

“We do a pre-program assessment of each individual and out of that we determine what the specific issues are that the individual is talking about, we look at the background of the relationship and the stressors that may have pre-existed or the strengths that may have pre-existed, the psychological makeup of the caregiver and how all of that interacts with a very specific listing and describing of the particular problems they are having at this time, in their life, with the person they are engaged with. So it’s a very detailed analysis of the unique care situation from an emotional, practical, psychological, and family context.”

2. Consider the relationship between the caregiver and care recipient

Responding to the unique care situation of a caregiver requires programs to acknowledge and consider the quality of the existing relationship between the caregiver and the care recipient, and appreciate that the care experience involves both people. It is important for programs to understand that caregiving duties are often performed within the pre-existing role of spouse, child, or parent, and that the pre-existing relationship between the caregiver and care recipient may undergo stress and strain.

A program representative honed in on this indicator during a key informant interview:

“The main problem for the caregiver is first of all, their self-perception; they are not a caregiver. What they are is a husband or a wife, and they are trying to enact that role in relationship to the person with the disease. The disease is eroding that relationship to a minor or a huge, major degree, and the struggle becomes one of ‘what is going to happen to me?’, ‘what is going to happen to my husband?’, ‘how can I care for him and at the same time survive?’, ‘what am I going to do over time?’”

What caregivers said

During a focus group session, a caregiver described one of the challenges she has faced in her relationship with her husband as a result of caregiving:

“Because [my husband] also is a stubborn man, he’s used to being in charge...and he will not admit that he’s not in charge. So there are little problems with he and I because I now have to take charge.”

Another caregiver described the impact her caregiving role made on the expression of intimacy between her and her husband:

“All of a sudden now you’re the mother. And that’s one thing with a parent and there’s a whole set of emotions there, and it’s quite another when you find you’re mothering your husband who still feels sexual and a man who wants to be in charge. You’re doing all these things that are mothering. It’s hard to separate that.”

In a key informant interview, one caregiver pointed out her opinion regarding the distinction between the caregiving role, and one’s commitment as a spouse:

"[Caregivers] are doing something extraordinary; it's not just being an ordinary spouse. It's beyond being an ordinary spouse even though you say 'until death do us part' and 'in sickness and in health' and all that sort of thing."

In another key informant interview, a caregiver discussed her opinion regarding the differences between providing care as a spouse, versus as an adult child:

"A daughter is in a very different position with the father than a spouse would be. A spouse has that intimate relationship with the father, a daughter doesn't. Changing my father's diaper was not an easy thing to do. I did it as sweetly as possible so that he wouldn't be embarrassed. Daughters caring for fathers is a very difficult thing."

Similarly, a caregiver discussed the challenges of providing care as an adult daughter during a key informant interview:

"About six weeks ago, I took away my mom's car keys. And that has been a nightmare. I'm pretty frail around the edges and my mom is very angry at me. The withdrawal of my mother's love because of the car keys is pretty traumatic for me."

Recognizing these types of challenges, a caregiver participant in a focus group session honed in on the need for programs to understand the relational context before providing education and support:

"It is hard for the caregiver support programs to suss out what the nature of the relationship is between the care recipient and the caregiver, and until that happens, the program can't really help them."

Examples of this indicator in action

The *Reitman CARERS program* offers group sessions targeted to specific relational issues, including intimacy, abuse, role changes with increasing responsibility, and marital conflict. The *First Link* program offers a "First Steps" series, which includes both the caregiver and care recipient and focuses on helping them build strategies to work together to manage the disease within their current relationship (e.g., problem solving and communication skills). The *You and Your Aging Parent* program focuses on providing education to help older adults and their adult children prepare for the potential impact of the aging process on their current lifestyle (e.g., adult children who live at a distance).

3. Include strategies to address family dynamics and roles

When families are dealing with highly stressful situations and are called upon to make important decisions about the care for a family member, unpredicted issues and tensions often rise between spouses and/or among children, siblings and grandchildren. Potential issues can occur around finances, living arrangements, which individuals will provide care, and powers of attorney, to name a few. Therefore, caregiver education and support programs should include strategies to help caregivers address and manage family dynamics and changing roles, and help them to handle difficult conversations.

What caregivers said

During a key informant interview, one caregiver discussed the unexpected nature of the issues her family encountered in planning care for her father, and later discussed her wish to have worked through the issues sooner:

“In terms of family dynamics, when you have a sudden illness, for us it did raise tension within the family. With siblings living at a distance, they definitely had strong opinions and took it upon themselves to express those strong opinions. The whole family dynamics and what you should and shouldn’t do, and who has power of attorney for health care decisions, and who’s supporting mom to do the planning and what does that planning look like, and ‘how dare you talk to mom about housing’. There are a lot of family issues that come forward and that is extremely stressful. I think we got off fairly easy, but I didn’t anticipate we would have any family issues.”

“It would be so much better if families could meet ahead of time, before anything like this happens to think about what you would do, how decisions should get made. Advanced care directives are great, but it was all the other decisions that I got caught up in. We all had very different ideas about housing. That was our most contentious issue, because with housing there are resource issues and care issues. It’s not maybe those more formal care directives, but it’s all of those other smaller pieces in thinking through what we are going to do. Even in terms of putting together a hospital visiting plan and ‘how do we manage that?’, which was another contentious issue for my family...That can really break a family and it can really lessen the care.”

In another key informant interview, a caregiver discussed her concerns about being the only person able to take care of her husband. She later went on to discuss her hesitance in relying on her family for help:

*“My worry is what if something happens to me? That’s my big worry. I don’t know what the kids would do. With two of them in the States, he can’t move there because they wouldn’t allow that. Matthew isn’t married. I don’t think he would fit well into Mike and Sarah’s home. So I don’t know what would happen. They’d have to get him full time help of some sort. I’ve asked him if he would like to move somewhere where it is less expensive to live, because it worries me that our condo fees are so high, but he says he can’t do that right now.”**

“My kids don’t live here. ...They would all help, but you don’t like to lean on your children. They have children of their own, and a life of their own.”

* Names have been changed to protect identity.

Examples of this indicator in action

The *First Link* program “Options for Care” session is meant to help caregivers through the decision-making process when more care is needed for their loved one (e.g., when it is time for long-term care). The *Reitman CARERS program* employs a social worker who helps families map out their support system and discusses the importance of including all family members when making plans for care. Wherever possible, The *Friends Caregiver Support Program* speaks to the entire family during the initial interview and intake process and they look at 25 key areas of the caregiver’s life that could be affected. A program representative explained the process:

“What we do is try to first of all figure out who the key people are in the family grouping; who the people are who are most involved in the person’s care. We need to know what the expectations are of the family. In some families, everyone wants to know everything and some families want to have a single spokesperson who is the key person who communicates information to the rest of the family. So a key piece is when we interview clients and their families, we want to get a sense of who we are communicating with.”

