

# Caregiver Stress: Supporting Caregivers in Primary Care

**Summary:** Caregiver stress is an important issue in Canada. It is estimated that 28% of Canadians are acting as caregivers. Caregiver burden can lead to poor physical, mental, social and financial health. Family physicians are in an ideal position to screen, recognize and help these individuals. General screening of wellbeing or use of a specific tool should be done empirically to known caregivers. Poor coping mechanism is highly associated with poor stress outcomes. Due to this, family physician must strive to support the caregiver in every stage of the care receiver's illness. Education, early access to supports and resources as well as working towards improving coping skills and behaviour management can help in improving mental wellbeing of caregivers.

## Case

- Mr. Lalonde is an 80 year old man you have been following in your practice
- Due to his decline in function, you recently gave a diagnosis of Alzheimer's Dementia.
- He lives with wife Martha (also your patient), who accompanies him to all his recent visits.
- They have been married for 60 years. Both have been patients of your practice for approximately 15 years.
- Since Mr. Lalonde can no longer take care of his IADLs, Martha has been responsible for all of the driving, cooking, cleaning and finances.
- He is brought by his wife on this visit because of her concerns that he has been agitated and anxious recently.
- You note that Martha looks quite tired. For the first time since you have known her you noticed that she is not wearing any make-up. She continues to ask you what she can do to help and what will happen to her husband.

## Epidemiology

- 28% of Canadians reported providing care in the past 12 months (Statistics Canada, 2012)
- Of these 28%; 89% reporting giving care over 1 year and 55% expressed feeling worried or anxious. (Statistics Canada, 2012)
- Main causes for the need of caregiving were:
  - Aging (12.2% of all causes)
  - Cancer (2.2% of all causes) (Statistics Canada, 2012)
- Spouses give on average ~ 14h of care; 10% give over 30 hrs/week (Statistics Canada, 2012)
- Of those giving over 20 hrs/week, a larger number report experience feeling anxious and worried (Statistics Canada, 2012)
- 20% of those caring for a spouse and 7% of those caring for their parents would like more financial help and were less likely to have received financial help (Statistics Canada 2015)
- Bimodal distribution (adult children and spouses) (Bruce 2005)

## Risk Factors

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- Gender: Being female (Kaye 2003)
- Poor coping and adaptability abilities (Seeher 2014, Mitrani 2005), avoidant coping behaviours (Taylor 2015)
- More impairment/difficult for caregiver to do their own ADLS and iADLS
- Increased behavioural symptoms (mainly aggressivity and agitation) of care receiver (Takai 2011, Ornstein 2013, Chiu 2012, Borson 2014); negative reactions to these symptoms (Seeher 2014)
- More hours of caregiving (Dahlrup 2015)
- May be caring for more than one family member (Kaye 2003)
- Self rated disability (Seeher 2014)

## Impact of Caregiver Stress

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- Decrease overall physical health, increase in MSK and tension complaints (Dahlrup 2015, Statistics Canada 2015, Chiu 2012)
- Decrease overall mental health, increase in depression, stress and anxiety (Dahlrup 2015, Takai 2011, Chiu 2012, Bruce 2005)
- Isolation and decrease social network
- Decreased quality of life (von Kanel 2012; Etters; Seeher 2014, Takai 2011)
- Decreased sleep quality (von Kanel 2012, Chiu 2012, Taylor 2015)
- Increase in pro-inflammatory cytokines (von Kanel, 2012)
- May increase difficulty in doing health care tasks (Giovanetti 2011)
- Increase burnout
- Earlier placement into residence or nursing home
- Decrease use/self referral to services in community (Kaye 2003)

## Screening for Caregiver Stress

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### Informal screening

- Screening can be informal in screening for risk factors and symptoms of stress, anxiety or depression.
- Take advantage of screening caregivers when you know that your patient care for someone or when seeing the person with dementia accompanied by their caregiver.
- The caregiver may not identify as such as they feel they are acting as family members (Ulstein 2006, Kaye 2003)

### Validated screening tools.

Alternatively, consider using validated screening tools such as:

1) The Zarit Burden Interview which has been validated the screening tool that has been most studied. It has been validated in various languages and across different ethnicities.

Zarit Burden Interview (recommended):

[http://dementiapathways.ie/\\_filecache/edd/c3c/89-zarit\\_burden\\_interview.pdf](http://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf)

2) Other validated screening tools have been validated include the Relative Stress Scale (Ulstein 2007), Dementia Services Mini-Screen (Borson 2014) and Caregiver Risk Screen (Huyck 2007) but are not available through the public domain.

Questions available through articles from references below.

