

# An evidence-based group psychotherapy program for informal dementia carers who are concurrently employed in the Canadian workforce

Mary Chiu, PhD, Virginia Wesson, MD, FRCP(C), Joel Sadavoy, MD, FRCP(C)  
& Director of Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training



CCNA  
Canadian Consortium  
on Neurodegenerative  
disease in Aging

MOUNT SINAI HOSPITAL  
Joseph and Wolf Lebovic Health Complex



Employment and  
Social Development Canada

Emploi et  
Développement social Canada

## The Reitman Centre Working CARERS Program

A therapeutic skills training program

Coaching Advocacy Respite Education Research Simulation



**Problem Solving, Negotiation, etc.**

**Therapeutic Simulation Video Demonstrations**

## Family Carers



**Family Carers**

- More informed and empowered management of care
- The carer's role is to support the person with dementia
- The carer's role is to support the person with dementia

**Support value of the carer**

- Support value of the carer is a key component of the overall care plan
- Support value of the carer is a key component of the overall care plan

## Family Carers in the Workplace

**Impact for Employers, Health Care and Society as a Whole**

- Lost productivity **CAD\$1.3 billion**
- Replacement and training of new workers
- Health care costs
- Human and social costs

**The case of working carers**

- Working carers face a complex set of challenges
- Working carers face a complex set of challenges

**The Professional Impact is Profound**

Additional coping and strategies may be



**Loss of interest in the world regarding working**

Loss of interest in the world regarding working

**Existing, isolated employer-led initiatives simply do not respond to the underlying problems associated with the increasingly complex caregiving role**

- Maintaining a productive and viable workforce
- Investment by business and government:
- Understanding impact of caregiving and creating targeted solutions
- Higher rates of employee retention

# OPPORTUNITY

An opportunity exists to design and deliver clinical interventions and resources for carers that are evidence-informed, practical, economical and fully evaluable

## Developmental Evaluation & Preliminary Research Findings

**Health Government System-wide**

**National Priority**

**Priority of Work-Long Term Impact on Society**

## Key Lessons Learned

**Key Government Successes & Challenges**

**Key Successes**

**Key Challenges**



# An evidence-based group psychotherapy program for informal dementia carers who are concurrently employed in the Canadian workforce

Mary Chiu, PhD, Virginia Wesson, MD, FRCP(C), Joel Sadavoy, MD, FRCP(C)  
 & Director of Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training

CCNA CCNY  
 Canadian Consortium on Neurodegeneration in Aging

MOUNT SINAI HOSPITAL  
 Joseph and Wolf Lebovic Health Complex

Employment and Social Development Canada  
 Emploi et Développement social Canada

**The Reitman Centre Working CARERS Program**  
 A therapeutic skills training program  
 Coaching Advocacy Respite Education Research Innovation  
 MOUNT SINAI HOSPITAL

Therapeutic Objectives  
 Specific Situation Video Demonstration

## Family Carers



Family Carers  
 Economic value of family carers

**OPPORTUNITY**  
 An opportunity exists to design and deliver clinical interventions and resources for carers that are evidence-informed, practical, economical and fully evaluable

- Maintaining a productive and viable workforce
- Investment by business and governments
- Understanding impact of caregiving and creating targeted solutions
- Higher rates of employee retention

## Developmental Evaluation & Preliminary Research Findings

Health Research Canada  
 FRI  
 CIHR

## Family Carers in the Workplace



Impact for Employers, Health Care and Society as a Whole  
 The rise of working carers  
 The Professional Impact is Profound

## Key Lessons Learned

Key Lessons Learned

# Family Carers





# Family Carers



- Skillful interpersonal and environmental management is our best intervention
- The family carer is at the frontline in dementia care
- Effective family caregiving has benefits

Kramer, 1997; Hollander et al, 2009; McCallion, et al., 1999; Mitchell and Kemp, 2000; Mittelman et al., 2006

# Economic value of family carers

*Annual replacement costs for family carers: An essential part of the health care infrastructure*



