

## **Promising Practices and Indicators for Caregiver Education and Support Programs**

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## Executive Summary

Many people, predominantly women, voluntarily provide health and social care to family members and friends. These efforts help sustain the healthcare system, as individuals are cared for at no public cost. Educational and support programs for these caregivers are designed to help them manage multiple, competing demands and stresses associated with their efforts. However, what makes programs effective is not easily or widely understood. According to a representative from a caregiver education and support program:

*“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. [Often], our service resources are external to collaboration with the caregiver and they are provided ‘to’ them.”*

Building on Ministry of Health and Long-Term Care’s (MOHLTC) 2008 “Caring about Caregivers” workshops, Echo: Improving Women’s Health in Ontario funded this project to identify promising practices and indicators for caregiver education and support. Researchers at Saint Elizabeth conducted the study in collaboration with caregivers, representatives of current programs, and stakeholders.

The study began with a review of research studies on effective programs and moved to a web-based review of currently-available programs across Canada. We then talked to caregivers about their experiences with education and support programs and conducted a web-based consultation on draft promising practices and indicators. What we learned is that caregiving is challenging, and programs can make a positive impact; however, there is potential to better meet the needs of caregivers. Some examples of what caregivers told us:

*“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.”*

*“[The caregiver support 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.”*

*“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.”*

Based on what the literature says is effective, features of current programs, our consultation with program representatives, and most importantly, what caregivers told us, we identified 5 promising practices and 20 indicators of effective caregiver education and supports programs.

<b>Promising Practices</b>	<b>Promising Practice Indicators</b>
#1 Respond to the Unique Care Situation	1. Ask caregivers what they need; tailor services and content accordingly
	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

We believe that these promising practices and indicators can be put into action right away within existing programs and in building new programs. A complementary **Guide to the Promising Practices and Indicators for Caregiver Education and Support Programs** provides additional caregiver commentaries and examples to help organizations use the indicators within existing programs. We believe that it would be challenging for a single organization to provide a program that meets all 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.

## Recommendations for the future

The key outcomes of this research are 5 promising practices and 20 indicators of effective caregiver education and supports programs, which have implications in three main areas: design of programs, delivery of programs, and future research possibilities. With this in mind, we have developed a set of recommendations for Echo to ensure that the momentum of the findings from this research is carried forward.

### *Recommendations to encourage the use of the promising practices and indicators*

1. **Continue to work with the research team and partners to ensure wide dissemination of the findings of this research** to encourage broad uptake and application of the promising practices and indicators in the development or improvement of caregiver education and support programs.
2. **Identify a number of organizations/programs/agencies** that will apply the promising practices and indicators in developing new programs and in evaluating and improving existing programs, and then **make their experience known** to others.
3. Encourage program providers to **involve caregivers** when using the indicators to evaluate existing programs and when identifying gaps and opportunities for improvement, and to then **provide feedback** on their use of the promising practices and indicators.

### *Recommendations to build on the foundation of the promising practices and indicators*

4. **Identify a working group** to evaluate and monitor the use of the promising practices and indicators (and the *Guide to the Promising Practices and Indicators for Caregiver Education and Support*) over the next 18 months.
5. **Work on the following next steps as priorities:**
  - a. Facilitate the development of a working group to determine ways to **increase the awareness and accessibility** of existing caregiver education and support programs.
  - b. Identify and pursue opportunities for embedding the promising practices and indicators in **accreditation programs** (that is, in accreditation standards, policies, processes and/or guidelines).
  - c. Support the development of a **guide on how to involve caregivers** in the design, delivery, and evaluation of caregiver education and support programs to ensure the caregiver voice is heard and that programs are meaningful, relevant, and realistic for caregivers.
  - d. Support the development of a **guide to assist organizations in partnering with each other** to assist caregiver education and support programs to address all of the promising practice indicators.
  - e. Support further research in the **development of a formal evaluation tool** to critically appraise existing education and support programs and to evaluate the extent to which newly-developed programs address the promising practices and indicators.
  - f. Support further research in the development of **outcome measures** for caregiver education and support programs, linked to the promising practices and indicators.
  - g. Support further research on how **gender and cultural considerations** could, and should, influence the development, operation, and evaluation of caregiver education and support programs.

