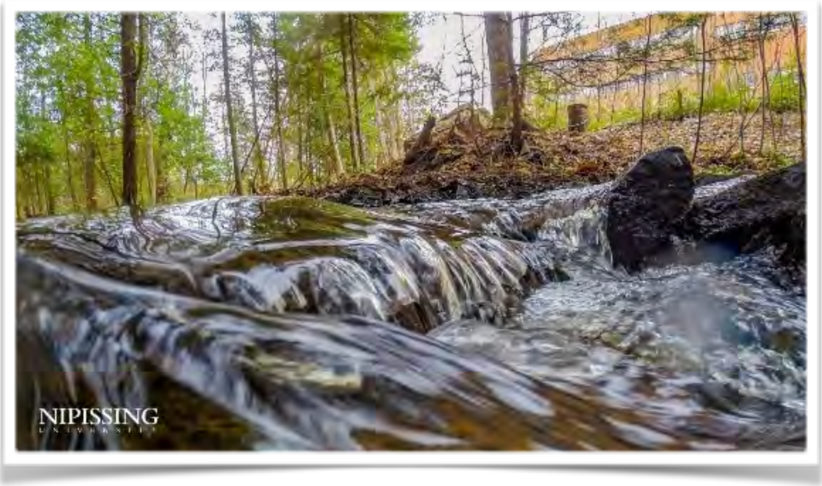
RDS CANADA NEWSLETTER

Aanii! Bonjour! Hello!



April has ushered in a new season; the chill and frost of winter has given way to the warmth and rebirth of Spring! April is national poetry month. We also celebrate Earth Day in April; we pause to appreciate the blue and green spaces across Canada, our connections to Mother Earth, and our duty to ensure sustainable life.

We have made significant strides in the development of Rare Dementia Support Canada, and are pleased to share updates in this newsletter.

Rare Dementia Support (RDS) Canada

RDS Rare Dementia Support
CANADA
Advice • Community • Learning

We are pleased to announce the hiring of two RDS Canada staff.

Jen Gordon has been hired at Manager of RDS Canada. Jen is a Registered Social Worker with the Ontario College of Social Workers and Social Services Workers and will manage and provide leadership for the delivery of direct support services.

Louise Ells has been hired as the Secretary for RDS Canada. Louise, care partner for her husband, who is living with young onset dementia, brings experience in organization, communication and empathy.

Jen and Louise look forward to meeting you virtually and providing services through Rare Dementia Support Canada.

RDS Canada phone: 705-474-3450 ext. 4266

Rare Dementia Support Canada is a support service for Canadians affected by rare or young onset dementia. The service is led by Nipissing University and funded through a generous donation from The Hilary and Galen Weston Foundation.

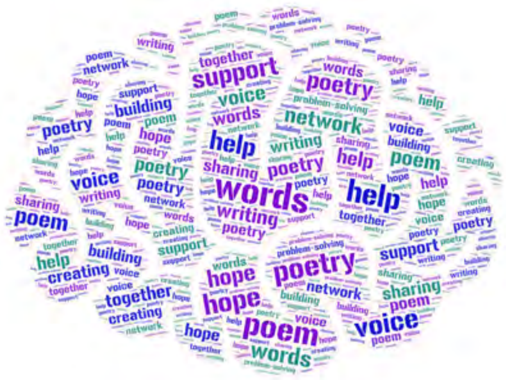
RDS Canada provides:

- Tailored information and learning resources for people living with rare or young onset dementia, care partners and professionals.
- Individual, family, and group support.
- Canada-wide services provided by a team of practitioner specialists, researchers, educators and individuals with lived experience.

These supports are free of charge, and 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.

Become a Member

To access supports and resources, please register using this link. Anyone affected by dementia, as well as professionals and researchers are welcome to become a member, there is no cost for membership.



Inaugural virtual support group: Words Together

Our inaugural support group is called *Words Together* and will begin in May! This group is for adults living with a diagnosis of a rare or young onset dementia, in early stage, who wish to connect with others. Participants are welcome to be accompanied by another person (family or friend) for support.

