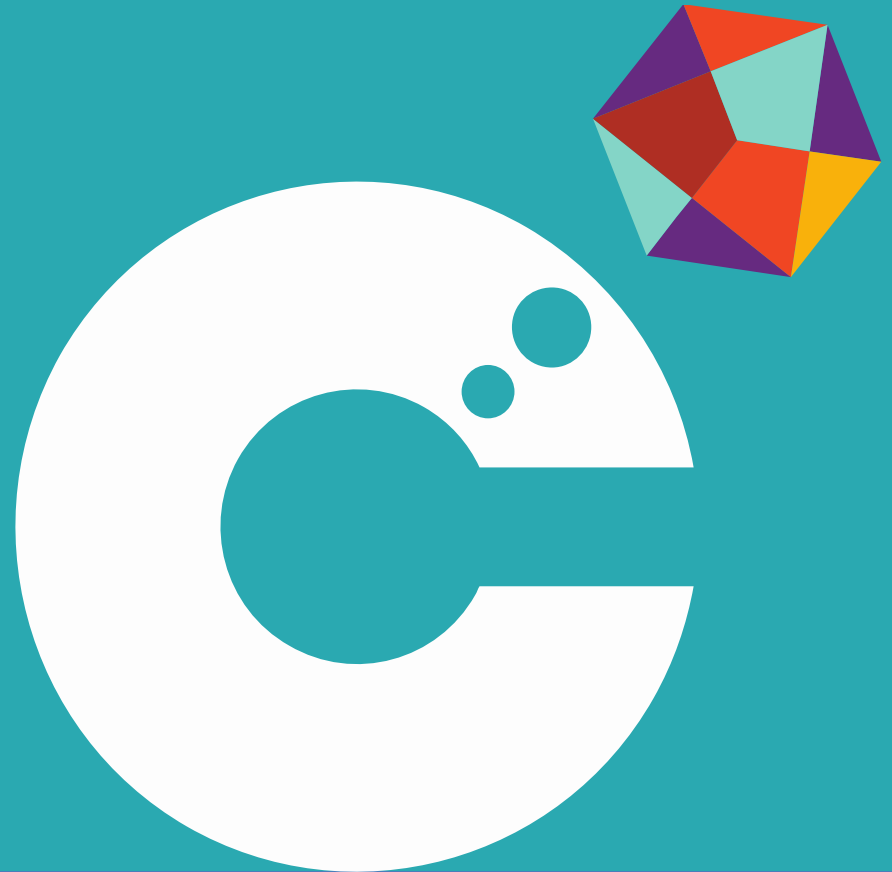


Out of the Shadows and Into the Circle: Partnering with Family Caregivers

Brenda Westcott
Office Administrator,
Family Caregiver Since 2009

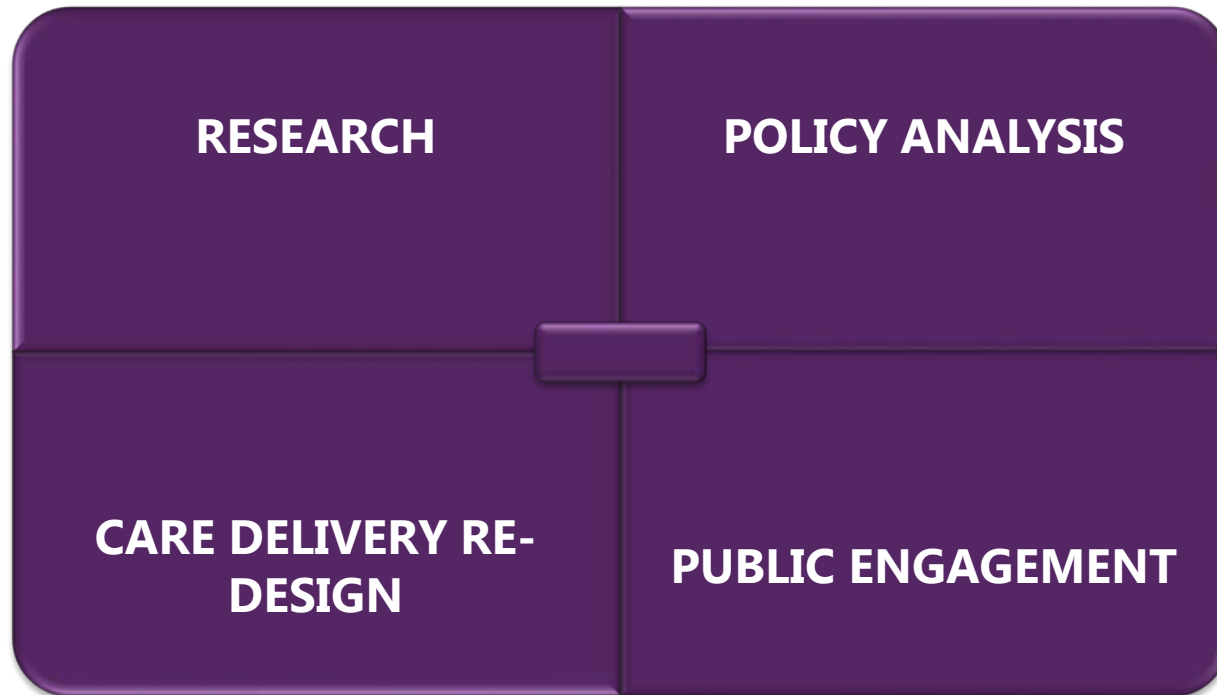
Genevieve Obarski
Executive Lead, Program Implementation
The Change Foundation

