

Family Caregivers: Even the “Backbone” Needs Support



DR. JANICE KEEFE

CHAIR & PROFESSOR DEPARTMENT OF FAMILY STUDIES & GERONTOLOGY
DIRECTOR, NOVA SCOTIA CENTRE ON AGING
LENA ISABEL JODREY CHAIR IN GERONTOLOGY
MOUNT SAINT VINCENT UNIVERSITY

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KEY MESSAGES

Caregivers ARE BACKBONE OF OUR COMMUNITY SUPPORT SYSTEM

Assessing the needs of Caregivers is critical

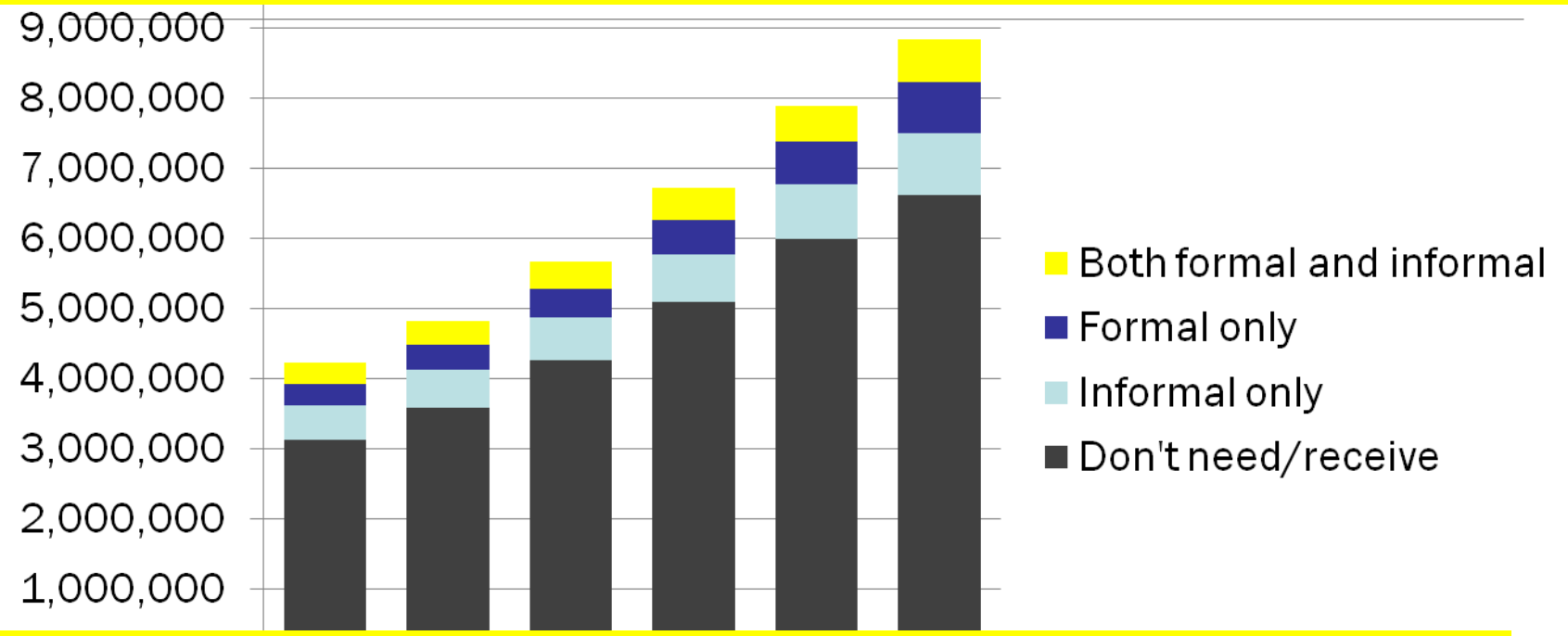
What are the current policies and program to support caregivers ?

What else should be in place?

What about the future care needs?

REALITY #1

Our Population is Aging: When senior need care, it is mostly provided by family - BUT assuming their continued availability is problematic.