# Promising Practices and Indicators for Caregiver Education and Support Programs

## Purpose of this study

Many people across Ontario voluntarily provide health and social care to family and friends. About 70% of the total number of people providing unpaid care are between the ages of 45 and 64,<sup>1</sup> one in four is 65 years of age and older<sup>2</sup> and one in five employed Canadians has both child and elder care responsibilities.<sup>1</sup> Further, women provide 68% of care for children and 52% of care for adults in their households.<sup>3</sup> A conservative estimate of the annual value of the efforts of caregivers 45 years of age and over to provide care to older adults is \$25-billion.<sup>4</sup> Given 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.<sup>5</sup> 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 care can result in caregiver stress, depression, emotional strain,<sup>6</sup> loneliness, decline in physical health, and financial losses.<sup>7,8</sup> Particularly for women, providing care can negatively affect work and participation in the labour market, and interfere with social activities.<sup>3</sup>

Many people voluntarily providing health and social care do not use education and support programs,<sup>9,10</sup> 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.<sup>7</sup>

Echo: Improving Women's Health in Ontario funded this study to determine the current promising practice education and support programs for family members and friends who care for others and to create recommendations for cost-effective education and support priorities for a range of people across Ontario. This project builds on the Ontario Ministry of Health and Long-term Care's 2008 Workshops "Caring about Caregivers"<sup>5</sup> and will inform ECHO's future work and engagement with others interested in supporting people who provide care and support on a voluntary basis.

Recently, Echo published the *Ontario Women's Health Framework*.<sup>11</sup> This Framework articulates a vision for improving women's health in Ontario and strategic priorities based on the identification of gaps and opportunities for effecting change. One priority is to "design and implement care delivery systems that strengthen the reliability and quality of care." (p.27) As evidence-based standards of care assist in reducing inequities in health, the Framework calls for the development and implementation of "practice standards that include specific evidence-based gender and sex considerations." While this study has identified promising practices and indicators rather than practice standards, the intent and purpose of the strategic priority was applied in this work.

## Overview of the study approach

There were 6 phases in this study.\* In **Phase 1**, a **steering committee** was formed to guide the study and reflect on analyzed data and results. The Committee was comprised of caregivers and representatives from the Ontario Caregiver Coalition, Echo: Improving Women's Health, Family Support Association, Woolwich Community Health Centre, Department of Family Relations and Applied Nutrition, University of Guelph, and member organizations of the Canadian Caregiver Coalition. See Appendix A for the Steering Committee members.

**Phase 2** involved a **search of published research studies** to identify information regarding education and support programs for caregivers, and the best practices for providing education and support.

In **Phase 3**, on [www.CareToKnow.org](http://www.CareToKnow.org), the knowledge exchange and social networking site of the Saint Elizabeth Care to Know Centre, people were invited to **share stories of caregiving** and experiences with education and support programs they have encountered. We also conducted a **jurisdictional review**, to identify key examples of education and support programs in Ontario and across Canada. An online request for information about education and support programs was also sent to program providers and researchers, and all were asked to forward it to interested colleagues, associates, friends and relatives. This was supplemented by an additional review of online and printed information concerning education and support programs.

**Phase 4** focused on the articulation of **draft promising practices and indicators** of effective education and support programs. In **Phase 5**, the draft promising practices and indicators were made available for **stakeholder consultation**. **Phase 6** involved **focus groups** and **interviews** to confirm findings from phases 3, 4 and 5. Caregivers in Toronto, Ottawa, Kingston, Thunder Bay, Huntsville, London and Chatham gave their **perspectives on caregiving and their education and support needs** through focus groups and an additional 4 caregivers participated in key informant interviews. Six caregiver education and support program representatives provided commentaries and examples of the promising practices and indicators through individual key informant interviews. A workshop was held on November 14, 2011, to review the draft promising practices and indicators with a variety of caregivers, program facilitators, and key stakeholders to discuss how these might be used in practice. Combined, these perspectives shaped the final version of the promising practices and indicators.

