
RDS CANADA NEWSLETTER

Hello! Bonjour! Aanii!

Summer has arrived in Canada! We hope you are enjoying the long, light-filled days and the beauty this season brings.

RDS Canada Logo



Image: Summer Solstice Sky of peachy-pink clouds above the Ottawa River

Social Media

Get social with us! Follow us for the latest updates on the emerging service, what's new with our research and more!

Instagram & Twitter:
@RDSCanada

In This Issue

Knowledge Exchange
Research Updates
Student Placements

Rare Dementia Support Canada - Service Updates

The support services at RDS Canada continue to develop! These services are free of charge to those who register and are delivered in partnership with RDS UK, a world leading service provided by University College London Dementia Research Centre and funded by the National Brain Appeal. A key component of RDS Services is direct support, individual and group. Our latest developments include the launch of our group services. RDS Canada is currently running a biweekly group for family and friends of someone with a diagnosis of rare or young onset dementia and are registering members for additional group starting over the summer months. The purpose of all RDS Canada groups is to create a confidential, virtual space where people with shared experiences can connect and discuss. Membership registration is required. Please see the following page for more details:



Image: A Road in a Wood
(Hawthornden Castle,
Scotland) and a line from
Frost's poem *The Road Not
Taken*

Family & Friends Group: This group is designed for anyone who is a family or friend to someone living with a diagnosis of rare or young onset dementia. This virtual group uses the Zoom platform and meets bi-weekly, on Tuesdays from 1 pm – 2:30 pm EST. The Family and Friends group will be facilitated by Jen Gordon, MSW, RSW. For more information, please see the flyer at the end of this newsletter.

PCA Support Group: The PCA Support Group is designed for anyone who is living with a diagnosis of Posterior Cortical Atrophy (PCA), their family members and/or friends. This virtual group uses the Zoom platform and meets monthly, on the third Thursday of the month from 1 pm – 3 pm EST. The PCA Support group will be co-facilitated by Jen Gordon, MSW, RSW, and Mary Pat Sullivan, PhD, MSW, RSW. We are currently accepting registrations and this group will start on July 21st. If you, or someone you know may like to participate please contact us.

The Road Less Travelled (TRLT): This group is designed for family members or friends of a person living in the later stages of a dementia diagnosis. TRLT is a grief and loss group and is offered in collaboration with RDS UK. This virtual group uses the GoTo Meetings platform and meets weekly over an eight-week period. This is a group program with guided, facilitated discussions on the complexities of grief and loss in the context of rare or young onset dementia. TRLT will be co-facilitated by Jen Gordon, of RDS Canada, and Jill Walton, of RDS UK, and will include participants from both Canada and the UK. We are currently accepting registrations and this group will start on August 16th. If you, or someone you know may like to participate please contact us at RDS Canada.

As RDS Canada services develop we will increase these offerings to include further diagnosis specific groups and topic specific conversations such as: considerations for travel, planning for holidays, maintaining social connection and more.

For more information about any of our support groups, please contact us at rdscanada@nipissingu.ca, or (705) 474-3450, ext. 4266.

The Road Not Taken

By Robert Frost

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveler, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, as just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way leads on to way,
I doubted if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I—
I took the one less traveled by,
And that has made all the difference.



Knowledge Exchange 2022

The third annual virtual Knowledge Exchange was hosted on Thursday June 16 with a focus on primary progressive aphasia. Knowledge Exchange 2022 was organized in collaboration with the Aphasia Centre of Ottawa (ACO). There was an impressive attendance of over 120 people from across Canada and other parts of the world. The first presentation by Dr Chris Hardy of the Dementia Research Centre, University College London, UK highlighted the defining speech and language features of the major PPA syndromes as well as research findings around stages and future directions in PPA research more generally. Following Dr. Hardy, Evelyn Weger, RSW, and Joanne Winckel, SLT, of the Aphasia Centre of Ottawa, discussed how the organization has evolved to meet the needs of individuals affected by PPA including the types of services ACO provides. Dr. Aida Suárez-González, of the Dementia Research Centre, University College London joined the event from Spain and discussed evidence-based rehabilitation and support therapies currently recommended for people living with PPA. Dr. Suarez-Gonzalez talk included information on the rehabilitation of language, strategies to maintain activities of daily living, management of psychological symptoms and the value of support groups in PPA. The final presentation by Dr Anna Volkmer of the Division of Psychology and Language Sciences, University College London, UK highlighted the important work of speech language pathologists in supporting both the person living with PPA and their family/friends. Dr. Volkmer's talk included different strategies that can improve or maintain day to day conversations and interactions as well as manage swallowing difficulties.

