Partners panel: COVID 19 - The game changing impact on caregivers and persons with dementia

This panel will discuss the impact of COVID-19 on people living with dementia, caregivers, advocates, and healthcare professionals. The panel will bring forward these perspectives with regard to the pandemic’s influence on people at different stages of the dementia journey, the shift to remote care and remote social connection, and key areas that require further research and policy change.

**Moderator:** Dr. Julie Robillard is an Assistant Professor of Neurology at the University of British Columbia (UBC), Scientist in Patient Experience at BC Children’s and Women’s Hospital (C&W) and Faculty member of Neuroethics Canada. She leads the Neuroscience, Engagement and Smart Tech (NEST) lab and oversees a range of initiatives related to patient experience research at C&W. Dr. Robillard brings her background in neuroscience and biomedical ethics to the evaluation and development of novel technologies to support brain health across the lifespan. A particular interest of her research is the integration of emotion modeling in a wide range of technologies, from eHealth resources to mobile apps. More recently, she has secured one of the inaugural New Frontiers in Research grants to implement emotional alignment algorithms into social robotics. Together with her team and through international interdisciplinary collaborations, she is exploring co-creation processes, development and applications of social robots in both older adult and youth populations. Dr. Robillard is passionate about patient engagement and in her role as a Scientist in Patient Experience she is working with a number of groups at C&W and UBC to advance the capture, analysis and improvement of patient experience in both research and care. She is interested in using technology to provide novel means of engagement and patient experience evaluation strategies. Dr. Robillard holds provincial, national and international leadership roles: she is Chair of the Ethical, Legal, Social Impacts Committee of the Canadian Consortium on Neurodegeneration in Aging, a member of the Technology and Dementia Executive Committee of the International Society to Advance Alzheimer’s Research and Treatments, and a member of the Board of Directors of the Medical Device Development Centre of British Columbia, among others.
Panelist: Dr. Saskia Sivananthan is currently the Chief Research and KTE Officer at the Alzheimer Society of Canada. Previously, she served as a senior strategy and policy advisor consulting for the World Health Organization (WHO) on its overall global dementia strategy. Dr. Sivananthan co-drafted the WHO’s Global Action Plan on the Public Health Response to Dementia which was unanimously adopted at the 170th World Health Assembly by all 194 member-states. She and her team were also responsible for developing the WHO Global Dementia Observatory, an online platform for collating data to support countries to develop evidence-based policies in dementia and monitor progress toward targets outlined in the dementia action plan.

Dr. Sivananthan is a neuroscientist and health data scientist who uses population-level data to understand aging. She works in health system development and with governments on health services, policy and strategies to improve health for older adults with complex needs and those living with dementia. An active researcher, Dr. Sivananthan holds a PhD in Health Services & Policy Research from the University of British Columbia, and an MSc in Neurology and Neuroscience from McGill University.

Panelist: Claire Webster is a Certified Alzheimer Care Consultant, Certified Professional Consultant on Aging, as well as a Conference Speaker and Educator in the field of caring for an individual with dementia. She is Founder and President of Caregiver Crosswalk Inc., a consulting firm that provides education and support services to help individuals navigate the journey of Alzheimer’s disease and/or dementia related illnesses.

Claire works in collaboration with McGill University’s Faculty of Medicine and the Division of Geriatric Medicine and is the Founder of the McGill Dementia Education Program and “McGill Cares”, a weekly webcast series designed to support family caregivers. As a former caregiver to her late mother, Claire has had first hand experience in dealing with the overwhelming emotional and physical impact that caring for a family member with dementia places on the individual and family members.

Panelist: Dr. Samir Sinha is the Director of Geriatrics at Sinai Health System and the University Health Network in Toronto and an Associate Professor of Medicine at the University of Toronto and the Johns Hopkins University School of Medicine. He is also the Director of Health Policy Research at Ryerson University’s National Institute on Ageing.

A Rhodes Scholar, Samir is a highly regarded clinician and international expert in the care of older adults. He has consulted and advised governments and health care organizations around the world and is the Architect of the Government of Ontario’s Seniors Strategy. In 2014, Maclean’s proclaimed him to be one of Canada’s 50 most influential people and its most compelling voice for the elderly.

Panelist: Christine Rieck Buckley is the Chief Executive Officer of the Canadian Nurses Foundation (CNF), Canada’s only national charity that raises funds exclusively for nursing education and research. She has helped lead this organization for the past eight years setting new and innovative goals, including raising over one million dollars for indigenous nursing education and research. Prior to CNF, Christine worked with the Canadian Nurses Association, in a number of roles, the most recent being Manager of Regulatory Affairs. Christine has also worked internationally as the chair of the International Council of Nurses, International Nurse Practitioner /Advanced Practice Nurse Network health policy subgroup. Originally from Montreal, Christine completed both her undergraduate and graduate degrees at McGill. Christine has several publications that focused on the role of advance practice nurses nationally and internationally.
The lived experience perspective

**Moderator:** Carrie McAiney is an Associate Professor in the School of Public Health and Health Systems at the University of Waterloo, Schlegel Research Chair in Dementia at the Schlegel-UW Research Institute for Aging, and Scientific Director of the Murray Alzheimer Research and Education Program. Carrie also serves as the KTE Co-Lead for the CCNA, and is a co-principal investigator on CCNA’s Team 19 - Research on the Organization of Health Services for Alzheimer’s (ROSA). As a health services researcher, Carrie works collaboratively with persons living with dementia, family care partners, providers and organizations to evaluate the impact and implementation of interventions and approaches that aim to enhance care and support for individuals living with dementia and their family members, and to improve the quality of work life for dementia care staff.

