Caregiver Centered Care

Education designed for healthcare providers to support family caregivers.

ABOUT THE COURSE

Caregiver-Centered Care Education is co-designed to equip health and community care providers with the knowledge, skills, and resources to provide person-centered care to family caregivers. Person-centered care, that respects and involves family caregivers in the planning and delivery of support services for the care receiver, while also recognizing and addressing the family caregiver's own needs, preferences, and wellbeing. It is crucial for fostering meaningful and positive care outcomes for all involved in the care journey—providers, family caregivers, and the people they care for.

WHO IS PROVIDING THIS COURSE?

The Caregiver-Centered Care is a Program of Applied Research & Innovation in Health Services Delivery in Family Caregiving led by Dr. Jasneet Parmar, Professor from the Department of Family Medicine, University of Alberta. Dr. Parmar and a team of over 130 multi-level interdisciplinary team of researchers, educators, health providers and leaders, educational designers, and family caregivers co-produced the Caregiver-Centered Care Competency Framework© in a Modified Delphi Process in 2019[1,2], the Foundational Education in 2019- 2020[3] and Advanced Education in 2021-2023.

WHY EDUCATION FOR HEALTCARE PROVIDERS ABOUT FAMILY CAREGIVERS?

Family caregivers (carers, care-partners) are our current largest care workforce. We define family caregiver broadly as any person who takes on an unpaid caring role providing health, social, emotional, and practical support for people with mental or physical illness, disability, or frailty from aging.

In 2018, Statistics Canada General Social Survey confirmed that one in four (26 %, 7.8 million) Canadians age 15+ contributed to 5.7 billion hours of unpaid care, the equivalent of 2.8 million full-time workers and an annual economic value of $97.1 billion [4]. Health providers rely heavily on caregivers to carry out care plans and discharge recommendations, reduce length of hospitalizations, reduce emergency and acute care wait times [5,6]. Home care and chronic disease pathways depend on caregiver support. However, because of advancements in medicine, longer lifespans, and cost-cutting measures that shift care responsibilities onto families, caregiving trajectories are much longer and more challenging. Caregivers now shoulder not only personal care and extended activities of daily living, but also medical and nursing duties traditionally done by regulated health professionals. In our siloed health and social care systems, they are the de facto care coordinators finding, negotiating for, and coordinating resources [7,8].

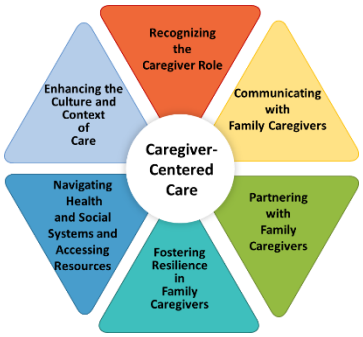
Without systematic support, family caregiver distress rates are soaring. Statistics Canada reported 44% of family caregivers were distressed in July-August 2022 [9]. Much of family caregiver burden is related to interactions with health providers and the health system [10-12]. American caregivers of older adults who helped with medical appointments or coordinated care between providers were significantly more likely to report burden compared to those who did not assist with these health care interactions [12,13] A recent study involving Canadian employees from various industries (automotive, manufacturing, insurance, research and development, health and social services, municipal government), highlighted that the number of hours spent organizing and coordinating healthcare tasks, rather than other family care tasks like housework, was associated with increased family-work conflict[14]. It is essential that health care systems and providers determine ways to make health care interactions less burdensome for family caregivers.

UNIVERSITY OF ALBERTA

Developed in the Department of Family Medicine at the University of Alberta, this is a program of applied research and innovation in health services delivery.

Healthcare Providers should see family caregivers not just as resources to carry out treatment plans, support the person, or the way to reduce health costs, but as a partner in that enterprise who may need information, training, care, and support [15-17]. However, the Editor of the Canadian Family Physician noted, "family caregivers are under recognized, under-supported, and underused. Few health care professionals have received training in caregiver engagement, and typically there is a reluctance to collaborate with caregivers and an unwillingness to involve caregivers in the care process in a meaningful fashion"[17]. University of Alberta Neurologist Dr. Janis Miyasaki doesn't think family caregivers are underused, but rather under-engaged, which sometimes leads to family caregivers being overused and under-supported by the health care system. Researchers and health providers are now recommending competency-based education for healthcare providers to effectively recognize, communicate with, and engage caregivers as partners on the care team [15-23].

