What We Heard
from Caregivers Across Ontario

Regional Geriatric Programs of Ontario - Caregiver Education and Training Project

April 2019

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To understand and respond to the learning needs of family and friend caregivers of seniors living with frailty, the Regional Geriatric Programs of Ontario (RGPO) initiated the Caregiver Education and Training Project.

Based on a co-design process to develop educational resources for caregivers of seniors living with frailty, we hosted 10 focus groups in communities across Ontario. Connecting with 133 caregivers and 78 interprofessionals, this report highlights what we heard.

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To view the First Year Report on Co-Designing Educational Resources with Caregivers go to www.rgps.on.ca or contact our office to request a copy.

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With Gratitude

Dear Caregivers,

We would like to express our gratitude to the caregivers who took time from their busy schedules to join us in focus groups and share stories of their caregiving experiences. We heard from caregivers of family members and friends from across the province. We have deepened our understanding about what they want to learn to care for a senior living with frailty. This project would not be possible without the participation of caregivers and their commitment to the people they care for.

The Regional Geriatric Programs of Ontario would like to acknowledge the Ministry of Health and Long-Term Care for recognizing the important role that caregivers play in supporting the well-being of seniors living with frailty. The Ministry has provided funding for this Caregiver Education and Training Project.

We are also grateful for the time and dedication of the interprofessional staff from local Regional Geriatric Programs across Ontario who supported our efforts by hosting focus groups in their communities, and helped us connect with caregivers.

Building on the strong foundation provided by the Senior Friendly 7 topics proposed by the Regional Geriatric Program of Toronto, this project incorporates fresh perspectives and ideas from caregivers. This collaboration has been a great example of how co-design can be used to co-develop resources with and for the people who will use them. The results from focus groups described in this report will be used to develop educational resources to meet the learning needs of caregivers across the province.

Please follow along with us as we progress into the second year of the project. Watch for the educational resources that will be tested over the summer and launched later in 2019.

