CANADIAN CENTRE FOR ELDER LAW
BRITISH COLUMBIA LAW INSTITUTE

Engaging People Living with Dementia in Decision-Making

JANUARY 2022



1822 East Mall
University of British Columbia
Vancouver, BC, V6T 1Z1

bcli.org/ccel

About the Project

People living with dementia often find that their decision-making rights are not respected.

Some people assume that if you have dementia you cannot understand information or make choices. This exclusion happens within health care institutions and also within the larger community.

The goals of this project are to:

- work with people living with dementia to be meaningfully involved in decision-making; and
- create resources for teaching healthcare stakeholders how to support people living with dementia to participate as much as possible in decisions that impact their lives.



Meet the Advisory Council



Mission

The Advisory Council Members:

- Review outreach materials and provide input
- Identify people and organizations to consult
- Reflect on evaluation findings
- Provide feedback on draft educational tools
- Better understand consultation findings
- Represent the council at events
- Participate in critical project leadership decisions

Meet the Advisory Council

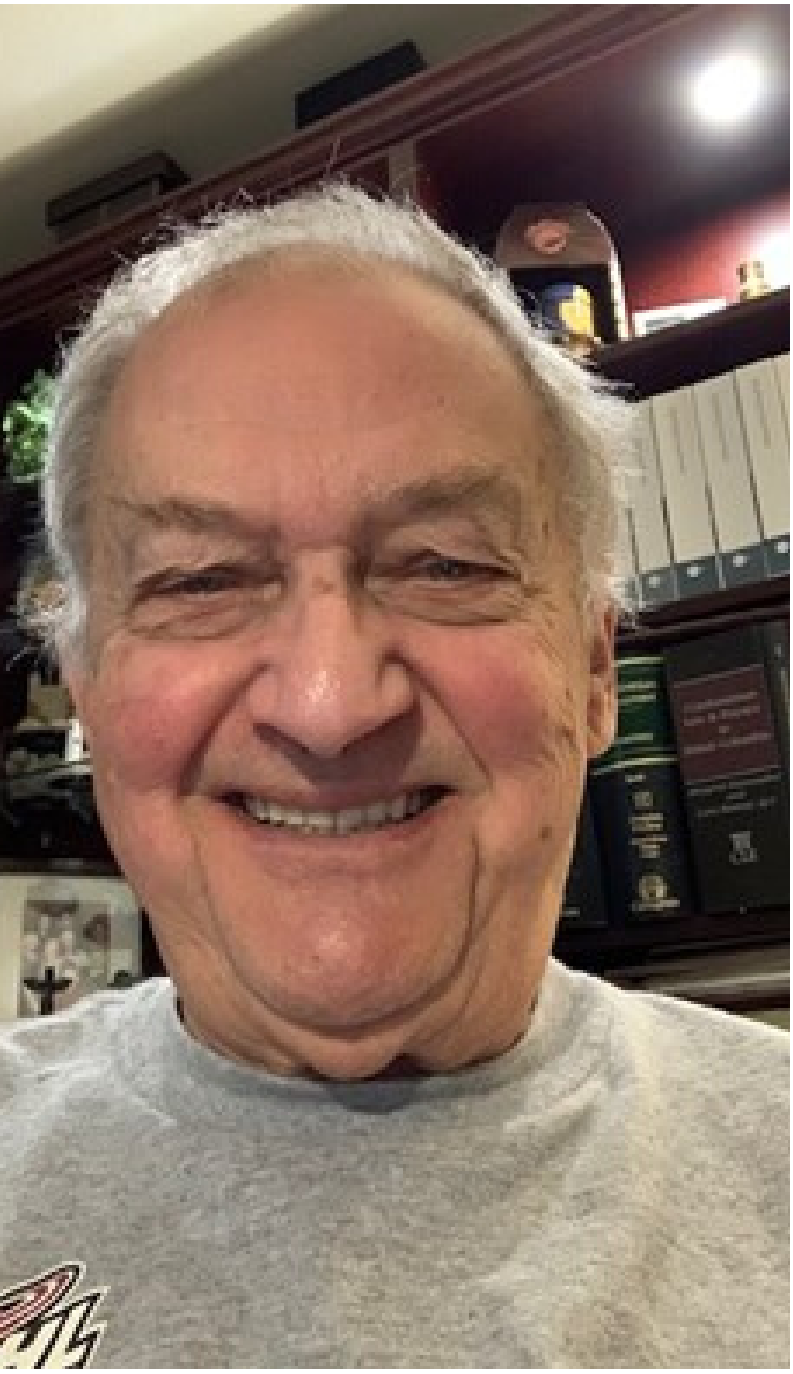
Craig Burns



Craig Burns' career has been in not for profit management, mostly with Canadian Red Cross, the University of British Columbia, and YMCA. With a diagnosis of Alzheimer's dementia in spring 2016, Craig took sick leave and then early retirement.

