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Dementia Assessments in Primary Care:

How to obtain and utilize family and caregiver perspectives

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Enhancing Life

Learning Objectives

At the end of the session, participants will be able to:

1. Discuss how family/caregiver perspectives can impact dementia diagnoses and management
2. List ways that family/caregiver perspectives can be efficiently obtained in primary care practice

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Identifying Functional Impairment

1. **For a diagnosis of dementia , we need corroborated information on functional impairment due to cognitive decline**

Activities of Daily Living

INSTRUMENTAL ADL's

- Manage medications
- Handle money, bills, shop
- Use telephone
- Prepare food

BASIC ADL's

- Bathe/shower
- Walk
- Toilet
- Transfer (bed/chair)
- Feed self

Functional Activities Questionnaire

In the past 4 weeks, did the patient have any difficulty or need help with:	Not applicable	Normal	Has difficulty, but does by self	Requires assistance	Dependent
1. Writing checks, paying bills, or keeping financial records	N/A	0	1	2	3
2. Assembling tax records, business affairs, or papers	N/A	0	1	2	3
3. Shopping alone for clothes, household necessities, or groceries	N/A	0	1	2	3
4. Playing a game of skill or working on a hobby	N/A	0	1	2	3
5. Heating water, making a cup of coffee, or turning off the stove	N/A	0	1	2	3
6. Preparing a balanced meal	N/A	0	1	2	3
7. Keeping track of current events	N/A	0	1	2	3
8. Paying attention to, understanding or discussing a TV program, book or magazine	N/A	0	1	2	3
9. Remembering appointments, family occasions, holidays, or medications	N/A	0	1	2	3
10. Traveling out of the neighborhood, driving, or arranging to take busses	N/A	0	1	2	3

Adapted from: Pfeffer RI, Kurosaki TT, Harrah CH, et al. Measurement of functional activities of older adults in the community. J. Gerontol 1982;37:323-9.

Identifying Functional Impairment

1. Pharmacist can review medication adherence
2. Money management tasks
   - **Counting**: *Provide patient with a bag of real money (variety of bills and coins): "I want you to count this bag of money and tell me the total amount of money you have."*
   - **Naming:** *"Can you tell me what this coin is called?" (done with loonies, toonies, quarters, dimes, nickels)*
   - **Making a purchase**: *"You go to a store and in your purse/wallet you have a $5 bill and a $20 bill as well as 2 loonies and 4 quarters. Your purchase comes to $6.25. What will you use to pay for this purchase?" (If the answer is $20, cue "is there another way you could pay with mor exact change?")*
   - **Writing a cheque:** *Provide a bill and copy of a cheque. "Let's pretend you received this bill in the mail and you need to write a cheque to pay for the bill. Can you fill in this cheque? Date it using today's date."*

Identifying Depression in Dementia

- Depression affects 20% of persons with dementia

Prince M, et al. Alzheimer's Disease International 2009

- Late life depression is a risk factor for dementia
  - Depression is associated with approximately two-fold increase in risk of developing dementia

Cherbuin N, et al. BMJ Open 2015
Wilson RS, et al. J Neurol Neurosurg Psychiatry 2004
Saczynski JS, et al. Neurology 2010
Dotson VM, et al. Neurology 2010
Ownby RL, et al. Arch Gen Psychiatry 2006

2. Need corroborated information when screening for depression in dementia

Identifying Depression in Dementia

Geriatric Depression Scale (GDS)

Each answer indicated by an asterisk (*) counts as 1 point.

1.	Are you basically satisfied with your life?	Yes	**No** *
2.	Do you often get bored?	**Yes** *	No
3.	Do you often feel helpless?	**Yes** *	No
4.	Do you prefer to stay home rather than going out and doing things?	**Yes** *	No
5.	Do you feel pretty worthless the way you are now?	**Yes** *	No

A GDS-5 score of 2 or more indicates possible depression.