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\*A full description of the study methodology is in a separate Technical Appendix.



## Research findings

### Spouse/parent/child/friend or “caregiver”?

In the literature, and among providers of caregiver education and support, there is a tendency to call an unpaid person providing care an “informal caregiver” or “unpaid caregiver”. While these terms are widespread, and therefore convenient to use, they were contested by our Steering Committee members as inappropriate. First, the words “informal” or “unpaid” can have negative connotations. For example, think about the difference between the titles “family caregiver” and “informal caregiver”, or between “voluntary caregiver” and “unpaid caregiver.” Therefore, we have avoided the terms “informal” and “unpaid” to describe caregivers.

Second, there was a concern that designating someone as a “caregiver” in relation to another person who has a chronic disease, for example, may imply that caregiving is completely new between the individuals. However, in most cases, there is a long-standing and close relationship between the person providing and the person receiving care and support, and over the course of that relationship, there has been an ebb and flow in the giving and receiving of mutually-beneficial care.<sup>10,12</sup> Similarly, Pearlin and colleagues<sup>13</sup> have stated that, contrary to some of the contemporary views and commentaries on “caregiving,” caregiving itself is not a role: “instead, caregiving refers to particular kinds of actions that are found in the context of already established roles, such as wife-husband, child-parent.” (p.583)

There can be a point in time, however, when one person’s actions in a relationship become considerably different<sup>9</sup> in their:

- **direction** (predominantly or exclusively from one person to the other),
- **frequency** (from minimal to a certain number of hours a day),
- **duration** (from a few days to an extended period), or
- **nature** (moving from and between assistance with minor medical issues, assistance with tasks around the house, and assistance with walking, eating, bathing, and toileting).<sup>10</sup>

At this point, there is often a need for education and support.

In light of the importance of the relationship in these circumstances, we investigated whether the use of an alternative to the term “caregiver” (for example, “care partner”) would be more appropriate. When we spoke to caregivers in our focus groups and interviews, however, they considered themselves “caregivers” and found alternative terminology unsatisfactory.<sup>14</sup> We have therefore continued to use the term “caregiver”.

Nonetheless, the caregivers we talked to emphasized that it is important for education and support programs to recognize the underlying, pre-existing relationship between the caregiver and the care recipient, encompassing the burdens, as well as the joy and meaning,<sup>10,15-20</sup> which the relationship and the caregiving entail.

## What research studies tell us is effective

In the published academic research studies we reviewed, the caregiver education and support programs covered a wide range of approaches and activities. Acton and Kang<sup>21</sup> described the following types:

1. **Support group** – Caregivers with similar issues or caregiving roles come together on a regular basis. Their interactions are usually unstructured and not pre-designed with specific content. The purpose is generally to share and benefit from other caregivers' experiences, give mutual support, and increase connections among group members. A variant is a program of identifying "friends" or peer supporters to coach and provide advice and information to caregivers.<sup>22</sup>
2. **Education** – Caregivers are provided with standardized information about such topics as the disease process, disruptive behaviours, and caregiving to enhance the ability of the caregiver to manage the problematic behaviours. Sometimes the education program includes the opportunity to practice new skills.
3. **Psychoeducational programs**—Include both education and supportive interventions, either tailored to the individual or provided to a group, perhaps in a support group, that focus on the psychological and informational needs of caregivers.
4. **Counselling** – Counsellors with specific training identify caregivers' needs and facilitate increased understanding of such issues as the problematic behaviours of care recipients. The counselling is given in groups or one-on-one, and generally individualized, rather than standardized, information is provided.
5. **Multicomponent interventions** – These combine two or more of the other types of interventions described above.