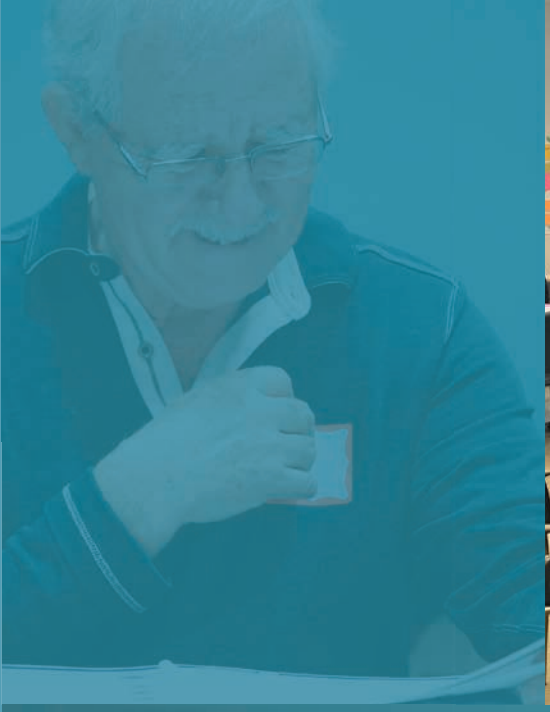
With our sincere thanks,

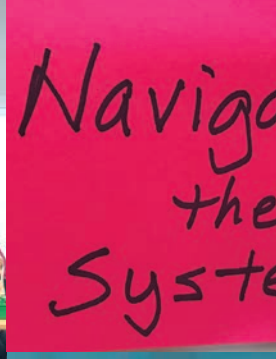
Kelly Kay

Co-Chair
Project Steering Committee

Dr. Jacobi Elliott

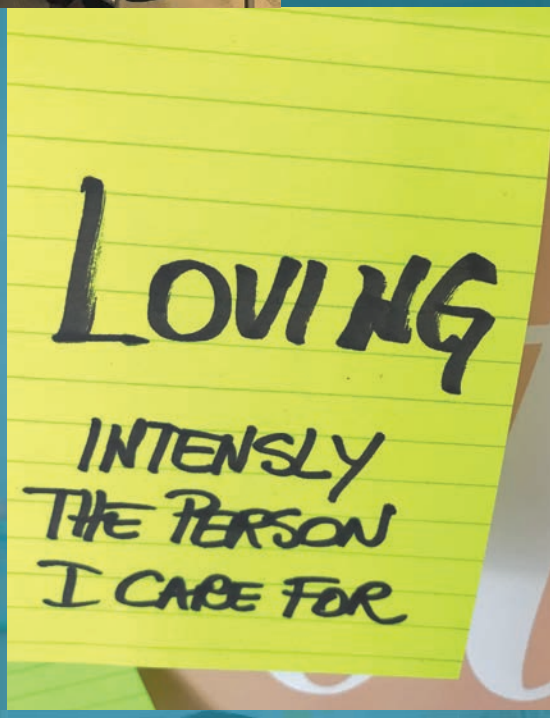
Co-Chair
Project Steering Committee

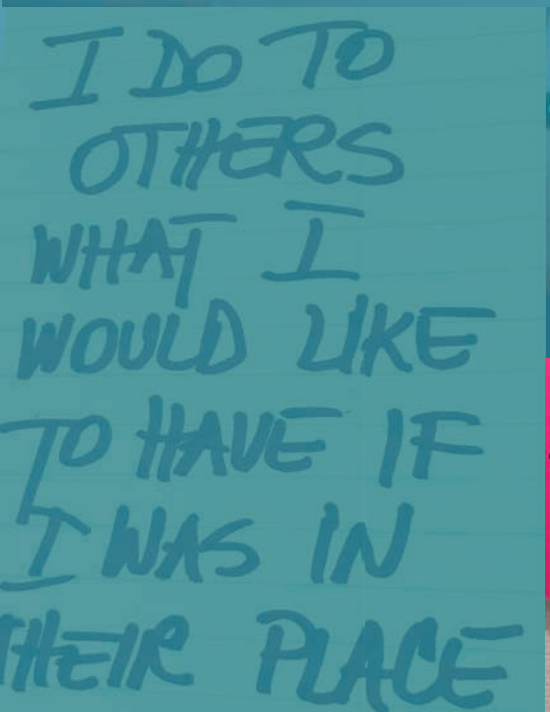


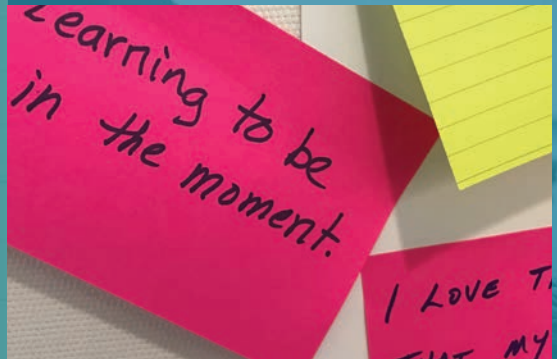


"You don't have to be a professional to be a caregiver"

Ottawa Participant







Introduction

Seniors Living With Frailty

Canadian seniors are living at home longer and their caregivers are providing up to 75% of their health care needs. These seniors may be dependent on their caregivers to help with daily functioning and they are living longer often with more than one chronic health issue (National Academies Press, 2016).

Who are their Caregivers?

A caregiver could be any family member, friend or neighbor who provides personal, social, psychological and physical support to a senior living with frailty.

Many caregivers who provide help and support to vulnerable seniors are relied upon to provide medical care in the home, to navigate complicated health and long-term care systems, and to serve as substitute decision makers with little or no formal training.

The average caregiver spends 19 hours a week on caregiving duties. One in ten caregivers provide more than 30 hours of care in a week and most feel that their person would be in much worse condition if it weren't for their daily support (The Change Foundation, 2018; Health Council of Canada, 2012; Sinha, 2012).

They are "Overwhelmed..."

Caregivers in Ontario say they're responsible for the organization of all or most of the complicated aspects of seniors' care. In The Change Foundation's *Spotlight on Ontario Caregivers* (2018), caregivers said they are "Overwhelmed. ...and a strong majority wishes there was somewhere they could go for advice and to ensure they are using all available resources" (The Change Foundation, 2018 p.10).

Supporting the education of caregivers has been identified as an ethical imperative within an aging Ontario (Pennacchini & Tartaglini, 2014).

We listened to the stories and experiences of 133 caregivers from communities across Ontario.

The Caregiver Education and Training Project

In 2018, to address caregivers' learning needs, the Regional Geriatric Programs of Ontario (RGPO) started the Caregiver Education and Training Project (CETP). It is funded by the Ontario Ministry of Health and Long-Term Care.

