



Rare Dementia Support

Advice Community Learning



“ We provide holistic support for people living with rare dementias and their families ”

PHOTO BY PRISCILLA DU PREEZ ON UNSPLASH

What is Rare Dementia Support ?

Rare Dementia Support offers specialist social, emotional and practical support services for individuals living with, or affected by, a rare dementia diagnosis. Our vision is for all individuals with, at risk of or supporting someone with one of these forms of dementia to have access to information, tailored support and guidance, and contact with others affected by similar conditions. RDS welcomes people from all areas of society affected by a rare dementia regardless of gender, age, marital or family status, race, ethnicity or sexual orientation.

SUPPORT



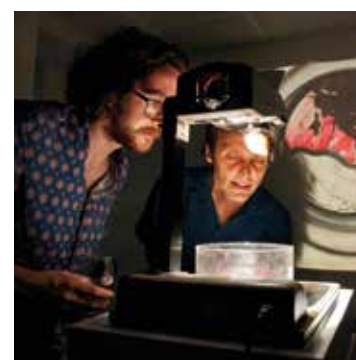
We provide holistic support for people living with rare dementias and their families, through one-to-one, small group and large group support services at every stage of a rare dementia diagnosis

EDUCATION



We provide education and training for professionals working with people living with rare dementias, as well as resources to raise awareness and increase understanding

RESEARCH



We pioneer research into individual and group support and into strategies and interventions for people with a diagnosis and their care partners and families

IMAGE CREDITS: FARNETT | GRAHAM | SANDERSON | GILBERT | WELLCOME

What does RDS offer to members?

“At RDS we aim to offer continuous community and support at every step. We try to tailor advice to you, your specific dementia and your situation, so we can offer the right help at the right time”

PROFESSOR SEB CRUTCH, CLINICAL LEAD FOR RARE DEMENTIA SUPPORT

ONE-TO-ONE SUPPORT

- **Direct Support Team** – empathetic and empowering one-to-one email, phone and video call support, with signposting to relevant services including a free legal advice service.

LARGE GROUP MEETINGS

- **Diagnosis specific meetings** – offering a chance to meet with others in a similar situation.
- **Carer-only meetings** – (any rare dementia diagnosis) with separate meetings for those in the ‘earlier’ (e.g. post-diagnostic) and ‘later’ stages.
- **Webinars** – to hear about the latest research, member stories and updates on RDS activity.

SMALL GROUP MEETINGS

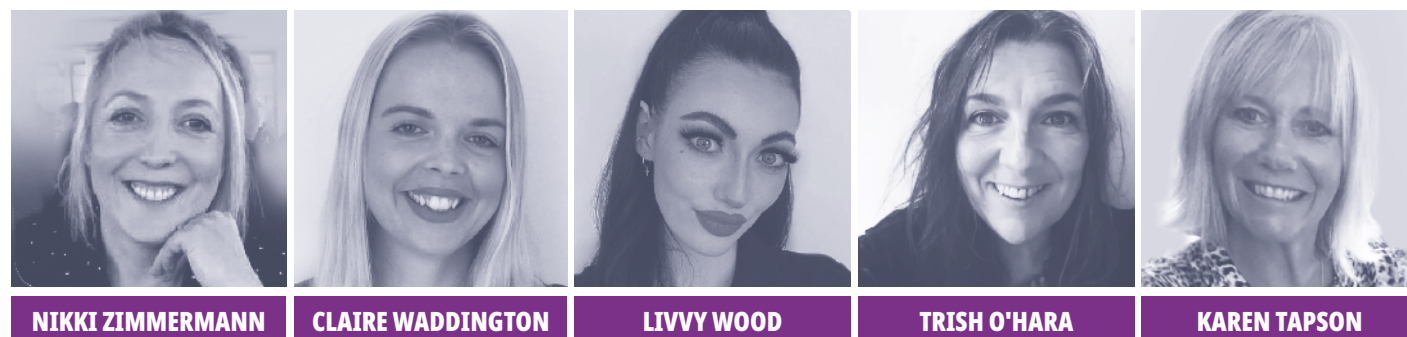
- **Regular peer group meetings** – opportunities for groups of up to 12 members (separate groups for people living with a rare dementia and care partners) to meet via video call with a member of the RDS team to spend time sharing experiences, questions and advice.
- **Regional support groups** – in various locations across the UK offer a chance to meet (in person and online) with others living with a rare dementia in your local area.
- **Themed programmes & workshops** – information and resource sharing sessions.
- **Bereaved carer meetings** – discussions for those who have previously cared for someone living with a rare dementia diagnosis.