GDS-5 Score _____

- "Use of GDS is limited to cognitively intact or mildly impaired elderly patients"

Sharp LK, et al. Am Fam Physician 2002

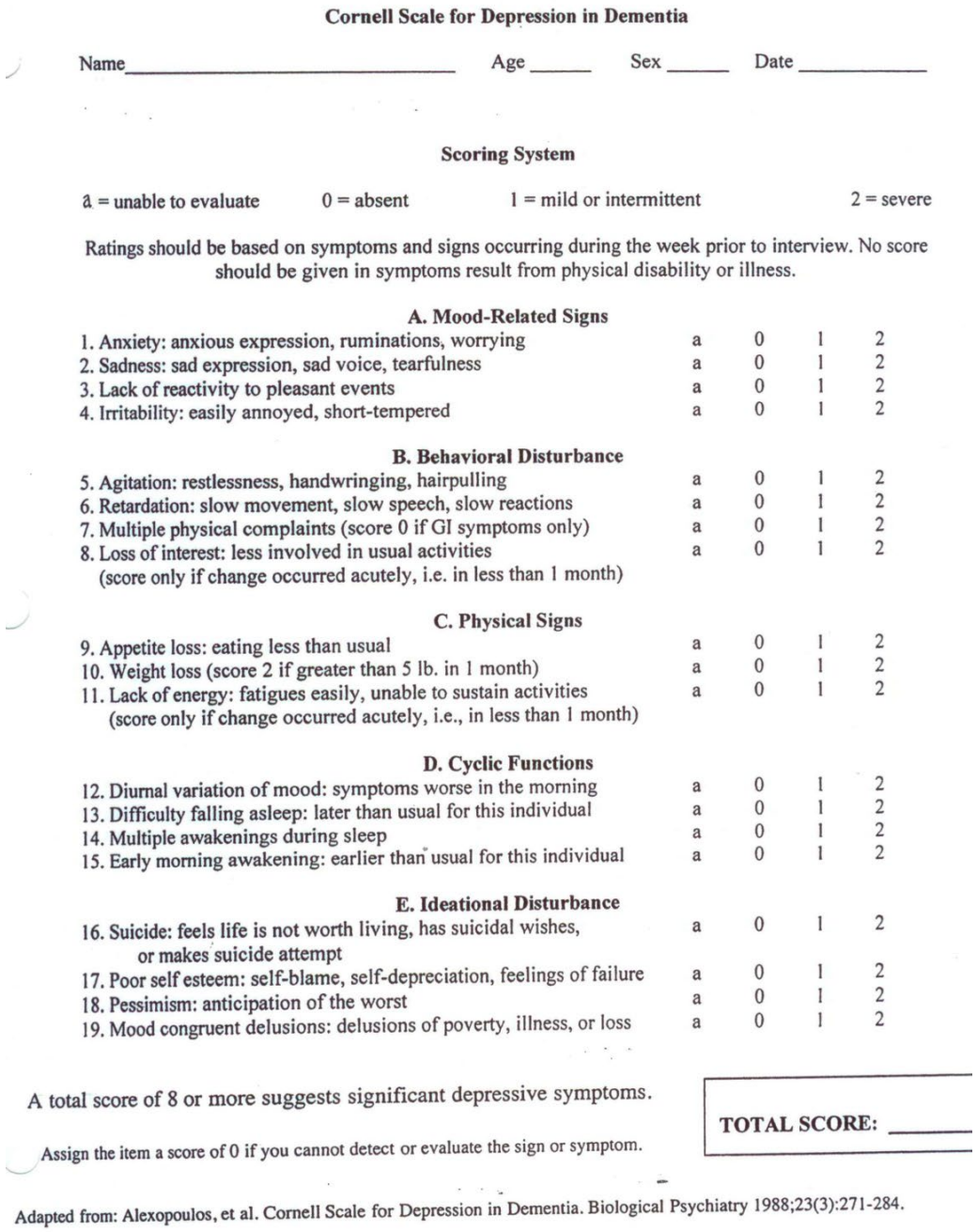
- In 47 patients with dementia with mean MMSE scores 17-21, sensitivity for detecting depression was 0.72 for GDS and 0.97 for CSDD

Korner A, et al. Nordic J Psychiatry 2006

Cornell Scale for Depression in Dementia (CSDD)

- Takes 20 minutes, administered to patient and caregiver separately
- Score of 8 or more is suggestive of depression
- Validated in both cognitively-intact and cognitively-impaired persons

Korner A, et al. 2006



Cornell Scale for Depression in Dementia

Name_____ Age _____ Sex _____ Date _____

Scoring System

a = unable to evaluate 0 = absent 1 = mild or intermittent 2 = severe

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given in symptoms result from physical disability or illness.