The literature on caregiver education and support programs and approaches is vast and no consensus has emerged on standard methods for measuring and assessing effectiveness, or reporting the features of programs that are being evaluated. Nonetheless, there are a number of trends in the literature that emerge as potential guideposts for improving caregiver education and support programs.

### **General**

1. Generally, the effects of caregiver interventions of all kinds are small and of relatively short duration,<sup>23-38</sup> though some studies found an extended or delayed effect of interventions focused on depression<sup>39-41</sup> or self-reported health status.<sup>42</sup>
2. Interventions generally do not improve quality of life or overall well-being,<sup>25,35,43</sup> though some interventions combining social support and problem-solving training appear to affect well-being positively.<sup>30</sup>
3. Objective caregiver burden (that is, the effect of the duties and tasks that the caregiver has agreed to provide) is not affected by most interventions,<sup>24,25,32,44,45</sup> presumably because most do not deal with this issue directly.<sup>36</sup>
4. Involving the caregiver's family in an education or support program appears to be more effective than not having them involved.<sup>29,31,46</sup> One reason might be that including family members allows their support roles to be clarified.
5. Interventions for caregivers of persons with dementia are overall less successful than those for other caregivers, likely because of the unpredictable stressors involved.<sup>24,38</sup>

### **Types of programs and supports**

6. Interventions to increase knowledge, particularly about a disease, are generally the most effective interventions – as measured by the uptake of information, satisfaction with the program,<sup>24,25,30,31,35,36,45,47-56</sup> and increases in preparedness for caregiving.<sup>21,49,50,57-64</sup> However, they may not affect the overall caregiving experience,<sup>29,43,45,65-67</sup> and indeed, they may increase burden and decrease well-being<sup>35,42,47,59,68</sup> or accelerate decisions to institutionalize the care recipients,<sup>43</sup> presumably because they make the extent of the burden facing the caregiver over time explicit.
7. Caregiver support groups increase the knowledge that caregivers have,<sup>30</sup> increase their satisfaction with the caregiving experience,<sup>69</sup> and reduce their loneliness and social isolation.<sup>70,71</sup> Support groups can empower caregivers to overcome cultural and gender expectations and norms that have limited their caregiving capacity.<sup>72</sup>
8. Psychoeducational interventions are effective across a range of outcomes,<sup>24,25,29,65,73-77</sup> but individual interventions are likely to have specific and not generalized effects.<sup>44,78-81</sup> For example, an intervention focused on depression is unlikely to affect burden or anxiety.
9. Multicomponent interventions appear to have greater effect overall,<sup>24,32,54,56,76,77,82-84</sup> likely because they seek, at least implicitly, to address a range of issues.<sup>84</sup> However, multicomponent interventions do not appear to have a consistent, specific effect on depression<sup>24</sup> or anxiety.<sup>25</sup>
10. Exercise programs appear to be helpful in reducing depression and increasing self-reported health, but some caregivers report that these programs can interfere with their caregiving responsibilities.<sup>85</sup>

### **Conduct of programs and supports**

11. The effectiveness of any program or support depends on background and contextual factors,<sup>24,83,86</sup> and programs that are individualized as a result of specific assessments of need are more effective than general or generalized programs.<sup>24,26,28,39,40,42-44,48,61,64,81,87-93</sup>
12. Caregivers can feel positively about the opportunity to provide care to someone who needs support to stay at home, and they can find meaning in it. In such cases, the “uplift” they feel may buffer or mitigate the negative aspects (for example, the burden) they experience in providing care.<sup>10,15-18</sup>
13. If a caregiver is required or encouraged to participate actively in an intervention, it is more likely to be successful.<sup>42,62,94-96</sup>
14. Technology-based interventions can be as effective as in-person interventions<sup>34</sup> but they are more likely to be successful if they are individualized and not general.<sup>97-100</sup> However, technology-based interventions are not effective with people who are not comfortable with the technology.<sup>98,101,102</sup>
15. Structured and intensive (or concentrated) interventions are successful<sup>36,40,42,56,90,97,103</sup> and interventions over an extended period of time can be successful in specifically relieving depression.<sup>24</sup>