Roger Marple lives in Medicine Hat, Alberta and is the proud father and grandfather of 3 grown children and one grandson. He is an avid sports enthusiast, enjoys playing tennis and golf, loves to travel and knows his way around the kitchen with a real appetite for baking. Roger worked for Alberta Health Services and has worked in supply management in the south zone for over 23 years. He also has young onset Alzheimer’s disease. Roger was invited to join the Alzheimer Society of Canada’s advisory group to help raise awareness of the needs of people with dementia, including the specific needs of people living with young onset and/or early stage dementia. Roger also serves on the board of directors of the Alzheimer’s society of Alberta and North West Territories and is active in supporting dementia research in Canada. Since his diagnosis in the summer of 2015, Roger has made it his mission to dispel myths about the disease and the stigma associated with dementia. He is a firm believer that you can live well with this disease regardless of challenges and is passionate about sharing his message of hope.

Lisa Poole is a family care partner from Calgary. Lisa is on Dementia Network Calgary’s Strategic Council, AGE-WELL’s Older Adult and Caregiver Advisory Committee, Alzheimer Society of Canada’s COVID19 and Dementia Task Force, the Canadian Foundation for Healthcare Improvement (CFHI) Community Based Dementia Working Group, founded Dementia Connections Magazine, and is the co-Chair of Dementia Advocacy Canada.

**Topic network session: Who are your KTE audiences?**

**Facilitator:** Carrie McAiney is an Associate Professor in the School of Public Health and Health Systems at the University of Waterloo, Schlegel Research Chair in Dementia at the Schlegel-UW Research Institute for Aging, and Scientific Director of the Murray Alzheimer Research and Education Program. Carrie also serves as the KTE Co-Lead for the CCNA, and is a co-principal investigator on CCNA’s Team 19 - Research on the Organization of Health Services for Alzheimer’s (ROSA). As a health services researcher, Carrie works collaboratively with persons living with dementia, family care partners, providers and organizations to evaluate the impact and implementation of interventions and approaches that aim to enhance care and support for individuals living with dementia and their family members, and to improve the quality of work life for dementia care staff.
**Topic network session: Bio samples in dementia research**

*Facilitator:* Dr. Poirier received his undergraduate training at Université de Montréal in biochemistry. Shortly after, he joined Dr. André Barbeau’s group at the Clinical Research Institute of Montreal where he completed his Ph.D. on the neurobiology of Parkinson’s disease and the neurotoxicity of MPTP and Aluminum. He was then invited to join the Alzheimer’s Disease Research Consortium of Southern California in Los Angeles as research associate. It is in California that he discovered the important role of apolipoprotein E, a key cholesterol trans- porter that acts as a powerful modulator of brain repair and, serves as a key player in Alzheimer’s disease pathophysiology. McGill University and the Douglas Institute recruited him back in the spring of 89 to establish a research program specialized in neurodegenerative diseases with a strong focus on Alzheimer’s disease genetics.

**Topic network session: Diversity in dementia research**

*Facilitator:* Aline Moussard, Ph.D. is a neuropsychologist specialized in applied research related to the use of music as a tool for cognitive stimulation, project manager at the Centre de recherche de l’Institut universitaire de gériatrie de Montréal, and currently coordinating a multisite research project on dementia prevention using cognitive training and stimulating leisure activities to build and strengthen cognitive reserve in healthy older adults.

*Facilitator:* Dr. M. Natasha Rajah received her Ph.D. in Experimental Psychology from the University of Toronto in 2003 and did her post-doctoral training at U.C. Berkeley, 2003-2005. She joined the Douglas Institute in 2005 as Assistant Professor at the Department of Psychiatry. In 2007, she was awarded a prestigious CIHR New Investigator Salary Award and in 2009 she was promoted to Associate Professor. Dr. Rajah’s research is focused on the cognitive neuroscience of memory and aging. In 2011 Dr. Rajah was promoted to Director of the Douglas Brain Imaging Centre. Dr. Rajah currently holds a FRQ-S Junior 2 Research Scholar Award.

**Special presentation and closing statement**

To close this event, we have decided to offer you a gift, a gift of time, of friendship and laughter with William J. Thomas, a humor columnist and stand-up artist, a writer and horse lover, and also a former caregiver to his mother Margaret who passed away from Alzheimer’s. WJ Thomas is the author of *Margaret and Me*, a book where he uncovers in a humoristic fashion the ups and downs of being a caregiver.

The show is followed by CCNA’s Scientific Director, Dr Howard Chertkow, closing statement and the Trainee Poster Competition award presentation.