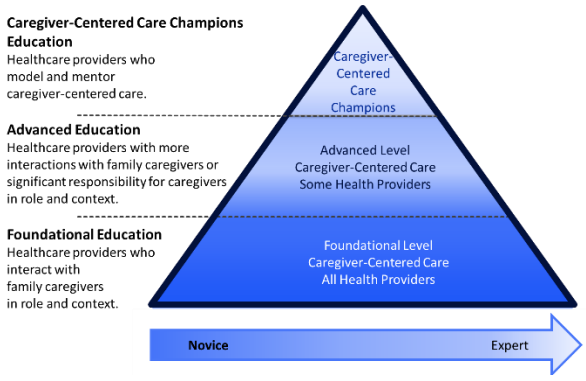
CAREGIVER-CENTERED CARE EDUCATION



The Caregiver-Centered Care education is based on literature reviews of best practices in interdisciplinary education[24-30] and follows the six domains in the Caregiver-Centered Care Competency Framework©: Recognizing the Family Caregiver Role, Communicating with Family Caregivers, Partnering with Family Caregiver, Fostering Family Caregivers' Resilience (wellbeing), Navigating Health and Social Systems and Accessing Resources, and Enhancing the Culture and Context of Healthcare. Learning is facilitated through clear learning objectives, video vignettes based on real-life case studies, subject-matter experts, and interactive exercises that promote critical thinking, encourage reflection and self-assessment. The Caregiver-Centered Care education is all designed to be delivered flexibly, either facilitated-in-person or virtually. It is free online at www.caregivercare.ca.

3 LEVELS OF EDUCATION

As recommended by stakeholders co-designing the Caregiver-Centered Care Competency Framework, we are co-producing three levels of Caregiver-Centered Care Education Foundational, Advanced, and Champions.
All the online modules take 45-60 minutes to complete and learners receive a continuing competency certificate on completion of each module.



Level 1: Foundational Education is designed for all healthcare providers who interact with family caregivers. No prerequisites are required. The module follows Lacey, a student nurse whose mother was recently diagnosed with early onset dementia as she learns about the six Caregiver-Centered Care competencies she needs to support caregivers from her health workforce colleagues at the hospital.

COVID-19 Education offers more fulsome practice for communicating in stressful situations, like a pandemic or flu outbreak. The module follows Gordan Cruikshank family caregiver to his wife, and long-term care facility manager Estelle Wagner, as they deal with changing restrictions. It is designed to improve health providers' comfort and confidence in perspective taking, empathic communication, and navigating uncertainty together with family caregivers.

Level 2 Advanced Level Education is designed for health and social care professionals who interact with family caregivers frequently, are involved in case management and care planning, or oversee other healthcare professionals who interact with family caregivers. The video vignettes follow the Fawcett family caregivers, husband John Fawcett, son Chad and daughter Carly as they care for wife and mother Leanne after discharge home with major stroke. The six modules provide in-depth instruction on and practice in the six Caregiver-Centered Care competencies: Recognizing the Family Caregiver Role, Communicating with Family Caregivers, Partnering with Family Caregiver, Fostering Family Caregivers' Resilience (wellbeing), Navigating Health and Social Systems and Accessing Resources, and Enhancing the Culture and Context of Healthcare. Each module takes 45-60 minutes to complete (~6 hours) and each comes with a continuing competency certificate on completion.

Level 3 Champions' Education will be released in summer 2024, is designed for health and social care professionals who lead, model, and mentor Caregiver-Centered Care competence within their practice. These individuals may be in formal or informal leadership roles within their areas of practice and act as influencers of improved quality of care. Topics covered in this bundle build on concepts presented in the Foundational (Level 1) and Advanced (Level 2) Education.

COURSE GOALS

Upon completion of the full suite of Caregiver-Centered Care Education for Healthcare Providers the learner will be well prepared to implement what they have learned to enhance their practice and setting. We hope that once you take the first module, you will be inspired to complete all levels and become a Caregiver-Centered Care Champion!

Upon completion of the education, learners will be able to:

- Explain the importance and value of family caregivers' contributions to the people they care for, the healthcare system, and society.
- Recognize family caregivers' roles and responsibilities.
- Build and maintain positive relationships with family caregivers through effective communication.
- Identify the benefits of including family caregivers and their expertise as part of the care team.
- Describe strategies that promote the health and wellbeing of family caregivers.
- Identify and overcome barriers to access of services and supports for family caregivers.
- Identify individual bias through self-reflection to improve interactions with and support of family caregivers.
- Apply Caregiver-Centered Care in my practice, setting, communities, and networks.