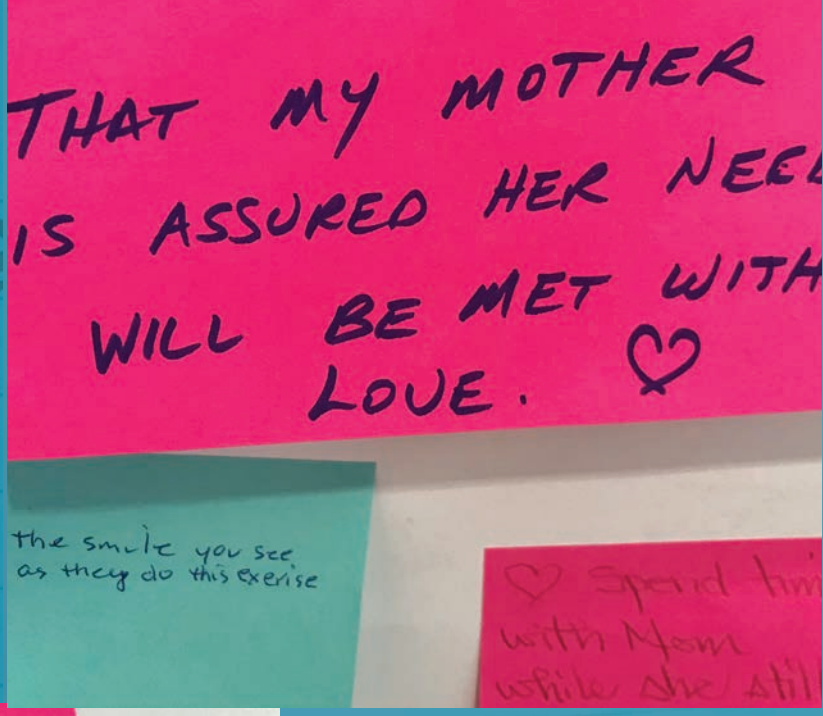
Working in collaboration with caregivers, the project team is refining and designing educational resources that fit the diverse needs of caregivers of seniors living with frailty. One such tool is the Senior Friendly 7 (SF7) Toolkit, developed by the Regional Geriatric Program of Toronto. The SF7 Toolkit provides practical advice for caregivers on seven topics relevant to the care of older people living with frailty. The project team is eliciting caregivers' feedback on this SF7 Toolkit and other topics to learn more about caregivers' learning needs and preferences.

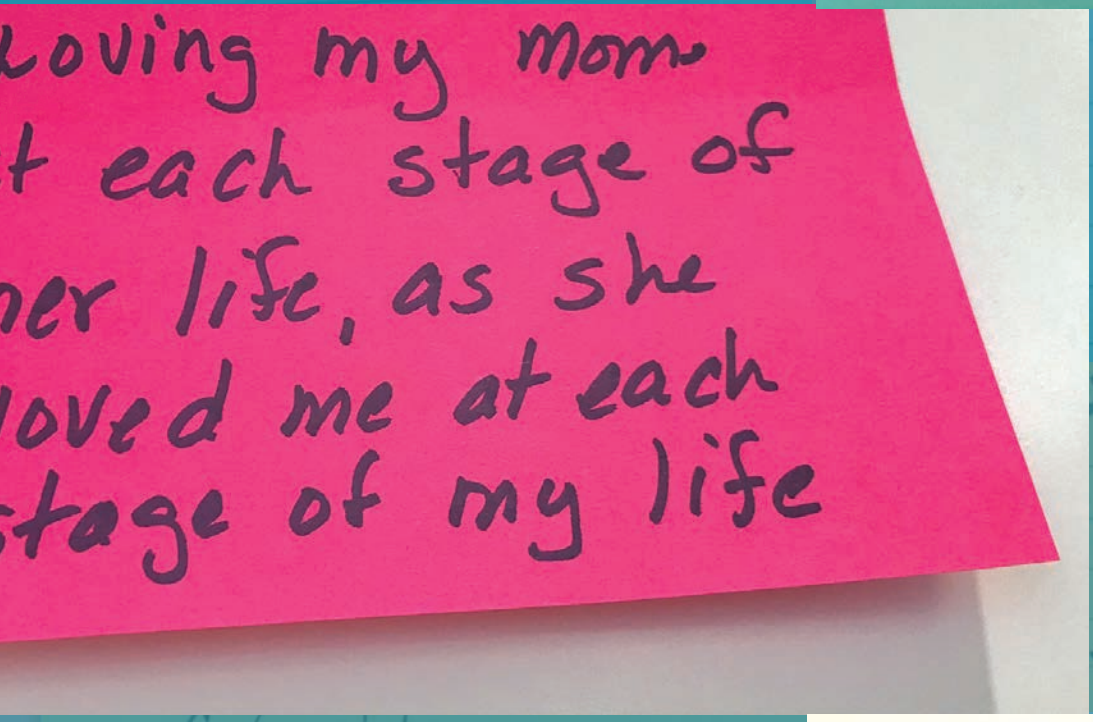
The project team organized focus groups[1] in facilitated sessions in ten communities across Ontario. These sessions were conducted with the help of trusted community and health care professionals from the local Regional Geriatric Programs in each area. We listened to 133 caregivers as they responded to our questions, told their stories, and shared their caregiving experiences. This summary report highlights what we heard.

