

# ONTARIO CAREGIVER COALITION

## CARING FOR CAREGIVERS: BRIDGING THE GAP

**April 14, 2016**

**Lisa Levin**

Chair, Ontario Caregiver Coalition



# 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.
- 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



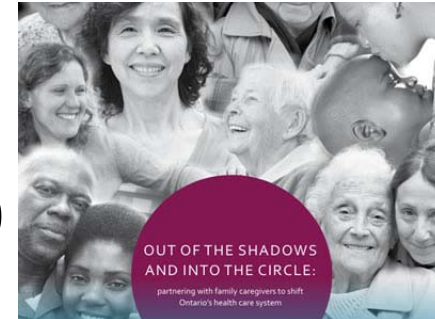
- **Scattered Models of Excellence**

- ✓ 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)

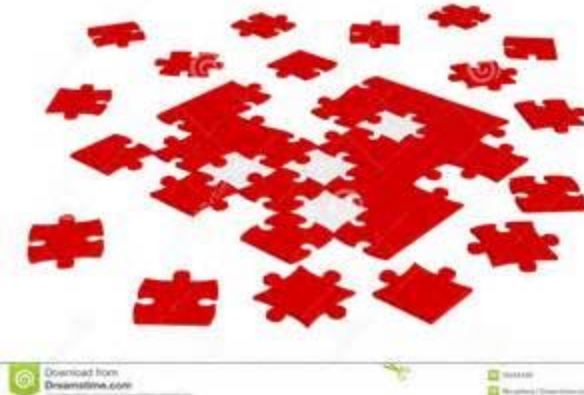


- No financial compensation for CG who cannot work or have had to reduce their working hours; no refundable tax credits in Ontario to benefit unemployed or low income caregivers



## 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](http://www.ontariocaregivercoalition.ca)**

To reach Lisa - llevin19@yahoo.ca

