



# Canadian Caregiver Coalition

Championing the well-being of family caregivers in Canada

Nadine Henningsen, President

Catherine Suridjan, Public Policy & Stakeholder Relations Lead



Je suis une proche aidante.  
I am a **caregiver**.



# Canadian Caregiver Coalition

Diverse Voices – One Focus

Canadian Movement  
(2000)



Local and National Service Providers & NGOs

Global Movement  
(2012)



IACO International Alliance of Caregiver Organizations



# Canadian Caregiver Coalition

---

## Core Principles

**Family caregivers** are individuals (family members, neighbours, friends and other significant people) who take on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness.

- Embrace a citizen-centred approach.
- Collaborate to stimulate action.
- Inform and influence policy and programming.



# Canadian Caregiver Coalition

## Creating a Movement

### Scale Up

Strategic Advocacy

- Strategic “Asks”
- Change how issue is viewed
- Common Vision

### Scale Out

Pan-Canadian Network

- “Unusual Bedfellows”
- Increase Partner Capacity
- Catalyst of Change (Individual & Organizational)

### Virtual Coalition

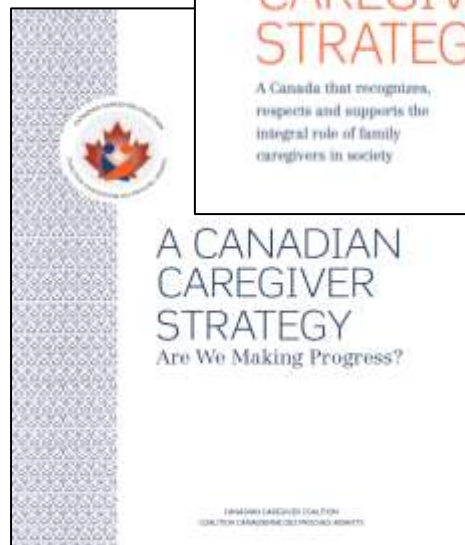
A Call to Action

- Cohesive Flexible Framework
- Synergy – Individual / Organizational
- Passion vs Structure



# Canadian Caregiver Coalition

## Call to Action – Canadian Caregiver Strategy



1

Safeguard **HEALTH & WELLBEING**

Minimize **FINANCIAL** burden

2

3

Enable **ACCESS** to information

Create **FLEXIBLE WORKPLACES** and  
**EDUCATION ENVIRONMENTS**

4

5

Invest in **RESEARCH**



# Canadian Caregiver Coalition

## Strategic Advocacy

Family Caregivers are part of....

- Federal Government Initiatives
- National Seniors' Strategy
- National Palliative Care Framework
- Provincial Government Initiatives
- Harmonized Principles for Home Care
- “Our government’s plan also recognizes the tremendous time and resources required of family caregivers”
  - Governor General David Johnston, Speech from the Throne, 2011





# Canadian Caregiver Coalition

## Building Capacity



- Supporting the development of local Coalitions



- Leadership role in a National Caregiver Action Plan



- Facilitating an International Voice



- Championing Caregiver Awareness



# Canadian Caregiver Coalition

Together, we make change happen



# MOBILIZING ACTION

FAMILY CAREGIVERS IN CANADA







# Canadian Caregiver Coalition

## Mobilizing Action – Project Purpose

To **develop tangible action points** and stimulate momentum that will address the physical, psychosocial, and financial needs of family caregivers.





# Canadian Caregiver Coalition

## Mobilizing Action – Collaborative Engagement

59 Participants =  
caregivers, researchers, health professionals, service providers, non-governmental organizations, employers, community support groups, governments

2 day action planning roundtable + E-Delphi consultation



**INTEGRATED AND SHARED ACTION PLAN**



# Canadian Caregiver Coalition

## Mobilizing Action – From vision to action

### INCREASE AWARENESS

- Prime Minister Proclamation
- Caregiver Awareness Day in Ontario
- NGOs to recognize and support FCG
- Facilitating the voice of caregivers
- FCGs are part of seniors strategy
- FCGs are part of election discourse

### IMPROVE ACCESS

- User friendly information (hub/spoke)
- Technology-enabled access
- Capacity building for health care providers

### ALLEVIATE FINANCIAL BURDEN

- Flexible financial options (i.e. CCB and Caregiver Tax Credit)
- Funding options to support home and community supports

### CREATE SUPPORTIVE WORKPLACES

- Corporate tax incentives for employers
- Human resource strategies



Je suis une **proche aidante**.  
I am a **caregiver**.