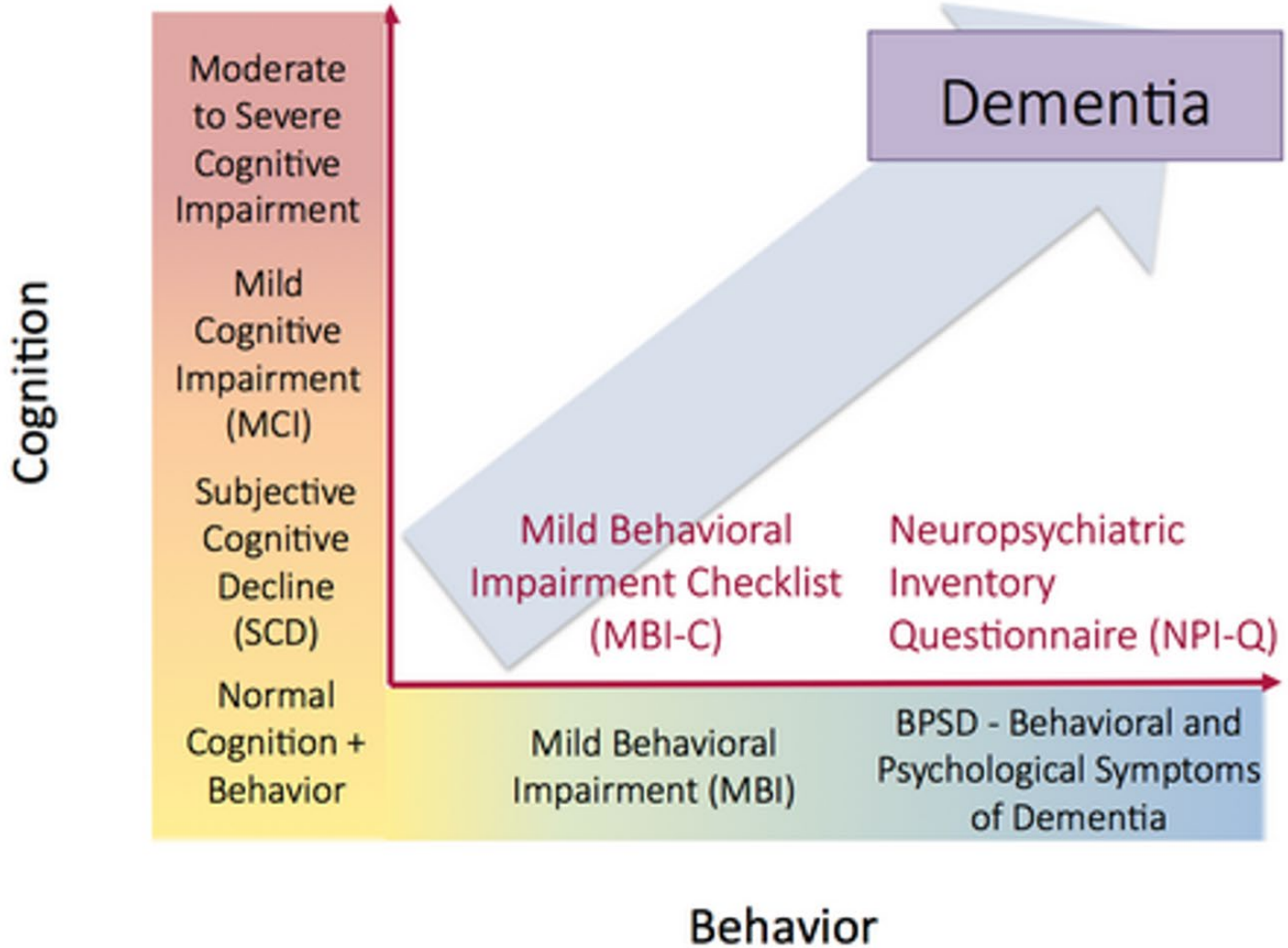
A. Mood-Related Signs				
1. Anxiety: anxious expression, ruminations, worrying	a	0	1	2
2. Sadness: sad expression, sad voice, tearfulness	a	0	1	2
3. Lack of reactivity to pleasant events	a	0	1	2
4. Irritability: easily annoyed, short-tempered	a	0	1	2
B. Behavioral Disturbance				
5. Agitation: restlessness, handwringing, hairpulling	a	0	1	2
6. Retardation: slow movement, slow speech, slow reactions	a	0	1	2
7. Multiple physical complaints (score 0 if GI symptoms only)	a	0	1	2
8. Loss of interest: less involved in usual activities (score only if change occurred acutely, i.e. in less than 1 month)	a	0	1	2
C. Physical Signs				
9. Appetite loss: eating less than usual	a	0	1	2
10. Weight loss (score 2 if greater than 5 lb. in 1 month)	a	0	1	2
11. Lack of energy: fatigues easily, unable to sustain activities (score only if change occurred acutely, i.e., in less than 1 month)	a	0	1	2
D. Cyclic Functions				
12. Diurnal variation of mood: symptoms worse in the morning	a	0	1	2
13. Difficulty falling asleep: later than usual for this individual	a	0	1	2
14. Multiple awakenings during sleep	a	0	1	2
15. Early morning awakening: earlier than usual for this individual	a	0	1	2
E. Ideational Disturbance				
16. Suicide: feels life is not worth living, has suicidal wishes, or makes suicide attempt	a	0	1	2
17. Poor self esteem: self-blame, self-depreciation, feelings of failure	a	0	1	2
18. Pessimism: anticipation of the worst	a	0	1	2
19. Mood congruent delusions: delusions of poverty, illness, or loss	a	0	1	2