Most 'Old' people do not need help - however an increasing proportion will need to receive it from formal care



Family and friend caregivers are important. We need to recognize and support what they do.



My Mom Genevieve 1924-2013

Family/Friend Caregiving in Canada

What Does the Research Tell Us?

-46% of Canadians had been caregivers at one point in time.

-In 2012, 8.1 million Canadians provided care to a family member.

Of these , 75% are employed. Most of these work full time (69% women, 72% men).



- Both men and women provide assistance – however, the type of assistance that women provide tends to be more intense and results in higher levels of stress

CAREGIVING IN CANADA

Family/friend Caregivers:

Often invisible and unrecognized but critical ingredients in the maintenance and growth of the aging population



Dilemma: Caregivers need to be recognize as individuals with rights to their own services and supports. At the same time public policy will need to be targeted to caregivers who provide a certain amount of care (not help).

The Gendered Nature of Care

Care & Support in the Community

Women live longer

More Women than men provide care

Women combine multiple responsibilities

Home Care needs

- Women have higher chronic illness
- Women paid/non paid caregivers
- Great economic consequences at work
- Men receive more formal care services

Nursing Home Care

- Most workers
- Most residents
- Most family/friend

WOMEN

Policies are premised on assumption that families (woman) are available

Potential Challenges for caregivers in community

Societal

- Competing responsibilities within different systems (work/family/care)
- Role clarity
- Identifying resources/supports

Financial

- Trying to hold a job/jobs
- Remuneration/pensions/benefits
- Reduced working hours
- Need to turn down paid work or quit job

Personal

- Varying expectations of “care”
- Family dynamics
- Finding time to reach out to get assistance

Emotional

- Caregiver stress and burnout
- Fear for safety of the care recipient and/or self
- Fear of the future;
 - Coping with next stage of disease

Challenges IN RESIDENTIAL CARE

Emotional Stress

- Promises that could not be kept
- Visits that are upsetting
- ...
- ...
- Care
- Fear
- No

Within facilities

- Role clarity with staff
- Mixed messages from staff
- ... staff, resident, relationship centred s/supports