Words Together will run weekly on Tuesdays from early May to mid June. The group will focus on post diagnosis experiences such as sharing your diagnosis with others, navigating specialist support, strategies for living well in the face of challenges, and more. During the 6-week group participants will co-create a group poem to convey and express lived realities of dementia. No previous poetry writing or reading experience is necessary.

In addition upcoming group supports will include:

- The Road Less Travelled: Our journey with grief and loss, A program for carers of people living with rare dementia. Starting in August 2022
- Posterior Cortical Atrophy (PCA) Group. Start date TBA
- Open group for family or friends supporting someone with a rare or young onset dementia. Start Date TBA

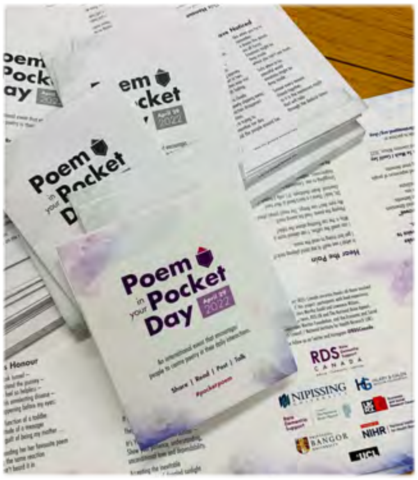
For more information on these groups please contact rdscanada@nipissingu.ca

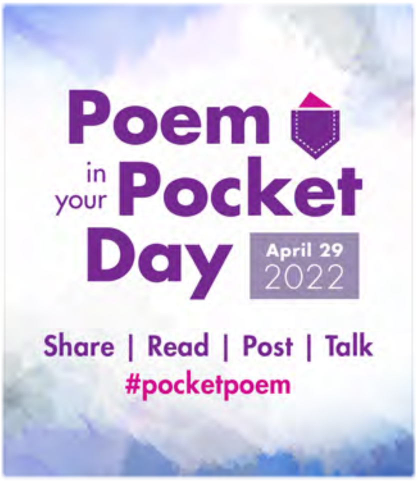
Visit of RDS UK Manager

Nikki Zimmermann, support team lead for RDS UK, will be visiting Canada in July. She will spend time with the RDS Canada staff in North Bay providing support to our team as we build our services. We look forward to this visit as we build our connections and strengthen support for people affected by rare or young onset dementias.

National Poetry Month

April is National Poetry Month, a month set aside to celebrate poetry's contribution to understanding human experience. As part of the Rare Dementia Support (RDS) Impact Study, we have used poetry as a methodology to learn more about the experiences of living with a rare or young onset dementia. We asked people with rare or young onset dementias and their care partners to respond to 4 different prompts. These words have been put together into poems by professional poets, Martha Gould and Lawrence Wilson, and reflect a powerful narrative of what it means to be affected by a rare or young onset dementia. This month RDS Canada has been engaged with multiple events through the League of Canadian Poets to share this poetry with the public.





Poem-in-your-pocket

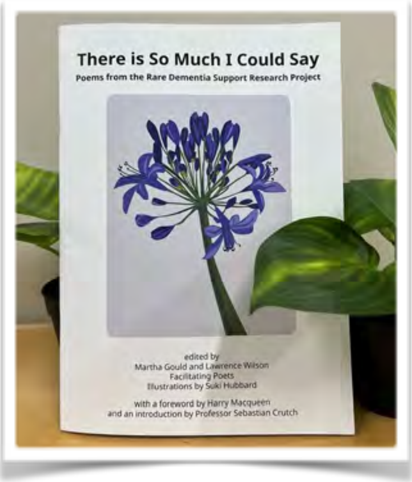
Poem-in-your-pocket day is an international event to encourage people to centre poetry in their daily interactions and share pocket-sized poems. This year, PIYP day is celebrated April 29th.The RDS Canada team & members of our Advisory Circle were out in the community in North Bay, Thunder Bay and Gananoque distributing poems from the study.Thank you to everyone who stopped to chat and ask questions, and to the organizations that supported us!