A total score of 8 or more suggests significant depressive symptoms.

Assign the item a score of 0 if you cannot detect or evaluate the sign or symptom.

TOTAL SCORE: _____

Adapted from: Alexopoulos, et al. Cornell Scale for Depression in Dementia. Biological Psychiatry 1988;23(3):271-284.



Courtesy of Zahinoor Ismail, MD, FRCPC

MBI-C

- 34 items, 5 domains, completed by family informant
- Intended for case detection in community-dwelling, functionally independent older adults
- Not yet validated for clinical diagnoses

Ismail Z, et al. J Alzheimers Dis 2017

Mild Behavioral Impairment (MBI) Criteria

ISTAART-AA MBI criteria [11]

1) Changes in behavior or personality observed by patient, informant, or clinician, starting later in life (age ≥50 years) and persisting at least intermittently for ≥6 months. These represent a clear change from the person's usual behavior or personality as evidenced by at least one of the followings:
   a) decreased motivation
   b) affective dysregulation
   c) impulse dyscontrol
   d) social inappropriateness
   e) abnormal thought and perception;
2) Behaviors are of sufficient severity to produce at least minimal impairment in at least one of the following areas:
   a) Interpersonal relationships
   b) Other aspects of social functioning
   c) Ability to perform in the workplace.
   The patient should generally maintain his/her independence of function in daily life, with minimal aids or assistance.
3) Although comorbid conditions may be present, the behavioral or personality changes are not attributable to another current psychiatric disorder, traumatic or general medical causes, or the physiological effects of a substance or medication
4) The patient does not meet criteria for a dementia syndrome. (e.g., Alzheimer's disease, frontotemporal dementia, dementia with Lewy bodies, vascular dementia, other dementia). MCI can be concurrently diagnosed with MBI.

MBI, mild behavioral impairment; MCI, mild cognitive impairment.

