

Preparing Carers to Provide Care at Home for Loved Ones with Dementia: **The Reitman Approach**

Cyril & Dorothy, Joel & Jill Reitman Centre
for Alzheimer's Support and Training

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Proposition:

**Carers should be a
Target Population for
Health Policy and Service
Development**

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Why be concerned about carers?

Is There a Rationale For Formal Health Policies and Clinical Programs for Carers?

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Profile of Canadian Carers

- 97% with dementia have at least 1 carer
- Majority of informal carers are individuals within the patient's own family
- 70% women(29% wives 24% daughters)
- 50% > 65 yrs; 36% > 70

• (Statistics Canada, 2003 General Social Survey; Canadian Study of Health and Aging Working Group, CMAJ 1994; 150 : 899; Statistics Canada, www.statcan.ca).

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Family Carers are Essential to Dementia Care Infrastructure but have little knowledge and few skills

- Daily management of **Behavioural and Safety issues**
- Basic and instrumental **ADL**
 early stages - complex tasks; e.g. banking or driving.
 As the disease progresses - everyday functions; e.g. feeding, dressing and safety; decision making - treatment, finances, and LTC

(Lund, Geriatric Nursing 2005; 26: 152).

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Economic Cost

Replacement/imputed costs for unpaid carers

- Can 2009 **CAD \$25-\$26 billion** (Hollander et al 2009)
- UK 2007 - **£87 billion** (Buckner and Yeandle 2007)
- US 2006 - **US\$354 billion** (Gibson and Houser 2007)
- Aus 2005 - **A\$30.5 billion.** (Access Economics Pty Limited 2005)

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Disproportionate Physical Risks

- Higher prevalence of **physical symptoms** than non-carer peers
- More **doctors visits**
- higher rates of **prescription drug use**
- poorer subjective **ratings of health**
- Compromised **immune** function
- Exacerbation of pre-existing **illness** - diabetes
- hypertension other cardiovascular diseases

(Baumgarten et al., 1992; Hooker, 1992; Katon et al., 1982; Pruchno 1989; Schulz 1995; Kiecolt-Glaser 1987; Vitaliano et al 2003; Lee et al 2003)

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Disproportionate Physical Risks

- Higher rates of **depression** (14 –47%).
10% meet DSM criteria for depression
- Estimated that 7 –31% take **psychotropic meds**
- More likely to suffer a **relapse** of pre-existing psychiatric illness
- More likely to over-use substances such as **alcohol**.
- **Emotional vulnerability: anxiety, grief, guilt, rage**

(Akkerman & Ostwald 2004; Alspaugh et al 1999; Baumgarten et al., 1992; Brown et al. 1990; Burns & Rabins., 2000; Coon et al, 2003; Dura et al 1991; Schulz et al., 1995; Saad et al. 1995;)

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Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training

**A program for family carers living at
home with loved ones who have
dementia**



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The Reitman Centre Offers Comprehensive Short and Longer Term Carer and Care Recipient Clinical Services

- **The Reitman Group Program**
- Comprehensive Geriatric Psychiatric Services
- (Memory Clinic Assessment and Treatment)
- Individual / Family Assessment and Intervention

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Some Key Goals of the Centre

1. Empirically Supported Clinical innovation
2. Create and systematize (manualize) an effective “therapy-based training” method for family CGs
3. Develop technology based communication among carers (e-learning project)
4. Policy initiatives (Stakeholder Forum in June)
5. Training centre for professional caregivers
6. Adapt Program for Ethnocultural Communities

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Formal Partnerships

- University of Toronto Standardized Patient Program
- International Federation On Aging
- Yee Hong Centre for Geriatric Care

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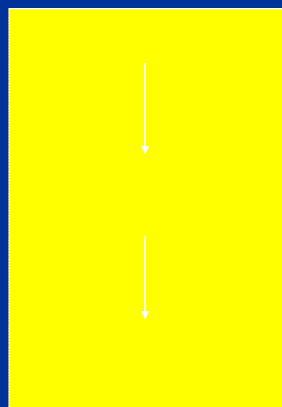


The program teaches skills and addresses emotional - based risks to carers and barriers to caregiving

Key Clinical Goal:
to use evidence-based therapies for prevention of and therapeutic intervention for carer burden and distress.

