January 30, 2022

RDS IMPACT STUDY NEWSLETTER

Hello! Bonjour! Aanii!

Happy 2022! We hope that the holiday cheer and time with family and friends can continue to be a source of hope and strength in this New Year. We also hope that you continue to stay safe and well.

2021 was a busy year for our research team; we appreciate all participants, individuals and organizations who supported and contributed to the progress of our work. We are looking to build on these successes in 2022! Important developments will be shared in this newsletter as well information on our studies and how to connect with us.

RDS Canada Logo

**Rare
Dementia
Support**
Advice Community Learning
Canada

Social Media

Rare Dementia Support Canada can now be found on both Instagram and Twitter. Follow us for the latest updates on the emerging service, what's new with our research and more!

Instagram & Twitter:
@RDSCanada

Announcing RDS Canada

We are very pleased to announce that Dr Mary Pat Sullivan recently received funds to establish a rare and young onset dementia support service. Rare Dementia Support Canada is a support service for Canadians living with rare and young onset dementia led by Nipissing University. This service is a partnership with Rare Dementia Support (RDS), University College London in the UK. RDS is a world-leading service provided by UCL Dementia Research Centre and partners and funded by the National Brain Appeal. Informed by our learning from the RDS Impact Study, RDS Canada will provide a virtual space for anyone affected by a rare or young onset dementia offering access to tailored information, individual and group support and connection with others who are affected by similar conditions, as well as professional education and training opportunities. We will keep you updated on developments!
We encourage you to follow our social media accounts for the latest news.

To view the full press release please click [HERE]

Reflection

Vicky Willis, former care partner and member, Advisory Committee

Research poetry Group:
The process to find the words that define my feelings, in the poetry research study has been very therapeutic. The poet has beautifully used our words to connect people across the country with similar experiences. It brings awareness so others may understand the reality of this journey. I have enjoyed this experience and love the results of the poetry. To be part of this research has been very gratifying.

Advisory Committee: I am privileged to participate in the Advisory Committee with RDS. The Committee's projects aim to make living with a diagnosis of an early-onset or rare dementia an easier journey. The commitment to hear the voice of the Lived Experienced is rewarding. I am grateful to share my experience which gives me the opportunity to help others.

January is Alzheimer's Awareness Month

January has been Alzheimer's Awareness Month in Canada. Led by the Alzheimer Society, the commemoration emphasizes our collective responsibility to understand dementia and support people with lived experience. Raising awareness and addressing stigma reinforces human rights and pushes for policy change, the RDS Impact Study Team is encouraged in our own work by this monthly commemoration. More information on this year's event HERE.

2022 National Poetry Month

National Poetry Month is held every April to celebrate poetry's contribution to understanding human experience. One of the innovative methods on the RDS Impact Study involves the use of poetry as a research method. Done as a group activity, participants are asked to respond with a few words or phrases to prompts which are then compiled into a poem by a poet. The original words will be analyzed to inform our understanding of rare dementias and the poems will be used to raise awareness among the general public.

Throughout this newsletter we will be sharing reflections from people involved with RDS Impact Study. These reflections include comments from: Cindy McCaffery, Vicky Willis and Martha Gould about their experience participating in the research poetry project.

Rare & Young Onset Dementia Knowledge Exchange 2022

Plans are ongoing for the third edition of our Knowledge Exchange. We are looking forward to working with the Aphasia Centre of Ottawa and partners in the UK for the Knowledge Exchange 2022. **Please save the date: Thursday June 16th.** Further information will be provided in our March newsletter.

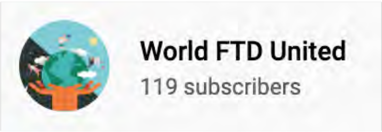
CAG Conference, 2021

Conference Website HERE

World FTD Week

In our previous newsletter we announced for video or written submissions on behalf of the World FTD United Team, to commemorate 2021 World FTD Week. Videos were received from people with lived experience, researchers, and health professionals from across the globe capturing the lived experience of FTD, offering care and support strategies, and sharing reasons for hope.

The videos have been compiled and can found on the World FTD United YouTube page HERE.



World FTD United

119 subscribers

Canadian Association of Gerontology conference, 2021

The research team participated in the 2021 virtual conference of the Canadian Association on Gerontology (CAG) which was held October 20-23. Joining other participants form across Canada and the rest of the world, we presented three papers on the innovative methods of the RDS Impact Study, Research Poetry and Talking Lines, and the Social Connections and Living with Dementia Study and the use of Ecomaps. These methods adopt alternative approaches to data collection and participant engagement using drawing and poetry.