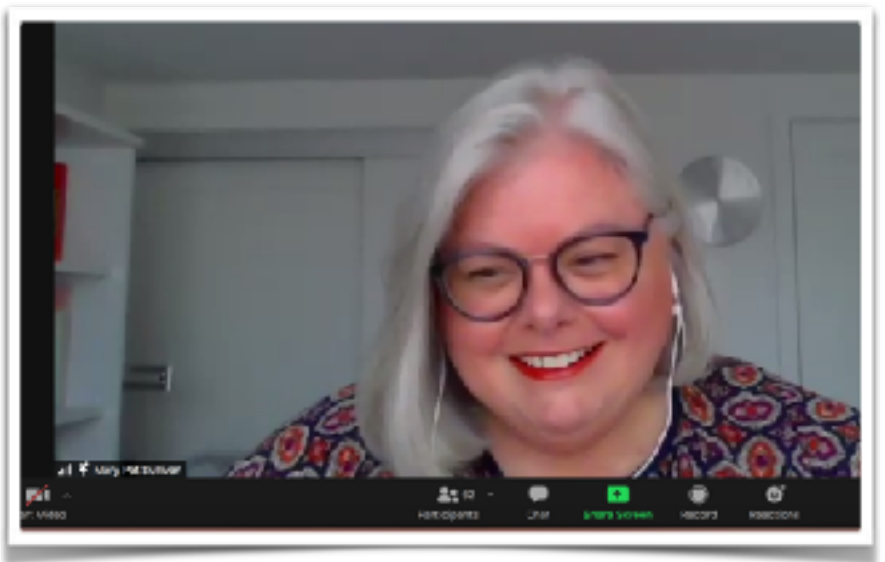
There is So Much I Could Say



Image: Poetry Anthology, 'There Is So Much I Could Say'

The recently published anthology 'There Is So Much I Could Say' can be purchased at this [link](#). These poems were written by Rare Dementia Support Impact Study research participants, and edited by poets Martha Gould in Canada and Lawrence Wilson in the United Kingdom. Money raised from the sale of the anthology will be used by the National Brain Appeal, in part to build the world's first Rare Dementia Support Centre.

RDS Canada Lead, Dr Mary Pat Sullivan presented updates on the RDS Impact Study and how we are translating knowledge from the study into evidence-based advice, care and support for Canadians affected by rare or young onset dementia through Rare Dementia Support Canada. We are thankful to our speakers and attendees for contributing to the success of this year's event. The discussions highlighted the complexities of dementia, the diversity of experience for someone living with primary progressive aphasia and the value of care and support that is informed by learning from research.



Research Updates

Rare Dementia Support (RDS) Impact Study

We continue to recruit for the RDS Impact Study, we welcome new participants into the study until December 2022. We know a lot about Alzheimer's disease diagnosed in later life, but less is known about other types of dementia, particularly the rarer forms that typically affect people under age 65. The aim of the study is to better understand the experiences of people affected by rare or young onset dementia and their support needs. Participation in the Impact Study is open to anyone living with a rare or young onset dementia (such as posterior cortical atrophy, fronto-temporal dementia, primary progressive aphasia, Lewy body dementia or young onset Alzheimer's disease)



Image: a young woman sitting at a conference table, smiling

Student Placements at RDS Canada

RDS Canada is excited to host and open to student placements for students in health and allied health programs. Those who come to learn will have the opportunity to learn about direct support services and research on support services, for people affected by rare or young onset dementia. We are pleased to share that we will have a fourth year Bachelor of Social Work student joining RDS Canada in September. We welcome Gabrielle Ouellette to RDS Canada. Please see Gabrielle's bio on pages 6 and 7.

as well as their family/friends living anywhere in Canada. Your participation will involve annual interviews with a member of our research team, to the researcher will ask questions about your experiences, feelings, and opinions living with or caring for someone living with a rare or young onset dementia. If you are interested, please feel free to email Dr. Adetola Grillo (adetola.grillo@nipissingu.ca).



