

CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn

Bridging the Knowledge Gap in
Home and Primary Health Care



Assessing and Addressing Caregiver Needs in Complex Care

Presenter:

Dr. Allison Williams PhD FCAHS, FRSC, Canada Research Chair in the Care Economy, Aging and Policy (Tier 1)
Professor of Geography, McMaster University

Panelists:

Claire Webster, PAC, CPCA, Founder and Ambassador, McGill Dementia Education Program
Founder and President, Caregiver Crosswalk Inc.

Anna Malfara, Regional Director York Region, Spectrum Health Care, Certified Gerontological Nurse, CNA

Host: Jennifer Campagnolo, CHCA
April 1, 2026

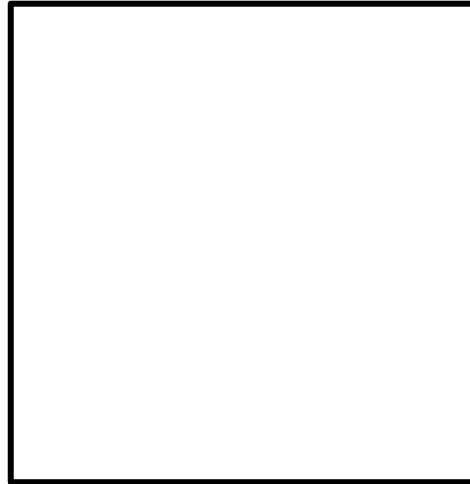
Land Acknowledgement



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Introductions



Dr. Allison Williams PhD FCAHS, FRSC
Canada Research Chair in the Care Economy,
Aging and Policy (Tier 1)
Professor of Geography,
McMaster University



Claire Webster, PAC, CPCA
Founder and Ambassador,
McGill Dementia Education Program
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Caregiver Crosswalk Inc.



Anna Malfara
Regional Director York Region,
Spectrum Health Care,
Certified Gerontological Nurse, CNA



Assessing & Addressing Caregiver Needs in Complex Care: Zarit Burden Interview (ZBI)

*Project ECHO Home and Community Care
Canadian Home Care Association*

Presenter: Dr. Allison Williams, Professor & Canadian Research Chair
(Tier 1) in the Care Economy, Aging & Policy

Subject Matter Expert (SME)
Date: April 1, 2026



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Land Acknowledgement

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Carer-employees (CEs)

- 1 in 4 Canadians

- 1/3 of Canada's workforce

- CEs aged 40-

- Are balancing paid employment with unpaid care
- Over 5.2 million Canadians

- Are CEs – those balancing paid employment with unpaid care

- Make up most CEs in the workforce (53%)

- Most experienced & often best trained employee pool

What can happen if you don't support carer-employees?

Example of potential negative impacts





Employees are feeling the strain

46%

experience presenteeism (being at work but distracted or struggling due to caregiving)



40%

report fair or poor mental health



33%

report fair or poor physical health



51%

missed part or full days of work due to caregiving responsibilities



1 in 7

reduce their paid work hours



80%

feel tired



79%

feel anxious



73%

feel overwhelmed



6%

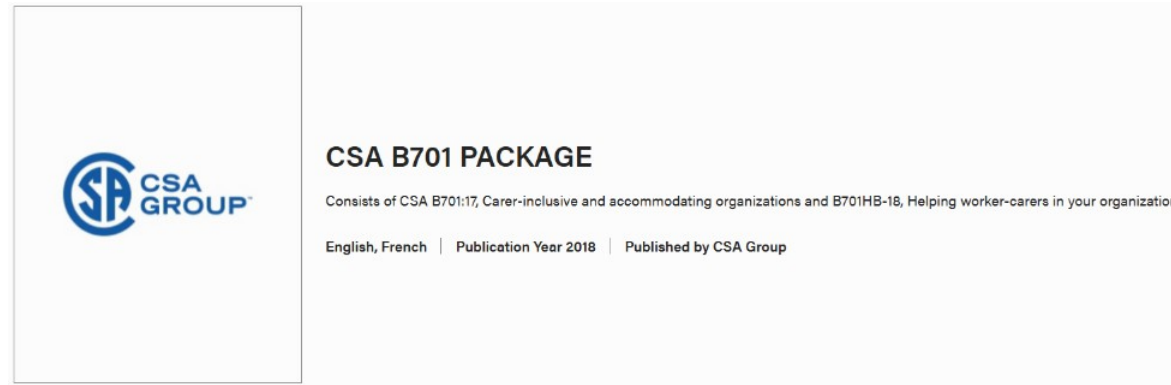
(approx. 214,000 Canadians) left or intended to leave the workforce due to caregiving