## **Gender issues in caregiver education and support programs**

When we reviewed the reported studies in the academic literature and the responses to our online request for information about programs, we used a gender-based analytical approach.<sup>104,105</sup> We searched for indications that the programs had considered the potentially different needs and responsiveness of men and women, and subgroups of men and women, and that the researchers in the various studies had evaluated the potential differential effectiveness of the programs for men and women separately.

We found little evidence of programs being designed with gendered needs in mind. Some studies have considered the different effects of psychoeducational interventions on men and women, and found that such programs may have different positive effects,<sup>46,54,88,89,101,106</sup> and so may also have different negative or neutral effects. Nonetheless, these kinds of analyses and observations were uncommon in the literature. Instead, there were frequent observations by study authors that programs were mostly used by women, and, consequently, there were implicit, and sometimes explicit, assumptions that if such programs were effective, they effectively responded to the needs of women.

There is a small body of research reported in the literature about the needs of male caregivers for education and support programs. Often, this research examines only the experiences of men in their caregiving, assuming, but not revealing, that men's needs and experiences are different from women's,<sup>107</sup> at least to a degree that would, or should, influence the design of education and support programs.<sup>108</sup> In general, the studies have identified that men are less likely to know about, seek out and use education and support programs,<sup>109-111</sup> and there is speculation on whether this pattern is due to men's attitudes toward help-seeking, men's abilities to negotiate the landscape of helpers and supports,<sup>109,111</sup> or the inappropriateness of the programs to address their needs.

A survey of caregivers of people with dementia showed that men and women had similar patterns of access and use of community services such as support groups and educational programs, but men used emotional support from other family members, friends and co-workers less.<sup>10</sup> This may signify that the support groups and educational programs either do not assist with men's approaches to others for emotional support, or, if they do, men do not respond to the programs in the same way that women do.

Further, there exists research which demonstrates that women report more distress as a result of their caregiving actions than men,<sup>109</sup> but, the literature does not address definitively whether the different distress reaction of males is a result of their different role and status in society, with a different coping style or approach,<sup>109,111</sup> men adopting a more task-oriented<sup>112</sup> or "managerial"<sup>110</sup> (rather than nurturing-centred) approach to providing care, or their need to change the nature of relationships, not only with the care recipient, but with networks of personal support.<sup>113</sup> Of course, a more general issue surrounding the measurement of distress arises: do men report less distress when traditional distress measurement tools are used but actually suffer other negative effects from their caregiving actions (for example, injury to self-esteem and emotional difficulties adjusting to new responsibilities<sup>110</sup>) that are not usually measured in research studies?

Another possibility regarding the reasons for the different experiences of men and women has been raised by Bédard and colleagues.<sup>8</sup> They observed that male and female care recipients have different rates and severity of what they call "problem behaviours" – physical and sexual aggression toward their caregivers. Thus, the responses and reactions of male and female caregivers – and thus their needs for education and support – may be different, not only because of their own gender, but because of the gender of the individuals they are caring for.

Overall, reported research studies identify some areas where there may be room for different approaches to education and support programs for men and women. However, the research has not advanced to a stage that allows evidenced-based identification of specific ways and means to develop and deliver education and support programs along gender lines. There are, though, suggestions in the literature about accommodating men's needs by structuring support groups differently, labelling them as "skill-building classes," and limiting attendance to men only.<sup>111</sup>

### **Overview of reviewed programs**

There were 77 responses to our online request for information about education and support programs in Ontario and across Canada. We found that most caregiver education and support programs are structured around a particular health issue or diagnosis and focused primarily on providing information specific to the disease.<sup>114</sup>

Almost all of the reviewed programs listed goals focused on alleviating some negative aspect of providing care (such as "burden") by enhancing caregiver education, support, or both. The most common methods of education and support listed within program goals included raising awareness, providing information, and providing resources.

