



# Rare and Young Onset Dementia: Translating learning from the multicentre Rare Dementia Impact Study to Rare Dementia Support Canada

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UK Research  
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NEURO  
MUSCULAR  
BRAIN INJURY  
STROKE EPILEPSY  
BRAIN TUMOUR  
DEMENTIA PRION  
PARKINSONS  
MIGRAINE  
SPINAL  
MULTIPLE  
SCLEROSIS



**RDS** Rare  
Dementia  
Support  
C A N A D A  
Advice • Community • Learning

**Rare  
Dementia  
Support**  
Advice Community Learning



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# Rare, Inherited and Young Onset Dementia

- 5 – 25% of people with dementia have a diagnosis of a rare, inherited or young onset dementia (Brotherhood et al., 2019).
- Symptoms are often atypical leading to an incorrect or delayed diagnosis (Woolley et al., 2011).
- Distinct life stage challenges due to young age of onset (Harding et al., 2018; Griffin et al., 2016).
- Poorly understood by health and social care practitioners (McIntyre et al., 2018).
- Under researched and unaccounted for in the design and delivery of health and social care (Stamou et al., 2020; Harding et al., 2018).

# Rare, Inherited and Young Onset Dementia

- Lewy body dementia
- Young onset Alzheimer's disease
  - Familial Alzheimer's disease
- Primary Progressive Aphasia
  - Nonfluent/Agrammatic variant
  - Semantic variant
  - Logopenic variant
- Frontotemporal dementia
  - Behavioural variant
  - Corticobasal syndrome
  - Familial frontotemporal dementia
- Posterior Cortical Atrophy
- Others
  - Alcohol related dementia
  - HIV associated dementia
  - Vascular dementia
  - Down syndrome and Alzheimer's disease
  - Mixed dementia
  - Creutzfeldt-Jakob disease
  - Huntington's disease





# Rare Dementia Support (RDS) Impact Study

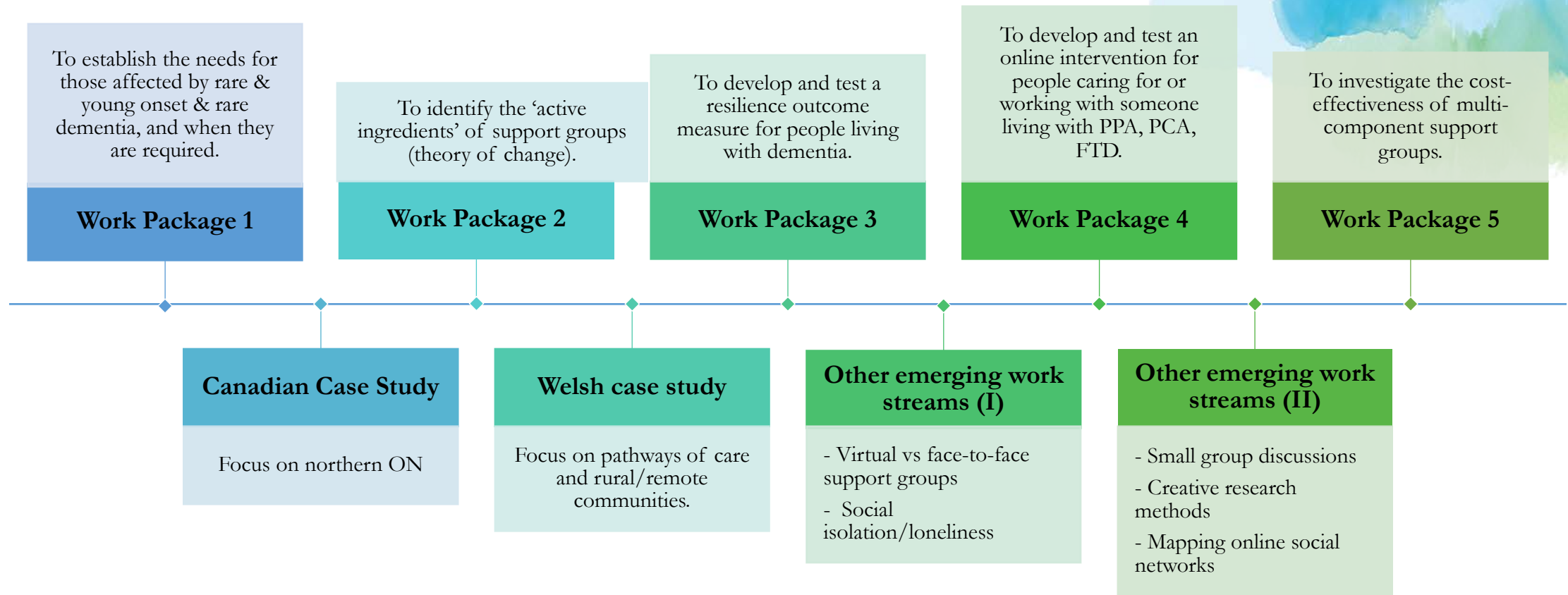
- 5-year study funded by the UK Economic & Social Research Council/National Institute for Health Research (£3.7 million).
- Aim to examine what are effective supports for people living with rare and young onset dementia, including what support looks like in different contexts and what is most cost effective.
- Professor Sebastian Crutch (PI) Neuropsychologist, Dementia Research Centre, University College London.