Source(s): https://rapp.ualberta.ca/wp-content/uploads/sites/49/2023/05/Employed-Caregivers-in-Canada-Infographic-Series-Compilation_2023-05-15.pdf
https://canadiancaregiving.org/wp-content/uploads/2024/06/CCCE_Caring-in-Canada.pdf

Developing Supportive Policies for Carers in SMEs

CSA B701:17 (R2021) Carer-inclusive and accommodating organizations standard



CSA B701 PACKAGE

Consists of CSA B701:17, Carer-inclusive and accommodating organizations and B701HB-18, Helping worker-carers in your organization

English, French | Publication Year 2018 | Published by CSA Group



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Developing Supportive Policies for Carers in SMEs







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 How to Implement the Carer Standard? — Access Here >	 Media: What's New? — Learn More >



Recognizing Burnout

What is Burnout?

Burnout is defined as a pervasive state of mental, physical and emotional exhaustion. Burnout is multidimensional, often due to several conflicting roles, events and responsibilities in your life. It can result in a number of adverse effects, such as anxiety, depression, feeling overwhelmed and isolated, and an inability to meet demands. Common stressors include a combination of: job demands, school demands, carer fatigue, and interpersonal conflict. One's experience with burnout is highly personal and subjective, thereby, signs of burnout may vary.

HOW TO RECOGNIZE BURNOUT IN YOURSELF:

- Lack of energy and motivation, easily fatigued
- Frequent illnesses such as colds, migraines, headaches, muscle pains
- Changes in appetite
- Change in sleep quality and/or quantity
- Chronic feelings of self-doubt
- Irritability
- Cynicism and pessimism
- Feelings of isolation
- Feelings of dread
- Loss of satisfaction from activities that previously were enjoyable
- Putting off things to do
- Disengaging from work, family, or personal responsibilities
- Substance abuse

Burnout is often co-morbid with or precedent to many mental health problems. It is important to recognize these symptoms early to address them at their root or reach out for professional services.

Treatment:

- Seek professional help through workplace referrals or EAP
- Counselling
- Self-care behaviour (i.e. Meditation, exercise, reading)
- Short-term or long-term break (from work or familiar responsibilities)
- Reduce screen time
- Build or call upon your social network
- Seek community support groups or support services



How to Recognize burnout in your employees

It is important as a manager, supervisor or team leader to recognize if one of your employees may need help. While burnout can begin in any facet of an employee's life, it has ripple-like effects that will inevitably carry over to their work life. Look out for the following signs and aim to address these signs with compassionate language:

- Loss of enthusiasm in their work
- Frequently working late
- Unable or difficulty in meeting deadlines
- Disinterested or quiet demeanor
- Seemingly detached from their environment and coworkers
- Interpersonal conflict
- Decline in overall performance

Potential Causes:

- Lack of control
- Lack of accommodations or supports
- Conflicting responsibilities
- Inadequate resources to perform job
- Uncaring/unsupportive workplace culture
- Lack of time
- Lack of rewards
- Financial constraints

Prevention:

- Increase participation in decision making processes. This gives employees greater control in their own choices and ability to contribute to decisions, thereby increasing satisfaction
- Offer flexibility in their work arrangements. Employees will have greater sense of control over their environment that allow them to set routines or schedules most beneficial to them.
- Increased communication. By fostering discussions, employees may feel less isolated and receive greater social supports.
- Increasing feedback about performance using compassionate language. The language that supervisors and coworkers use implicitly convey messages and attitudes. Using supportive language creates a more friendly and compassionate environment.

Tips from Psychotherapy

- Express empathy – requires reflecting, listening and attention to your employee. Matching facial expressions, affect vocal tone, inflection and energy levels are basic ways for supervisors and coworkers to demonstrate empathy and respect towards others in difficult situations.
- Other suggestions include: not interrupting someone's talking, not being judgmental, not dismissing someone's belief, and not talking too much in general.



- Avoid argumentation – argumentation results in individuals not truly hearing each other and often can devolve into power struggles and demotivation. Adjust to employee resistance instead of direct opposition, using roll with resistance techniques
- Roll with resistance – recognize that attacking or confronting someone or an issue head on is often ineffective. In order to elicit change in behavior, employees must feel heard and respected. Common techniques involve making factual or neutral statements (“you are unhappy with your situation”), to help legitimize feelings and move employees out of patterns of argumentation, frustration, and denial.
- Develop discrepancy – focus attention on how employee’s current situation is different from their ideal in order to build a goal. Separate the person from their behaviors to foster constructive discussions on how elicit change.
- Support self-efficacy – employers need to develop sense of self-efficacy in their employees to keep them motivated. This often involves fostering feelings of hope, support but also feasibility in accomplishing and maintaining changes. Unless employees believe what they want/are doing is possible, their behavior will revert to denial.