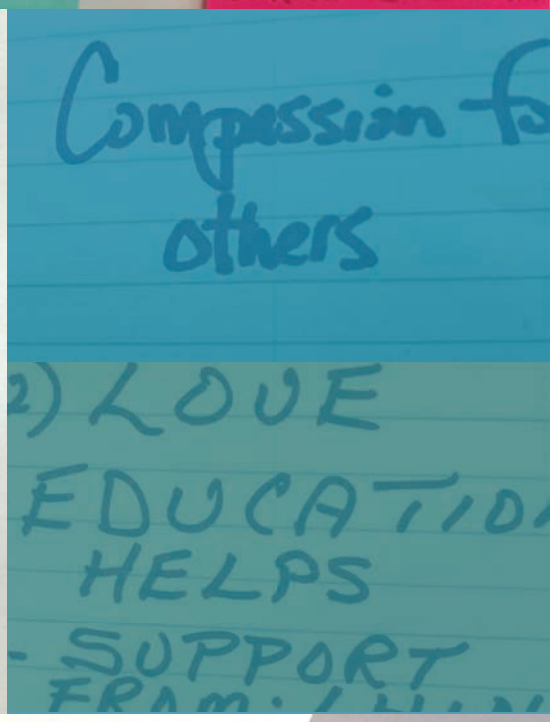
[1] In this report we refer to the facilitated in-person sessions we organized as "focus groups" for simplicity. While a focus group typically refers to a single activity (e.g. a group discussion around particular questions), our sessions included additional activities. During these sessions, caregivers completed individual tasks (e.g. completed individual questionnaires), and participated in small and large group discussions. They described their caregiving experiences, brainstormed their personal strengths and preferred learning approaches and reviewed materials (i.e. SF7 Toolkit) to offer feedback.

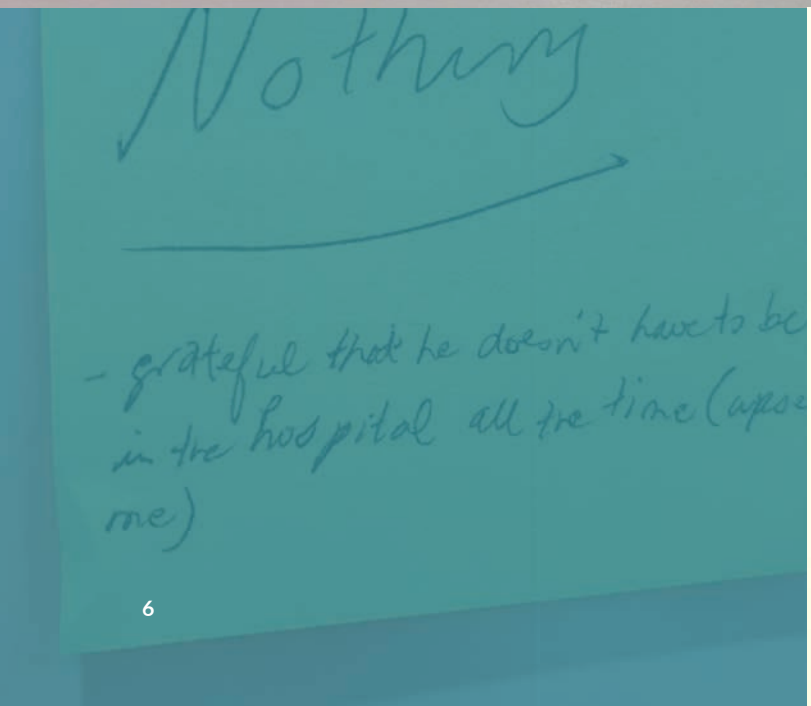
"... really helpful - can I keep this book?"

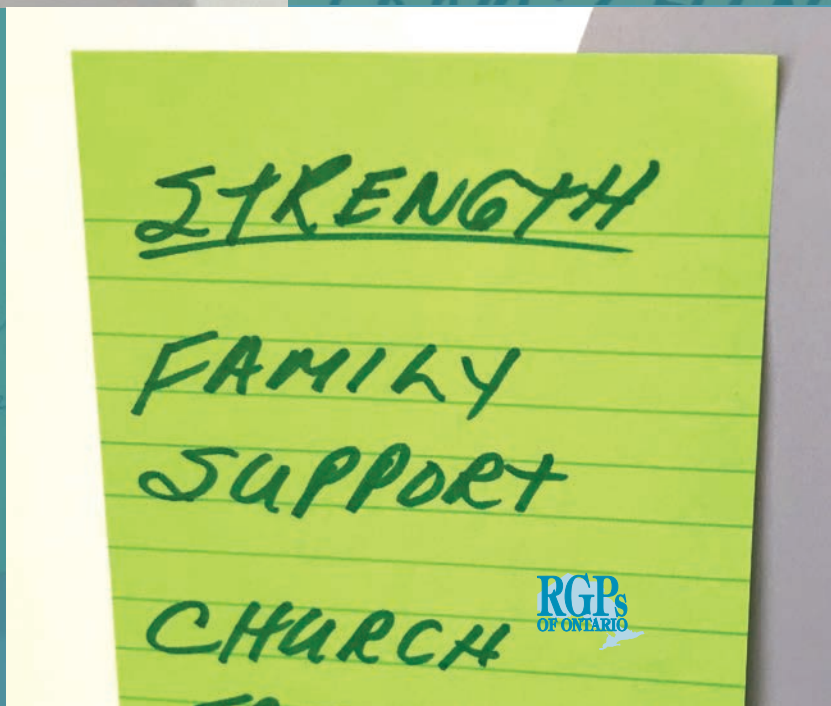
Peterborough participant











What We Asked

Caregivers are the experts on what they want to know and how they prefer to learn. The voices of caregivers were given priority in the focus groups, as facilitators led caregivers though discussions about the five following questions:

1. What increases caregiver strength in the caregiving role?
2. What would caregivers teach other caregivers, knowing what they know now?
3. What do caregivers want to learn (about the SF7 topics) and what do they think about the SF7 Toolkit?
4. What do caregivers want to learn beyond the SF7 Toolkit?
5. How do caregivers prefer to learn about frailty?