4. Consider the influence of gender

Responding to the unique care situation also requires programs to consider gender-specific needs. We found little evidence that the needs of women and men have been broadly and explicitly addressed in the development and delivery of education and supports to caregivers. Instead, there appears to be a working assumption that, because it is women who predominantly use caregiver education and support programs and many programs have been shown to be effective, the programs are successfully meeting the needs of women. Programs must be sensitive to the different challenges that women and men face, and the successes and challenges that each gender has in caregiving. During a key informant interview, a program representative discussed the gender differences he has witnessed in facilitating caregiver education and support:

“There’s a difference in the quality of isolation and loneliness that men experience versus women. The need for affiliation amongst women is different than that amongst men. The ability to express emotion is often different, although it’s not an absolute rule. Issues exist in the experience of burden.”

What caregivers said

During a focus group session, one caregiver spoke out about her observations on the differences between male and female caregivers, according to her experiences in a support group:

“We’re women after all. Generally we are the ones that are caregivers. There are very few men in our group. But what I find is that it is much easier for a man to get help than a woman. The women’s ‘I can do it, I can do it’ attitude comes into play, whereas a man would say ‘I can’t do it’ right off the bat. There’s no shame in men saying ‘I can’t keep a house and look after my wife too’. So they get all this help immediately whereas we hold back and say ‘I can do it.’”

Similarly, in a key informant interview, another caregiver discussed her perception of the differences between men and women in their experiences providing care:

“My experience with men caregivers is they want to fix things, and these diseases can’t be fixed so it’s very frustrating for them and having like-minded people to speak to helps them cope.... Women have normally been the nurturer in the family so they are just extending that role. Some women were good mothers so they will be good caregivers. Some people just can’t handle it.”

Examples of this indicator in action

The *Friends Caregiver Support Program* takes gender into account during the intake process in order to determine what issues are present and help participants choose relevant and interesting session topics. The *Reitman CARERS program* has mixed groups of men and women. A training component for group facilitators focuses on how to mold mixed groups effectively by honing in on potential differences between men and women in their need for affiliation and their experience of loneliness and burden. Similarly, the *COMPASS* program has mixed groups and makes an effort to pair men within groups so that they are not isolated.

5. Recognize cultural influences

Finally, programs need to recognize the cultural context within which the caregiving actions take place. This includes considering the influence of expectations, norms, beliefs and behaviours which are characteristic of a particular ethnic, social or age group. Further, there is a need for program staff and/or volunteers (intake, administration, facilitators) to recognize what is different about helping someone who is “other” than themselves.

What caregivers said

During a focus group session, one caregiver discussed the influence of her ethnicity on her ability to ask for help:

“Being of an Italian background, I was of the belief you have to be a good wife, you have to do everything, don’t complain...now I look back and think I didn’t ask for help because I thought that was weakness and I needed to do it myself, but now I realize I denied people the opportunity to help because I didn’t ask them.”

A caregiver in another focus group discussed the impact of age differences between those providing and receiving education and support:

“When my mother was dying, my father needed as much care as she did. But all these people were coming into the home. I had to put a stop to it when they were sending a social worker... to help my father deal with the fact that his wife of 60 years was dying. She looked 15 – I know she was probably 24 or 25. She had nothing to say to my dad who was 80 at the time that would make any sense or difference to him. There has to be a sensitivity there in that department – what did she have to offer life-wise for my father’s loss? Nothing.”

In an additional focus group session, a caregiver pointed out the need for more education and support for caregivers who are adult children:

"I find that usually the spouses are taken care of, and it's geared toward older people. In any of the meetings I've been to, and I've been to many, there has never been anybody, sort of my age... My mom is only 67 and so she's very young. There must be some sort of program for the younger generation."

Examples of this indicator in action

The *Reitman CARERS program* has a satellite program for the Chinese community and is developing another program for the Portuguese community. Program facilitator training materials have cultural perspectives and nuances embedded within them. The *Friends Caregiver Support Program* partnered with a First Nations community to adapt their program to meet cultural needs, and assisted in the training of community Elders to facilitate the program. According to a program representative:

"The caregiver group was a natural fit for the First Nations because they believe in a non-hierarchical structure; literally a circle of care, and the value they place on elders is even higher than the values we place on them in white, North American society."

This program also provides a meal during their sessions and tries to be sensitive to the food preferences of different ethnic groups who may be attending. Further, the *VHA Rebound and Reconnect* program operates within diverse communities and offers respite services by PSWs who speak many different languages. The *VON Education Series and Support Groups* offer sessions in French to address the needs of French-speaking Acadian populations in Nova Scotia. *COMPASS* works with partner organizations to target different groups (e.g., immigrant communities).

Promising Practice #2

Stimulate Caregiver Involvement and Interest

Caregivers are often at risk of experiencing social isolation and burnout as a result of their demanding care schedule and activities.⁵ Therefore, programs need to be cognizant of how to help caregivers connect the education and support they receive to their unique care situation. In order to encourage caregivers to explore and apply additional avenues of support and resources, it is important that caregiver education and support programs go beyond providing one-way information sessions and focus on an interactive approach through stimulating caregiver involvement and interest.

There are 4 promising practice indicators that provide further details of how programs can stimulate caregiver involvement and interest.

6. Foster networking among caregivers

One way that programs can stimulate caregiver involvement and interest is through engaging participants in forms of peer support to allow caregivers to teach and learn from each other's experiences. Peer support can also help caregivers validate their emotions and reduce feelings of loneliness and isolation. Therefore, programs should consider facilitating peer support groups, which can be attended by caregivers only, or which may include both caregivers and care recipients. Consideration should also be given to offering support groups for those at different stages in the caregiving journey. The support group may also be general or disease-specific and should last for several weeks or months so that individuals have the opportunity to establish meaningful connections that might continue outside of the group setting. According to one program representative:

"Many facilitators have said that at the end of the four week learning series people will want to continue meeting, so they have developed those connections with each other and are supporting each other ongoing."

What caregivers said

During a key informant interview, a caregiver discussed the benefit of connecting with other individuals who are in the midst of providing care and support:

"I don't have any peers through other social connections that are caring for a parent. Most of my friends thankfully have parents who are well and have not experienced what I've experienced. Although they are wonderful in terms of listening and understanding and being empathetic, they don't have the same depth of knowledge of what it's like to be there. So it is helpful to talk to people who are actually there."

During several of the focus group sessions, caregivers discussed the benefit and experience of peer support in a group environment:

"It is amazing how much we caregivers help each other and bond in a few short hours. Conversation is very soothing to the stressed."

"It took me a while to get there [to the support group], but once I got there, I realized just how much I needed it. I needed to know that life went on even with a horrible diagnosis...and I got that there. I found camaraderie, but I also found that people were actually happy!"

"Trenton has a very good support group, nobody dealing with parents, but it was ok, it was good. While the stories weren't the same, the issues were the same."

During a focus group session, one caregiver discussed her positive experience in a disease-specific support group offered to caregivers separate from the care recipient:

"[The caregiver group] really helped us through a lot of difficult times because, even though our situations were all different, because we were dealing with the same illness...there were a lot of things we could say that others could really relate to. And we couldn't tell our spouses those feelings. With the frustrations of being a caregiver, sometimes you can't tell your spouse because they would be very hurt by it but you also need to get it off your chest."