## Care and Work: A Balancing Act



CARE & WORK  
A Balancing Act

# CULTURE



"Supporting our staff is the socially responsible change we want to see as **a new standard for all employers in Canada.**  
We have to do our best to take care of each other."

**Connie**

PRESIDENT AND  
CHIEF EXECUTIVE OFFICER  
*Closing the Gap*





CARE & WORK  
A Balancing Act

# CULTURE



“Being a health care provider, **we see firsthand the strain caregiving can have on family caregivers.** We implement flexible practices so that our employees can be efficient family caregivers and still excel at their job.”

**Lori**

CHIEF EXECUTIVE OFFICER  
*Spectrum Health Care*

**Spectrum** Always with you.  
HEALTH CARE



# CULTURE

CARE & WORK  
A Balancing Act



"We always encourage leaders to have good conversations with their team and to support them to put their family and the health of their family first. It **starts from the very top with our President**, who leads by example."

**Anna**  
DIRECTOR OF  
HUMAN RESOURCES  
Becton Dickinson



"Start small, **start by having conversations** with employees. If people start talking about it and there is awareness, **things will evolve.**"

**Nancy**  
CHIEF CLINICAL EXECUTIVE &  
SENIOR VICE PRESIDENT  
Saint Elizabeth





# BALANCING

CARE & WORK  
A Balancing Act



"It is like I am pacing myself for a marathon –  
I just live day by day and try to keep going somehow."

**Susan**

Caring for her mother with a heart condition  
RISK MANAGEMENT ASSOCIATE  
VHA Home Health Care



"My wife and I look after our parents  
and our children, and **somewhere  
in the middle** we also have to make  
sure we look after our financial security  
and personal well being."

**Paresh**

Caring for his father with  
Alzheimer's disease  
MOBILE PLATFORM LEADER  
Saint Elizabeth



CARE & WORK  
 A Balancing Act

# RESOURCES



"I have always wanted to look after my mom by myself. Financially, I couldn't. **I needed to work.**"

**Salwa**

Cared for her mother with post-stroke complications  
 PERSONAL SUPPORT WORKER  
 ParaMed Home Health Care



"My mind is always on his needs, my family needs, and work needs. It is like you are **working all the time - 24 hour care.**"

**Evelyn**

Caring for her father with multiple health conditions  
 PERSONAL SUPPORT WORKER  
 Bayshore Home Health



CARE & WORK  
A Balancing Act

# RELATIONSHIP



"My parents did not stop parenting me when times got hard, so I know that **I will not stop caring for them** no matter how hard being a caregiver may be."

**Nahid**

Caring for her parents with multiple health conditions

CORPORATE BILLING AND  
PAYROLL MANAGER  
*Spectrum Health Care*

# APPRECIATION

CARE & WORK  
 A Balancing Act



**"I can't lose my job but I also can't neglect my mother.** So when you have a manager that is very understanding and supportive, it really helps."

**Sarah**

Caring for her mother with cancer  
 CALL CENTER ASSOCIATE  
 Closing the Gap



**"To work somewhere where they can be accommodating and understanding that you have to be away from work to take care of someone else, and not necessarily yourself, is a really good feeling."**

**LeQuisha**

Caring for her mother with multiple health conditions  
 CALL CENTER ASSOCIATE  
 Closing the Gap



**"To be able to look after my dying father and youngest brother until their last breath was the best care I ever gave".**

**Fei**

Cared for multiple family members at their end of life  
PERSONAL SUPPORT WORKER  
ParaMed Home Health Care

**CARE & WORK**  
A Balancing Act

**INSPIRATION**



**"It makes me feel proud that I am taking care of somebody that, first of all, is in distress and doesn't have the mobility to do things."**

**Dennis**

Caring for his aging mother  
PERSONAL SUPPORT WORKER  
Saint Elizabeth



visit our website at [www.ccc-ccan.ca](http://www.ccc-ccan.ca)

Catherine Suridjan  
[csuridjan@cdnhomecare.ca](mailto:csuridjan@cdnhomecare.ca)

*thank you*



Je suis une proche aidante.  
I am a **caregiver**.