This is what we heard...

"I find discussions like this are very beneficial. People talking and telling their stories, and then learning from each other. But also professionals being there, to answer our questions, and help by giving us material."

Cobourg Participant

What We Heard

Throughout the focus groups, facilitators encouraged caregivers to share their learning needs, using open discussion, written surveys, and lots of sticky notes! Caregivers started by sharing what increases their strength in the caregiving role and what they would teach other caregivers knowing what they know now.

1. WHAT INCREASES CAREGIVER STRENGTH IN THE CAREGIVING ROLE?

Caregivers expressed the need to continue their own lives and engage in self-care, in recognition of personal needs, hobbies, and friendships. There was discussion about the impact that the role has on the caregiver and their experience of judgement associated with caregiver decisions. Caregivers shared ways that they increase their strength in six key areas:

- Linking to strong social supports.
- Feeling knowledgeable.
- Feeling supported by the health care system and professionals.
- Being really good at self-care.
- Focusing on positive feelings resulting from caregiving.
- Drawing upon "a source within myself".

"My friends and family are my rock that gets me through"

Thunder Bay Participant

2. WHAT WOULD CAREGIVERS TEACH OTHER CAREGIVERS, KNOWING WHAT THEY KNOW NOW?

Caregivers shared many tips based on their experience:

- Understand your caregiver role and what to expect.
- Understand the goals and wishes of the senior you are caring for.
- Get connected.
- Know how to care for yourself.
- Never stop advocating for your person.

"Every time a disease progresses the individual changes, and the caregiving strategy has to change ..."

Orillia Participant

3. WHAT DO CAREGIVERS WANT TO LEARN AND WHAT DO THEY THINK ABOUT THE SF7 TOOLKIT?

When the Senior Friendly Seven (SF7) Toolkit was introduced, caregivers identified their learning needs and gave general feedback on language and layout.

"Right away, I found three or four things I did not know."

London Participant

Communication Style

"Speak to me in a way that I can understand, not with medical jargon"

Kingston Participant

Caregivers expressed very clearly that the language used needs to be more "caregiver friendly", with fewer acronyms or clinical terms and more practical tips. Where clinical terms are necessary, it would be useful to have a glossary of definitions with clear explanations.

What about me?

Caregivers noted that they felt information about caring for the caregiver was missing. They expressed that a toolkit for caregivers needs to be created.

"Self-care is not selfish, it's essential!"

Hamilton Participant

Caregivers said they want practical strategies

"I appreciate the information about these topics all in one place, but what would be most helpful is to talk about strategies"

Cobourg Participant

In most of the SF7 categories, caregivers identified they want to learn strategies:

- to communicate with health care professionals
- to encourage independence of their person
- to cope with a person's refusal of care (eg: food, mobility equipment, medication,)
- to prevent conditions associated with each category (eg: pain, delirium, depression, incontinence, etc.)

Caregivers said they want more information on every SF7 Topic:

In addition to strategies for coping with and navigating health care processes and systems, caregivers identified information and resources they wished to learn about in each of the SF7 Topics: (Mobility, Delirium, Continence, Polypharmacy, Pain, Nutrition, and Social Engagement)

Mobility

Feedback on the SF7 toolkit:

- The mobility level assessment and care plan do not seem linked.

What Caregivers say they want to learn about mobility:

- How to transfer a person with limited mobility safely.
- Where to find resources for equipment, transportation and accessibility.

What's missing from the SF7 toolkit:

- Information about falls and falls prevention.

Delirium

Feedback on the SF7 toolkit:

- The flowchart is overwhelming.

What Caregivers say they want to learn about delirium:

- How is delirium different from dementia?
- How do I identify delirium?

What's missing from the SF7 toolkit:

- Treatment, what to expect when seeking help.
- What do I do if I suspect delirium?
- When do I seek help?

Continence

Feedback on the SF7 toolkit:

- The decision tree is "too much."

What caregivers say they want to learn about continence:

- Types of products, where to find them, cost.
- On the impact of incontinence on relationships.

What's missing from the SF7 toolkit:

- What about bowel incontinence?
- Handwashing tips.

Polypharmacy

Feedback on the SF7 toolkit:

- There is too much information, and the prescribing tips section is not for caregivers.

What Caregivers say they want to learn about polypharmacy:

- Organizing medications, (blister packs, reminders, toolkits).

What's missing from the SF7 toolkit:

- Information about supplements, cannabis.
- Who can help caregivers with medication and questions about alternatives?

Pain

Feedback on the SF7 toolkit:

- More useful tips for caregivers about pain management.