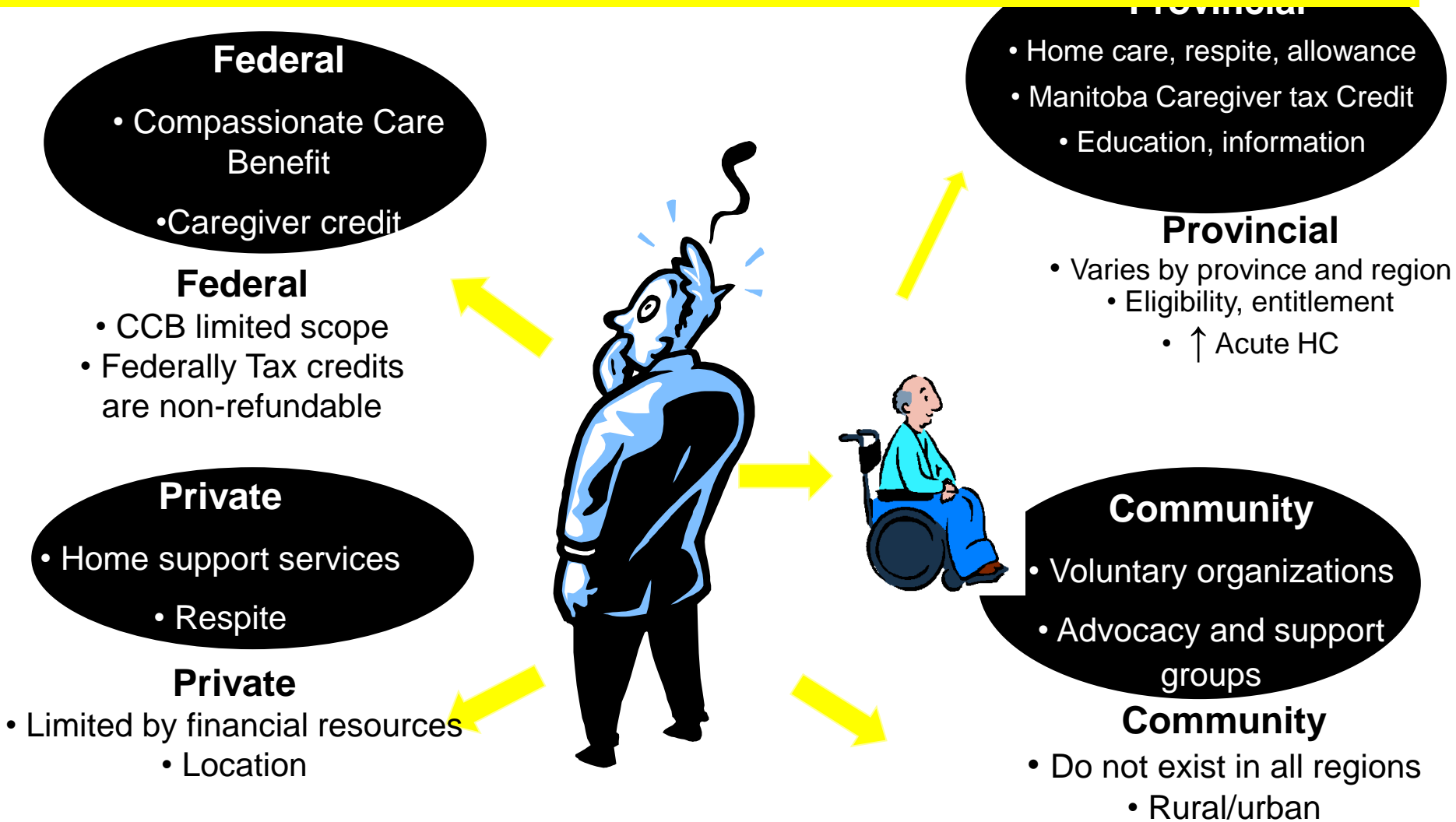
GUILT !