CAD\$25-\$31 billion (Hollander et al., 2009)



£87 billion (Buckner and Yeandle, 2007)



US\$450 billion (Reinhard et al., 2015)



A\$60.3 billion (Deloitte Access Economics Pty Ltd 2005)







# Family Carers in the Workplace

Employers, Health Care and Society as a Whole

Activity: **CAD\$1.3 billion**  
Cost of recruitment and training of new workers  
Productivity costs  
Health and social costs

Duxbury and Higgins, 2012; Feinberg et al., 2011; Sinha 2012;



Family working carers

On a slow, downward spiral you think you are doing okay until you find that "Holy cow, I can't concentrate the way I used to be!"

I haven't gone for a walk in more than 2 years. I feel stuck and I have become more stressed, argumentative and negative.

Even though I'm physically at work, I find myself preoccupied with what's happening at home. I worry about my mother.

All of a sudden you're mulling over the same thing, glancing at the same paper for 45 minutes.

That "work" getting "So it's not really work, it's just a distraction. You're not really working, you're just trying to keep your mind off home."

How many people go to work every day with a heavy heart?

Prezi  
Balancing work and caregiving may have:

Lack of research and information regarding working carers' needs and how they juggle multiple roles

Existing, isolated employer-led initiatives simply do not respond to the

# Impact for Employers, Health Care and Society as a Whole

- Lost productivity: **CAD\$1.3 billion**
- Replacement and training of new workers
- Health care costs
- Human and social costs

Cynkar and Mendes, 2011; Duxbury and Higgins, 2012; Feinberg et al., 2011, Sinha 2012; Witters, 2011





# The Professional Impact is Profound

*Individuals juggling work and caregiving may have:*



- Higher levels of absenteeism and presenteesim
- Greater inclination to turn down promotions
- Tendency to scale back to part time hours
- Lost wages and benefits

Lily, 2010; Alzheimer Society of Canada, 2011; AARP Public Policy Institute, 2012



# The case of working carers

You're on a slow, downward spiral where you think you are doing okay and then you find that, "Holy cow, I can't concentrate the way I used to be able to."

I haven't gone for a walk in more than 2 years. I feel stuck and I have become more stressed, argumentative and negative.

It's just all consuming and so you ride the frustration, you ride the anger.

All of a sudden you're mulling over the same thing; you're looking at the same paper for 45 minutes.

Even though I'm physically at work, I find myself preoccupied with what's happening at home. I worry about my mother.

*I find myself getting 5 or 6 panicky phone calls a day from my father saying, "You've got to come home right away!"*

*I don't have any other life. I go to work and I come home.*



**Even though I'm physically at work, I find myself preoccupied with what's happening at home. I worry about my mother.**



*I find myself getting 5 or 6  
panicky phone calls a day  
from my father saying,  
"You've got to come home  
right away".*

I haven't gone for a walk in more than 2 years. I feel stuck and I have become more stressed, argumentative and negative.



# Lack of research and information regarding working carers' needs and how they juggle multiple roles



**Existing, isolated employer-led initiatives simply do not respond to the underlying problems associated with the increasingly complex caregiving role**

**Income and  
job protection**

**Options for Leave**

**Flexible work  
arrangements**



- Maintaining a productive and viable workforce
- Investment by business and government:
  - Understanding impact of caregiving and creating targeted solutions
- Higher rates of employee retention



Prezi

# OPPORTUNITY



- Maintaining a productive and viable workforce
- Investment by business and government:
  - Understanding impact of caregiving and creating targeted solutions
- Higher rates of employee retention

# OPPORTUNITY

*An opportunity exists to design and deliver clinical interventions and resources for carers that are evidence-informed, practical, economical and fully evaluable*



# The Reitman Centre Working CARERS Program

---

A therapeutic skills training program



Coaching Advocacy Respite Education Research Simulation



# The Reitman Centre Working CAREERS Program

- Innovative partnership model among government (ESDC), not-for-profit (Reitman Centre) and corporate (Ceridian EAP) sectors
- Supported by 5-year Canadian federal government grant
  - CAD\$2.84 million
- Tailored to the needs of working family carer
- Offers carers practical knowledge, skills and strategies to enhance and sustain their labour market participation