June 8th, 2017



A Minute on the Change Foundation

Ontario's independent policy think tank – committed to changing the debate, practice and experience in health care – with the intent of prompting system-wide improvements for patients and caregivers. Here is how we influence the system:



DEFINING FAMILY CAREGIVERS

- **Family caregivers** are people – family, friends, neighbours – who provide critical and often ongoing personal, social, psychological and physical support assistance and care, without pay, for family members and friends in need of support due to frailty, illness, degenerative disease, physical/cognitive/mental disability, or end of life circumstances.



WHO ARE ONTARIO'S FAMILY CAREGIVERS?



IMPACT ON EMPLOYMENT AND WORK-LIFE BALANCE

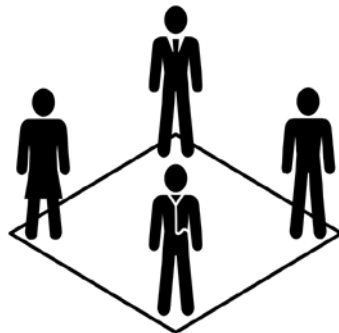
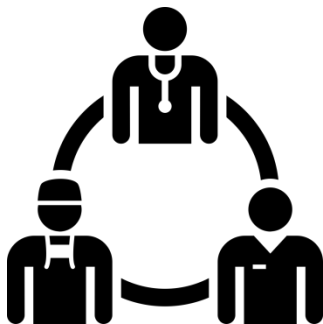
The 2.5 million caregivers (76%) who are trying to balance caregiving and paid employment were asked about the impact caregiving has had on their work in the past 12 months:

- 30% (N= 741,000) came in to work late or left early because of caregiving duties
- 29% (N= 735,000) missed six days per year (on average) of paid employment because of caregiving duties
- 1% (N= 33,000) quit their jobs voluntarily, or were fired, within the past year because of their caregiving responsibilities



WHAT ARE THE IMPACTS OF CAREGIVING?

- ✓ 23% (N= 771,000) provide anywhere between 10 to 99 hours of care per week
- ✓ 1/3 Performing medical tasks, as part of their caregiving role
- ✓ 2% (N= 77,000) caregivers are providing 100 or more hours per week of care to their loved one (the equivalent of more than two full-time jobs)
- ✓ 47% Reported some level of stress
- ✓ Nearly 1 in 10 (9%) Reported their caregiving role as highly stressful
- ✓ 31% (N= 1,000,000) Felt they had no choice in taking on their caregiving responsibilities



The Caring Experience

ENGAGEMENT ACTIVITIES- 2016



298
CAREGIVERS

Focus Groups:
130 caregivers

Workshops:
120 caregivers

In-depth interviews:
30 caregivers

Journey mapping activities:
18 caregivers



223
PROVIDERS

Home & Community Care:
83 providers

Mental Health:
47 Providers

Acute Care:
44 providers

Palliative Care:
17 providers

Primary Care:
16 providers

Pharmacy:
11 providers

Pediatric Care:
5 providers

Stories Shared, Voices Heard: Ontario's Health Providers

“I’m reluctant to ask the family caregiver how they are doing...”

...because I’m not sure how I could help them if they weren’t doing well.”