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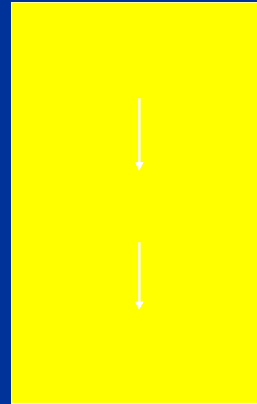
A Model of Carer Burden



Brodaty, International Psychogeriatrics 1996; 8 (S3): 455

A Model of Carer Burden

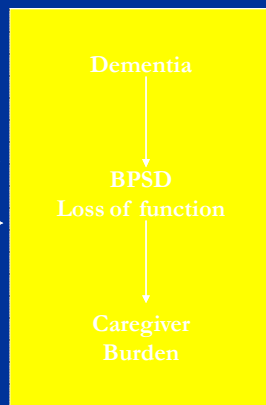
Poor knowledge
Isolation
Guilt
Anxiety
Depression
Shame
Poor relationship
Low intimacy
Negative emotions
Care provider
Wife/female
Poor family support
Physical illness
Immature personality
Emotional coping



Adapted from Brodaty, International Psychogeriatrics 1996; 8 (S3): 455 Brodaty 1996, Burns et al 2000; Kneebone et al, 2003; Van Den Wijngaart et al 2007

A Model of Carer Burden

Poor knowledge
Isolation
Guilt
Anxiety
Depression
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Poor relationship
Low intimacy
Negative emotions
Emotion focused coping
Care provider
Wife/female
Poor family support
Physical illness
Immature personality



Good health
Support
Knowledge
Skills
Empathy
Good relationship
PS Coping style
Respite
Good health
Humour
Mature Personality
Philosophical stance

Adapted from Brodaty, International Psychogeriatrics 1996; 8 (S3): 455 Brodaty 1996, Burns et al 2000; Kneebone et al, 2003; Van Den Wijngaart et al 2007

Data indicate combined interventions for Care Recipient and Carer are most effective

Reitman offers a joint concurrent program

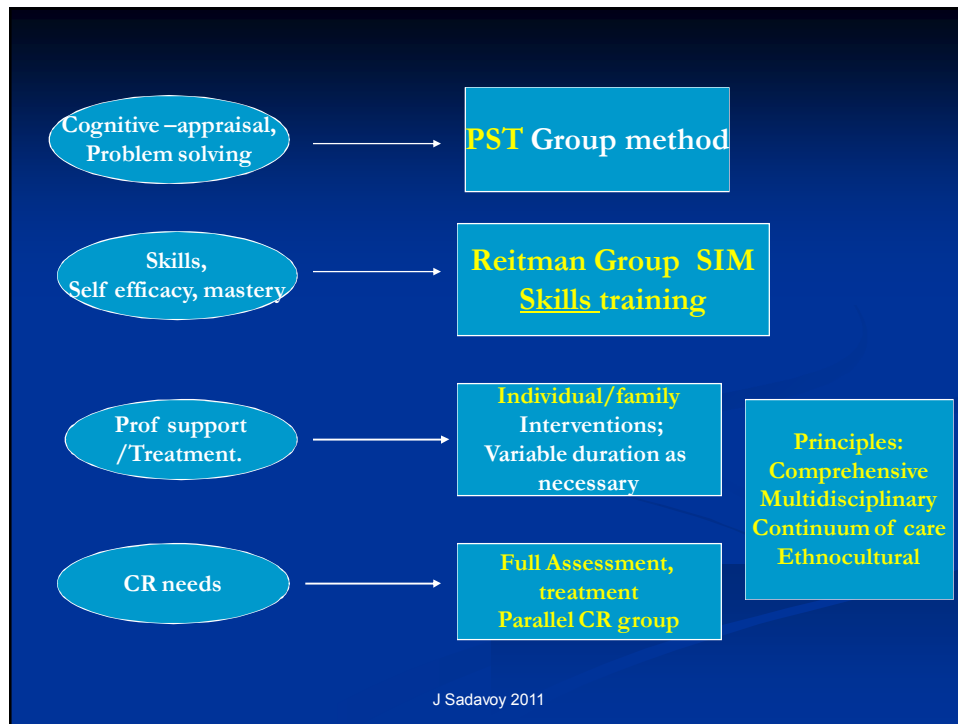
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Evidence-based Clinical Goals for Carers