Further, while the literature cites individualization as a key to effectiveness, most of the reviewed caregiver education and support programs listed very broad program goals and identified generalized outcomes such as 'enhanced knowledge and support,' which are not specific to the program or to caregivers. For multi-component programs, overall goals were not often linked directly to the different components offered. Finally, most of the programs that were reviewed identified goals which take a reactive rather than a proactive approach to caregiver education and support.

Many of the reviewed programs were multifaceted in nature. For example, many programs included an individual information component (usually printed information) and a group support component, such as group counselling. There was significant variation in the extent to which education programs were interactive. Some programs provided in-person sessions as their education component, others provided static information, and some programs provided both. Very few programs offered online interactive resources for use by caregiver participants, a few did not have a website at all, and those that did, generally provided static information online.

Most of the reviewed programs had no formal referral process, and therefore must be discovered by caregivers themselves. A very few programs listed formal referral from a physician or other health professional as a mode of access.

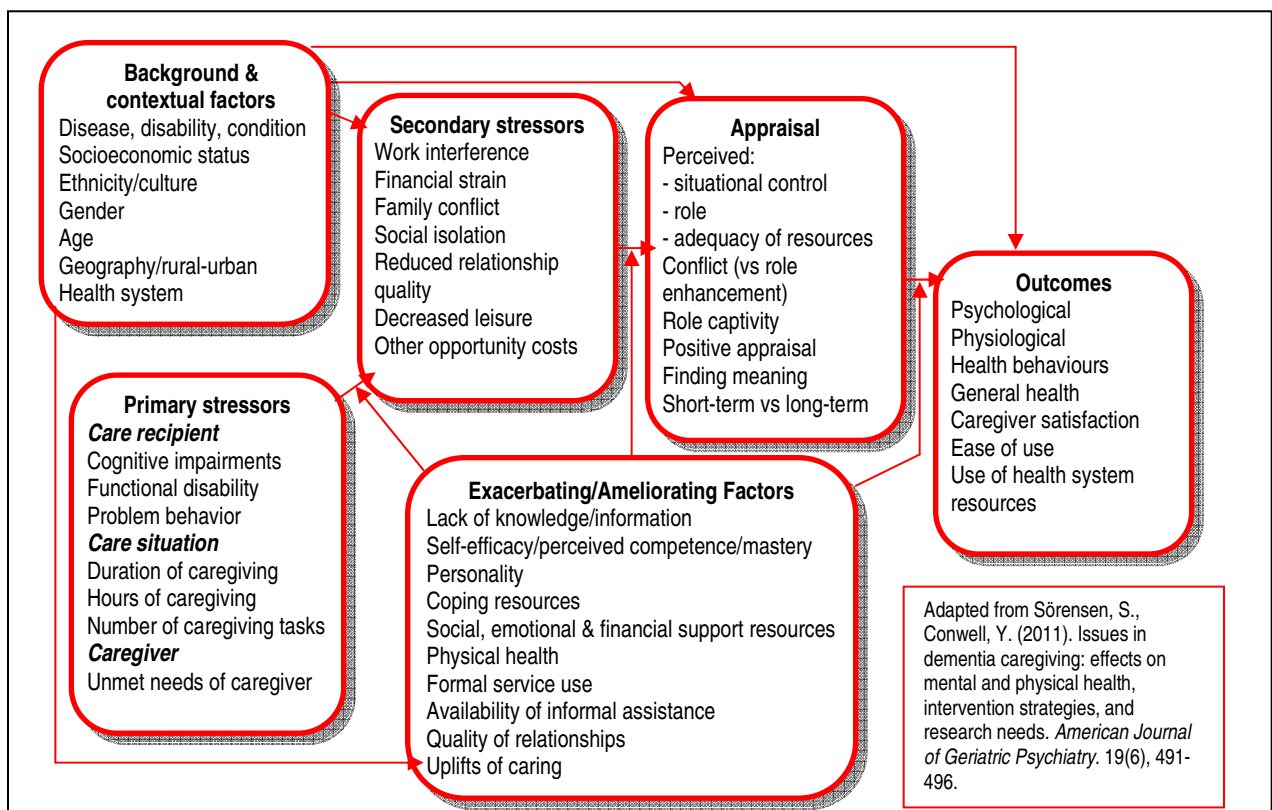
### **A framework for understanding caregiver education and support**