Caregiver Self-Assessment Questionnaire (self administered, good online self-test):

<http://www.healthinaging.org/resources/resource:caregiver-self-assessment/>

3) Screening tools that are anxiety and depression specific

## Management and Support for Caregiver Stress

The I-SEE-U Framework from Mount Sinai's is an excellent way to think about management of Caregiver stress in primary care:

I)nclude	Include means to include the caregiver as part of the care plan but also to include the caregiver as a partner of the care team. Dementia is often characterized by lack of insight into one's condition and so it is the caregiver who becomes our partner in care and the one that carries out most treatment recommendations and interventions. Including the caregiver is not only crucial for a successful management of dementia but also contributes to the caregiver feeling heard, respected and valued.
S)creen	Screen stands for screening and identifying caregiver stress and burnout. In order to identify caregiver stress it is important to be aware of the different factors that may contribute to caregiver stress versus ones that may augment resilience. Through using formal and informal methods to actively assess and screen caregiver stress we can make the caregiver feel visible and supported and avoid crisis.
E)ducate	Educate is about empowering the caregiver to learn and know more about dementia to enable him/her to better understand the nature of the person with dementia's behaviour and to learn and develop skills to respond more effectively.
E)xtra help	Extra help stands for support such as: emotional, educational , financial and respite services to relief the caregiver from his/her caregiving duties to take time to care for themselves. It is also just as important to remember that as clinicians/health providers we as well are caregivers and it is important to take care of ourselves.
U)nderstand	Understand stands for understanding the caregiving experience. Part of this understanding is recognizing the complexity of being both a caregiver and a husband/wife/daughter/son and the challenges it brings with it. Understanding is also about how we translate this realization into effective and supportive communication with caregivers.

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## Interventions

### Physical and Mental Help

- Listen and give them control as to what they need from the system.
- Maintain good relationship and open conversation
- Reserve time/appointment to discuss specific health problem and issues of the caregiver and not only of the patient with the diagnosis of dementia
- Treat physical and mental illness appropriately
- Emphasize importance of maintaining their own health, healthy eating habits, physical activity and taking breaks from caregiving (Ulstein 2007)
- Educate about expected prognosis, expected changes in behaviour and course of disease (Kaye 2003)
- Focus on coping strategies, mindfulness (Whitebird 2012)
- Encourage to contact local community resource center or services as most have caregiver support programs
- Training programs through local resource centers (Bond 2016), dementia societies or online
  - Dementia society
  - Online coping skills training: <http://elevator-carers-coping-skills.com/>

- [WHO online 72h access course: https://www.isupportfordementia.org/en/dementia-and-caregiving](https://www.isupportfordementia.org/en/dementia-and-caregiving)
- Online resources
  - Alzheimer Disease International  
<https://icaniwill.alz.co.uk/icaniwill/library/family-carers-and-friends.html>
- Refer to counselling when appropriate. CBT (Rodriguez-Sanchez 2012) and psychosocial intervention has been shown to improved caregiver strain by improving coping skills and expectations (Huyck, 2007, Peacock 2003, Ulstein 2007).
  - Encourage continuation of social activities as much as possible, or take advantage of social programs aimed at caregivers and their family member.
- Encourage use of support network and continued contact with family and friends.

### Social Help

- Encourage caregivers to contact their local Dementia Society. It is never too early to encourage use of support. By adding supports early on in the disease, the person with dementia may have an easier acceptance of these services later in disease progression (Ornstein 2013). Supports include social events, information sessions, and support groups for caregivers.
- Encourage use of respite care services and validate need to have breaks from caregiving role.
  - Respite care services available as day program, overnight respite, and individuals that come in the individual's home.
  - Fee paying or publicly funded through the Local Health Integration Network (LHIN)
- Encourage to use available home services and home care.
  - Fee paying or publicly funded through the LHIN
  - Meals, Driving, Cleaning, Grocery services.
  - PSW care or nursing care
  - Resources per region: <http://www.thehealthline.ca/>
- Encourage advance care planning and power of attorney. <http://www.makingmywishesknown.ca/get-started/>
- Should the caregiver no longer be able to take care of their loved one, help with transition to residence or nursing home if necessary.
- Remember that caregiver stress/burden does not end once their loved one is institutionalized. They may continue to care for them and experience difficulties and stress despite no longer being the main provider of care for basic needs.

### Financial Help

- Disability Tax Credit. Remind caregivers of Disability Tax Credit from the government of Canada. Caregivers may claim unused portion
- Medical expenses credit. Patient with dementia may also qualify for medical expenses credit which can cover some in house services
- If caregiver is working, encourage to enquire about paid leave for caregiving as well as access to their Employee Assistance Program.
- If the person living with dementia's health acutely changes or become critically ill or injured, the caregiver may apply for the Family Caregiver Benefit for Adults
  - Up to 15 weeks
  - Should the person living with dementia's overall state declines and the life expectancy is less than 6 months
  - Up to 26 weeks

- Family Caregiver and Compassionate Care benefits can be combined sequentially

## Resources anywhere in Canada

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- The Alzheimer's Society has chapters in all provinces  
[www.alzheimer.ca](http://www.alzheimer.ca)