Image: a group of adults discussing current events

Social Connections and Living with Dementia (SID) Study

This study is funded by the Retired Teachers of Ontario (RTOERO) Foundation and is focused on understanding how social isolation and/or loneliness is experienced by people living with dementia and their care partners, and how their relationship influences this experience. The SID study is running until 2023. One of the goals of the study is to contribute to the development of practical, educational, dementia care resources for recognizing and coping with social isolation and loneliness. These outputs will be designed for professionals as well as people living with dementia, their families and friends. The study is open to anyone residing in Ontario, who is living with dementia and/ or their care partners. Those who volunteer to participate will engage in different ways: 1) for someone living with dementia and their care partner, this will involve participation in interviews, completion of questionnaires and an guided creation of an eco map at least twice a year. 2) for someone caring for a person living with dementia in long-term care home, this will involve participation in a one-time interview and completion of questionnaires. If you are interested, please feel free to email Dr. Adetola Grillo.

Gabrilie Ouelette

“My name is Gabrielle Ouellette, and I will be entering my 4th year of the BSW program at Nipissing University this fall of 2023. I am thrilled to announce that I have been offered the opportunity to conduct my 4th-year placement at Rare Dementia Support Canada. Ever since I have been a young girl, I have always longed to pursue a career that will be able to highlight my people-centric nature and empathetic personality. I have always known that I wanted to be able to make a difference in my hometown community of North Bay Ontario. At Nipissing University, I have been fortunate enough to be able to unearth my passion for Social Work. This placement opportunity with Rare Dementia Support Canada will allow me to expand on the knowledge and skills I have gained throughout my years in the social work program and apply them within a specialized field and setting. I look forward to working alongside and learning from Dr. Sullivan and placement supervisor, Jen Gordon. I am eager to contribute to the important work of Rare Dementia Support Canada.”

Online educational course for PPA, PCA, FTD

As part of the RDS Impact Study, an online course has been developed to provide education on symptoms and care strategies for PPA, PCA and FTD. These courses are designed for people who are caring for anyone living with PPA, PCA or FTD and are open to friends and family of someone with a diagnosis. . These courses are self-paced, offered online and run for seven weeks at a time. Access to internet as well as a computer, laptop or smart phone is required to participate. Those who wish to take part will be assigned to either of two groups, a test group, where you will participate in the online course for seven weeks or a control group, where you will be offered another intervention. (Please note that if you are assigned to the control group, you will be offered the course at the end of the seven-week testing period). In addition, you will also complete pre and post questionnaires . If you are interested and would like to trial these educational modules for family and friends of someone living with PPA, PCA or FTD, please feel free to email Dr. Adetola Grillo (adetola-grillo@nipissingu.ca).



Image: a woman working at a laptop computer

Gabrilie Ouelette

"Mon nom est Gabrielle Ouellette et je commence ma quatrième année de travail social, à l'université du Nipissing, cet automne 2022. Je suis excitée d'entreprendre mon dernier stage de la quatrième année avec Rare Dementia Support Canada. J'ai toujours voulu avoir une carrière gratifiante qui me permettrait d'utiliser ma personnalité sociale et empathique pour pouvoir faire une différence dans ma ville natale de North Bay, Ontario. A l'université du Nipissing, j'ai découvert ma passion pour le travail social. La chance de faire mon stage avec Rare Dementia Support Canada m'offrira certainement de développer davantage mes connaissances et habiletés obtenus durant mes trois dernières années d'études en travail social pour pouvoir ensuite les appliquer dans un domaine et environnement spécialisé. J'attends avec enthousiasme la chance de travailler et d'apprendre auprès du Docteur Sullivan et la superviseure de stage Jen Gordon. J'ai hâte d'offrir ma contribution au travail important de Rare Dementia Support Canada."