One approach to interpreting and understanding what is effective and important in caregiver education and support is to step back and understand what factors might influence the needs of caregivers and their responsiveness to education and support offerings from others who want to help them.

Drawing on two previous models of caregiving,<sup>13,115</sup> Sörensen and Conwell<sup>116</sup> developed a heuristic conceptual framework, which illustrates the complex factors that are at play when education and support efforts are planned, delivered or evaluated for caregivers providing care for someone with dementia.

We adapted the framework (Figure 1) to apply to diseases, disabilities or conditions in addition to dementia as another “contextual factor,” similar to gender, age and socioeconomic status. As well, in our review of the literature, we identified additional outcomes that have been assessed by education and support programs, including caregiver satisfaction, ease of use (especially when technology is being used), and use of health system resources. Accordingly, we have added these factors to the adapted framework in Figure 1.

**Figure 1 – Factors involved in planning, delivery and evaluation of caregiver education and support programs**



## Caregiver perspectives

Our research approach and method emphasized listening to and responding to the voices of caregivers in the identification of promising practices and the development of indicators. We included caregivers as members of our steering committee, and we validated our evolving findings with caregivers in focus groups and interviews. What caregivers told us was rich in detail and led us to critically reflect on what we learned from research studies and current programs. The following quotations from a variety of caregivers provide a context for understanding the final version of the promising practices and indicators.

### Assessment

*“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.”*

### Relationships

*“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.”*

### Family Dynamics

*“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 healthcare 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.”*

### Gender

*“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 woman’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.’”*

### Culture

*“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.”*

### **Networking**

*"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!"*

### **Connections to Services**

*"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?"*

### **Online Interactive Supports**

*"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.'"*

### **Absorbing/Applying Information**

*"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?"*

### **Care for the Caregiver**

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

### **Different Emotional Stages**

*"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.'"*



### **Caregiver 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."*

### **Positive Experiences**

*"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 six 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."*

### **Understanding the System**

*"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 resource 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."*

### **Practical Strategies**

*"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."*

### **Changing Information Needs**

*"The education was more centered 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."*

### **Respite**

*“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.”*

### **Transportation**

*“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.”*

### **Convenience**

*“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.”*

### **Welcoming Approach**

*“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.”*

## Promising practices and indicators

An ongoing, iterative dialogue between the research team and steering committee led to an initial consensus on five draft promising practices and 15 draft indicators. These were identified based on consistency between what the literature says is effective and what is currently being exercised in practice. We were also guided by our adapted version of Sørensen and Conwell's heuristic framework.

We subjected these draft promising practices and indicators to strict scrutiny after our discussions with caregivers in focus groups and interviews. The number of indicators increased, from 15 to 20, to reflect caregivers' perspectives on what they need to be able to participate in programs, and also a different arrangement and alignment of promising practice indicators to better reflect their expressed needs.

<i>Promising Practices</i>	<i>Promising Practice Indicators</i>
#1 Respond to the Unique Care Situation	1. Ask caregivers what they need; tailor services and content accordingly
	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

## Using the promising practices and indicators

In this report, we have identified promising practices and indicators and, as will be discussed in the section on recommendations and next steps, we propose that additional guides and tools be developed and that there be further research conducted based on these practices and indicators.