## Resources in Ontario, Canada

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First Link (<http://dementiahelp.ca/>)

- [Brochure](#)

Referral Forms

- Toronto:  
<https://alzheimerontario.wufoo.eu/forms/first-link-online-referral-form/>
- Brant, Haldimand Norfolk, Hamilton Hadland  
<https://www.alzhn.ca/our-services/first-link-referral-form/>
- Dufferin County  
<http://www.alzheimer.ca/sites/default/files/files/chapters-on/dufferincounty/pdf%20files/first-link-referral-form.pdf>
- Durham <http://www.centraleasthealthline.ca/pdfs/First%20Link%20Referral%20Form%20PDF.pdf>
- London and Middlesex  
[http://www.southwesthealthline.ca/pdfs/ASLM\\_First\\_Link\\_Referral\\_Form\\_2017.pdf](http://www.southwesthealthline.ca/pdfs/ASLM_First_Link_Referral_Form_2017.pdf)
- Niagara  
<http://www.alzheimer.ca/en/niagara/We-can-help/Get-connected/First-Link>
- Muskoka  
<http://www.alzheimer.ca/sites/default/files/files/chapters-on/muskoka/fl%20electronic%20%20referral%20form%20muskoka%202013%201.pdf>
- Renfrew County  
<http://dementiahelp.ca/download/dsorc-pro-referral-form?wpdmdl=2079>
- Thunder Bay  
<http://www.alzheimer.ca/sites/default/files/Files/chapters-on/thunderbay/First%20Link%20-%20Referral%20PAD%20Main%20Sheet%20-%20Revised.pdf>
- Waterloo Wellington  
<http://www.alzheimer.ca/sites/default/files/files/chapters-on/ww/admin/updated%20asww%20referral%20form%20-%20february%202017.pdf>

Resources by Local health integration network (LHIN)

- Resources per region and type targeted at caregivers: <http://www.caregiverexchange.ca>

Ottawa counsellors specializing in Elderly Person Disorders

- <https://www.psychologytoday.com/ca/therapists/elderly-persons-disorders/on/ottawa>

## Handouts

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Useful handouts for caregivers

- [http://www.alzheimer.ca/sites/default/files/files/national/core-lit-brochures/asc\\_first\\_link\\_e.pdf](http://www.alzheimer.ca/sites/default/files/files/national/core-lit-brochures/asc_first_link_e.pdf)
- <http://www.mhfa.com.au/resources/mental-health-first-aid-guidelines>
- <http://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/prc-dementia-resources-for-primary-care/dementia-toolkit-for-primary-care/caregiver-support/how-to-handle-challenging-behaviours-in-people.pdf>

- <http://www.mountsinai.on.ca/care/psych/patient-programs/geriatric-psychiatry/prc-dementia-resources-for-primary-care/dementia-toolkit-for-primary-care/caregiver-support/60-tips-electronic-version-530.pdf>
- <http://dementiahelp.ca/get-information/caregivers-role/>
- [https://www.alz.org/national/documents/brochure\\_caregiverstress.pdf](https://www.alz.org/national/documents/brochure_caregiverstress.pdf)
- [http://dementiaphways.ie/\\_filecache/b1b/689/46-practicalguidefamilycaregivers.pdf](http://dementiaphways.ie/_filecache/b1b/689/46-practicalguidefamilycaregivers.pdf)
- [http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Dementia%20Care%20Basics\\_0.pdf](http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Dementia%20Care%20Basics_0.pdf)
- [http://dementiaphways.ie/\\_filecache/b1b/689/46-practicalguidefamilycaregivers.pdf](http://dementiaphways.ie/_filecache/b1b/689/46-practicalguidefamilycaregivers.pdf)
- [http://dementiaphways.ie/\\_filecache/aa3/2b8/51-life-for-caregivers.pdf](http://dementiaphways.ie/_filecache/aa3/2b8/51-life-for-caregivers.pdf)
- [http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Caregiving%20Checklist\\_0.pdf](http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Caregiving%20Checklist_0.pdf)
- [http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Help%20for%20Caregivers\\_0.pdf](http://giic.rgps.on.ca/sites/default/files/Patient%20Handout%20-%20Help%20for%20Caregivers_0.pdf)

## Resources for Primary Care

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- American association of family physicians  
<https://www.aafp.org/afp/2000/1215/p2613.html>
- BC Doctors: Organizing your practice to support Family Caregivers:  
[https://www.doctorsofbc.ca/sites/default/files/family\\_caregiver\\_resource\\_guide\\_for\\_physicians\\_-\\_toolkit.pdf](https://www.doctorsofbc.ca/sites/default/files/family_caregiver_resource_guide_for_physicians_-_toolkit.pdf)  
<http://giic.rgps.on.ca/sites/default/files/1%20Caregiver%20Support%20-%20Knowledge%20and%20Practice%20Tips.pdf>

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## About this Document

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