We are pleased to report that RDS Team members Veronika Williams and Jen Gordon recently presented at the Northern Ontario School of Medicine (NOSM) Northern Health Research Conference. On behalf of the Rare Dementia Support Impact Study Veronika's and Jen's presentation focused on the translation of learning from the multi centre Rare Dementia Impact Study which is informing the services of Rare Dementia Support Canada.. Hosted by the Northern Ontario School of Medicine University (NOSM)/ École de médecine du Nord de l'Ontario (EMNO), this 17th annual conference focuses on research in Northern Ontario and was offered in a hybrid format for the first time, allowing participants to join in person and remotely.-

Rare Dementia Support Canada is one of many positive, tangible outcomes resulting from the research of the ongoing Rare Dementia Support Impact Study. Working with RDS UK, RDS Canada is now converting the study's results into evidence-informed advice and support for Canadians who are affected by rare or young onset dementia. This helps to fill a gap in the health care system by addressing the needs of younger people, and those with atypical dementia. RDS Canada's direct support, resources, and information now offer a choice to people who previously found virtual support outside of Canada, or tried to fit into a model of support for older people living with Alzheimer's disease.

It is always exciting for academics to disseminate their knowledge.

We wish to acknowledge and thank the study's funders, the Economic & Social Research Council and National Institute for Health Research in the United Kingdom (UK).



Spotlight On: Live Well - Dementia Connections



Dementia Connections magazine was founded by Lisa Poole in 2017. Originally launched as a regional magazine for readers in the Calgary area, the magazine is now available online. Recently renamed *Live Well – Dementia Connections*, the publication aims to “amplify the voices of lived experience and share expert advice about living well with dementia.” As well, the team, led by editor Carolyn Brandly, seeks to “reduce stigma and increase public awareness, to improve access to supports and services for families impacted by dementia, to encourage participation in research and to serve as a resource for the healthcare workforce.”

Spring/Summer 2022 issue highlights:

- **Shining a Light on Frontotemporal Dementia**
- **Creative Approaches Improve Care**
- **Eating Well at Home with Dementia**
- **Design for Dementia: Soundscapes**
- **Long-distance Care Partnerships**
- **Working Around Barriers to Care**

Click [this link](#) for a free issue of this magazine.

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:

Dr. Adetola Grillo: adetola.grillo@nipissingu.ca

Dr. Mary Pat Sullivan: marypat.sullivan@nipissingu.ca

Jen Gordon, MSW, RSW: jen.gordon@nipissingu.ca



Family & Friends Group

Your wellness is important.

The RDS Canada Family & Friends group is designed for anyone who is family or friend to someone living with a diagnosis of rare or young onset dementia.

Meet the Team

Jen Gordon, MSW, RSW
Jen is a social worker, registered in the province of Ontario, and is the facilitator of the Friends & Family Group

Mary Pat Sullivan, PhD, MSW, RSW
Mary Pat is a social worker and Lead for RDS Canada services. Mary Pat may occasionally facilitate group discussions.

Louise Ells
Louise is the secretary for RDS Canada. She is the main person to answer our phones and can provide practical support to get set up on Zoom.

The purpose of the group is to create a confidential, virtual space where people with shared experiences can connect and discuss.

This support group is biweekly, and each session runs for 1.5 hours. Registration is required and there is a virtual pre-group meeting with the group facilitator.

Join us from the comfort of your home! We will have conversations together on topics such as:

- managing change,
- acceptance,
- asking for help,
- impacts of myths & stereotypes,
- grief and loss,
- self-care and wellness.

This support group is virtual and will be held over Zoom.

You Will Need

- Access to a computer, tablet or phone with video.
- High speed internet.

We can provide practical support to get set up on Zoom.

email: rdscanada@nipissingu.ca
phone: 705-474-3450 ex. 4266

06.07.2022