[Guidelines taken from Jackson, S. E., & Schuler, R. S. \(1983\). Preventing employee burnout. Personnel, 60\(2\), 58-68.](#)

Other Supports

The [CSA B701:17 Carer-inclusive and accommodating organizations Standard and B701HB-18 Helping worker-carers in your organization Handbook](#) are formalized tools to help employers create, implement and maintain carer-friendly workplace practices, irrespective of size or sector. Carer-employees can refer to these tools for strategies of how to approach their employer in determining ways to support and accommodate them.

[Allison M. Williams, PhD, Professor of School of Earth, Environment and Society, McMaster University, Hamilton, Canada](#)

[Principal, CIHR/SSHRC Healthy Productive Work Partnership Grant “Scaling up the Carer-Inclusive Accommodating Organizations Standard” FRN: HWP-146001 \(CIHR\); 890-2016-3018 \(SSHRC\)](#)

RESEARCH

Open Access



Factors influencing changes in health related quality of life of caregivers of persons with multiple chronic conditions

Wendy Duggleby^{1*}, Allison Williams², Sunita Ghosh³, Heather Moquin⁴, Jenny Ploeg⁵, Maureen Markle-Reid⁶ and Shelley Peacock⁷

Abstract

Background: The majority of care for older adults with multiple chronic conditions (MCC) is provided by family (including friends) caregivers. Although caregivers have reported positive benefits to caregiving they also experience decreases in their physical and mental health. As there is a critical need for supportive interventions for this population, it is important to know what influences the health of family caregivers of persons with MCC. This research examined relationships among the changes from baseline to 6 months in health related quality of life (SF12v2) of family caregivers caring for older adults with multiple chronic conditions and the following factors: a) demographic variables, b) gender identity [Bem Sex Role Inventory (BSRI)] c) changes in general self-efficacy [General Self Efficacy Scale (GSES) (baseline to 6 months) and d) changes in caregiver burden [Zarit Burden Inventory (ZBI)] baseline to 6 months. Specific hypothesis were based on a conceptual framework generated from a literature review.

Methods: This is a secondary analysis of a study of 194 family caregivers who were recruited from two Canadian provinces Alberta and Ontario. Data were collected in-person, by telephone, by Skype or by mail at two time periods spaced 6 months apart. The sample size for this secondary analysis was $n = 185$, as 9 participants had dropped out of the study at 6 months. Changes in the scores between the two time periods were calculated for SF12v2 physical component score (PCS) and mental component score (MCS) and the other main variables. Generalized Linear Modeling was then used to determine factors associated with changes in HRQL.

Results: Participants who had significantly positive increases in their MCS (baseline to 6 months) reported lower burden (ZBI, $p < 0.001$), and higher general self-efficacy (GSES, $p < 0.001$) and Masculine BSRI ($p = 0.025$). There were no significant associations among variables and changes in PCS (baseline to 6 months).

Conclusions: Our findings suggest that a masculine gender identity (which incorporates assertive and instrumental approaches to caregiving), and confidence in the ability to deal with difficult situations was positively related to improvement in mental health for caregivers of persons with MCC. Decreases in perceptions of burden in this populations was also associated with improvements in mental health. Further research is needed to explore ways to support caregivers of older persons with multiple chronic conditions living at home.

Keywords: Caregivers, Quality of life, General self efficacy, Gender identity

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article

Gender and sex differences in carers' health, burden and work outcomes: Canadian carers of community-dwelling older people with multiple chronic conditions

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Using two waves of survey data on family carers caring for older adults with multiple chronic conditions in Ontario and Alberta, this article provides a sex and gender analysis of 194 carers' health outcomes. Gender and sex differences were examined on the following health outcomes: general self-efficacy; physical and mental health composite scores; overall quality of life; and the Zarit Burden Inventory – as well as experiences with work interference for carer-employees. Multivariate ordinary least squares linear regressions were used to estimate the effects of sex and gender, controlling for the carer's socio-demographic and geographic characteristics, as well as for the characteristics of the care recipients. Sex and gender were found to have differentiated effects on each health outcome examined, providing evidence for specifically targeting health interventions by sex and gender. First, sex matters, as illustrated by the fact that female carers were found to be experiencing more negative health impacts than male carers (shown in the physical composite score and the quality of life score). This suggests that health-related interventions need to be targeted at female carers. Further, male carers are more likely to experience less carer burden, and more work interference, than female carers. Second, gender matters, as illustrated by the fact that masculine and androgynous genders showed significantly positive associations with general self-efficacy. This suggests that carers with feminine and undifferentiated gender roles experience more challenges with general-self-efficacy and could benefit from training and educational interventions to enhance their confidence in the caring role.