What caregivers say they want to learn about pain:

- How can caregivers identify pain?
- How a person should respond to medications (too much, too little, side effects).
- How to manage the impact of pain on other areas of a person's life (anxiety, sleep, nutrition, isolation, addictions, mobility, etc.).

What's missing from the SF7 toolkit:

- Non pharmacological ways to manage pain for caregivers (but don't use the word "non-pharmacological").
- Side effects to look for.

Social Engagement

Feedback on the SF7 toolkit:

- Include practical tips for caregivers to engage their person in social activities.

What caregivers say they want to learn about social engagement:

- How to assess and respond to social isolation and loneliness as two separate things.
- How to cope with judgement, persons' embarrassment, build confidence.

What's missing from the SF7 toolkit:

- Role of pets, music.
- Information about depression
- Isolation and loneliness prevention strategies.
- Resources for social outings, support groups.

"People are dealing with different doctors, all saying different things and prescribing different things."

Ottawa Participant

Nutrition

Feedback on the SF7 toolkit:

- More practical planning tips and advice.

What caregivers say they want to learn about nutrition:

- Sufficient food and hydration levels
- Meal planning.
- Safety (choking, self-feeding, eating what they want, etc.).
- How to access dietitian, local assistance with meals and nutrition.

What's missing from the SF7 toolkit:

- Oral and denture care information.
- Hydration.
- Food/drug interactions.
- Digestion with age.
- End of life and nutrition.
- Food refusal strategies.

Beyond the SF7 Topics

Many caregivers expressed that while the SF7 toolkit was a valuable resource, there were many topics not covered. Caregivers in all 10 focus groups identified topics other than those covered in the SF7 Toolkit, such as:

- Where do I find local resources and existing educational content for caregivers?
- How do I encourage a frail senior to be as independent as possible?
- What do I do when they say no?
- How do I access support for myself and maintain self-care?
- How do I advocate for a person living with frailty when communicating with health professionals and community services?
- Where do I find information about frailty at any stage beyond the SF7 toolkit?
- How do I plan ahead for the person living with frailty?
- What about caregiving for a person with dementia?
- Where do I learn how to manage risk and maximize safety?

"We talk about the frailty continuum, I think we have a caregiver continuum."

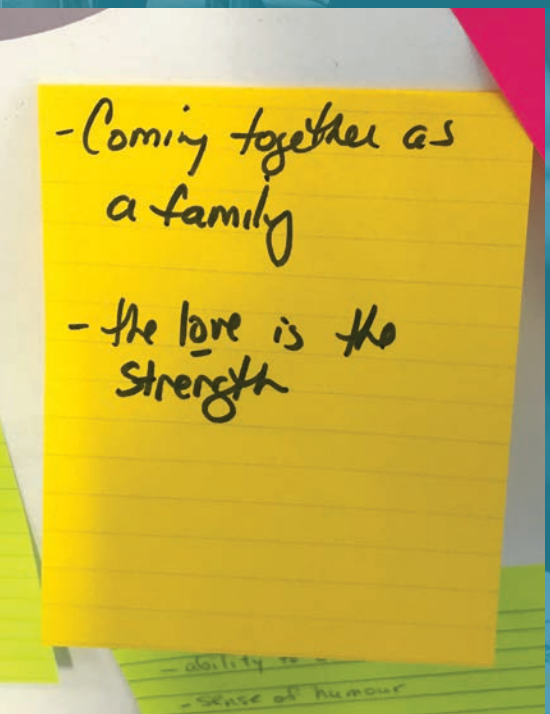
Oshawa Participant

"I think our current society isn't in the mindset of caregiving and I wonder if we should start thinking about introducing how to do caregiving very early."

Oshawa Participant

"We need a toolkit that helps us find local services and supports"

Hamilton Participant



4. HOW DO CAREGIVERS PREFER TO LEARN ABOUT FRAILTY?

Caregivers indicated that they would prefer to receive education about frailty in "caregiver-friendly" language, with practical advice and in-home strategies within each of the seven topics. While they would generally prefer to learn through support groups and online, all caregivers agreed that access to printed educational material was important, particularly for individuals who do not have access to the internet.

" I hadn't really thought about delirium in this way until it was framed as a medical emergency that can be prevented or reversed"