Personal

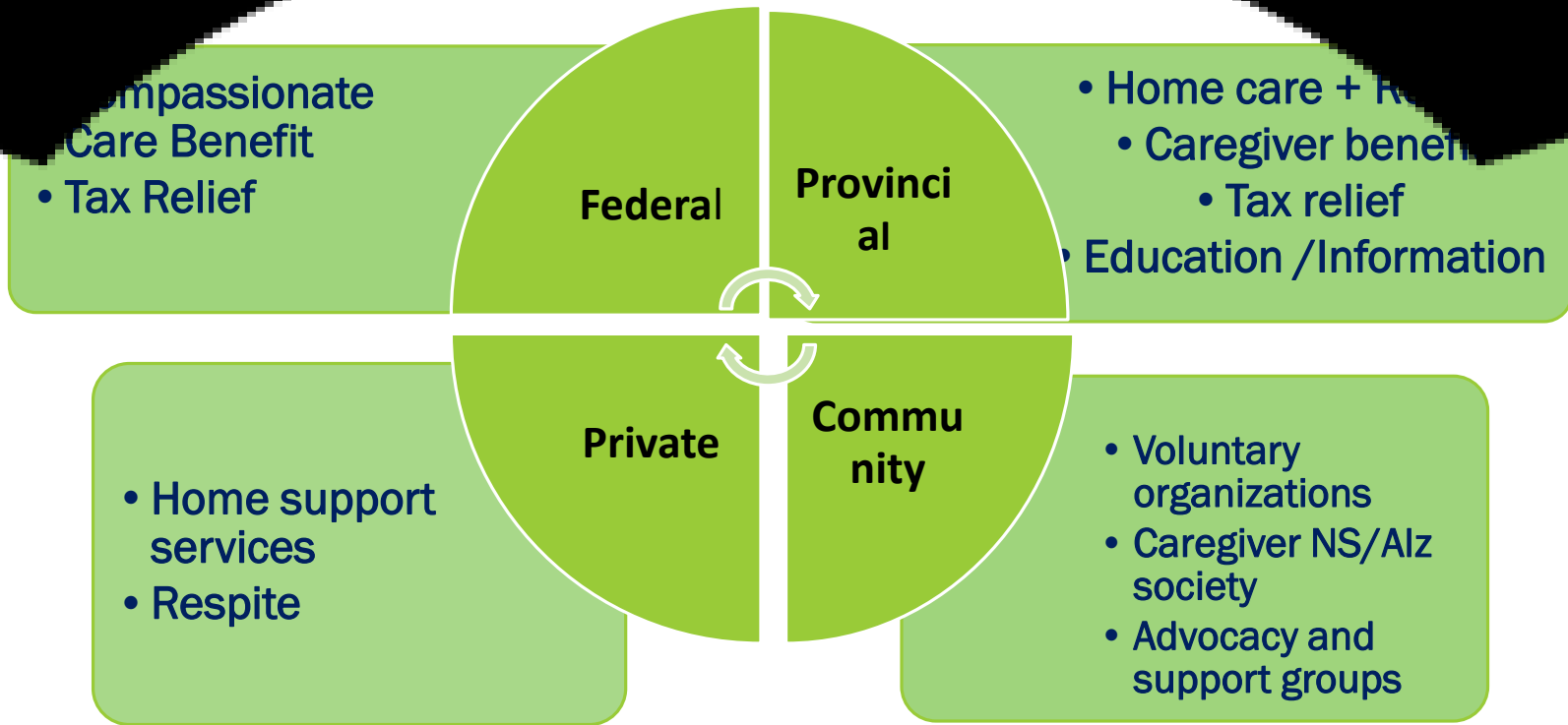
- Varying expectations of “care”
- Family dynamics
- Own health issues
- Other family dramas
- Additional Cultural expectations

- ... in financial support
- Affordability when on fixed income
 - Spouse in community
 - Trying to hold a job/jobs

System of supports for family/friend caregivers is limited and inconsistent; their role as caregiver, ambiguous.



Caregiver Assessment



ASSESSING NEEDS

The C.A.R.E Tool

(Guberman, Keefe, Fancey, Barylak, 2006)

➤ An assessment of Caregivers' Aspirations, Realities and Expectations C.A.R.E.

- A multi-dimensional psycho-social assessment instrument
- Designed to collect information from the caregivers' perspective on the many different aspects of his/her situation
- Looking to pinpoint the key areas of difficulty being experienced by the caregivers
- Specific difficulties can then be matched with supports that would assist the caregiver

Our journey of work on caregiver assessment

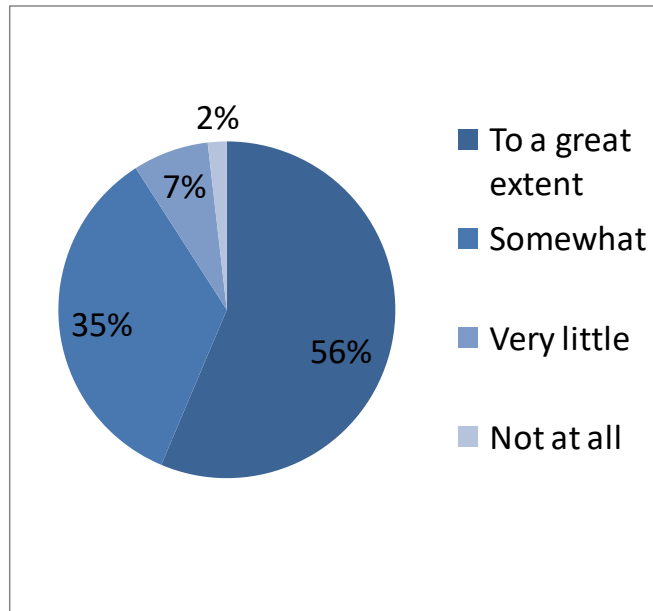
Study 1 (1999-2000) (Guberman et al.)	Study 2 (2003-2007) (Keefe et al.)	Study 3 (2009-2013) (Keefe et al.)	Study 4 (2011-2013) (Seniors Health Strategy Unit)
C.A.R.E. Tool evaluated for validity and reliability across groups of caregivers and practitioners	Assessed impact on CGs of persons with/without dementia; Examined conditions of successful implementation	Determined optimal timing of assessment for older spousal CGs of a partner with cognitive impairment	Evaluated respite services for CGs using the C.A.R.E. Tool to identify needs