# The Reitman Centre Working CAREERS Program



- Small group based (6-10)
- 8 weekly sessions (2 hours each)
- Tailored education about dementia
- Problem Solving Techniques (PST) used to address specific problems of caregivers
- Simulation and expert coaching to teach new approaches to caregiving challenges
- Throughout the program, emotional issues are addressed as they arise

# Problem Solving Techniques (PST)



- Teaches a structured and systematic approach to identifying and finding solutions for caregiving problems
- Teaches effective problem-focused coping skills
- Reduces emotion-focused coping



# Therapeutic Simulation

- Learning from hands-on experience
- Focus on interaction and relationship
- Guided re-enactment
- Uses a specially trained simulated patient
- Expert coaching helps carer learn new, more effective approaches to manage emotional challenges, gaps in knowledge, skills and attitudes



# Therapeutic Simulation Video Demonstrations



Eric coached by clinicians and simulation patient to try different communication strategies through a simulated situation



# Developmental Evaluation & Preliminary Research Findings

Federal  
Clinical inte  
who are emp



CIHR  
Canadian Institutes of  
Health Research

Federal government funded research:  
Clinical intervention for family caregivers  
who are employed in the Canadian workforce



**CIHR IRSC**  
Canadian Institutes of Health Research  
Instituts de recherche en santé du Canada



**CCNA CCNV**  
Canadian Consortium on Neurodegeneration  
in Aging  
Consortium canadien en neurodégénérescence  
associée au vieillissement



# National Survey

National Study on Balancing Work, Family and Caregiving English ▾

**Section A: Your Job**

The questions in this section ask about your job and your experiences with your employer. Please select the most appropriate answer for each question.

---

Please indicate how often you experience the following when at work.

	Rarely	Infrequently	Sometimes	Frequently	Always
I feel I am bursting with energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel strong and vigorous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel enthusiastic about my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My job inspires me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I get up in the morning I feel like going to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel happy when I am working intensely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel proud of the work I am doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get immersed in the work I am doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get carried away when I am working	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

In the past six months, how often have you thought about leaving your current organization to work elsewhere?

Never	Monthly	Weekly	Several Days per Week	Daily
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1. Pinpoint the unique challenges and needs of working carers
2. Investigate the impact work has on caregiving and vice versa
3. Inform the design and delivery of interventions

# Focus Groups Using Appreciative Inquiry Approach

- Exploration of
  - Impact of Working CARERS Program on participants
  - Feasibility and sustainability of Working CARERS Program in rural communities





1. Pinpoint the unique challenges and needs of working carers
2. Investigate the impact work has on caregiving and vice versa
3. Inform the design and delivery of interventions

# Key Lessons Learned

## Carers and Working Carers:

- Complex, poorly understood needs
- Often a distant addendum in the medical model
- The unit of care might be better thought of as the carer-care recipient dyad



## Key Factors to Ensure Success in Implementation and Dissemination

Effective interventions for carers are:

- ✓ Scalable
- ✓ Accessible
- ✓ Involve effective partnerships
- ✓ Evaluable



Williams et al. 2016, Aging and Mental Health

## Carers and Working Carers:

- Complex, poorly understood needs
- Often a distant addendum in the medical model
- The unit of care might be better thought of as the carer-care recipient dyad