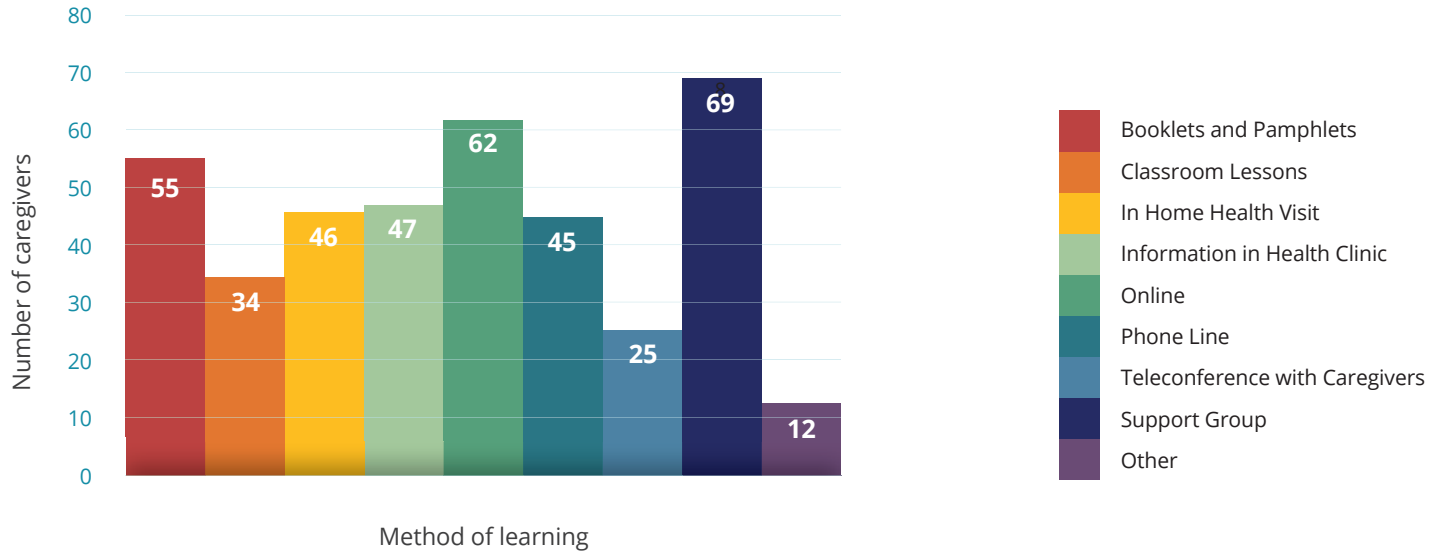
Thunder Bay Participant

"We need these resources."

Hamilton Participant

How caregivers prefer to learn

Caregivers prefer most to learn through support groups and online, but print materials should be available.



Next Steps

The project is transitioning from data collection about learning needs to the creation of learning outcomes and curriculum design, informed by an educators working group (a group of experts in knowledge translation, frailty content, curriculum design, and adult education). A Caregiver Advisory Panel will be convened in the next phase of this project. This will enable caregivers to provide continuous input as educational resources are designed.

The project is now focused on designing curriculum, informed by what caregivers have told us. In response to significant interest among caregivers to remain involved with this project, the CETP team will continue to engage them in multiple ways, by sending progress reports and inviting them to co-design and test the educational curriculum.

Caregiver Feedback on the Focus Group Process

Thanks to caregivers who took time out of their busy schedules to share their stories and experience, we have deepened our understanding of what they want to learn as they care for seniors living with frailty.

Caregivers expressed how they felt at the completion of the focus group sessions:

" Encouraged " ...
" I have to be honest, I didn't want to come because I was so anxious – but now I feel so much lighter "

London Participant

"I must take a moment to tell you all that your valuable work is so appreciated and I thank each and every one of you and I look forward to more."

Oshawa Facilitator

Glossary

Caregiver

Caregiver describes a family member or friend, caring for a senior living with frailty. This individual is unpaid for their caregiving duties (The Change Foundation, 2018).

Frailty

Frailty is a state of health where a person experiences increased vulnerability to health decline and a decreased ability to maintain independence. Frailty makes it challenging for a person to "bounce back" or rally the strength their body needs to heal from illness or injury. The chance of becoming frail increases with age and results in declining health, poor quality of life and higher dependence on family members or friends for support (Canadian Frailty Network, 2018).

Co-design methodology

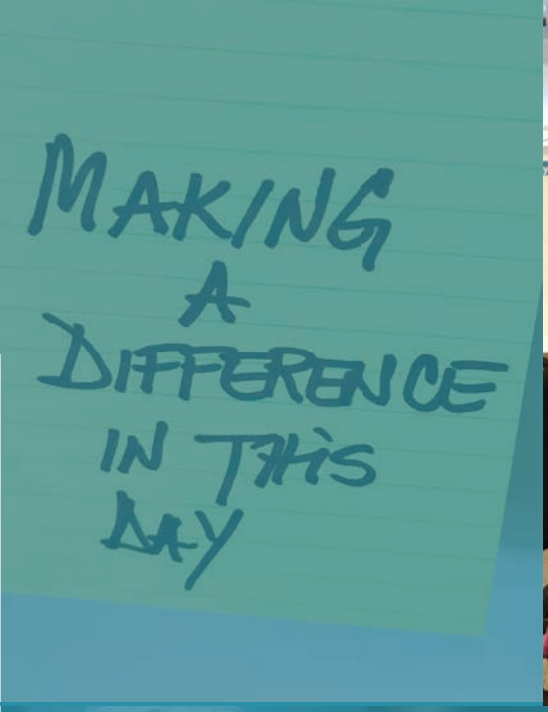
Co-design is a method of creating something new with the end users (knowledge experts) of the product. Collaboration with end users leads to the identification of gaps in a process, solutions are recommended, and feedback is used to inform the creation of something meaningful for those meant to use it (Thabrew et al, 2018).