Poetry Pause

Two poems, *Accept This Honour* and *Hear The Pain,* have also been promoted by the League of Canadian Poets as part of 'Poetry pause'. 'Poetry pause' is a 'daily poetry dispatch' initiative inspired by the Academy of American Poets' 'Poem-a-day'. The League of Canadian Poets circulates poems by emerging and seasoned poets digitally to a mailing list of over 10,000 people. We are pleased that poems from the study will be reaching a huge audience. You also can read, *Accept This Honour* and *Hear The Pain* on the League's Facebook, Twitter or Instagram pages.

Cross-Pollinations

On Wednesday March 30, Dr. Mary Pat Sullivan, Martha Gould, and Jen Gordon participated in cross-pollinations, a webinar series hosted by the League of Canadian Poets and the Canadian Association for Health Humanities. Hosted monthly, the series features discussions related to healthcare, art, healing, and the humanities. The session focused on how poetry has been used in the study to understand the experiences of people affected by rare or young onset dementias. Attendees also had the opportunity to listen to readings of some poems. We thank the League of Canadian Poets for this opportunity to raise awareness of rarer dementias, and attendees from across Canada and the United Kingdom. A recording of the discussion can be found on the League's YouTube page. In addition to the activities through the League of Canadian Poets we have also launched a poetry volume, through The National Brain Appeal.



Launch of *There Is So Much I Could Say*

Thirty-two of these poems have been published in the book, *There Is So Much I Could Say.* The foreword was written by 'Supernova' filmmaker, Harry Macqueen. Illustrations by Suki Hubbard and an introduction by Rare Dementia Support (UK) lead Professor Sebastian Crutch. *There Is So Much I Could Say* is funded by The National Brain Appeal and is available to purchase on their website.

Rare and Young Onset Knowledge Exchange 2022

This year's Knowledge Exchange is scheduled for Thursday June 16 from 9.00am to 12 noon (ET). The live virtual event is a public engagement activity of the RDS Impact Study and RDS Canada, that brings together researchers, practitioners, and people with lived experience to discuss current knowledge and evidence-informed practice in the care and support for rare or young onset dementias.

This year's theme is on primary progressive aphasia and will feature the following presentations:

- Advances in Primary Progressive Aphasia: Understanding speech, language, and auditory symptoms – by Dr Chris Hardy, Dementia Research Centre, University College London Institute of Neurology, United Kingdom
- Rehabilitation and support therapies for people with PPA – by Dr Aida Suárez-González, Dementia Research Centre, University College London, United Kingdom
- Speech, language and swallowing in Primary Progressive Aphasia: A whistlestop tour on the role of the speech and language therapist – by Dr Anna Volkmer, Division of Psychology and Language Sciences, University College London, United Kingdom
- Primary Progressive Aphasia: creating community for people affected by PPA through innovative professional interventions – by Evelyn Weger and Joanne Winckel, Aphasia Centre of Ottawa, Canada

Mary Pat Sullivan and Jen Gordon will also provide updates on RDS Canada and RDS Impact Study. For more information on presentations and to register for this free event, please visit the Eventbrite link HERE.

Rare Dementia Support Impact Study Updates

Survey for Health/Social care professionals

We are inviting health and social care professionals who work with people affected by rare or young onset dementias to participate in an anonymous online survey. The survey is a part of the creative poetry project of the RDS Impact Study and will ask you to read and listen to three poems and respond to some questions about your experience. By participating, you will help us better understand how poetry can be used to inform professionals and the general public about the experiences of people affected by rare or young onset dementias. You will also have the opportunity to learn more about this population, which may impact your own practice and knowledge about rare or young onset dementias. The survey should take 15-20 minutes to complete. Please feel free to share with your networks, the link will remain live until May 31, 2022.