key words Gender • sex • carer burden • work interference

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Williams, A., Wang, L., Duggleby, W., Markle-Reid, M., & Ploeg, J. (2017). Gender and sex differences in carers' health, burden and work outcomes: Canadian carers of community-dwelling older people with multiple chronic conditions. *International Journal of Care and Caring*, 1(3), 331-349.

<https://doi.org/10.1332/239788217X15079062338928>

Burden on Caregivers of Adults with Multiple Chronic Conditions: Intersectionality of Age, Gender, Education level, Employment Status, and Impact on Social Life*†

Sunita Ghosh,¹ Won Yong Choi,² Allison Williams,³ Wendy Duggleby,⁴ Jenny Ploeg,⁵ Maureen Markle-Reid,⁵ and Shelley Peacock⁶

RÉSUMÉ

L'analyse de l'intersectionnalité est l'étude des identités sociales qui se chevauchent ou se recoupent. L'intersection d'identités sociales peut avoir une incidence sur la perception du fardeau assumé chez les aidants naturels prenant soin de personnes âgées atteintes de maladies chroniques multiples (MCM). Le but de l'étude était d'explorer l'interaction des facteurs sociaux sur le fardeau associé aux soins apportés aux personnes âgées atteintes de MCM. Au total, 194 aidants de personnes âgées atteintes de MCM ont été recrutés en Alberta et en Ontario. Les données de l'enquête ont été recueillies à deux reprises, à six mois d'intervalle. Les modèles additifs et multiplicatifs ont été analysés à l'aide d'un modèle linéaire généralisé afin de déterminer l'intensité du fardeau de l'aidant. L'interférence sociale moyenne à élevée (impact sur la vie sociale) était associée à un fardeau plus lourd lorsqu'ajustée en fonction de l'âge, du sexe, du niveau de scolarité et de la situation professionnelle. Les résultats principaux de l'interaction à cinq facteurs suggèrent que les hommes avaient généralement des scores de fardeau inférieurs à ceux des femmes. Indépendamment de leur niveau de scolarité et de leur situation professionnelle, les femmes ont obtenu des scores de fardeau plus élevés. Ces résultats enrichissent les publications actuelles, en suggérant des domaines de recherche supplémentaires pour combler les lacunes dans les connaissances, et supportent des idées d'interventions en santé publique axées sur les aidants et fondées sur des données probantes.

ABSTRACT

Intersectionality analysis is the study of overlapping or intersecting social identities. Intersecting social identities may have an impact on the perception of burden by family caregivers of older persons with multiple chronic conditions (MCC). The purpose of this study was to explore the interaction of social factors on the burden of caring for older adults with MCC. A total of 194 caregivers of older adults with MCC were recruited from Alberta and Ontario. Survey data were collected at two time points, six months apart. Additive and multiplicative models were analysed using a generalised linear model to determine the level of caregiver burden. Medium-high social interference (impact on social life) was associated with higher burden when adjusted for age, gender, education, and employment status. The overall results of the five-way interaction suggest that males in general had lower burden scores than females. Irrespective of their education and employment status, females had generally higher burden scores. These results add to the current body of literature, suggesting areas for further research to fill knowledge gaps, and promoting ideas for evidence-guided public health interventions that focus on caregivers.

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Zarit Burden Interview (ZBI)

- ZBI is one of the most widely used instruments for assessing the burden experienced by caregivers of persons with dementia
- ZBI provides a comprehensive assessment of subjective burden, specifically assessing emotional, physical, social & financial stress
- Clinician Uses: screening for high-risk, assessment of stressors (role strain/time demands, personal strain/emotional and/or physical exhaustion), guiding & following intervention strategies, preventing institutionalization through tracking changes in carer well-being - often in dementia, cancer & stroke populations
- Many different versions – 4 to 22 items; available in multiple languages
- For clinical environments, the shorter 4-item or 12-item version may be most efficiently employed as it is recognized as the screening version
- Can be self-administered or conducted via interview by a clinician

Name: _____

Date: _____

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2) Do you feel embarrassed you're your relative's behavior?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5) Are you afraid what the future holds for your relative?	0	1	2	3	4
6) Do you feel strained when you are around your relative?	0	1	2	3	4
7) Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
12) Do you feel uncertain about what to do about your relative?	0	1	2	3	4