Another caregiver discussed the validation she got in a group where everyone was dealing with a particular emotion, regardless of the care recipient's diagnosis:

"At the support group, we had a wonderful thing We had a person with MS, another whose child had committed suicide, it was all about who was grieving. When I found out I wasn't the only one whose kids walked away, I won't say it made it better, but it made it easier."

Finally, during a focus group session, one caregiver discussed the potential benefit of peer support for both herself and her husband in a program that offered concurrent groups for both the caregiver and care recipient:

"It feels to me that a drop-in, perhaps in a local school, which would operate afternoons daily, with one or two professionals and a few volunteers, would be a great boon to me. It's always easiest to talk informally and to share information that way. Knowing I could drop in with [my husband] who has Alzheimer's, and both of us could share in some appropriate activities, for example, I with a psychologist in a discussion group and he with an occupational therapist in a "memories" group, would truly help give an extraordinary support to us. Knowing there is a daily drop-in with coffee and conversation close by for dementia sufferers and their caregivers would help to alleviate the twin issues we face, of isolation and burn-out."

Examples of this indicator in action

The *First Link* program takes a dialogue-based approach where the facilitators break the larger group into smaller group discussions so that caregivers have the opportunity to share with each other. The *Reitman CARERS program* has introduced a maintenance component, including drop-in sessions to help caregivers continue the connections they have made with each other and support they receive.

According to a program representative:

"We recognize that what we are building is a platform over 10 sessions, and then we didn't anticipate this, but over time it became clear that to cut things off after 10 sessions, while practical, is not the best way to help people. So we've continued with a maintenance program over a period of a year, and we've just implemented a drop-in program so that people can continue... networking. So we promote the networking by continuing the process. It's a bit labour intensive, but we are on-call for that group once a month."

COMPASS encourages caregivers to attend drop-in community support groups to obtain extra support, in addition to an eight-week educational workshop module. The CancerChatCanada *Canadian Caregiver Support Group* offers professionally-facilitated online support groups that meet once per week for up to 90 minutes in a live “chat” room on the Internet. Most of the groups meet for 10-12 weeks, but some groups are ongoing. Group discussions are focused around common experiences or concerns and questions. Members are encouraged to speak openly and to support each other. The *Friends Caregiver Support Program* attempts to make their group sessions pleasant social experiences. They place great value in allowing time for casual chit-chat and recognize that the group is not all about the education. They help to create little social networks of people to reconnect rural caregivers to the larger community. The *VON Education Series and Support Groups* take a more structured approach to peer support by facilitating a circle discussion. A program representative described this method:

“For the peer support, the way that we facilitate this group is that we kind of use what’s called a talking circle so that everyone has an opportunity to speak so we don’t just gather in a room and there’s coffee and people just mingle and chit chat with one another but it’s very structured...If Mary Smith, for an example, is speaking then Mary Smith has the floor. Once she’s done, if somebody has a comment, or somebody has a suggestion to Mary about a situation that she’s dealing with then they are able to do so at that time.”

7. Make connections to community services

Caregiver education and support programs can help caregivers by working with them to establish connections within their community. Many caregivers have a limited awareness of their options for education and support. Most often, caregivers must conduct their own research on support services, and are left to take the initiative in contacting program coordinators regarding their participation. One way programs could address this barrier is to better advertise program components to the general public and foster connections with caregivers through formal referrals facilitated by program representatives or community health professionals.

However, programs need to go further in actually making these connections, for example, by making the necessary phone calls on behalf of caregivers and following up to ensure meaningful connections have been made. This would also involve considering the support necessary (e.g., respite) for an individual to be able and comfortable to leave the care recipient for a period of time, in order to make use of community services. Several program representatives felt very strongly that helping caregivers connect to community resources goes beyond providing information, and requires an active approach:

“Usually they will say, ‘please do not give me another number to call’; and that’s understandable. In that situation the last thing they want to do is repeat their story all over again... They don’t want to go to a website, they don’t want to read a pamphlet. They just want someone to physically come to their home and roll up their sleeves and look after the care while they do what they need to do whatever they need to do.”

“I’m a strong believer that if you can’t provide services that are outside of the scope of what you can do but you recognize that there is a real need there, then there is a real responsibility on agencies to make sure that the appropriate referral is done... Health care providers...need to take that extra step to make sure people are appropriately supported and receive the support they need, and as I said, if that means picking up the phone and helping him or her make that appointment and get that referral, then I think that’s what needs to happen.”

“The creation of community connections is important if it’s a real connection. What doesn’t work very well is ‘here’s a pamphlet for the local day care program’. ‘How am I going to get my husband there?’ ‘How do I convince him to go?’ So there’s a real breakdown there. It’s really the bridging the individual from one service to the next.”

What caregivers said

During a focus group session, one caregiver described the amount of work required to coordinate services in addition to providing care:

“Even though I had care 12 hours a day, I still did all the evenings, all the overnights.... I feel very fortunate that we were able to, I was able to assist my parents to remain in their home, but it’s a tremendous amount of work, all that coordinating It’s a lot of work. I’m glad I was able to do it, but....”

During a focus group session, another caregiver discussed the lack of awareness about available community programs and supports:

“I think [caregivers] only find out [about programs] if they are lucky. For example in Kingston at the movement disorder clinic, there are over a thousand individuals that go through there each year with Parkinson’s disease and we have a membership of 96 families. Where are the other 900? Why don’t they come? Have they heard about us? Why haven’t they heard about us? How do we reach these people?”

Recognizing these challenges, several caregivers, in both focus groups and key informant interviews, described their need for hands-on assistance in making connections with community services, as opposed to just being given information:

“They send you this huge package of information and you say okay, here I am with this package of stuff about what I’m supposed to do and what she [the care recipient] is supposed to do but since I live [in a rural area and there aren’t as many services], what am I supposed to do with it?”

“Sending someone a flyer in the mail isn’t going to do it. They might have the information and they might keep it and come back to it later and think ‘hmm this is interesting’, and then in December when they are cleaning up from Christmas they might say ‘Oh that might be interesting to go to, but oh gee it was in October’. Things get piled up when you are a caregiver.”

Examples of this indicator in action

As the name of the program suggests, making connections to community services is one of the key goals of the *First Link* program. Facilitators work with the caregivers during the series to develop an individualized plan for support and actively make referrals based on identified gaps in services. Similarly, the *Reitman CAREERS program* has developed a document which breaks down community resources into relevant categories, and social workers partner with caregivers to “map out” and address their service needs in each category. The *VHA Rebound and Reconnect* program intake process is completed by a social worker who provides a referral service to connect individuals with other community resources, regardless of whether they meet eligibility criteria to participate in their particular program. The *Friends Caregiver Support Program* also helps caregivers with system navigation by making referrals to community agencies and services. The *You and Your Aging Parent* program provides early education on the services that are available in the Ottawa area and connects individuals to necessary resources early on in their journey. *COMPASS* employs a “Caregiver Advisor” who goes into people’s home as a supportive counselor and gets them connected to the right people.