Virtual Workshop: Social Isolation, loneliness, and older people: What's the problem?

Held on October 28, 2021 this virtual workshop provided an opportunity for academics, older people, people living with dementia, family care partners as well as health and social care practitioners to engage and learn about current perspectives and research evidence exploring the "the problem" of social isolation and loneliness among older people in Canada and across the globe.

Several key messages from the presentations included evidence from research that loneliness and social isolation is not a problem of older age, rather it is common across all age groups; that there are gaps in our knowledge of loneliness; and that interventions to address loneliness, particularly in people living with dementia, need to be tailored and based on more thorough research.

We were happy to welcome Professor Christina Victor and Professor Holly Nelson-Becker from Brunel University London. Full view of the program HERE .

Reflections

Erna de Burger Fex,
Care Partner

Our experience on the research study, Social Connections and Living with Dementia, has been most interesting and involved. My husband and I have learned things about each other which were surprising. We have been married 58 years and I thought I knew how he thought about the answers to the questions posed but that was not so. That was very valuable to me in understanding him better on his Alzheimer journey. It is my journey too as his caregiver so that is very important. I appreciate being a participant in this research project and will continue to assist as much as possible for as long as needed.

Martha Gould,
Consulting Poet

As the Canadian poet working on this research project, I have been very moved by what the respondents have to say about their experiences with early onset dementia and the difficulties of finding recognition and appropriate care. In creating a poem out of their words, I piece together snippets of ideas and try to make larger wholes that evoke the depths of feeling and distress in the respondents' words. The act of looking for expression, like opening a Pandora's box of possibilities, also often leads to a glimmer of Hope that many of the respondents feel when they know they are cared for and loved. The project and the poetry are offers of recognition and connection.

Reflections

We so appreciate all the participant, individuals and organizations who have supported and contributed to the progress of our work. The reflections that you are reading in this newsletter are from members of our Advisory Committee and participants in research. We are so appreciative for all of these contributions.

Cindy McCaffery,
Care Partner and Co-founder, YouQuest

Recently, friends at my young-onset dementia care partners' support group meeting commiserated how they've been besieged with surveys to measure their stage of burnout and the burden of looking after a loved one with dementia. When considering a request to complete yet another survey, we care partners often ask ourselves, “Do I want to spend 15 minutes on another dry survey or would I rather spend that time on something that takes me away from dementia, something pleasant like reading a book?”

So, it's refreshing that the RDS Impact Study takes an intriguing approach to learn how care partners are holding up. Expressing their feelings in a drawing or poem provides care partners with another method of stating those hard to express feelings of how we are coping and where our trigger points lie.

Having dementia during the income-earning years brings issues unique to this age group: children are still at home; mortgages need to be paid; and nest eggs might not exist. The lack of supports that are readily available to seniors with dementia adds insult to injury.

Research into young-onset dementia is limited, likely because the syndrome is considered unusual in younger people. However, roughly 16,000 Canadians have young-onset dementia; in Alberta, a whopping 10 % of the people diagnosed with dementia are under 65 years of age. Therefore, it's vital to find the causes of dementia, locate biomarkers, and get diagnoses faster so families can plan for the coming changes in roles, income, and living arrangements. Take a look at the YouQuest website HERE to find out more about Cindy's work.

New Member of Research Team

We are pleased to welcome Jen Gordon to the RDS Impact Study Team. Jen has a Master of Social Work, from Laurentian University, and is a Registered Social Worker with the Ontario College of Social Workers and Social Services Workers. She has lived and worked in Northern Ontario for majority of her adult life, with close family ties to both Thunder Bay and North Bay districts. Her direct practice experience has included adventure therapy with all ages, clinical work with trauma survivors, therapeutic group work and more. In addition to the direct practice, she holds particular interest and training in post-traumatic growth, mindfulness, neurodiversity and neurorehabilitation. Her work as a social worker is guided by the Ethics and Standards of Practice with a focus on equity, diversity, and inclusion in relation to health services in Northern Ontario.

Jen is particularly interested in the northern, rural, and remote experiences of those with lived experience and their carers. As a research assistant for the RDS Impact Study Canada, she looks forward to working on participant recruitment and outreach and learning alongside participants with lived experience.