	Never	Rarely	Sometimes	Frequently	Nearly Always
13) Do you feel that you should be doing more for your relative?	0	1	2	3	4
14) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15) Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16) Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17) Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18) Do you feel your relative is dependent upon you?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
19) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20) Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
21) Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22) Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

Scoring Instructions: Add Items 1-12 **Total 1-12 (maximum score = 48)** _____

Add Items 13-21 **Total 13-21 (maximum score = 36)** _____

Score #22 (maximum score = 4) _____

Total Score (88) _____

Zarit Caregiver Burden Assessment (**Short, 12-items**)

Name: _____

Date: _____

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring and meeting other responsibilities?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel your relative affects your relationship with others in a negative way?	0	1	2	3	4
5) Do you feel strained when are around your relative?	0	1	2	3	4
6) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4
8) Do you feel your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Scoring Instructions: Add Items 1-12 **Total 1-12 (maximum score = 48)** _____

Zarit Caregiver Burden Assessment **(Screen, 4-items)**

Name: _____

Date: _____

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel that because of your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?	0	1	2	3	4
3) Do you feel strained when you are around your relative?	0	1	2	3	4
4) Do you feel uncertain about what to do about your relative?	0	1	2	3	4

Scoring Instructions: Add Items 1-14 **Total 1-4 (maximum score = 16)** _____

Q&A

More Information on ZBI:

Request to access to various ZBI versions:

<https://eprovide.mapi-trust.org/instruments/zarit-burden-interview>

Dr. Zarit's webpage:

<https://eprovide.mapi-trust.org/zbi-zarit-burden-interview/#:~:text=The%20ZBI%20also%20differs%20from,time%2C%20and%20measuring%20treatment%20outcomes>

Meet Mrs. Sinclair*

Health Status and Family Context:

- 82yrs, lives alone in a bungalow in Dartmouth, NS and is strongly attached to her home, church, and neighbourhood.
- Margaret has moderate Alzheimer's disease, osteoarthritis, hypertension, type 2 diabetes, and urinary urgency, with declining memory and judgment; she currently receives limited home care, including personal care three mornings a week and occasional nursing visits.
- Her daughter Elaine, who lives nearby in Cole Harbour, is her primary caregiver and helps daily with meals, medications, appointments, supervision, and overnight support; her son David, who lives in Ottawa, is concerned about her safety and feels more support or supervised care may be needed.
- In recent weeks, Margaret's confusion, suspicion, repeated calls, resistance to care, nighttime waking, and attempts to leave the house have increased, leaving Elaine highly stressed and increasingly worried about her mother's safety at home.

* This case study is based on real-world events and experiences but is a composite scenario, with names and identifying details changed to protect privacy and confidentiality.

Meet Mrs. Sinclair*

Caregiver Elements:

Strained: Elaine appeared tired, distracted, and tearful.

Overextended: Work and self-care are slipping.

Distressed: She feels guilty, overwhelmed, and ashamed.

Overwhelmed: Available supports feel like too much to manage.

A key piece is that different parts of the system are seeing different warning signs

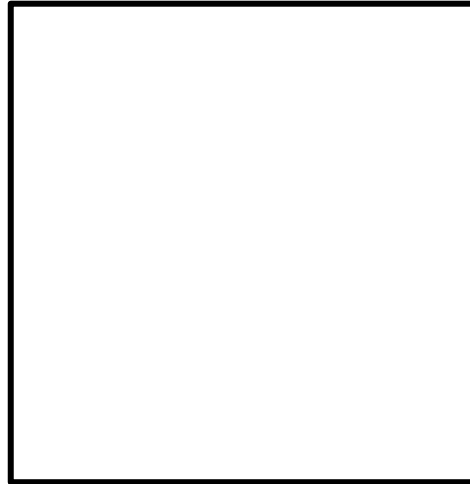
Personal Care Providers: Staff note increasing resistance to care, worsening confusion, greater reliance on Elaine.

Home Care Nursing: Nursing notes increasing caregiver strain, growing safety concerns at home, possible weight loss, and difficulty managing routines and next steps.

Primary Care Provider: notes dementia progression, monitors chronic conditions and medications, but understanding of caregiver strain, safety risks and day-to-day challenges is limited by brief office visits.

* This case study is based on real-world events and experiences but is a composite scenario, with names and identifying details changed to protect privacy and confidentiality.

Discussion / Q&A



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April 29, 2026 12 – 1pm Eastern

Presenter: Dr. George Heckman MD, FRCP(C),

Thank you for taking a moment to complete the survey!