8. Offer online interactive program components

In order to foster caregiver involvement and interest, education and support programs should also offer online interactive program components. Some caregivers may not have the option of attending in-person support groups due to busy schedules, living arrangements, or geographic barriers. Further, an increasing number of individuals are becoming comfortable using computers and social networking tools and therefore some caregivers may simply feel more comfortable engaging in education and support activities online. Therefore, in order to reach a broader range of caregivers, it seems appropriate to encourage the engagement of caregivers in online interactive environments.

What caregivers said

During key informant interviews and focus groups, several caregivers mentioned that they used the Internet to search for resources related to the care recipient’s condition and caregiving. One of the caregivers specifically spoke about using media and social networking to share her and her husband’s experiences with others:

“We had already started seeking caregiver stuff. At first, any time I would talk about it, I would be crying. It’s scary because you don’t know what’s happening. Now you talk to him and he’s perfectly normal. We did a piece for CTV, and you can see it; he set up a Facebook page and it’s on there, and he says in that ‘I feel fine now, but I know I have this disease.’”

Examples of this indicator in action

We did not find many programs that offer online interactive services. However, the *CancerChatCanada Canadian Caregiver Support Group* is a program that is facilitated entirely online, and is intended to anonymously connect individuals with a diagnosis of cancer all across the country in a supportive environment.

It is important to note that several of the other example education and support programs included in this report indicated that they are in the process of thinking about and working towards incorporating interactive online elements to their programs. For example, one program representative noted:

“What I would like to do over time is to improve the accessibility of this program for the caregivers. Attached to that will be the opportunity to filter resource needs for people, to individualize it a bit more [through technology].”

Through our research process we also became aware of several other online programs and/or resources that are meant to assist caregivers in their role providing care. For example, Saint Elizabeth has recently launched an online repository of resources and information for caregivers called the “Caregiver Compass.”* Similarly, VON has an online information resource called “Caregiver Connect.”† In terms of interactive online solutions to education and support, VHA Home Health Care is working with *The Caring Voice Network*‡ to offer free, online education sessions.

9. Help caregivers apply knowledge and skills

There is an abundance of information available to caregivers; however, they often require assistance in knowing how to apply the knowledge and skills to their own situation, which is crucial if they are going to be able to truly benefit from the education and support that programs offer. Therefore, programs should include active and/or hands-on learning activities where caregivers have the opportunity to practice and try out what they have learned through the program content and from other caregivers. A program representative expressed support for this indicator:

“What we have found is that people have lots of information and they get lots of education. What they don’t do is absorb it and refer it to their specific situation and given circumstances at a given moment in time. Pure education is an academic exercise, unless it is embedded in an understanding and process that addresses the emotional barriers that individuals have to actually absorbing all of this.”

What caregivers said

During a focus group session, one caregiver described how difficult it can be to absorb and apply information she received:

“Sometimes there was so much information; you can’t always absorb it all because you are overwhelmed. These people come in and tell you all this great stuff, but how much of it are you really going to catch?”

Another caregiver discussed the usefulness of practicing learned techniques within a program setting using an active, hands-on approach:

* <http://www.caretoknow.org/flash/compass/>

† <http://www.von.ca/en/caregiver-connect/home/default.aspx>

‡ <http://www.careringvoice.com/>

“Mount Sinai, I found fascinating. They had a girl come in, who was an actress, and she acted the part of your mate, and it was fascinating to see how close she was. She gave us methodology on how to deal with things.”

Examples of this indicator in action

The *First Link* programs includes activities in which caregiver groups break off into pairs and try to brainstorm and help each other find ways to apply what they have learned within the context of their own situation. The *Reitman CARERS program* includes a role-play component, where actors and actresses act out the role of the care recipient who has dementia, in order to help caregivers practice communication strategies to deal with behaviours that may occur as a result of the disease. *COMPASS* encourages caregivers to keep a journal and runs an exercise called “Yeah...but”, where caregivers discuss something they would like to do, but cannot because of their role (e.g., ‘Yeah, I want to go on vacation....but I cannot’). The group is asked to help the caregiver brainstorm strategies around these barriers.

Promising Practice #3

Address the Emotional Context of Providing Care

While in the literature there was some discussion about the physical effects of caregiving (for example, lifting a care recipient can result in back injuries), much of our dialogue with caregivers and many of the research studies we reviewed focused on the emotional stress and strain that caregiving can cause. Therefore, it is essential that programs address the emotional context of providing care experienced by caregivers, and how it might affect not only their ability to provide care, but also their ability to participate in, or benefit from the education and support a program offers. Program representatives seemed to agree with the importance of addressing the emotional aspect of providing care. One program representative stated:

“The emotional context of care is a potent obstacle to the use of any other interventions or resources. So, the elements of addressing the emotional context include creating an effective relationship with the caregiver. Impersonal interventions in this highly charged emotional environment don’t work very well.”

There are 4 promising practice indicators that provide further details of how programs can address the emotional context of providing care.

10. Reinforce that caregivers need to care for themselves

In addition to providing support to caregivers through group sessions and counselling, programs should encourage and enable caregivers to care for themselves, and help caregivers acquire and strengthen their coping strategies. Programs might consider promoting the importance of proper nutrition, exercise and looking after their own health needs, which can often be forgotten when caring for someone else. Another challenge that caregivers face as a result of providing care and support is stress and strain on their personal life and other important roles including, for example, mother, wife, employee and friend. Therefore, programs must encourage caregivers to take breaks from providing care in order to maintain other significant relationships and engage in activities they enjoy.

Several program representatives reinforced the importance of self-care and taking breaks:

"[Caregivers] are so needing to have that break. They just want a qualified, sensitive, warm person who's going to look after their loved one while they go out with a friend, or go to a movie."

"How many would accept a position with an employer who asked you to work 24/7 with no breaks and no vacation time? Everybody said well we would never do that while I said nobody expects you to do that as a care partner either. Really, it is important that you have breaks and it is important that you do things for yourself. So, we may feel guilty when we do that, that's the emotion part but the truth part of that is that we know we need to have a break. We try to act based on the truth and not on the emotion."

"One scenario is that 'I have no time for myself'. What does that really mean? When we started to narrow this down, it was 'I don't see my friends anymore, and what I did with my friends was to play golf every Wednesday for 4 hours' That is what I need. Respite is a relative rather than absolute concept. One can speak in general terms, that relief from the overwhelming nature of caregiving is essential for people, but the nature or the content of respite needs to be specified, and it won't be specified unless one inquires in a very specific way."

What caregivers said

During focus groups and key informant interviews, several caregivers described the overwhelming and all-encompassing nature of providing care:

"I don't really have a life, because my life revolves around taking care of her.... I don't think I'm going to survive."

"At first I blocked it all out. My dad was in the hospital and I would not let myself break down. I was the stoic daughter. It was really interesting for me, I carried on like that for months and did not break down even once because I guess I was just wrapped up in the situation..."