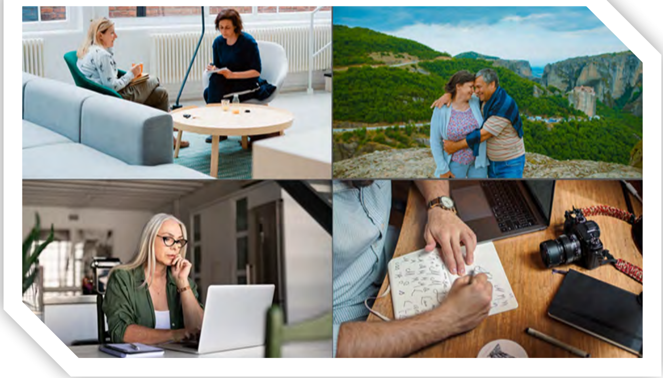
Exploring connections and loneliness at the time of care transitions

The Social Connections and Living with Dementia (SID) Study is a two-year study funded by the Retired Teachers of Ontario (RTOERO) Foundation, focused on learning more about experiences of social connections, isolation and loneliness in people affected by dementia.

An emerging theme we are exploring involves the impact of the transition to long term care on social connections and experiences of loneliness. Participants in our study have been sharing that this transition brings with it particular changes for the person living with dementia as well as their family care partners individually and collectively, and we would like to learn more about this experience. If you or know someone you know may be interested in sharing experiences during one confidential virtual interview, please let us know.

We are also still recruiting for other parts of the study. Eligible participants include a person living with dementia living at home and their care partner, who will complete an eco-map depicting social connections and longitudinal questionnaires about their experiences of isolation and/or loneliness.

Testing web-based PPA educational program for care partners



As part of the RDS Impact Study, we have developed an online program for care partners of people living with Primary Progressive Aphasia (PPA). The program is hosted on a website. We want to test (a) how easy you find the program to use, and (b) whether it can help provide better support, both for you as a care partner and for the person living with PPA.

In taking part, you will receive either the PPA web-based program or alternative support, which you can work through at your own pace over seven weeks. The way you use the program will be analyzed. We will also ask you to complete some online questionnaires before, just after, and sometime after you have worked through the program or alternative support. If you receive the alternative support, you will be sent a link to the PPA web-based program later in the year. Please feel free to contact a member of the research team for further information.

Rare Dementia Support (RDS) Impact Study is still recruiting!

The RDS Impact Study is the first major study of its kind, receiving the equivalent of $6m, to learn more about support needs and care preferences of people affected by rare or young onset dementia. The study also explores the value of different types of support groups for social, emotional and practical support. Funded by the Economic and Social Research Council (ESRC)/National Institute for Health Research (NIHR) in the UK, the study is a collaboration between Nipissing University, University College, England and Bangor University, Wales. What we learn through collaboration between researchers, people with lived experience and professionals will help us recommend, strengthen and develop needed support services and interventions, such as RDS Canada.

Eligible participants are individuals living with a rare or young onset dementia (such as frontotemporal dementia (FTD), primary progressive aphasia (PPA), posterior cortical atrophy (PCA), Lewy body dementia (LBD), young onset Alzheimer's disease (YOAD), familial FTD or familial AD) and their care partners, who are invited to participate in interviews and completion of questionnaires.

We are recruiting for both of our studies until the end of 2022. If you would like to participate, please feel free to contact the research team:

Adetola Grillo (adetolag@nipissingu.ca) or Mary Pat Sullivan (maryps@nipissingu.ca)

MERCI! MIIGWECH! THANK YOU!

As our work continues to expand, we are excited about the future and the change we are creating! We are thankful to everyone who has been part of our success, including:

- Our funders, The Hilary and Galen Weston Foundation; Economic and Social Research Council/National Institute for Health Research

TO REMAIN CONNECTED WITH US

To register or learn more about RDS Canada, the RDS Impact Study, or any of our other activities, please email rdscanada@nipissingu.ca or a member of the team:

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