Craig now advocates to bring awareness and reduce the stigma of dementia in society. In volunteer capacities he is a spokesperson, leadership group committee member and a director on the governing Board for the Alzheimer's Society of B.C. He also participates in a research advisory group for the Canadian Consortium for Neurodegenerative Aging. For the Alzheimer's Society of Canada, Craig serves as a Citizen Reviewer, working with other persons living with dementia and caregivers on the Quality of Life and Care Panel, reviewing research proposals. Craig is a volunteer patient for the University of British Columbia Medical School, assisting physicians in educating medical students on the subject of dementia.

Meet the Advisory Council



JP Daem

Jean-Pierre Daem is currently President of Hestia Management Ltd., a project management firm specializing in multi-family residential housing. After completion of post-secondary degrees at UBC and SFU in Physiology, JP entered the business world and operated a strata management company for 35 years. Since 1974, he has taught, authored and addressed topics related to the various facets of common interest communities (condos and co-ops) locally, nationally and internationally. He has also been actively involved in the public domain at all levels (local, provincial and federal) as well as in education (Douglas College, ERIBC and CAI).

JP is hoping to put these many experiences to use to help preserve the rights of those affected by dementia against unwarranted, uninformed and unjust decisions and restrictions impacting the waning lives of aging members of our society regardless of their socio-economic status, racial ancestry, spiritual beliefs or gender orientation.

Meet the Advisory Council

Lynn Jackson



Lynn Jackson began her career as a Registered Nurse. She is a proud member of the Metis Nation of BC with sixth generation roots stemming from the Manitoba Cree. Lynn was diagnosed with dementia in 1999 and is now medically retired. Her current interests include advocating for people with dementia and increasing awareness of Alzheimer's disease and related dementias. She has spoken locally, nationally and internationally in an effort to promote better diagnosis, access to treatment and inclusiveness. Lynn has taken a particular interest in breaking the stigma surrounding a diagnosis of dementia.

Lynn has participated in numerous Alzheimer's Disease International working groups helping its member countries become more inclusive of people with dementia. She is one of the founders of DASN International (2001), an internet based organization by and for those diagnosed with early stage dementia. She has participated in numerous planning and advisory committees over the years.

Meet the Advisory Council



Mario Gregorio

Mario Gregorio was diagnosed with vascular dementia in 2008 and has been an advocate to create awareness, reduce stigma and educate the public about dementia. He has a passion in mentoring students and participates in various research projects to create dementia friendly initiatives and digital platforms that enhance the quality of living for people with dementia.

Mario worked with a telecommunications company as a data analyzer. He is the current editor for the Insight newsletter for ASBC and a member of the advisory committee and a citizen reviewer for Alzheimer Society Research Program and member of the National COVID 19 Task Force. He serves in the PFEC (Patient and Family Ethics Committee) and the World Class 2026 project for the New St. Paul's hospital. He is one of the eight people from across Canada who wrote the Charter of Rights for People with Dementia.

Meet the Advisory Council

Jerry Gosling



Jerry Gosling is 82 years of age and married for 61 years to Norma. They have one daughter Debbie and three adult grandsons. Jerry is a very active senior and involved with several non-profit organizations holding executive positions. He is President of the BC Old Age Pensioners Org., President of the Abbotsford Branch of the Canadian Hard of Hearing Association (CHHA), President of the BC Gov"t Retired Employees Assoc, Vice President of CHHA-BC, and Vice President of the Council of Senior Citizens Org.(COSCO). Jerry also serves on the BC Advocates Council of Advisers with Isobel Mackenzie, BC Senior Advocate and teach classes to seniors through Cosco and UVIC. In 2010 he successfully lobbied City Council to get a street named after the Gosling family, which ran Goslings of Abbotsford from 1920-1985. Cyprus Street was re-named Gosling Way.

Jerry looks forward to serving on the Dementia Council and learning more about this dementia.

Meet the Advisory Council



Myrna Norman

Myrna Norman is an advocate for People Living with Dementia, their carers, families and communities.

Diagnosed in 2009 with Frontol Temporal Dementia, and becoming aware that there was little to no support for her or her family, it only seemed the right thing to do, to advocate. Thirteen committees in all and this work has helped her to keep her progression at bay, or at least slowly moving on.

About CCEL & Partners

About CCEL

The CCEL conducts research, and develops reports and educational tools about legal and policy issues related to aging.

The CCEL is part of the BC Law Institute, BC's non-profit independent law reform agency.

For more information about this project and the CCEL, go to bcli.org/ccel

Partners

Alzheimer Society BRITISH COLUMBIA

Family Caregivers of British Columbia

CRPD Centre for Research on Personhood in Dementia

Funder

vancouver foundation