In order to cope with the stress of providing care, several caregivers discussed their self-taught strategies during a focus group session:

1: *"You need a scream room. I've got one. It's called the garage. I informed the neighbours."*

2: *"I go to the garden."*

3: *"I've felt lots of times like going out to the backyard and screaming my head off."*

Another caregiver described the need for programs to teach caregivers additional strategies to help themselves:

“There was a lot of information about how to help [my husband] with his condition but I would have like to know more about how I can help myself so that I can be strong and have a balance in my life.”

During a key informant interview, another caregiver described her positive experience in helping her mother recognize the importance of self-care:

“She started learning how to self-manage. I saw a transition a few months after. She was in this busy, busy, busy state for the first few months looking after all the medical things and trying to be the best caregiver that she could. Then there was almost this turning point where we started looking at the fact that she can’t do this at this pace forever. We needed to look at her own self-care and tapping into community services, and her own quality of life...I saw a real change in her in terms of her own language and telling people ‘no I have to do things for myself, because if I’m not well, I can’t look after my husband.”

Examples of this indicator in action

The *First Link* program educational content places a large emphasis self-care, including skill-building to manage stress, the importance of exercise, social connections, staying mentally active and maximizing brain functioning. The *Reitman CARERS program* takes a “therapeutic” approach, focusing on improving caregiver coping/problem solving skills and emotional regulation, including how to deal with feelings of depression, anxiety, fear, anger, rage, and entrapment. *COMPASS* includes self-care in the name of the program (Caregiver Orientation of Personal Assets and Strengths for Self-care) and provides an eight-module workshop that focuses on the emotional side of the caregiving role, giving participants tools to better care for themselves. Topics covered include the emotional journey, putting yourself first, and caregiver burnout.

The *VHA Rebound and Reconnect* program requires that caregivers use the available respite time to take a break and do something for themselves. According to a program representative:

“This program is about enhancing the mental wellness of the caregiver so that the caregiver can continue enjoying the caregiving role. After a while, they are so stressed out that they end up not liking that person anymore. By offering this, they can connect with something that they love.”

In the *VON Education and Support Series*, caregivers are encouraged to brainstorm activities they would like to participate in, outside of their role in providing care. A program representative explained this program component:

“We give them a worksheet to identify some things that they find beneficial for their own well-being. So for some, as an example...it’s walking on the beach, that’s my me time, that’s where I can kind of unwind, that’s what rejuvenates me those types of things, so we say, how can you implement that? If walking on the beach is something you used to enjoy doing but you’re not finding the time to do that now, how is it that you can actually find a time to make sure that you incorporate that into your life, whether that’s daily, or weekly, or however. So we kind of break it down to make it very, very doable, very manageable, and measureable.”

11. Recognize the different emotional stages of caregiving

It is important for programs to recognize that each stage of the caregiving journey may bring with it different emotions. The caregiver’s emotional state at the time of diagnosis may be different than when the condition is stable, when facing difficult decisions such as moving a care recipient to a long-term care facility or when caregiving ends. Caregiver emotions may also vary from day to day, based on other stressors they are facing. Further, caregivers may face “crises” from time to time during their role in providing care.

Therefore, education and support programs should support caregiver emotional well-being by preparing them for the range of emotions they may experience, as well as recognizing their vulnerability and need to have hope and meaning in their situation. Programs need to be sensitive as to where a particular caregiver is in their journey of providing care and provide ways for them to connect with others who are in, or have passed through, similar stages so that they receive relevant support from others.

A program representative supported this idea:

“Our experience is that caregivers struggle a lot with those issues of emotion, identity, future, who they are, being submerged and overwhelmed, with isolation, loneliness, a whole variety of things, which evolve out of the illness but are not the illness process itself.”

What caregivers said

During a key informant interview, a caregiver discussed programs that did not target her, or her husband’s, stage in their emotional journey:

“I went and we signed up for that course and I was accepted. He did not like the group. He went to pacify me, but soon found that the other people were far worse off than he was, and that made him quite uncomfortable really. Similarly, I tried the chat room for Lewy Body and as I told you, found them way, way beyond where I was. They were talking about lifts to get people out of bed, and there would be posts like ‘I’m sorry your partner died’, and I wasn’t ready to hear that, and I just wrote a note saying ‘I’m not ready for this’.”

Another caregiver talked about why it is difficult for caregivers to interact with others who are in different stages of providing care, and therefore experiencing different emotions:

“I think there are some people who don’t want to go to groups like that because they don’t want to see the future, and that’s understandable....some people want to know the future and some people don’t... Some people don’t even want to come to our general meetings because there are people in wheelchairs and they don’t want to see that.”

One of the caregivers in a focus group spoke about some of the emotions she has been dealing with in caring for her husband:

“My husband has had some cognitive problems and it’s embarrassing for him. It hurts me because it’s hurting him. You have all the emotion that comes up. It’s harder to deal with your own emotions reacting to the situation than it is to actually deal with the situation - dealing with all the stuff that hurts your heart.”

Another caregiver commented on the need for having someone in the community she could reach out to during her times of need:

“What I have found comforting during that really quiet, dark time in the middle of the night when you just want to give up is having a phone number you can call. I have called in the middle of the night when I didn’t know what to do [with my mother] and they were there for me.”

Examples of this indicator in action

The *First Link* program is structured as a series of five sessions which address different stages in the journey of providing care (First Steps, Next Steps, Care Essentials, Options for Care, Care in the Later Stages). The intake process ascertains where an individual would fit best within the series. The *Reitman CAREERS program* trains facilitators to recognize vulnerability, need for hope, trust, consistency, and personalized responses. The format of *COMPASS* is an eight-week workshop structured specifically around the emotional journey of providing care and is combined with a support group. The CancerChatCanada *Canadian Caregiver Support Group* generally selects members of the online support groups on the basis of their stage in the cancer journey.

12. Affirm caregiver competence and confidence

Caregivers often feel overwhelmed and may doubt their ability to continue to care for the care recipient at home, even if they would like to do so. There is often a heavy focus on managing the disease within caregiver education and support programs, but caregivers also need help to be able to separate their own achievements and progress from the progression of the disease. It is important for education and support programs to support and encourage caregivers’ beliefs and confidence in their own competence by providing them with knowledge, skills and resources, but also by providing them with opportunities to reflect on their experiences and share their successes.

What caregivers said

During a key informant interview, one caregiver discussed her challenge in recognizing her limits and being satisfied with her abilities:

“You do reach a point where you do have to put it all into perspective and say ‘I can do the best I can, but I have many roles in my life and I need to limit this particular role because I have all of these other things I have to do’. I had to be honest with myself and give myself permission to be honest and say ‘this is all I can do.’”

