

ONTARIO CAREGIVER COALITION

CARING FOR CAREGIVERS: BRIDGING THE GAP

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OUTLINE

1. Ontario Caregiver Coalition – Background

2. Where we have been?

3. Where we are now?

- The good news
- The gaps
- Caregiver burnout
- The Caring Experience

4. Where do we go from here?

ONTARIO CAREGIVER COALITION - BACKGROUND

- Established in 2009 with seed funding from the Canadian Caregiver Coalition

OCC Mission:

Dedicated to recognizing the importance of unpaid caregivers in Ontario by:

- raising awareness of the value they add to the health care system
 - advocating for improved, fair access to needed support.
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- Self-supporting through voluntary contributions of resources (financial and in-kind) by members

ONTARIO CAREGIVER COALITION - BACKGROUND

Membership:

Group of diverse organizations and individuals (now over 95 members), including:

- home care agencies
- community support agencies
- academics
- CCAC's
- health charities
- individual caregivers



EVERYONE IS TOUCHED BY CAREGIVING

- Most Ontarians have been or will be a family caregiver
- 29% of Ontarians – or 3.3 million people – are caregivers.
- Caregivers are all ages, including seniors, young carers and members of the ‘sandwich generation’
- 70% of caregivers work



WHERE HAVE WE BEEN?

- Health care structured itself around needs of the system, not necessarily the patient.
- Caregiving not recognized as a role that required support.
- Health care/home care fragmented –patients/caregivers get “lost” trying to navigate.
- Transitions of care very challenging.
- No caregiving leave except to provide care at end of life.



WHERE ARE WE NOW? THE GOOD NEWS

- **Patient Centred Care often being implemented – “sometimes” includes caregivers**

- ❖ Patient advisory committees
- ❖ Co-design
- ❖ Accreditation requirement



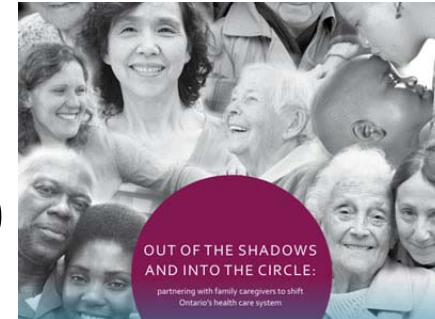
- **Scattered Models of Excellence**

- ✓ Wesway, Thunder Bay – self directed funding
- ✓ Caregiver Support Programs – Family Caregiver Connections; “Elizz”; Health Charities support groups
- ✓ Reitman Centre – Sinai Health System
- ✓ Health Links

WHERE ARE WE NOW ? THE GOOD NEWS

- **Reports call for increased caregiver supports**

- ✓ Dr. Sinha – Living Longer Living Well
- ✓ Donner Report – Bringing Care Home
- ✓ Change Foundation – Strategic Plan 2015-20



Patients First - A Roadmap to Strengthen Home and Community Care

- Statement of values for patient/caregiver centred care
- Levels of Care Framework; Bundled Care
- Increased funding
- Self-directed care
- Expand caregiver supports – training, education and respite

WHERE ARE WE NOW? THE GOOD NEWS

Bill 21

- *Bill 21 – Leaves to Help Families* (amendment to ESA) - effective Oct. 1, 2014
- Up to 8 weeks of job-protected leave to care for a family member with a serious medical condition



WHERE ARE WE NOW? THE GAPS



WHERE ARE WE NOW? THE GAPS

- Workplace supports continue to be random (other than Bill 21)