5 key response areas:

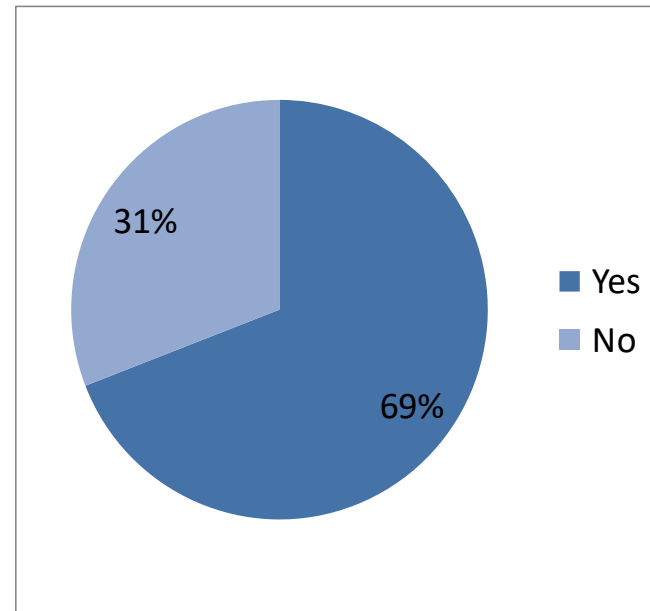
- Future Planning
- Crisis Planning
- Emotional Health
- Physical Health
- Supervision/Support

Insights from Caregivers

CG SEES THEMSELVES WITH NEEDS THAT ARE DIFFERENT FROM THEIR PARTNER



FIRST OPPORTUNITY TO DISCUSS CAREGIVING SITUATION

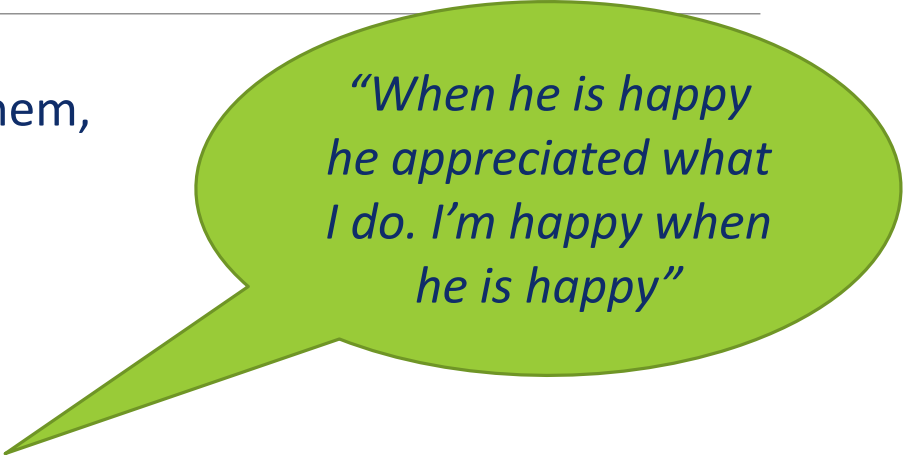


Caregiver's Positive Experiences:


1. quality of relationship
 2. feeling of accomplishment
 3. meaning and purpose
-

1. Quality of Relationship

- Reflecting on the bond between them, knowing the actions are reciprocal
- Cherishing past memories
- Enhanced closeness
- Being together, companionship
- Relationship continuity
- Care recipient showing affection, appreciation