In a focus group, caregivers discussed the need for programs to provide caregivers with specific recognition around their skills and abilities:

#1 - *“I think there’s an opportunity there for caregiver programs to emphasize the caregiver’s abilities not just to acknowledge them and ‘gosh, you’re wonderful’”--*

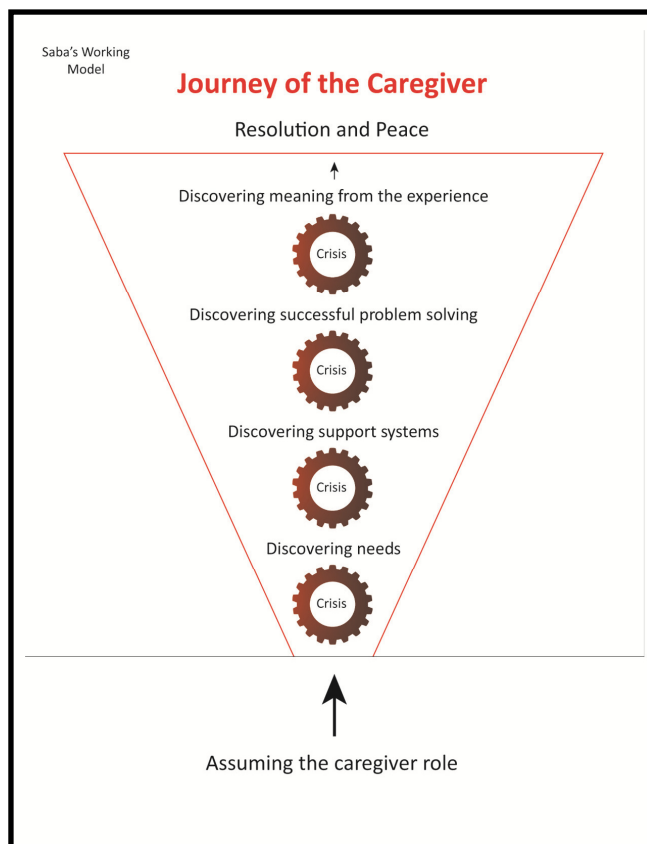
#2 - *“That makes me really angry!”*

#1 - *“-- but to acknowledge the wisdom, skill, the experience, to recognize innate abilities, of being able to know more about our loved one than anyone else in the world.”*

Dawna Saba, a caregiver on our steering committee, said that it would have been good to have help in putting her experience in context, and she produced the “Journey of the Caregiver” (right) with the hope that other caregivers would benefit from it – she said it would have helped her visualize and mark her progress in her caregiving journey.

Examples of this indicator in action

The *First Link* program focuses on building skills, empowering people and helping them build their capacity to fulfill the caregiving role. The *Reitman CARERS program* uses problem-solving techniques and simulations because their evaluations have shown that competency and self-efficacy are the two most positive things that can be influenced in terms of caregiver burden. The *Friends Caregiver Education Program* believe that people are attending the program because they haven’t given up and have a desire to succeed as a caregiver and, therefore, the program tries to amplify the feeling that they can make it work by providing tools, services, and support.



13. Encourage caregivers to consider their positive experiences

Another way programs can work to consider the emotional context of providing care is to be sensitive to both the positive and negative experiences of individuals who provide care and support to a care recipient. We discovered through our jurisdictional review that most programs have goals aimed at alleviating negative aspects of the caregiver experience. However, our review of the literature suggests that caregivers have the potential to feel positively about the opportunity to provide care, and stressed the importance of caregivers feeling “uplifted” when supporting someone. Therefore, caregiver education and support programs should consider providing opportunities for caregivers to reflect on their positive experiences, both in relation to the caregiving itself and in their lives outside of caregiving, and include opportunities for humour and acknowledgment of some of the “lighter” aspects of their lives.

What caregivers said

Many of the caregivers in the focus groups told us how important it was to maintain a sense of humour in order to cope with the challenges of caregiving:

“A sense of humour is what gets us through.”

One of the members of a support group said that they start each meeting with some humour or have “shout out” sessions, where each participant speaks about what they are grateful for, in order to start the meetings on a positive note. Many of the caregivers noted that they are now thankful for the little things in their lives and try to remember that their situation could be worse.

During a key informant interview, a caregiver also described her personal reflections on her experience providing care to her father:

“You find new meaning in your new reality and we’ve definitely had some really happy times over the past year or year and a half. The first 6 months were really intense. I don’t know that we could identify a lot of times where we could have stepped away and recognized the positive aspects, but definitely now.”

Examples of this indicator in action

The VON *Education Series and Support Group* takes time to focus specifically on the journey of caregivers and encourages participants to share “good news stories” and “successes” during group sessions. One of the sessions helps caregivers develop an inventory of positives/benefits of caregiving (e.g., spending more time with their loved one), in addition to the costs of caregiving (e.g., stress, isolation). Similarly, *COMPASS* encourages caregivers each week to brainstorm a positive experience throughout the week that can be shared at the following session. Additionally, the *First Link* program involves activities which have caregivers engage in discussions about challenges and rewards in their role providing care. This was described by a program representative:

“One exercise within the program is to talk with a partner and name one thing that you enjoy about your relationship with the person you are caring for, and one thing that is challenging for you. So they are looking at both, and trying to balance all of that.”

Promising Practice #4

Provide Relevant Information

There is currently an abundance of disease-specific information available for caregivers; however, it can be challenging for caregivers to find information that is relevant and tailored to their individual needs during different stages of their caregiving journey. Caregivers require more general education about how the system works and strategies to deal with practical issues related to managing the care recipient's condition on their own. This characteristic was supported by several program representatives:

“Caregivers are often very resourceful in looking for help and assistance, but are challenged by a highly fragmented system. So in their quest for information, or help, or support, they pick and choose from whatever they happen to come in contact with. There is very little there to provide a system guide or a systematic approach.”

“They struggle a lot because they don’t know how to navigate the system. It’s very, very complex, it’s very, very frustrating, and they are obviously at a loss most of the time.”

There are 3 promising practice indicators that provide further details about how programs could provide relevant information to caregivers.

14. Educate caregivers about how the system works

Caregivers often find it challenging to navigate the system and access services due to a lack of knowledge about how the system actually works, what services and resources are available to them and how to access these services. Caregivers need information about government and community services, such as how to obtain a wheelchair parking permit, what disability benefits/tax deductions are available, and how to access/maintain CCAC services. As advocating for services on behalf of the care recipient is often a large part of the caregiving role, programs should help caregivers understand how to make sure they maximize the support and services they receive.

What caregivers said

One of the caregivers noted that education to support the advocacy role is often missing from caregiver education and support programs:

“You’re very willing as a caregiver to be there for your partner but I think you’re also great advocates. You’re advocating to ensure the care is exemplary and that things are done properly...I think that is something we often miss in caregiver education programs.”

Another caregiver highlighted the need to reach out to caregivers who don’t know what is available and what to ask for:

“I really feel for those people who are waiting for the professionals to tell them what to do. It could just be knowing there is a CCAC out there. A lot of people don’t know what to ask for. Who is supposed to volunteer that information? Who are they seeing in their world that can give them that information?...When people know you’ve been through [a caregiving experience], you seem to be a resources and they come to ask you questions or when you hear someone struggling with something, you volunteer that information because you’ve been through the red tape and you know where you can help them to go to get some help and some answers or at least reassuring them that it’s okay to get help.”

Examples of this indicator in action

A component of a *COMPASS* workshop is to provide education on navigating the system, whether it’s home care, the hospital, or long-term care. The *Friends Caregiver Support Program* holds sessions focused specifically on educating caregivers about the system. A program representative described these sessions:

“We have workshops that are about empowering the caregiver to get the most out of the system and to be as well supported as they can be.”