Mild Behavioral Impairment Checklist (MBI-C)

Date: _____

Rated by: ☐ Clinician ☐ Informant ☐ Subject

Location: ☐ Clinic ☐ Research

Label

Circle "Yes" **only** if the behavior has been present for at least **6 months** (continuously, or on and off) and is a **change** from her/his longstanding pattern of behavior. Otherwise, circle "No".

Please rate severity: **1 = Mild** (noticeable, but not a significant change); **2 = Moderate** (significant, but not a dramatic change); **3 = Severe** (very marked or prominent, a dramatic change). If more than 1 item in a question, rate the most severe.

	YES	NO	SEVERITY
This domain describes interest, motivation, and drive			
Has the person lost interest in friends, family, or home activities?	Yes	No	1 2 3
Does the person lack curiosity in topics that would usually have attracted her/his interest?	Yes	No	1 2 3
Has the person become less spontaneous and active – for example, is she/he less likely to initiate or maintain conversation?	Yes	No	1 2 3
Has the person lost motivation to act on her/his obligations or interests?	Yes	No	1 2 3
Is the person less affectionate and/or lacking in emotions when compared to her/his usual self?	Yes	No	1 2 3
Does she/he no longer care about anything?	Yes	No	1 2 3
This domain describes mood or anxiety symptoms			
Has the person developed sadness or appear to be in low spirits? Does she/she have episodes of tearfulness?	Yes	No	1 2 3
Has the person become less able to experience pleasure?	Yes	No	1 2 3
Has the person become discouraged about their future or feel that she/he is a failure?	Yes	No	1 2 3
Does the person view herself/himself as a burden to family?	Yes	No	1 2 3
Has the person become more anxious or worried about things that are routine (e.g. events, visits, etc.)?	Yes	No	1 2 3
Does the person feel very tense, having developed an inability to relax, or shakiness, or symptoms of panic?	Yes	No	1 2 3
This domain describes the ability to delay gratification and control behavior, impulses, oral intake and/or changes in reward			
Has the person become agitated, aggressive, irritable, or temperamental?	Yes	No	1 2 3
Has she/he become unreasonably or uncharacteristically argumentative?	Yes	No	1 2 3
Has the person become more impulsive, seeming to act without considering things?	Yes	No	1 2 3
Does the person display sexually disinhibited or intrusive behaviour, such as touching (themselves/others), hugging, groping, etc., in a manner that is out of character or may cause offence?	Yes	No	1 2 3

Has the person become more easily frustrated or impatient? Does she/he have troubles coping with delays, or waiting for events or for their turn?	Yes	No	1 2 3
Does the person display a new recklessness or lack of judgement when driving (e.g. speeding, erratic swerving, abrupt lane changes, etc.)?	Yes	No	1 2 3
Has the person become more stubborn or rigid, i.e., uncharacteristically insistent on having their way, or unwilling/unable to see/hear other views?	Yes	No	1 2 3
Is there a change in eating behaviors (e.g., overeating, cramming the mouth, insistent on eating only specific foods, or eating the food in exactly the same order)?	Yes	No	1 2 3
Does the person no longer find food tasteful or enjoyable? Are they eating less?	Yes	No	1 2 3
Does the person hoard objects when she/he did not do so before?	Yes	No	1 2 3
Has the person developed simple repetitive behaviors or compulsions?	Yes	No	1 2 3
Has the person recently developed trouble regulating smoking, alcohol, drug intake or gambling, or started shoplifting?	Yes	No	1 2 3
This domain describes following societal norms and having social graces, tact, and empathy			
Has the person become less concerned about how her/his words or actions affect others? Has she/he become insensitive to others' feelings?	Yes	No	1 2 3
Has the person started talking openly about very personal or private matters not usually discussed in public?	Yes	No	1 2 3
Does the person say rude or crude things or make lewd sexual remarks that she/he would not have said before?	Yes	No	1 2 3
Does the person seem to lack the social judgement she/he previously had about what to say or how to behave in public or private?	Yes	No	1 2 3
Does the person now talk to strangers as if familiar, or intrude on their activities?	Yes	No	1 2 3
This domain describes strongly held beliefs and sensory experiences			
Has the person developed beliefs that they are in danger, or that others are planning to harm them or steal their belongings?	Yes	No	1 2 3
Has the person developed suspiciousness about the intentions or motives of other people?	Yes	No	1 2 3
Does she/he have unrealistic beliefs about her/his power, wealth or skills?	Yes	No	1 2 3
Does the person describe hearing voices or does she/he talk to imaginary people or "spirits"?	Yes	No	1 2 3
Does the person report or complain about, or act as if seeing things (e.g. people, animals or insects) that are not there, i.e., that are imaginary to others?	Yes	No	1 2 3