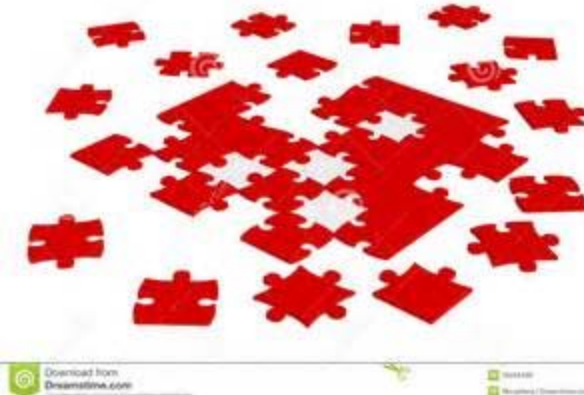


- No financial compensation for CG who cannot work or have had to reduce their working hours; no refundable tax credits in Ontario to benefit unemployed or low income caregivers



WHERE ARE WE NOW? THE GAPS

- System remains confusing
- Minimal home care for low and moderate needs individuals
- Patchwork of caregiver supports – often delivered in “disease silos”



WHERE ARE WE NOW? CAREGIVER BURN OUT

Caregivers burning out at a rate that has more than doubled since 2009/10 – 33% of Ontario's caregivers are burnt out.*

HQO – The Reality of Caring 2016



WHERE WE ARE NOW? THE CARING EXPERIENCE

- Province wide engagement with family caregivers
- Led by the Change Foundation in partnership with the Ontario Caregiver Coalition
- Focus on interaction between caregivers and health care system – not all caregiving issues
- Parallel process with front line staff and clinicians





The Caring Experience: By the Numbers

Province-wide town-halls

2 telephone town-halls

100 caregivers from across Ontario

Caregiver workshops

9 sessions across Ontario

120 participants



Journey mapping

Ontario-wide

18 participants

Online mini-surveys

Ontario-wide

Over 350 respondents



CARING EXPERIENCE - WHAT WE ASKED

Think about your experience as a caregiver in healthcare system:

- What do you feel?
- What do you need?
- What did you do?
- What would have made it better?



CARING EXPERIENCE - WHAT ARE THEY FEELING

- Unprepared
- Inadequate
- Unsure
- Isolated
- Lonely
- Wanting recognition



IN THEIR OWN WORDS

“I felt upset, shocked and angry to be forced to drive 9 hours for a 20 minute meeting where I was not listened to regarding my mom’s care.”

“I felt intimidated and that to be heard, it takes making a lot of noise.”

“I feel like I am always talking to the wrong person”

“I feel supported when professionals validate me.”

“I feel supported when staff call me to tell me that my mom fell.”

“I feel elated when we do have a PSW who is consistent and communicates with the rest of the team.”



WHAT WOULD MAKE IT BETTER

1. Care team includes family caregivers
 - CG involved in short and long term goal discussions.
 - Allows caregivers to ask for support and education
 - Helps caregivers set realistic expectations.
2. To be asked from the beginning if their role is to be a caregiver; and then be included in appointments and care planning.
3. A system that really “sees” the patient and their family or care partners and cares and treats them with respect.



WHERE DO WE GO FROM HERE?

1. Raise general awareness of caregiving
 - Bill 138 Family Caregiving Day
2. Family Caregiving leave – the new “maternity leave”
3. Financial supports for caregivers – refundable tax credits
4. Self-directed care



WHERE DO WE GO FROM HERE?

5. Patient AND Family centred care including:

- Asking caregivers how they are doing
- Assessing family caregivers
- Developing comprehensive patient and caregiver plans

COMPARE:

Patient Care Plan

-15 hours personal support/week **\$450**

Patient/Family Care Plan

-5 hours personal support/week \$150

-3 days at day centre/week
\$120

-7 meals on wheels x2
people/wk \$ 88

\$358

WHERE DO WE GO FROM HERE?

6. Adequate home care and respite care for current clients (very high needs/complex)
7. Home care and respite care for low/moderate needs clients available throughout the province
8. General curriculum – family caregiver training (similar concept to “parenting classes”)
9. General caregiver support groups



**For more information, or for
membership inquiries:**

www.ontariocaregivercoalition.ca

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