- Enhanced **practical skills**
- Improved **copmg/problem solving**
- Improved **emotional regulation**
- Enhanced sense of **mastery/self-efficacy**
- Reduced **depression/anxiety.**
- Improved **social (marital) interaction/support**
- Adequate **professional support**

Acton et al 2001; Brodaty et al 2003; Burns et al 2001; Gitlin et al 2003; Kneebone et al 2003; Pusey et al 2000; Schultz et al 2002; Smits 2007; Van den Wijngaart 2007

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Reitman Centre Staff

Social Workers:	2 FT
Psychiatrists:	3 FT (2 group, 1 OPD)
Residents:	2-3 (OPD +/- group)
Fellows:	1
Occupational Therapist:	1 (PT)
Simulated Patients:	3 (PT)
Care Recipient leaders:	2 (PT)
Administrator:	1 FT
EthnoCultural team (Scarborough):	5
International/Local Advisory Board	

Carer Outcome Measures

- **Coping:** Coping Inventory for Stressful Situations (Endler & Parker, 1990)
- **Emotional Regulation :** Five Minute Speech Sample (Magana et al., 1986)
- **Mastery :** Mastery (Pearlin & Schooler, 1978)
- **Caregiving Competence** (Pearlin et al., 1990)
- **Role Captivity** (Pearlin et al., 1990)
- **Role Overload** (Pearlin et al., 1990)
- **Depression:** GDS (Yesavage & Brink, 1983)
- **Social Support:** The Loneliness Scale (De Jong Gierveld & Tilburg, 1990)
- **Health:** Cumulative Illness Rating Scale for Geriatrics (Miller, Paradis & Reynolds, 1991)
- **Personality / Attachment:** Relationship Scales Questionnaire (Griffin & Bartholomew, 1994)
- **Caregiver Burden:** Burden Interview (Zarit,)

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Reitman Centre Protocol: a group method for spouses or children

4 phases:

1. **Assessment** - *Baseline evaluation* key behavioural problems+ psychological & social context of the carer
2. **(4 group sessions - 4-6/group; 2.5 hrs long)** dementia education, formal PST and cognitive methods based on presenting problems
3. **(6 group sessions)** - simulated situations for skills training; experienced actors; intensive expert coaching;
4. **Monthly Maintenance** - *Outcome evaluation*

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Sessions 1-4 outline

- **Session 1-** *Process*: Cohesion, respect, goals, process, Dementia *education*
- **Session 2-** *carer challenges*: Problem definition and lists
- **Session 3-** *Emotional* responses; link problems to emotions
- **Session 4-** Emotion/problem cont's; *intro sims*

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The 7 steps of the PST method

- First we'll Clarify and define your problems: problem list
- Then Establish together our objectives and achievable goals
- For each problem we will work out Solution alternatives by talking together and Brainstorming
- We'll discuss Pros and Cons of solutions and create decision guidelines
- We'll help you Choose the preferred solution(s)
- Then we'll work on ways to actually Implement the solution(s)
- Finally we'll Evaluate the outcome

Example of a 1st Group Problem list

- *Getting out of the house (caregiver)
 - Spouse's safety while away
- *No one to talk to; support system
- *How do I cope or react? Acting in ways we don't like
- *Frustration, and how to handle it
- Lack of continuity (cannot follow thought processes, no planning)
- Different abilities among types of memory
- Disorientation to place and time
- Change of personality; personality traits
- Spouse's response to suggestions
- One-track thoughts
- *Repetitive questions/statements
- Genetic component (Parkinson's symptoms)?
- Medications not helpful
- *Short-term memory deficits
- Not driving
- Choice of clothing; not changing clothes; dressing appropriately for weather; having to dress spouse
- Need for consistency/stability
- Others treating spouse differently
- Disinhibition/no control
- Obsessive compulsive behaviours
- Unable to reason
- Inability to manage medications
- Worries about wandering
- Getting spouses attention
- Confusing reality with dreams
- Seeming 'blank'
- Spouse worries/is anxious about plans for the day
- Spouse's frustrations/fears
 - Understanding their perspective and feelings
- *issues regarding outside help/support
- Forgetting when they have eaten; preparing meals at the wrong time; preparing food/drink in general
- Hygiene/bathing – cueing for these activities
- Sleeping: at night and during the day; more alert when engaged/interested
 - Finding activities of interest
- Apathy