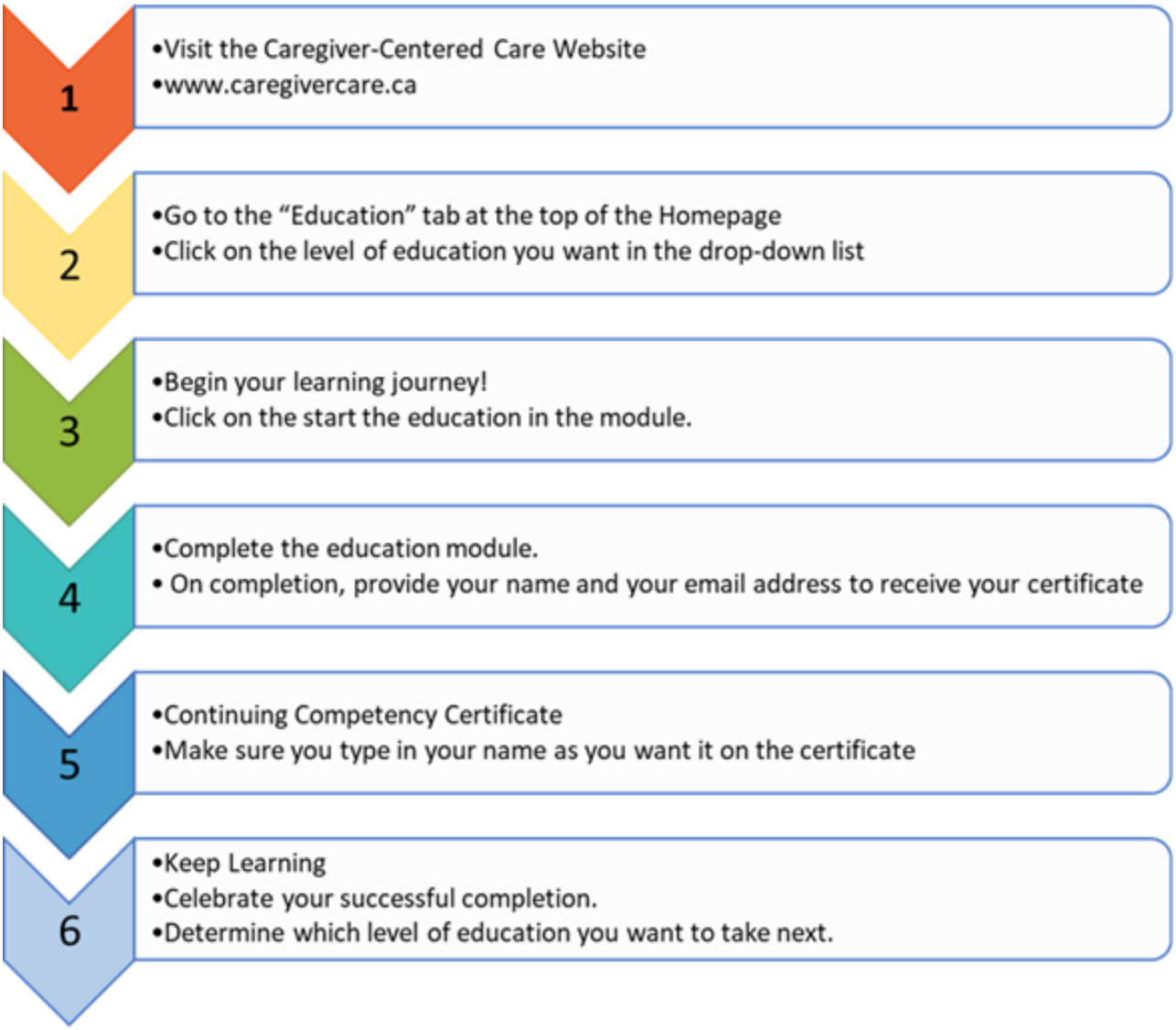
CERTIFICATES OF COMPLETION

Learners receive a Certificate of Completion after successfully completing the course content of each learning module.

TARGET AUDIENCE

Caregiver-Centered Care Education is designed for everyone who interacts with family caregivers, including healthcare students, individuals working in health and social care professions, health and social care leaders, and policymakers. Family caregivers also benefit from education. Anyone interested in knowing how to better support family caregivers is encouraged to enroll.