“When he is happy he appreciated what I do. I’m happy when he is happy”



“I know if I was sick they would care for me”

2. Accomplishment



*“CR is well
looked after
and kept
comfortable”*

*“Knowing that
I am helping
them to
remain in own
home and
community”*

- Ensures care receiver is well cared for
- Can be sure that care receiver is happy
- Identity maintenance
- Allows care situation to be tailored to personal situation
- Delaying/preventing institutionalization
- Discovering new strengths/capacity

3. Meaning and purpose



[Care] bears witness that the human person is always precious, even if marked by age and sickness.” Pope Francis

...is proud that she is able to provide care for her mother who had provided so much for her family

...is an honor to CR (cultural) and that children are being exposed to values of caring for the elders in the family

- Knowing they are doing all they can for someone
- Knowing they are making someone else's life better
- Fulfilling sense of duty/obligation
- Personal development and growth
- Feeling useful/valued/appreciated
- Helping other caregivers

Doing the right thing, fulfillment, satisfaction

How do we (as practitioners, clinicians etc)
view caregivers?

Reflection

How **DO I**
view

Family/friend
Caregivers ?

AS A RESOURCE

AS A CO-CLIENT

AS A PARTNER



Source: *Women on Home Care*, Published by the Canadian Women's Health Network

Consider our relationship with Practitioners

❖ Perceptions of Caregivers

- How do you as a caregiver perceive yourself ?
- How do you think practitioners perceive you ?

❖ Perceptions of Care Provides or Practitioners

- What is your perception of Practitioners??

❖ What are you EXPECTATIONS of Practitioners?



Guberman, Keefe, et al., under review

SUPPORTING CAREGIVERS



Practice approaches to support caregivers

Approach centered on:	The Family		
	Co-client	Resource	Partner
Focus	The negative impacts of caregiving on CG	CG as answer to public sector cutbacks	CG as genuine partners
Intervention	Problem solving: cognitive and behavior change	Maximizing competencies: Educating	Partnerships: recognize specific contributions, resources, knowledge

Guberman, Keefe, et al., under review

What Can I do ??

As a care provider, a clinician, a caregiver, a friend of a caregiver ...

- Take care of yourself
- Examine how you view the caregiver
 - As a resource; a co-client; a partner
- Examine your attitude
 - Family caregivers are complainers
 - Family caregivers are present
- Try focusing on the needs of the caregiver
 - How was your visit; How are YOU feeling about your visit;
 - One thing I've found to help encourage response...
 - REMEMBER many of us are guilt ridden and you are the person we take it out on
 - Give ideas ... Would you ever consider...



Other Ways to Support Caregivers

Private Sector

- **Health/Continuing Care**
 - Respite care/Home Care
 - Recognize caregivers as a client
- **Employment/Labour**
 - Enhance Leave policy – EI
 - Labour Standards policy
- **Health Human Resources**
 - Improve working conditions
 - Focus on Recruitment and retention
- **Income Security**
 - Enhance caregiver benefit
 - Refundable Tax credits
 - Pensions/Social Security benefits