You can contact the team at contact@rarementiasupport.org



“RDS has helped me to make the best of every day. They’ve helped me accept the down days but also have helped me to make many positive changes”

One to one support



The RDS Direct Support Team can provide guidance, information and signposting on a one-to-one basis, usually by email, phone or video call. The team offers empathetic, tailored support designed to engage, educate, enable and empower RDS members. Types of assistance the team regularly offer include:

- **Practical and emotional support** following the diagnosis of a rare dementia.
- **Navigation and guidance** through available health and social care services, helping people to seek appropriate assessments, benefits and entitlements as well as assisting with care planning.
- **Educational support** including providing information appropriate for people living with dementia, family, friends and healthcare professionals.
- **Advice and guidance** with later stages and transitioning into different care settings.

“The knowledge I have gained from my support call was like a voice ringing in my ears as we come across, and tackle different things, and that is SUPER helpful and confidence giving”

For information relating to a specific rare dementia diagnosis, please contact the RDS Direct Support Team at

contact@raredementiasupport.org or call us on 020 3325 0828

We will refer your enquiry to the most appropriate team member. **Please note** that phone calls will not be answered immediately, so please leave a voicemail message with your contact information.

Diagnosis specific large group meetings and webinars

Throughout the year we host a programme of in person large group meetings (in London) and online webinars. All RDS members are invited to attend the meetings relevant to them. This includes people living with or at risk of a diagnosis, as well as partners, carers, family and friends.

Our large group meetings provide an opportunity to meet others affected by the same condition, share experiences and ask questions in a relaxed setting. The large group meetings and webinars include speaker-led talks and question and answer sessions on a range of subjects, offering

information and advice as well as updates on the latest research. The primary focus of our London based large group meetings is having the opportunity to meet others in a similar situation. The meetings are organised around informal social time with tea, coffee and refreshments. We strive to make these meetings as accessible as possible – intellectually, physically and financially – and include experts both by profession and lived experience.

Previous meeting recordings can be found on the [RDS YouTube channel](#)



“Initially I was a little concerned that some were much earlier in the journey but it didn't seem to matter. It was clear what people wanted to talk about. At the end of the day people want the contact with others who are broadly in the same boat. There was a lot of positive sharing and support”

Our large group meetings

We currently host large group meetings and seminars for people affected by the following conditions:

LEWY BODY DEMENTIA (LBD)

is a form of dementia which is closely related to Parkinson's Disease and can affect thinking, memory, vision and movement.

“DLB is a rollercoaster, one day quite normal, other days are not”

PRIMARY PROGRESSIVE APHASIA (PPA)

is a term that refers to a group of dementias that affect a person's speech and language. We support people living with all forms of PPA, with a focus on Progressive Nonfluent Aphasia (PNFA), Semantic Dementia (SD) and Logopenic Aphasia (LPA).

“Losing the ability to talk takes away all the fun and games”



FRONTOTEMPORAL DEMENTIA (FTD)

refers to a group of dementias which mainly affect personality and behaviour or language and speech, depending on which areas of the brain are affected.

“FTD behaviour is so unexpected, it is difficult to actually translate or explain in words to other people, even to medical professionals, what is really happening with our loved ones”

FAMILIAL FRONTOTEMPORAL DEMENTIA (fFTD)

is an inherited form of Frontotemporal Dementia (FTD).

YOUNG ONSET ALZHEIMER'S DISEASE (YOAD)

refers to the approximately 5% of people with Alzheimer's Disease who are under 65 when their symptoms emerge. The personal and social consequences of young-onset dementia can be very different than those experienced by people diagnosed with dementia later in life.

“Such a wonderful reassuring event. The talks were as always very thorough and very carefully planned... a lifeline to so many of us”

POSTERIOR CORTICAL ATROPHY (PCA)

is a rare form of dementia which can initially cause difficulties with seeing what and where things are, for example when the person is driving or reading.