HOW TO ACCESS THE EDUCATION



UNIVERSITY OF ALBERTA

Developed in the Department of Family Medicine at the University of Alberta, this is a program of applied research and innovation in health services delivery.

References

1. Parmar, J.; Anderson, S. Caregiver-centered care competency framework. **2019**.
2. Parmar, J.; Anderson, S.; Duggleby, W.; Holroyd-Leduc, J.; Pollard, C.; Brémault-Phillips, S. Developing person-centred care competencies for the healthcare workforce to support family caregivers: Caregiver centred care. *Health and Social Care in the Community* **2020**, doi:https://doi.org/10.1111/hsc.13173.
3. Parmar, J.K.; L'Heureux, T.; Anderson, S.; Duggleby, W.; Pollard, C.; Poole, L.; Charles, L.; Sonnenberg, L.K.; Leslie, M.; McGhan, G.; et al. Optimizing the integration of family caregivers in the delivery of person-centered care: evaluation of an educational program for the healthcare workforce. *Bmc Health Services Research* **2022**, *22*, doi:10.1186/s12913-022-07689-w.
4. Fast, J.; Duncan, K.A.; Keating, N.C.; Kim, C. Valuing the Contributions of Family Caregivers to the Care Economy. *Journal of Family and Economic Issues* **2023**, doi:10.1007/s10834-023-09899-8.
5. Griffin, J.M.; Kaufman, B.G.; Bangerter, L.; Holland, D.E.; Vanderboom, C.E.; Ingram, C.; Wild, E.M.; Dose, A.M.; Stiles, C.; Thompson, V.H. Improving Transitions in Care for Patients and Family Caregivers Living in Rural and Underserved Areas: The Caregiver Advise, Record, Enable (CARE) Act. *Journal of Aging and Social Policy* **2022**, doi:10.1080/08959420.2022.2029272.
6. Schulz, R.; Czaja, S.J. Family Caregiving: A Vision for the Future. *American Journal of Geriatric Psychiatry* **2018**, *26*, 358-363, doi:10.1016/j.jagp.2017.06.023.
7. Taylor, M.G.; Quesnel-Vallée, A. The structural burden of caregiving: Shared challenges in the United States and Canada. *Gerontologist* **2017**, *57*, 19-25, doi:10.1093/geront/gnw102.
8. Law, S.; Ormel, I.; Babinski, S.; Kuluski, K.; Quesnel-Vallée, A. "Caregiving is like on the job training but nobody has the manual": Canadian caregivers' perceptions of their roles within the healthcare system. *BMC Geriatrics* **2021**, *21*, doi:10.1186/s12877-021-02354-z.
9. Statistics Canada. More than half of women in Canada are caregivers. **2022, 11, 08**
10. Schulz, R.; Beach, S.R.; Friedman, E.M.; Martsolf, G.R.; Rodakowski, J.; Everette James, A. Changing Structures and Processes to Support Family Caregivers of Seriously Ill Patients. *Journal of Palliative Medicine* **2018**, *21*, S36-S42, doi:10.1089/jpm.2017.0437.
11. Bosco, N. Caring for carers. Implications and repercussions of reduced attention to family caregivers on individual health and collective wellbeing. *Sociologia del Lavoro* **2018**, 120-135, doi:10.3280/SL2018-150007.
12. Mueller, A.; Beach, S.R.; Bowers, B.J.; Fields, B. Relationship Between Health Care Interactions and Care Partner Burden. *Families, Systems and Health* **2022**, *40*, 225-231, doi:10.1037/fsh0000675.
13. Semere, W.; Makaroun, L.K.; Beach, S.; Schillinger, D.; Rosland, A.M. Family Caregivers Navigating the Health Care System: Evolving Roles During the COVID-19 Pandemic. *Families, Systems and Health* **2022**, *40*, 268-273, doi:10.1037/fsh0000688.
14. Beauchamp Legault, M.È.; Chênevert, D.; Maisonneuve, F.; Mansour, S. How do Informal Caregivers of Seniors' Tasks Lead to Presenteeism and Absenteeism Behaviors? A Canadian Quantitative Study. *International Journal of Environmental Research and Public Health* **2023**, *20*, doi:10.3390/ijerph20075392.
15. National Academies of Sciences, E.; Medicine; Health; Medicine, D.; Board on Health Care, S.; Committee on Family Caregiving for Older, A.; Schulz, R.; Eden, J. *Families caring for an aging America*; 2016; pp. 1-345.
16. Shawn Tracy, C.; Nickell, L.A.; Upshur, R.E.G. Canada's health care system needs to care more about caregivers. *CMAJ* **2019**, *191*, E821, doi:10.1503/cmaj.72340.
17. Nickell, L.A.; Tracy, C.S.; Bell, S.H.; Upshur, R.E.G. Effect of an innovative model of complexity care on family caregiver experience. *Canadian Family Physician* **2020**, *66*, 194.
18. Badovinac, L.M.; Nicolaysen, L.; Harvath, T.A. Are we ready for the CARE Act?: Family caregiving education for health care providers. *Journal of Gerontological Nursing* **2019**, *45*, 7-11, doi:10.3928/00989134-20190211-02.
19. Riffin, C.; Wolff, J.L.; Butterworth, J.; Adelman, R.D.; Pillemer, K.A. Challenges and approaches to