However, we believe that these practices and 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. We have produced a complementary *Guide to the Promising Practices and Indicators for Caregiver Education and Support Programs* that provides additional caregiver commentaries and program examples to give some ideas about how organizations might use the indicators within existing programs.

One additional 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 each 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 that fill gaps in their own programs, and help caregivers link effectively and seamlessly to those partner programs.

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### **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*.

##### **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.

##### **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.

##### **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 care recipient, unpredicted issues and tensions often rise between spouses and/or among children, siblings and grandchildren. Potential issues can occur around finances, living arrangements, who in the family 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 effectively.

#### **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.

#### **5. Recognize cultural influences**

Finally, programs need to recognize the cultural context within which caregiving actions take place. This includes considering the influence of expectations, norms, beliefs and behaviours, which are characteristic of particular ethnic, social or age groups. 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.

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#### **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.<sup>5</sup> Therefore, programs need to be aware 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 to *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 the 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 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.

## **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.

## **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.

## **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 what they have learned through the program content and from other caregivers.

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### **Promising Practice #3**

#### **Address the Emotional Context of Providing Care**

While in the literature there was some discussion about the physical effects of caregiving (e.g., 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.

### **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.

### **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 home 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 particular caregivers are 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.

### **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.

### **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.

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#### 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.

#### **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 maximize the support and services they receive.

#### **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)

#### **16. Address informational needs over time**

The experience of providing care 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 these needs should consider the timing of the education and support 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.



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## 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.

#### **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 the care recipient. 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.

#### **18. Arrange for transportation if needed**

An additional barrier is the expense and logistics of arranging public or private transportation for either or both the caregiver and 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.

#### **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.

## **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.

## Recommendations for the future

The key outcomes of this research are 5 promising practices and 20 indicators of effective caregiver education and support programs, which have implications in three main areas: design of programs, delivery of programs, and future research possibilities.

With this in mind, we have developed a set of recommendations for Echo to ensure that the momentum of the findings from this research is carried forward.

### *Recommendations to encourage the use of the promising practices and indicators*

1. **Continue to work with the research team and partners to ensure wide dissemination of the findings of this research** to encourage broad uptake and application of the promising practices and indicators in the development or improvement of caregiver education and support programs.
2. **Identify a number of organizations/programs/agencies** that will apply the promising practices and indicators in developing new programs and in evaluating and improving existing programs, and then **make their experience known** to others.
3. Encourage program providers to **involve caregivers** when using the indicators to evaluate existing programs and when identifying gaps and opportunities for improvement, and to then **provide feedback** on their use of the promising practices and indicators.

### *Recommendations to build on the foundation of the promising practices and indicators*

4. **Identify a working group** to evaluate and monitor the use of the promising practices and indicators (and the *Guide to the Promising Practices and Indicators for Caregiver Education and Support*) over the next 18 months.
5. **Work on the following next steps as priorities:**
  - a. Facilitate the development of a working group to determine ways to **increase the awareness and accessibility** of existing caregiver education and support programs.
  - b. Identify and pursue opportunities for embedding the promising practices and indicators in **accreditation programs** (that is, in accreditation standards, policies, processes and/or guidelines).
  - c. Support the development of a **guide on how to involve caregivers** in the design, delivery, and evaluation of caregiver education and support programs to ensure the caregiver voice is heard and that programs are meaningful, relevant, and realistic for caregivers.
  - d. Support the development of a **guide to assist organizations in partnering with each other** to assist caregiver education and support programs that address all of the promising practice indicators.
  - e. Support further research in the **development of a formal evaluation tool** to critically appraise existing education and support programs and to evaluate the extent to which newly-developed programs address the promising practices and indicators.
  - f. Support further research in the development of **outcome measures** for caregiver education and support programs, linked to the promising practices and indicators.
  - g. Support further research on how **gender and cultural considerations** could and should influence the development, operation, and evaluation of caregiver education and support programs.

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## **Appendix A**

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