Mild Behavioral Impairment Checklist (MBI-C)

Cut off score for MBI (rated by informant)

- with Normal Cognitive testing: >8
- With MCI: >6

- Administer regularly, e.g. annually

- Even a modest score on the MBI-C is associated with incident cognitive decline and dementia, especially when those scores are sustained over a period of time

Source: Zahinoor Ismail

Caregiver Stress

- 70-81% of persons with dementia live in the community and for approximately 75% of these persons, care is provided by family and friends.

Brodaty H, et al. Dialogues Clin Neurosci 2009

- Caregiver stress is a significant predictor of early nursing home placement

Fisher L, et al.Gerontologist 1999

World Alzheimer Report 2022

54% of carers felt stress often or all of the time while tryiing to cope with their caring responsibilities

Impact of Caregiving

- 48% incidence of depressive disorders in caregivers of persons with dementia

Culjpers P. Aging Ment Health 2005

- Over 6 months, 24% of dementia caregivers have at least one ED visit or hospitalization

Schubert CC et al. J Gen Int Med 2008

- "Being a caregiver who is experience mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers"
  - After 4 years of follow-up, mortality risks were 63% higher than in non-caregiving controls

Schulz R et al. J Am Med Assoc 1999

3. **Screen for caregiver stress!**

Zarit Screen Measure of Caregiver Burden

To be completed by caregiver.
Indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

1. Do you feel that because of your relative that you don't have enough time for yourself?

"Never	"Rarely	"Sometimes	"Quite Frequently	"Nearly Always
0	1	2	3	4

2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?

"Never	"Rarely	"Sometimes	"Quite Frequently	"Nearly Always
0	1	2	3	4

3. Do you feel strained when you are around your relative?

"Never	"Rarely	"Sometimes	"Quite Frequently	"Nearly Always
0	1	2	3	4

4. Do you feel uncertain about what to do about your relative?

"Never	"Rarely	"Sometimes	"Quite Frequently	"Nearly Always
0	1	2	3	4

TOTAL SCORE_____

A score of 8 indicates high burden, and assistance may be indicated.

Bedard M, et al. Gerontologist 2001

Ambiguous Loss and Grief

- Ambiguous loss is a type of loss associated with the person with dementia being physically present but at times, psychologically absent

- Ambiguous loss can complicate grief

- Family caregivers grieve multiple, often progressive losses:
  - Loss of plans for the future
  - Loss of shared roles and responsibilities
  - Loss of a life partner

Key Events May Provoke Feelings of Loss and Grief

- Diagnosis of dementia
- Recognition of increasing loss of cognitive functioning
- Loss of ability to drive
- Person with dementia no longer able to go out alone
- Person with dementia no longer can be left alone
- Change in social circle, loss of friendships
- Need for external help in the home, assistance with personal care
- Need for respite
- Incontinence
- Aggressive or embarrassing behaviours
- Caregiver no longer recognized by the person with dementia
- Move to a care home
- Declining health, dying process and death
- Adjustment to loss of the caregiving role

Source: M. Martinez, UHN Memory Clinic

Managing Caregiver Stress

- Acknowledge and support feelings of ambiguous loss and grief
- Assess caregiver's level of stress, and monitor for depression and anxiety
- Refer to your local Alzheimer Society
- Establish a practical caregiver plan, eg. attendance at day programs, in-home support, respite care, future planning

Summary

1. Obtain corroborated information on functional impairment due to cognitive decline for a diagnosis of dementia
2. Obtain corroborated information when screening for depression in dementia
3. Ask about behaviours
4. Screen for caregiver stress!

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