involving family caregivers in primary care. *Patient Education and Counseling* **2020**, doi:10.1016/j.pec.2020.11.031.
20. Riffin, C.; Wolff, J.L.; Pillemer, K.A. Assessing and Addressing Family Caregivers' Needs and Risks in Primary Care. *Journal of the American Geriatrics Society* **2020**, doi:10.1111/jgs.16945.
21. Leykum, L.K.; Penney, L.S.; Dang, S.; Trivedi, R.B.; Noël, P.H.; Pugh, J.A.; Shepherd-Banigan, M.E.; Pugh, M.J.; Rupper, R.; Finley, E.; et al. Recommendations to Improve Health Outcomes Through Recognizing and Supporting Caregivers. *J Gen Intern Med* **2022**, *37*, 1265-1269, doi:10.1007/s11606-021-07247-w.
22. Charles, L.; Brémault-Phillips, S.; Parmar, J.; Johnson, M.; Sacrey, L.A. Understanding how to support family caregivers of seniors with complex needs. *Canadian Geriatrics Journal* **2017**, *20*, 75-84, doi:10.5770/cgj.20.252.
23. Holroyd-Leduc, J.M.; McMillan, J.; Jette, N.; Brémault-Phillips, S.C.; Duggleby, W.; Hanson, H.M.; Parmar, J. Stakeholder Meeting: Integrated Knowledge Translation Approach to Address the Caregiver Support Gap. *Canadian Journal on Aging* **2017**, *36*, 108-119, doi:10.1017/S0714980816000660.
24. Surr, C.; Sass, c.; Griffiths, A.; Oyebode, J.; Smith, S.; Parveen, S.; Drury, M. Dementia training design and delivery audit tool (DeTDAT) v4.0: Auditor's manual. **2018**, 22.
25. Surr, C.A.; Gates, C. What works in delivering dementia education or training to hospital staff? A critical synthesis of the evidence. *International Journal of Nursing Studies* **2017**, *75*, 172-188, doi:10.1016/j.ijnurstu.2017.08.002.
26. Surr, C.A.; Gates, C.; Irving, D.; Oyebode, J.; Smith, S.J.; Parveen, S.; Drury, M.; Dennison, A. Effective Dementia Education and Training for the Health and Social Care Workforce: A Systematic Review of the Literature. *Review of Educational Research* **2017**, *87*, 966-1002, doi:10.3102/0034654317723305.
27. Reeves, S.; Boet, S.; Zierler, B.; Kitto, S. Interprofessional Education and Practice Guide No. 3: Evaluating interprofessional education. *Journal of Interprofessional Care* **2015**, *29*, 305-312, doi:10.3109/13561820.2014.1003637.
28. Reeves, S.; Fletcher, S.; McLoughlin, C.; Yim, A.; Patel, K.D. Interprofessional online learning for primary healthcare: Findings from a scoping review. *BMJ Open* **2017**, *7*, doi:10.1136/bmjopen-2017-016872.
29. Reeves, S.; Palaganas, J.; Zierler, B. An updated synthesis of review evidence of interprofessional education. *Journal of Allied Health* **2017**, *46*, 56-61.
30. Riskiyana, R.; Claramita, M.; Rahayu, G.R. Objectively measured interprofessional education outcome and factors that enhance program effectiveness: A systematic review. *Nurse Education Today* **2018**, *66*, 73-78, doi:10.1016/j.nedt.2018.04.014.