Sessions 5-9 Simulations

Scenarios crafted to simulate and practice different Themes

- **Accusations** against the carer
- **How to say no** to unreasonable demands
- Dealing with **confusion, opposition and resistance**
- Dealing with **repetitiveness, angry outbursts, eating** and feeding
- **Telling others** about the illness of their loved one
- Moderating **angry expectations** of carer

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Process

- Scenarios acted out with simulated patient and carer
- Timeouts break into the action and discussion follows after which scenario is reenacted
- Once comfort is achieved, the next scenario is presented. Usually 3 scenarios per group session
- Emotional issues and conflicts emerge and are dealt with during the group process

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The Simulations

- It was only in the repetitions that I could see and practice other ways of being
- it was the repetition of the same scenario that proved to be most useful.
- It helped on two levels: a greater understanding/awareness of how the other felt and an awareness of what really was important emotionally as well as how the task could be accomplished
- Very helpful to make sure that all aspect of issue is dealt with.
- “start acting sooner”
- “As a caregiver, listening to, and participating in the simulations has taught me a new skill and has proven to be most helpful while practicing at home”
- “stressful but beneficial”
- (stressful) “At first until I got used to them”
- “was emotional”

Emotional challenges and barriers to changes part of all discussions

Loss of the prior relationship

Coping with the 2 realities of the relationship

Loss of oneself

Shame, guilt, ambivalence

Sadness, loneliness; unresolvable grief

Time pressures

Entrapment

“My life as a neutered object”; “decisions are life and death”; “thinking for 2 all the time”

Members reflections on Lessons Learned

- Ask their feeling- understand
- acknowledge his her perspective
- Accept that he/she is not who he/she was and cannot do what they did before
- Use statements and avoid asking questions
- Listen to his/her side, respect and validate his/her capability
- Pause before speaking or acting.
- Try to be patient
- Pick your battles
- logic often impossible
- Learn to ask for help, it's OK to ask for help.
- Accept more help - you can't do anything on your own.
- It's OK and necessary to take care of yourself.
- Acknowledge your own feelings of anger, denial, grief
- "I am not so alone"
- Education about the disease – changes in cognition and physical health
- "Wires do not connect anymore".
- Comprehension is impaired.
- Execute capacity power of attorney as needed.
- Involving family - grandchildren can be valuable allies
- "more on our shoulders"
- Do with him/her not to him/her, when possible.
- Relate to heart not to head
- Learn about resources available
- Anticipate the future.

Groups1-4 (N=13) dropout 1	Agree (%)	neutral	Disagree
improved skills coping/prob-solv	100		
improved ability to manage emotions	100		
more confident dealing with caregiving challenges	84	16	
more depressed and anxious after		7.7	92.3
Adequate professional support	92.3		7.7
Focus on emotions in caregiving helpful	92.3	7.7	
Simulations useful	84.6	7.7	7.7
Simulations stressful	23	23	54
Practicing helpful	92.3	7.7	
Simulations accurate to home situation	76%		
Program Helpful	100		
Overall satisfied	92.7	7.7	
Disappointed	0	7.7	92.3
Addressed needs	100%		

Some Key Outcomes

- Almost all said the groups were both important and effective- **skills training changed their behaviour and attitudes** and feelings about care recipient
- Many **specific problems** were solved – **driving; alcohol**
- **Practicing and repetition** were among the most helpful interventions
- **Heterogeneous** groups are acceptable (we are experimenting with specific adult children groups)
- **Professional support** highly valued as was **camaraderie** of the group
- **Maintenance**- 1 hour group/month- very well attended

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Progress

- Clinical groups
 - Inquiries- **151** (flow increasing)
 - Enrolments – **69** (plus care recipients)
 - Adult children groups begun; considering grandchildren's group
 - 10 week Groups MSH site: **9** (complete or in process); **5** recruited waiting to start; **3 concurrent** groups (starting in end of Jan.)
 - Wellness/Yee Hong Site – **Chinese Group 1** (Jan 24 11)
 - Maintenance groups- **7** ongoing monthly
- **Individual and family** therapy/support/education
- **Training seminars** for Professionals developed
- **Manual** written; e-learning in development
- All materials **translated** into Chinese
- **Pre-post measures** – formal analysis to begin after first 50 CGs
- **Demo video** completed
- External **collaborators**

Contact Information

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