## Rare Dementia Support Impact Study



# Rare Dementia Support (RDS) Impact Study



# Rare Dementia Support: Emerging Findings

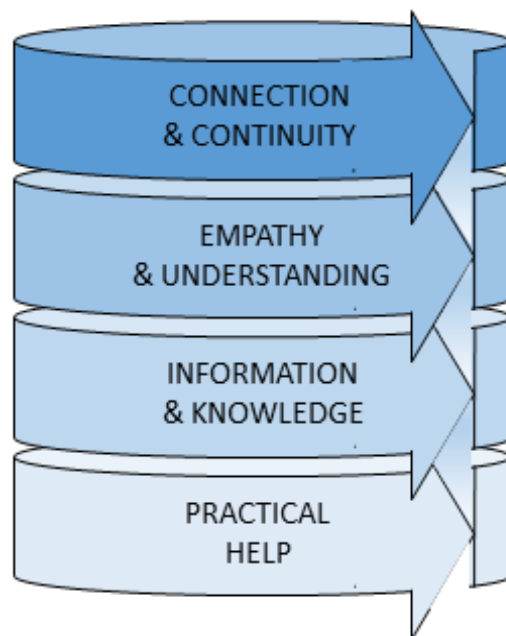
- Highly fragmented care and support
- Transition from diagnosis to support
- Timing of support (i.e. diagnosis, mid-stage vs late-stage, end-of-life)
- Disease specific (clinical characteristics) and non-disease specific support
- Peer and professional support
- Homogeneity in group construction
- Frequency and flexibility of support
- Informational, instrumental and emotional support - Specific support themes/types (e.g., social isolation and reconnection/male care partners/FTD)
- Virtual versus face-to-face
- Person living with dementia, care partners, families (intergenerational)
- Support for health and social care professionals



- Self-directed, free, continuous and tailored practical and emotional support
- Online individual, family and group delivery
- Support groups
  - Diagnostic specific groups
  - Family and Friends
  - A Road Less Travelled (Grief and Loss)
  - Words Together (Early Stage)
- Group conversations
  - Maintaining social connections
  - Navigating family celebrations
- Professional and peer support
- Culturally and linguistically relevant

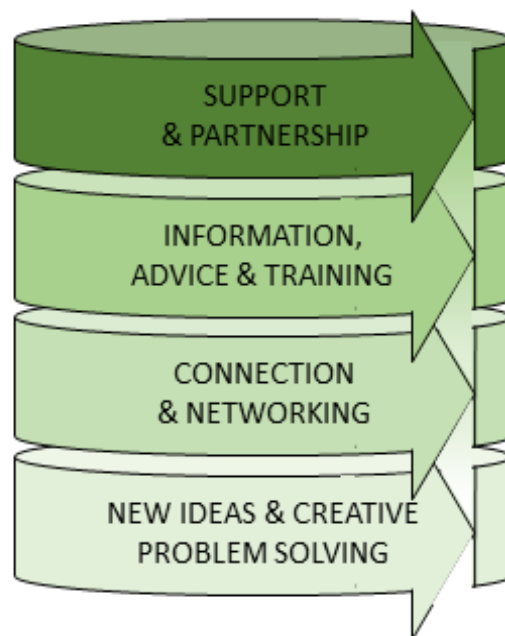
### PEOPLE WITH LIVED EXPERIENCE

Overall principle: To enable RDS members to find...



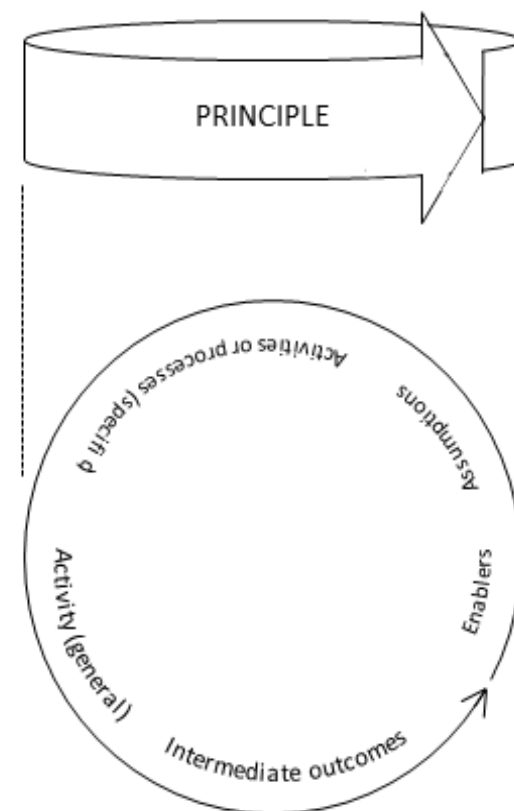
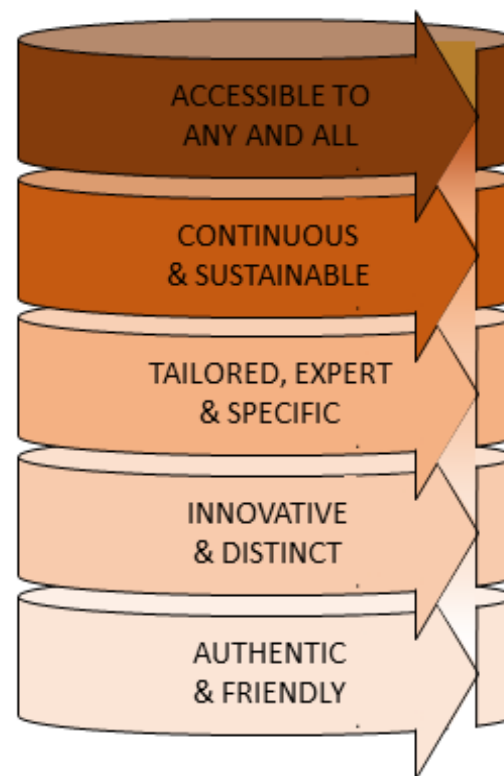
### PROFESSIONALS

Overall principle: For professionals to see RDS as a place providing...



### RDS AS A TEAM & ORGANISATION

Overall principle: Develop & maintain a support service that is...



Thank you for listening.

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