# 4 Key Elements of Successful Caregiving

Knowledge  
of the disease  
and treatment



Effective caregiving,  
communication &  
problem solving  
skills

Practical and  
professional  
support and  
resources

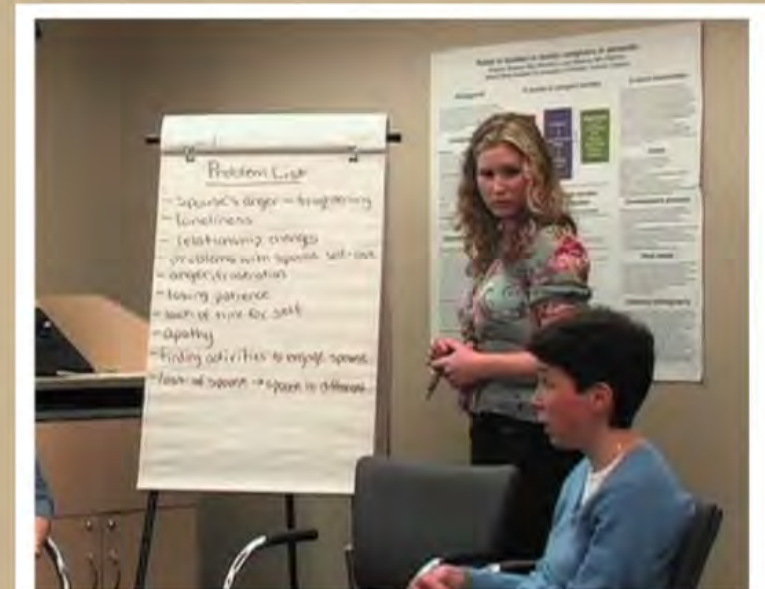


Emotional  
well-being

# Key Factors to Ensure Success in Implementation and Dissemination

Effective interventions for carers are:

- ✓ Scalable
- ✓ Accessible
- ✓ Involve effective partnerships
- ✓ Evaluable



Williams et al. 2014, *Aging and Mental Health*





## Successful Carers' Interventions, Supports and Policies:

- Demonstrate respect for working carers
- Respond to the individual needs of carers
- Use a multipronged approach
- Are provided consistently to all employees

ia



CCNA CCNV

Canadian Consortium  
on Neurodegeneration  
in Aging  
Consortium canadien en  
neurodégénérescence  
associée au vieillissement

**MOUNT SINAI HOSPITAL**  
Joseph and Wolf Lebovic Health Complex



Employment and  
Social Development Canada

Emploi et  
Développement social Canada



# An evidence-based group psychotherapy program for informal dementia carers who are concurrently employed in the Canadian workforce

Mary Chiu, PhD, Virginia Wesson, MD, FRCP(C), Joel Sadavoy, MD, FRCP(C)  
 & Director of Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training



**The Reitman Centre Working CARERS Program**  
 A therapeutic skills training program  
 Coaching Advocacy Respite Education Research Simulation

**Therapeutic Skills Training Program**  
 Includes: Problem Solving, Negotiation, Role Play, Therapeutic Video Demonstrations

## Family Carers

**Family Carers**  
 - More informed and empowered caregiver  
 - The caregiver will be better able to manage the care recipient's needs

**Support value of the program**  
 - Program demonstrated to include a number of key components:  
 - 1. Education  
 - 2. Support  
 - 3. Information  
 - 4. Skills  
 - 5. Empowerment

## Developmental Evaluation & Preliminary Research Findings

**National Priority**  
 - Health Canada  
 - Canadian Institutes of Health Research  
 - Alzheimer Society of Canada

## Family Carers in the Workplace

**Impact for Employers, Health Care and Society as a Whole**  
 - Lost productivity: **CA\$61.7 billion**  
 - Replacement and training of new workers  
 - Health care costs  
 - Human and social costs

**The case of working carers**  
 - Working carers face a complex set of challenges  
 - They are often the only source of support for their loved ones  
 - They are often the only source of income for their families

**The Professional Impact is Profound**  
 - Includes: Impact on productivity, Impact on quality of care, Impact on patient safety, Impact on patient experience, Impact on patient outcomes

**Existing, isolated employer-led initiatives simply do not respond to the underlying problems associated with the increasingly complex caregiving role**

**OPPORTUNITY**  
 An opportunity exists to design and deliver clinical interventions and resources for carers that are evidence-informed, practical, economical and fully evaluable

## Key Lessons Learned

**Key Lessons Learned**  
 - The program is a national priority  
 - The program is a national priority  
 - The program is a national priority