- An Ontario Health Provider

WHAT WE LEARNED FROM PROVIDERS

4 themes emerged as key to a productive family caregiver provider partnership:

- ✓ Good communication among family caregivers and providers
- ✓ Early and regular assessment of caregiver capabilities and needs
- ✓ Formal recognition of caregiver role
- ✓ Knowledge of and access to resources to partner with and support and family caregivers

❑ In addition to some important system issues:

- Perceptions about home care funding and services
- Carving out time and workload for family caregivers
- Privacy myths and realities
- Care gaps when in transitions
- Social System support for caregiving role
- Pressure to train family, barriers in training other providers



Stories Shared, Voices Heard: Ontario's Family Caregivers

"I didn't realize I was a caregiver."

"As far as I was concerned, I was just a wife trying to do everything in my power to help my husband during a difficult time – and to make sure that I too survived."

- An Ontario Caregiver

Introducing Brenda and Andy



From Listening and Learning to Action: The Changing CARE Initiative

- Informed directly by the needs and experiences of Ontario's family caregivers and health providers, Changing CARE is a new initiative designed to improve the experience of FCGs across ON.
- Changing CARE aims to develop local supports, programs, and resources that address four thematic needs identified by family caregivers and health providers:

Communication

Better communication and information exchange between family caregivers and health care providers.

Assessment

More identification and assessment of family caregivers to determine their needs, abilities, and expectations.

Recognition

Formal recognition, by providers and caregivers, of the role family caregivers play in the patient's care teams and with the person receiving care.

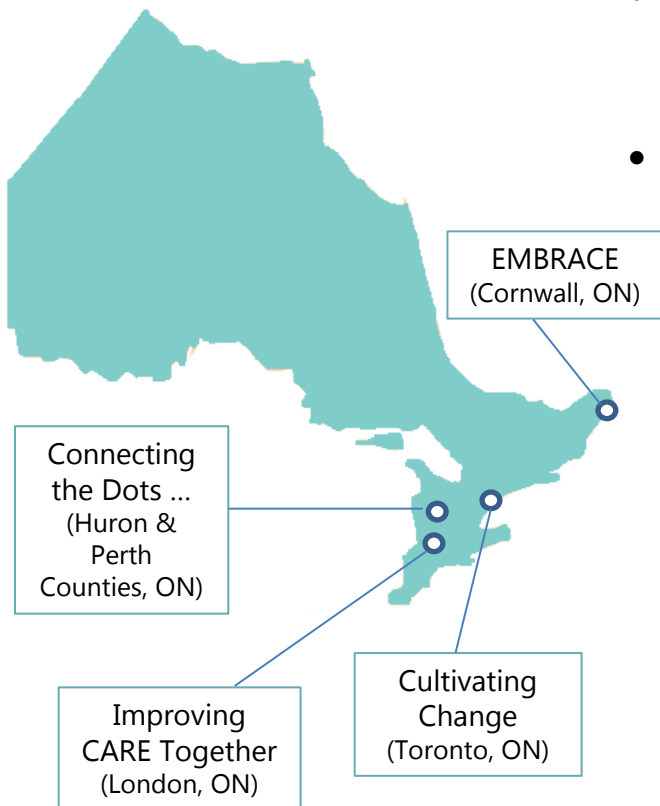
Education

More knowledge for providers and more opportunities for family caregiver support and education to develop key care skills, from counselling to medical task training.

Brenda, Andy and Family Today



The Changing CARE Initiative – Partnerships



- Four health care partnerships are being supported under the Changing CARE initiative.
- These partnerships:
 - Are poised to be leaders in FCG partnership, support and integration in the ON health care system.
 - Aim to inspire change in the way health care organizations, health care providers, and FCGs work together across ON's health care system.
 - Have been developed with FCGs in key design and decision-making roles — roles which will continue throughout the project's tenure.



What Success Looks Like for Changing CARE



- Caregivers as the key design and decision makers of each project solution/innovation.



- Caregivers as full partners, supported and integrated within the ON health care system.



- Capturing the hearts and minds of providers to transform care and inform an integrated system.



- Creating a social movement to change aligned to a shared purpose.
- Informing and influencing policy to better support FCGs.
- New resources emerging from Changing CARE designed and developed with the intent of scaling provincially.



FOR YOUR INFORMATION www.changefoundation.com

[A Profile of Family Caregivers in Ontario](#), Report of our engagement with family caregivers in The Caring Experience

[Stories Shared, Voices Heard: Ontario's Family Caregivers](#), Report of our engagement with family caregivers in The Caring Experience

[Stories Shared, Voices Heard: Ontario's Health Providers](#), Report of our engagement with healthcare providers in The Caring Experience

[Out of the Shadows and Into the Circle: From Listening and Learning to Action](#)
Implementing The Change Foundation Strategic Plan



Thank You.

For More Information:

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