15. Provide practical strategies for caring

In addition to requiring general education about how the system works, caregivers need practical information and strategies to assist them in learning more about the condition, what to expect in terms of its progression, and how to manage the illness at home. Programs can help caregivers prepare for what is to come and connect with relevant community services and resources. Some topics that programs should consider highlighting in their educational content include:

- Safety and accessibility (e.g., how to make their homes safe and accessible, what grants are available to assist, how to use mobility equipment, falls prevention, etc.)
- Understanding the condition/disease, related terminology (in plain language)
- Exercise
- Medication (e.g. what is available, how to obtain it, how to administer it)

A program representative provided support for this indicator:

“It’s not what a lot of people expect because the awareness of the disease is so low so that people are thrown into this without having the experience and the knowledge to respond to it. One of the biggest things is that it’s not intuitive. Most people the way they would normally respond to a situation is not maybe the best strategy when it comes to a dementia context.”

What caregivers said

One caregiver described an incident that precipitated her need for information on making her home safe for her husband with Parkinson's disease:

"My husband needs to sit to go to the bathroom. He tried to sit down but he missed. I was out and came back not long after he had this fall and he was wedged between the toilet and the wall. He was really shaken up. So I wanted to make things safe."

Similarly, another caregiver who provides care for her sister with a physical limitation described her need for information about making her home safe and accessible:

"We had to have accessibility within our home...I needed to find out how I was going to get her into the bathroom, and how she was going to toilet, how she was going to get off the bed. I needed somebody to give me feedback on what I needed to have in my home to make it safe for her."

During a key informant interview, a caregiver described her mother's challenge in trying to care for her father at home, on her own:

"It was a big eye opener for my mom because she thought his care was easier, and it was easier in the hospital because you have all the tools. It was a brand new unit and she was trained on how to transfer him safely, but it was a whole lot different when you are at home on your own. So I think she found that hard and she felt overwhelmed with the medical management things."

During a key informant interview, a caregiver described how she learned about medication management during an education session she attended:

"I have been to the Alzheimer caregiver groups, we've gone to lectures on medications, I've been to Mount Sinai and have had 10 sessions there, and now we have an individual session after the end of our group with a psychiatrist and a social worker. I've learned a lot from that."

Examples of this indicator in action

The *Reitman CARERS program* includes sessions on practical medical information, including topics such as medication management. The *First Link* program includes a series called "Care Essentials" to help caregivers with the practical components of their role. The *VON Education Series and Support Groups* hold sessions where they bring in community speakers to discuss issues of interest (e.g., tax benefits). *You and Your Aging Parent* focuses on helping caregivers and care recipients learn about safety adaptations in the home.

16. Address informational needs over time

The experience of providing care for a loved one is dynamic in nature and caregivers have different education and support needs depending on where they are in the caregiving process. Therefore, programs attempting to address their needs should consider the timing of the education and support that they provide and aim to target different stages of providing care. For example, at the time of diagnosis, caregivers may not need information about long-term care and palliative care options, but instead, may require information about how the healthcare system works, how to access services and about the condition or disease.

Of particular importance in addressing informational needs over time would be encouraging advanced care planning for those at the early stages of caregiving to allow caregivers to be proactive in their role and anticipate what the future might hold for a particular disease, diagnosis, or even age. This would also include focusing on decision-making strategies so that caregivers are prepared when faced with difficult decisions, planning ahead for safety adaptations for their homes and having discussions with their families about their preferences for when they require care. Education and support programs should continue to address important issues throughout the caregivers' journey and illness progression, including when the caregiving ends.

A program representative acknowledged the need for programs to be sensitive to the caregiving "journey":

"This is not a static process, it continues over time and it evolves and gets worse. There is very little in the environment that addresses that pattern of the disease."

What caregivers said

One of the caregivers illustrated the need for relevant education throughout the caregiving journey, particularly when caregiving stops:

"The education was more centred on the early part of the diagnosis and what to do. It didn't seem to grow and evolve as the illness evolved. When you go back to the resources, it's the same information you've read before. And one of the important stages is when the caregiving stops...you've got to re-integrate and you don't know how to do that. When the caregiving role has stopped, you have to figure out what your role in life is. Especially if you've been doing it for such a long time, that's all you've known, you've built your life around it and now you have to find something else. There are a lot of emotions around that...and life skills that you need."

Examples of this indicator in action

You and your Aging Parent consists of a series of educational sessions focusing on planning ahead during the aging process and helps caregivers and their loved ones consider important issues ahead of time, such as safety adaptations in the home and long distance caregiving. The *First Link* program includes five educational series that provide information based on the stage of the caregiving journey and disease. The *Friends Caregiver Support Program* tries to engage families in the planning process, from intake. A program representative described this process:

“When we do an intake we try to look at the big picture—‘Do they have a neighbour?’ ‘What about children?’ ‘Do they belong to a faith community?’ ‘What would happen in a crisis?’—we talk about those things.”

Promising Practice #5

Enable Caregiver Participation

Caregiving requires a significant amount of physical exertion, emotional effort, and financial resources and there is often very little time left over for personal and leisure activities. Programs need to recognize the variety of barriers that caregivers can face in finding and taking advantage of education and support programs. Caregivers may also struggle with finding opportunities to participate in personal activities to meet their needs and support their role (e.g., exercise). Therefore, programs should structure and supplement the services they offer in ways which will enable caregiver participation in a wide variety of beneficial activities, including education and support.

There are 4 promising practice indicators that provide further details on how programs can enable caregiver participation:

17. Arrange for respite if needed

When caregivers hear about education and support programs or other beneficial activities, they often do not have arrangements in place to support the care of the care recipient while they participate. Therefore, programs should arrange (or arrange for) respite services for the caregiver so that their choices for education and support are not limited by the care requirements of their loved one. Further, since caregivers can worry if they leave the care recipient for any length of time under the care of someone else, it is also important that programs ensure that both the caregiver and care recipient are comfortable with the service provider and the respite worker, either through an introductory visit or friendly telephone call. Additionally, programs might offer concurrent programming for care recipients so that caregivers are able to receive education and support and feel satisfied that their loved one's needs are being met.

What caregivers said

During a key informant interview, one caregiver discussed her struggle trying to make alternative arrangements for care for her father so that her mother could still maintain her social activities:

“I felt my dad was too young to go into long-term care, and I wanted my mom to still have a life. I felt guilty because it was almost that she got a worse end of the stick with the situation than my father did, because I felt that she was sort of suffering the brunt of all of this; not being able to go anywhere, being isolated, and yet, being totally aware of the situation. Whereas my dad, being cognitively impaired, I don’t think was totally aware of the situation. I was very worried for her.”

The caregiver then described her mother’s success with respite services and concurrent programming:

“They do different activities together, and activities separate. I think she goes to three different exercise classes each week, which are all very different, and she’s got my dad in a program in Hamilton. It’s a wood carving class that he goes to while she does her water aerobics in Hamilton. Then he’s got the day program while she does another exercise program, and she has a volunteer visitor come so that she can go to another one. Then she said ‘we need to do something for our cognitive stimulation’ so they go to the Canadiana program one morning a week at a local church, and they have a presenter come in who talks about different things, and that’s good for my dad because he’s always liked history and learning about things. So she’s kind of over time pieced together all of these support programs which I think is critical to their wellbeing.”