Reflections

Trisha Wilson,
Member, Advisory Committee
Performance Improvement Lead, St Joseph's Care Group

Through my experience as a Social Worker, supporting individuals living with dementia in Northwestern Ontario, I have witnessed many of the gaps and challenges that arise in meeting the unique needs of those diagnosed with a rare or young onset dementia. These gaps sometimes begin with my own knowledge and skill set, as most resources and curricula for health care professionals tend to focus on dementia in very general terms, with case study examples that are often reflective of the experiences of older adults, residing in large urban settings.

I decided to join the advisory committee earlier this year, as I felt it would support the development of my own capacity, in this regard. Additionally, it was an opportunity to become involved in research that will bring to light some of the needs not yet met and experiences not yet reflected in the existing resources and knowledge base, related to dementia care. Thus far, I have been inspired by the passion of the research team and impressed with the innovated ways they are engaging participants, in order to give their voices a platform. I am looking forward to wherever the research may lead us.

The image below is from the Centre for Ageing Better's first free library offering photographs of positive and realistic aging.

To see more visit their website HERE

Photo Credit: Paul Grogan

Reflections

Jessica Bertuzzi,
Member, Advisory Committee,
Public Relations & Education Manager, Alzheimer Society of Sudbury-Manitoulin North Bay & Districts

I am grateful to be a part of the RDS Impact Study and work alongside a dedicated team committed to advocating for persons living with rare forms of dementia and their care partners. I have met numerous individuals in the field of dementia, people living with, caring for, providing education, and conducting valuable research in the field. Each one has taught me something that I can apply to my work every day. Thank you to the participants who provide valuable tools and information, enabling us to be a small part in their journey, without them this would not be possible. I am looking forward to what the New Year will bring.

Participate on line!

Photo Credit: Peter Kindersley

We Continue to Recruit Participants

We continue to recruit participants. Rule of Three gives you insight into some of the work we are doing with participants, if you know someone who may be interested please connect them with the contacts enclosed.

Social Connections and Living with Dementia in Ontario

1. Aims: To learn more about the shared experience of dementia for people living with dementia and their care partners. To contribute to developing educational resources for dealing with social isolation for people with lived experience and practitioners
2. Eligibility: You are eligible if you are living in Ontario AND you have been diagnosed with dementia.
3. Duration and Activities: You and your care partner will be participating in interviews and drawing activities to capture your social connectedness twice a year until 2023. You can also participate in optional in-person talking or walking interviews toward the end of the study in 2023.

Rare Dementia Support (RDS) Impact Study

1. Aims: To better understand the unique experiences and needs of persons living with a rare or young onset dementia and their care partners. To contribute to the development of evidence informed support.
2. Eligibility: If you're living with or supporting someone (currently or formerly) living with a rare/young onset dementia, such as, frontotemporal dementia; young onset Alzheimer's disease; Lewy body dementia; posterior cortical atrophy; primary progressive aphasia; other rare/young onset dementias.
3. Duration and Activities: You'll be participating in interviews (individually or in a group), completing questionnaires, drawing, contributing to poetry to express the experience of living with or caring for someone living with dementia, or testing online rare and young onset dementia courses once or twice a year until 2023.

The Rare Dementia Support Impact Study

Is a collaboration between Nipissing University, Canada; University College London, England; and Bangor University, Wales, is funded jointly by the Economic and Social Research Council (UK) and the National Institute for Health Research.

Thank you!

Merci!

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We want to take a moment at the end of this newsletter to say thank you. Thank you!

To our research participants! To our collaborator, the Alzheimer Society Sudbury-Manitoulin North Bay & Districts, and to the networks of people with lived experience!

We would also like to thank our Advisory Committee and the group involved with the Social Connections and Living with Dementia Study. This study was a collaboration between Nipissing University, Canada and Brunel University London, UK and funded by the Retired Teachers of Ontario (RTOERO) Foundation.

With the announcement of RDS Canada it is so very important to us to thank our partners at Rare Dementia Support UK and our funders The Hilary and Galen Weston Foundation. This service will be the first of it’s kind in Canada and we are so very excited to get started.

Finally, a big thank you goes to the Economic and Social Research Council (ESRC), The National Institute for Health Research (NIHR) and colleagues at UCL and Banger Universities in the UK; the funders for the Rare Dementia Support Impact Study.

We invite questions and follow up.
To participate in any of our studies, or for more information about our research activities or events, please email:

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Dr. Mary Pat Sullivan: maryps@nipissingu.ca;
Jen Gordon, MSW, RSW: jennifeg@nipissingu.ca.