Government

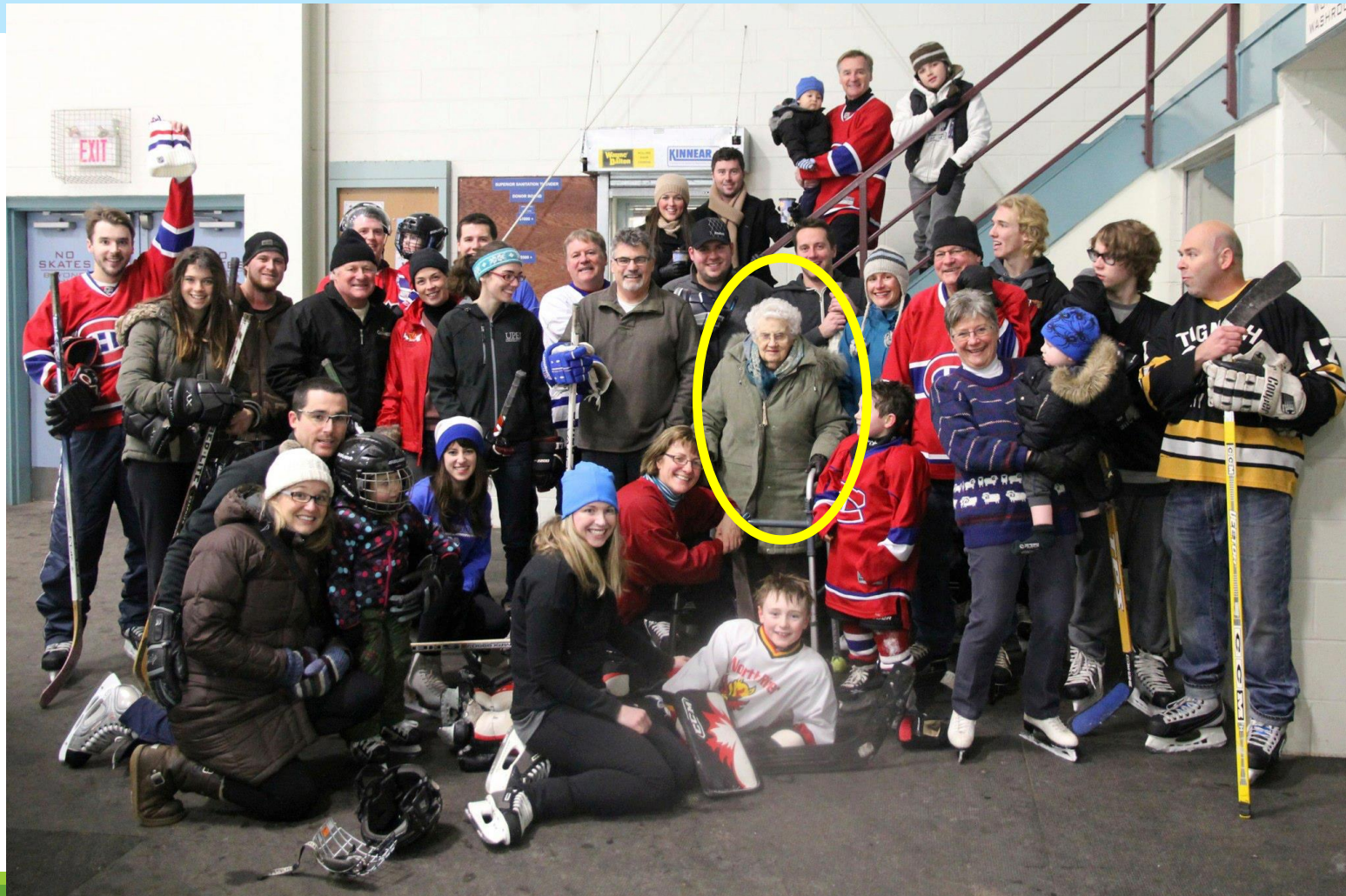
Voluntary Sector

- **Alzheimer's Society –**
 - Support Groups
 - Advocacy and Information
 - Educational series
- **Caregiver groups**
 - Communities
 - Church Groups
- **Senior's Centres**
- **Transportation/meals**