Examples of this indicator in action

Rebound and Reconnect is a program that is structured entirely around arranging respite services from VHA Home Care personal support workers so that family members are able to participate in an activity that they enjoy. The *Friends Caregiver Support Program* similarly arranges respite services so that a caregiver can attend the group sessions. They also offer concurrent programming for the care recipient. The *VON Education Series and Support Groups* program has access to VON Adult Day Programs for care recipients. Finally, the *Reitman CARERS Program* offers parallel programming for care recipients and brings caregivers and care recipients together at the end of each session to share their experiences.

18. Arrange for transportation if needed

An additional barrier is the expense and logistics of arranging public or private transportation for both the caregiver or care recipient, and also making the effort to physically travel to the program location. This becomes an even greater challenge when programs are offered in rural or geographically-dispersed areas where the distance between a caregiver’s home and the program location might be large. Programs can address this potential barrier by arranging for and subsidizing transportation services so that caregivers are able to safely and more conveniently travel to the program location.

What Caregivers said

During a key informant interview, one caregiver discussed her satisfaction with the transportation services that were provided to her parents through a local community service agency:

"I can't say enough good about the Seniors Support Services in Caledonia. They were wonderful. They sent someone into the house who talked about all of the support services that they offered and my dad could go and try the day program. The transportation services were fantastic."

Another caregiver discussed her use of Wheel Trans services to accommodate her husband's travel needs while she was out of the house attending to her own health and social needs:

"He's very possessive of my time, and when I'm out he will call and ask when I am coming home. He has always done that so it's more imminent now, and I have a cell phone so he can always reach me. I try to keep some sort of sensibility to this in terms of him wanting to take some courses. He audits a course on Friday morning at the University of Toronto, and he takes Wheel Trans to do that."

Examples of this indicator in action

The *Reitman CARERS Program* and the *Friends Caregiver Support Program* both link their participants with transportation services to allow for both the care recipient and caregiver to attend. A program representative from The *Friends Caregiver Support Program* felt very strongly about the need to address transportation and the respite issues discussed above:

"First of all, if we can support arranging transportation then people are more willing to participate because sometimes the barriers are just physically getting there or the respite for their loved one so if you can provide the respite for the loved one and manage transportation then usually they can participate."

19. Make the program convenient

As caregivers are often managing their role in providing care in addition to balancing their professional and personal schedules, their availability to participate in education and support programs can be limited. Therefore, in order to increase the likelihood of caregiver participation in education and support programs, it is important that caregiver convenience be considered in program design and delivery. Programs should survey caregiver participants to determine their timing and location preferences and consider additional factors such as driving conditions (e.g., for evening programs), geography, proximity to public transportation, and/or co-location with other frequently used services such as medical offices.

What caregivers said

During a key informant interview, one caregiver discussed timing as a barrier to her attending a program of interest:

“I would have gone to the caregiver support program at the Hamilton General; I was actually interested in that because they do recruit individuals from discharged patients so we would all be dealing with very similar situations. I would have liked to have gone to that. It was an afternoon program, I think it was four weeks, but because I work I couldn’t.”

Likewise, a caregiver participant in a focus group session discussed the scheduling barriers for education and support that she faces as a result of her full-time work schedule:

“Programs assume that the caregiver is retired and is there full-time. All programs [are] during the day and I can’t go because I’m working. Respite [a day out program] during the day isn’t really respite for me but that’s what they’re offering. If there was something in the evening, that would be good.”

Examples of this indicator in action

Both *First Link* and *The Reitman CARERS program* aim to schedule sessions during a convenient time of day for the caregiver participants. A representative from the *Reitman CARERS program* explained their scheduling process:

“We time the programs that we have to those time periods in the day when seniors are most able. We don’t put anything early in the morning. We don’t put pressure on people to get up at 7 in the morning to get ready for a 9 o’clock pick up. We don’t put things late in the day, because it gets dark and they can’t travel, and we try to consider all of that.”

Additionally, the *CancerChatCanada Canadian Caregiver Support Group* is an online program, which offers caregiver convenience because they can participate from their own home without having to worry about travelling or alternative care arrangements. *COMPASS* tries to schedule their sessions in convenient locations for caregivers. Finally, the *Friends Caregiver Support Program* holds their group sessions in close proximity to or within community health centres so that caregivers and care recipients can simultaneously attend to their medical needs. A program representative stated:

“The intent when we develop programs is always that they must be accessible, safe and wherever possible connected with some other community services that make it a more comprehensive day for that caregiver.”

20. Provide a welcoming and comfortable atmosphere

In order to encourage caregivers to participate in education and support programs, effort must be made to create an atmosphere where caregivers feel comfortable and open to sharing their experiences. This includes both ensuring the physical space is inviting, and that the demeanour of program staff (intake, administration, and facilitation) is friendly and positive in order to reduce any fear of social consequences (for example, embarrassment) through participation and to build rapport and trust with participants.

What caregivers said

During a focus group session, one caregiver discussed the importance of feeling comfortable in a group support atmosphere:

“You must be willing to give up the life you had planned, in order to live the life that is waiting for you. If you are open to that, you are open to a whole different set of friends who are very comfortable with each other because of this commonality of the disease...That is the main focus of our group – to make people comfortable.”

During a key informant interview, another caregiver described a friendly and informative telephone call she made:

“The people at Baycrest said ‘phone the Alzheimer’s Society and see what they are offering’ and my first reaction was ‘he doesn’t have Alzheimer’s’ and ‘what would I get out of it?’ but, I phoned anyways and I found that they were most willing to talk to me, first of all. Immediately, the first person came on and said they were a support person and that you could talk to them about anything...They suggested the caregivers’ group, and at that time they had a group as well for the people who have the disease.”

Examples of this indicator in action

First Link trains their program leaders to build rapport with caregivers by having them call registered participants prior to the first session to learn about their situation, their major concerns, and to answer any questions they might have. Similarly, *The Friends Caregiver Support Program* trains group leaders on how to be sensitive to group dynamics. A program representative discussed this idea:

“The person who is managing caregiver support groups needs to absent themselves and their personal preferences from the process. It’s really about understanding who the group is and what their dynamics are and what things they are interested in, not what they [the facilitators] are interested in.”

Further, the facilitators of the *CancerChatCanada Canadian Caregiver Support Group* help the groups establish the framework of the meeting and provide a safe, compassionate environment for people to connect with one another in productive and meaningful ways. Participants are encouraged to participate actively in their group, but at their own pace. Additionally, the *Rebound and Reconnect* program has trained social workers who answer telephone inquiries about the program, who are trained to deal with emotional crisis situations in a friendly manner. Finally, *The Reitman CARERS Program* tries to make the atmosphere of the session inviting by including social activities for caregivers and care recipients to complete together (e.g., making a snack, completing crossword puzzles, discussing current events).

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