“It was lovely to meet other people with PCA and relate to the same issues and problems, and to take on board their coping strategies”

FAMILIAL ALZHEIMER'S DISEASE (FAD)

is an inherited form of Alzheimer's Disease. It is caused by a genetic fault that runs in families.

“It's good to meet people and chat with families who have this form of dementia”

“I'm due to be symptomatic any time soon...our Alzheimer's is genetic and I'm feeling like everything I do at the moment...is that the start?”



Small group meetings

Small groups exist within RDS to create a sense of community and connection among those living with or caring for someone living with a rare dementia, and to explore specific topics and experiences.

REGULAR PEER SUPPORT GROUPS

Regular peer groups run monthly online, and are facilitated by professionals. We run a number of different peer support groups, distinct both in terms of their focus on different diagnoses, but also whether they are designed for people living with a condition or a caregiver.

REGIONAL SUPPORT GROUPS

RDS has more than 20 regional groups within the UK. There is no fixed size, shape or format of the groups. Some are for caregivers only; some for caregivers and those with a diagnosis. Some regional groups support people affected by a particular rare dementia diagnosis. Others bring together people with different rare dementias, recognising that amidst the differences there is much in common. RDS local groups are led by volunteers, who often have personal experience of rare dementias; partner groups are often led by professionals. Some meetings are formal, involving a common collective activity, question and answer session or more participatory activities. Others are informal and involve members meeting for a coffee or refreshments, getting to know one another, and sharing experiences and learning from others in



a similar situation. The frequency varies with each group – monthly, quarterly, or other intervals as the group decides.

THEMED PROGRAMMES & WORKSHOPS

We also offer themed programmes and workshops, involving a fixed number of information and resource sharing sessions to explore or learn about a particular issue or topic. We currently run 'The Road Less Travelled' to help identify and process pre-death grief, and Later Stage Carers Information Sessions to develop knowledge to make informed decisions around complex and sensitive issues.

BEREAVED CARER MEETINGS

Our bereaved groups are for those who have previously cared for someone living with a rare dementia diagnosis. The groups meet every two months, and provide an opportunity to explore different types of and reactions to grief, and to meet others in a similar situation.

For regular peer, themed and bereaved group enquiries, please contact the RDS Direct Support Team at contact@raredementiasupport.org

For regional group enquiries, please contact RDS Regional Support Groups Lead, Roberta McKee-Jackson at r.mckee-jackson@ucl.ac.uk.

Help us help you: Taking part in research

Rare Dementia Support is led by University College London, a world-leading research site. Evaluating our services and how we deliver support is central to us learning what works and what needs improving. The research we do now can help us make evidence-based changes that benefit you, and others, in the future.

By signing up to become an RDS member, you have the option to choose whether you would like to be a part of research. Our research programme has a range of activities you can get involved in, and activities differ in how much time they take. Whether simply allowing us to use the information we gather from you in the support service for research purposes, or getting involved in specific activities such

as testing new online support, your time and contribution to research is greatly appreciated no matter how big or small. Most of our research programme is offered online, so you can take part in research in the comfort of your own home.

There is also the opportunity to hear more about and take part in other research, including clinical trials, which test new medicines to try to slow or treat the specific diseases. If you would like to find out more about taking part in research, please firstly contact research@raredementiasupport.org and the team will put you in contact with the relevant researchers who can respond to your questions.



PHOTO BY CHRIS MONTGOMERY ON UNSPLASH

“Most of our research programme is offered online, so you can take part in research in the comfort of your own home”

How is RDS funded?

Rare Dementia Support

Advice Community Learning

Funded by
The National Brain Appeal

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

The National Brain Appeal charity directly funds the Rare Dementia Support service, providing £350k per annum to cover the majority of costs. In addition, the charity is actively fundraising up to £7million to create the world's first centre of excellence for rare dementias. The centre will focus on RDS' three pillars: Support, Education and Research.

The National Brain Appeal has a long history of championing research into dementias as well as funding support services for those affected and their families, as part of their wider remit to raise funds for The National Hospital for Neurology & Neurosurgery and the UCL Queen

Square Institute of Neurology – together known as Queen Square.



(Registered Charity No. 290173)

To make a donation please visit

The National Brain Appeal (RCN: 290173)

nationalbrainappeal.org/rds where you can make a one-off donation, set up a regular payment, join challenges and fundraising events, celebrate a life and leave a legacy.