Individuals/Families

Family and friend caregivers are the backbone

There are challenges but there are joys



Dr. Janice Keefe

Professor, Department of Family Studies and Gerontology

Director, Nova Scotia Centre on Aging

Lena Isabel Jodrey Chair in Gerontology

E-mail: Janice.Keefe@msvu.ca

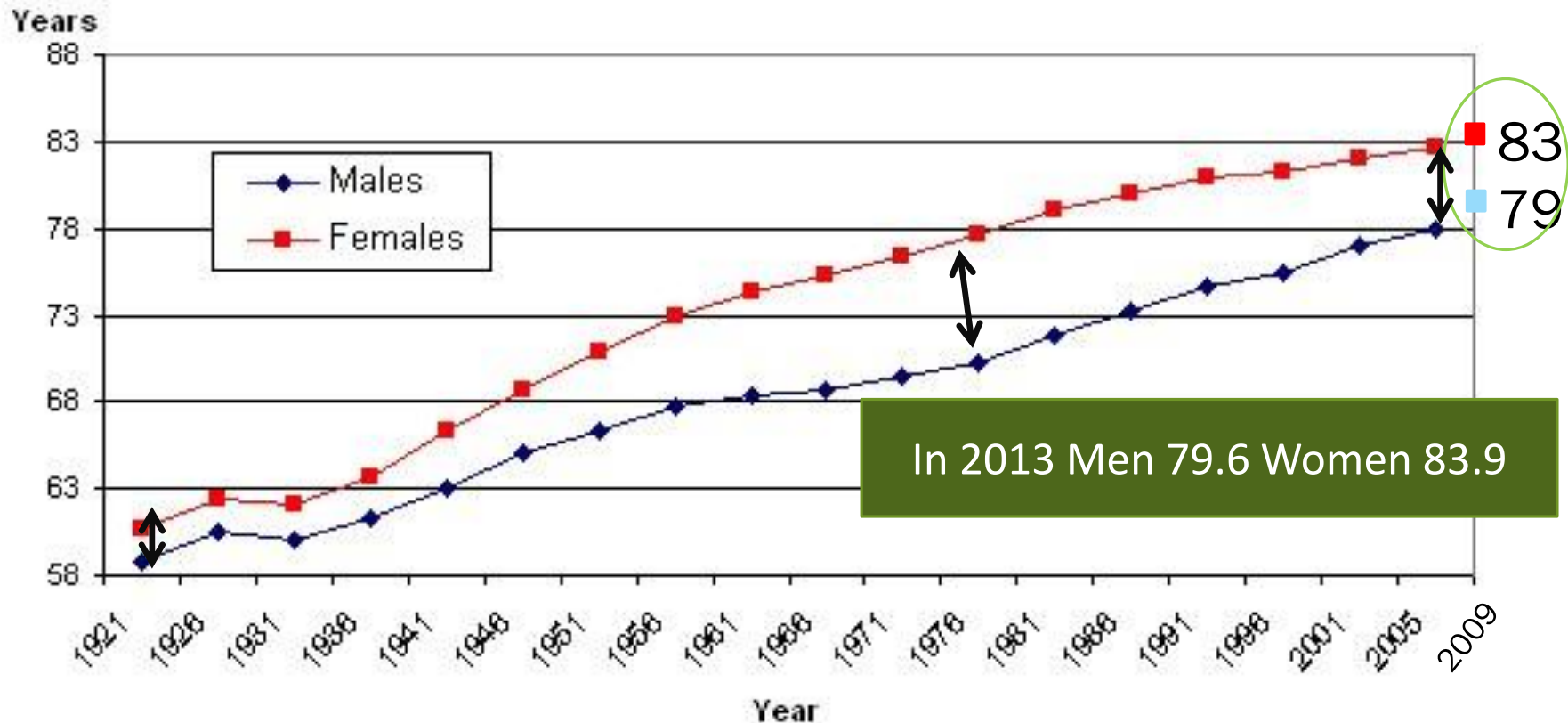
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www.msvu.ca/nsca

Life expectancy by sex has narrowed since '70s

Life expectancy at birth, by sex, Canada, 1956 to 2005



Source: 1921 to 1981: Nagnur D. *Longevity and Historical Life Tables, 1921 to 1981 (Abridged)*, Statistics Canada, Catalogue 98-506, 1986;
1986: Duchesne D, Nault F, Gilmour H, Wilkins R. *Vital Statistics Compendium 1996*, Statistics Canada, Catalogue 84-214, 1999;
1991 to 2005: CANSIM Table 102-0511, *Life expectancy, abridged life table, at birth and at age 65, by sex, Canada, provinces and territories, annual*.