Interprofessional Practice (IPP)

Interprofessional Practice (IPP) is a collaborative practice which occurs when health care providers work with people from within their own profession, with people outside their profession and with patients and their families (Ontario Shores Centre for Mental Health, n.d.).

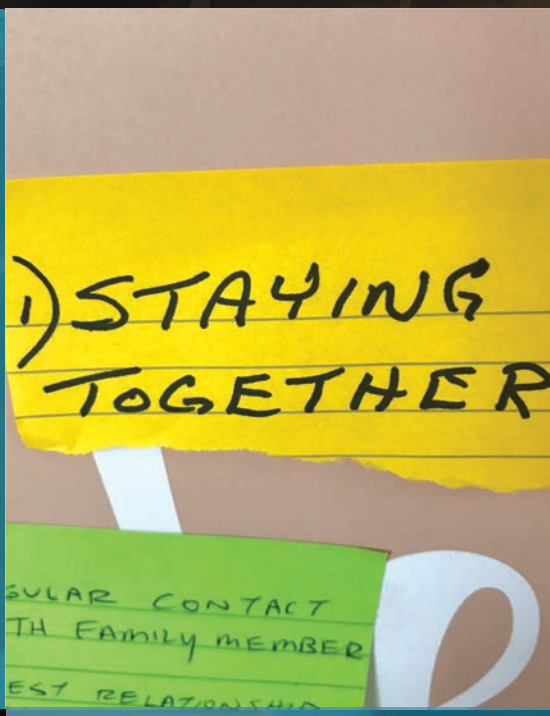
Senior Friendly 7

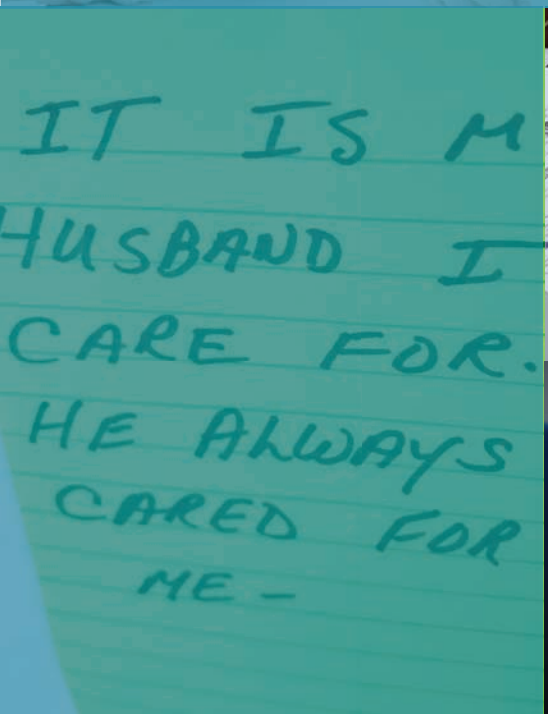
Senior Friendly 7 (SF7) are seven topics, identified by the Regional Geriatric Program of Toronto (RGP-T), as being major areas of focus in frailty and important to maintaining health and quality of life. The seven areas are: delirium, mobility, continence, nutrition, pain, polypharmacy, and social engagement. The RGP-T created the original SF7 Toolkit in which these topics are explored and information is shared with audiences across health sectors (Regional Geriatric Program of Toronto, 2019).

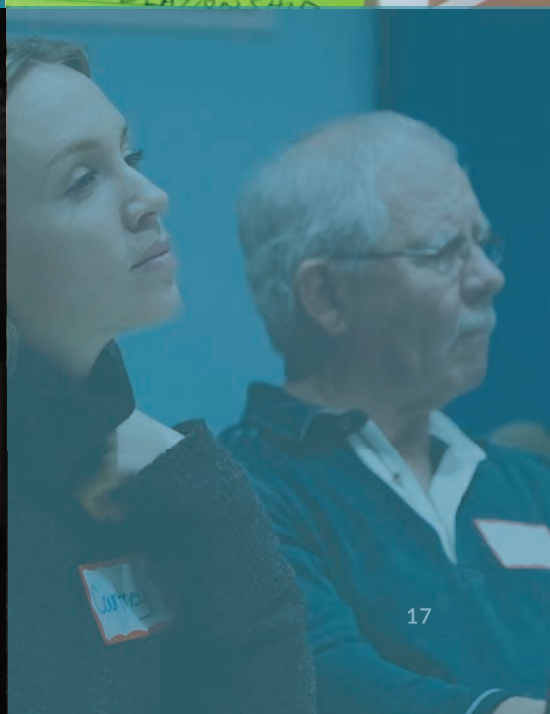


"I feel less alone after being part of this session."

Oshawa Participant







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