Alzheimer's Disease International

The global voice on dementia

World Alzheimer Report 2022

Life after diagnosis: Navigating treatment, care and support

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Serge Gauthier is a clinical neurologist specialising in the development of new tools for diagnosis and treatments for people living with Alzheimer's disease. He was the Director of the McGill University Research Centre for Studies in Aging from 1986 to 1997, and became a senior scientist of the CIHR-Rx&D program (Canadian Institutes of Health Research and Canada's Research-Based Pharmaceutical Companies) in 1997. Dr. Gauthier is the Academic Co-Lead for the Dementia Education Program and Professor Emeritus, Neurology and Psychiatry at McGill University. His accomplishments led to him being appointed to the Order of Canada in 2014 and the National Order of Québec in 2017.

Claire Webster

Claire Webster is a Certified Dementia Care Consultant (PAC), Certified Professional Consultant on Aging (CPCA), 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 Health Sciences and the Division of Geriatric Medicine. She is the Founder and Ambassador of the McGill Dementia Education Program and 'McGill Cares,' a weekly webcast series designed to support family care partners.

Stijn Servaes

Stijn Servaes is a neuroscientist and data scientist who specialises in the identification of early Alzheimer's disease using advanced statistical methods, artificial intelligence and state-of-the-art biomarkers. Currently, he works as a postdoctoral fellow at the Translational Neuroimaging Laboratory from the McGill University Research Centre for Studies in Aging after acquiring a PhD in neuroscience and medical imaging from the University of Antwerp.

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José A. Morais is Professor of Medicine at McGill University. He is a senior scientist at the Research Institute of the McGill University Health Centre (RI-MUHC) in the Metabolic Disorders and Complications axis. In 2009, he became Director of the Division of Geriatric Medicine, McGill University, as well as of the MUHC and Jewish General Hospital. He is also Co-Director of the Quebec Network for Research on Aging and is the Academic Lead of the Dementia Education Program of the McGill Faculty of Medicine and Health Sciences. He was the Founder and first Director of the Centre of Excellence on Aging and Chronic Disease of the RUISSS McGill from 2012–2015.

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Expert essay

The future of dementia care

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It is projected that by 2050, there will be 12.7 million Americans over 65 living with Alzheimer's disease, nearly double the 6.5 million living with it today[1]. People living with dementia have healthcare utilization that costs three times more than age-matched individuals without dementia. Dementia care is primarily delivered by about 11 million family carers who will deliver the equivalent of US $271 billion in unpaid care this year. At present, dementia is not typically diagnosed until later stages of the condition because of misattribution of symptoms to normal aging, denial, and primary care physicians not having adequate training in dementia work-up and diagnosis[2]. People living with dementia have poor clinical outcomes and high healthcare utilization because of untreated behavioural symptoms and carer strain[3]. As the United States population ages and neurocognitive disorders increase in prevalence, it is essential to develop a system of care for people living with dementia to meet their needs, and the needs of a strained healthcare system. This system should treat patients from diagnosis until end of life and should include screening, diagnosis, care, and in the future, treatment. Access to specialty physician-level dementia care is difficult for most people as there is a dearth of specialists and care is often siloed. Additionally, most people living with dementia do not need specialty medical care; rather, they need care that meets their needs based on their diagnosis, cognition, behavioural symptoms, and functional abilities. Utilizing existing resources and restructuring clinical care into team-based interdisciplinary models will allow for the management of most dementia patients at the primary care level. This is of particular importance because there is strong evidence that people living with dementia have worse outcomes from the rest of their co-occurring health conditions – and this should not be the case. Utilizing the best of technology, clinical evidence, and pragmatic clinical trials, we can aspire to meet the needs of our rapidly growing population of people living with dementia.

Developing a system of dementia care will require training teams of professionals to direct care from the primary care setting. This includes training advanced practice clinicians in basic cognitive exams and dementia assessment, training social workers and case managers in caregiver support and community-based dementia resources, and empowering primary care physicians to disclose dementia diagnosis to their patients, while managing these teams. Extending the reach of dementia specialists, such as neurologists, geriatric psychiatrists, and geriatricians, so they can influence the care of many patients without direct contact is essential to maintaining primary care as the locus of dementia care. Models for designing and implementing collaborative dementia care have been studied in detail and have shown to improve patient and caregiver quality of life, and to decrease healthcare spending. Some examples of care models include the University of Indiana Aging Brain Care model, the UCLA Alzheimer's and Dementia Care model, and the UCSF Memory and Aging Center Care Ecosystem model[4]. In addition to optimising and organizing the existing workforce for a surge of people with dementia, dementia care needs to become a focus or specialty track in training programs for advanced practice clinicians, social workers, and physicians. Creating a framework for care and populating it with a workforce that is trained in the standard of care will enable us to meet the needs of the aging population.

The eventual arrival of biomarker tests for dementia and disease-modifying treatments will transform how we treat dementia but will certainly not eliminate the need for holistic dementia care. While some will have the good fortune of Alzheimer's treatment during early stages, many people will be diagnosed when the condition can no longer be treated. Furthermore, treatments for other dementias (vascular dementia, synucleinopathies) are even further from being developed. Frameworks for dementia care will be necessary for the foreseeable future and we must invest in studying the development and implementation of humane models of care. Utilizing pragmatic clinical trials will allow healthcare systems to quickly roll out large-scale interventions and adapt them to meet the needs of the patient population and care resources. We have an opportunity to meet the needs of our aging population and their family carers through humane care, but we need to invest in our work force, care models, caregivers, and patients, while we wait for transcendent technologies to diagnose and treat dementias.

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