



SENIORS FOR SOCIAL ACTION (ONTARIO)

INFORMATION BULLETIN

STARTING THE NEW YEAR OFF RIGHT WITH RESOURCES FOR CAREGIVERS SUPPORTING LOVED ONES WITH DEMENTIA AND OTHER COGNITIVE DISABILITIES

January 2, 2024

For too long we, in Canada, have simply accepted a tragedy narrative about dementia and other cognitive disabilities. We see those who have them as a burden requiring care, and institutionalize them in the thousands. Dementia is one of the least understood conditions, in spite of its prevalence.

Enter a world-wide organization that is reimagining dementia in ways that create more respect for those who live with it, and provide excellent resources for those supporting people who have it.

This Information Bulletin is intended to provide resources to our members who are living with dementia and to caregivers. We are with you on this journey. You are not alone.

Reimagining Dementia – A Creative Coalition for Justice “is an international group of people living with dementia, carers/care partners, family and community members, dementia activists and allies, health professionals, advocates, artists, academics, policy makers, and others.” Their website is full of resources that help to transform the way that dementia is seen and treated. www.reimaginingdementia.com

Wisdom Gone Wild is a “vibrant, tender cine-poem, a filmmaker collaborates with her Nisei mother as they confront the painful curious reality of wisdom ‘gone wild’ in the shadows of dementia. Made over 16 years, the film blends humor and sadness in an encounter between mother and daughter that blooms into an affectionate portrait of love, care, and a relationship transformed.” <https://www.youtube.com/watch?v=6UFgtpdNz-U>

Memory Lane TV is “a multi-sensory and engaging series of programs adapted for people living with memory loss and their care partners”. <https://www.memory-lane.tv>

On Vanishing: Mortality, Dementia, and What It Means to Disappear (2020) “In On Vanishing, Lynn Casteel Harper, a Baptist minister and nursing home chaplain, investigates the myths and metaphors surrounding dementia and aging, addressing not only the indignities caused by the condition but also by the rhetoric surrounding it. Harper asks essential questions about the nature of our outsized fear of dementia, the stigma this fear may create, and what it might mean for us all to try to vanish well. Weaving together personal stories with theology, history, philosophy, literature, and

science, Harper confronts our elemental fears of disappearance and death, drawing on her own experiences with people with dementia both in the American healthcare system and within her own family. In the course of unpacking her own stories and encounters—of leading a prayer group on a dementia unit; of meeting individuals dismissed as “already gone” and finding them still possessed of complex, vital inner lives; of witnessing her grandfather’s final years with Alzheimer’s and discovering her own heightened genetic risk of succumbing to the disease—Harper engages in an exploration of dementia that is unlike anything written before on the subject. A rich and startling work of nonfiction, *On Vanishing* reveals cognitive change as it truly is, an essential aspect of what it means to be mortal.” Available in Canada on Amazon.ca: <https://www.amazon.ca/Vanishing-Mortality-Dementia-Means-Disappear/dp/1948226286>

Helpful Trauma-Informed Approaches to Dementia – Valuable Resource for Caregivers Trauma Informed Care for Persons with Dementia, Brain Failure, and Cognitive Impairment https://www.nhpco.org/wp-content/uploads/TIC_persons_with_dementia_etc.pdf

New Research Study – Dementia (London) May 29, 2023 Online edition
Transforming dementia research into policy change: A case study of the multi-country STRiDE project

“STRiDE was an ambitious four-year project in seven countries aiming to build capacity around generating and using research to support the development of policies to improve quality of life of people with dementia and their carers. The project's innovative approach combined rigorous academic research and hands-on civil society advocacy. This paper explores the project's unique strategy for policy change and compiles case-studies from several of the STRiDE countries. Finally, we share lessons learned and next steps to keep momentum for policy change going in each of these countries - and beyond.”
<https://pubmed.ncbi.nlm.nih.gov/37247637/> Or you can join Research Gate for free [https://www.researchgate.net/publication/371144403 Transforming dementia research into policy change A case study of the multi-country STRiDE project](https://www.researchgate.net/publication/371144403_Transforming_dementia_research_into_policy_change_A_case_study_of_the_multi-country_STRiDE_project)

"Don't Forget I'm Human" toolkit from the STRIDE Project - <https://stridedementia.turtl.co/story/anti-stigma-toolkit/page/1>

Wishing all of our members a Happy, Healthy New Year and all the things that bring you joy in 2024!