Rare Dementia Support
Advice Community Learning
Young onset dementia – improving the diagnosis process for people with atypical symptoms
Rare Dementia Support (RDS) is a world-leading, UK-based service provided by the UCL Dementia Research Centre (DRC) and partners and funded by The National Brain Appeal.

RDS supports people affected by 7 of the rare dementias including carers and bereaved carers.
Direct Support Team
What we do?

Non clinical, but clinically informed
Approx. 4,500 support enquiries p.a.

Navigation for specialised assessment
Psychoeducation & understanding
Emotional & practical support
Coping strategies & specific issues
Advance care planning
Empowering independence & wellbeing
Care options and transitioning
Group Support – Connecting people
Why?

Between 5% and 15% of people living with a dementia receive a diagnosis of a rare and often young-onset dementia.

30% of people living with a rare dementia first receive an incorrect psychiatric diagnosis.

Many are just left with a diagnosis of ‘dementia’.

There is a widespread lack of understanding about rare dementias and a shortage of dedicated resources to support people affected by rare dementias.
Navigation

Sources – self referrals, Alzheimer’s Society etc

Listen to concerns
Pre screen
Tap into clinical advice
Previous clinical intervention
Geographical location
Understanding Cognitive Neurology
Referral to NHNN

GP via NHS eReferral service

NHNN accept referrals nationally and from secondary and tertiary care
Natalie presentation 20 mins
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Post Diagnostic Support
Understanding the diagnosis

Four Lobes of the Human Brain

Symptoms
Impact
Ability
What sort of support is available for families

1:1 psychoeducational support or family support
Resources for:
• Living well
• Caring for a loved one
• Children

Educational webinars
Lived experience
Peer Support Groups
Large in person meetings
Putting things in place

• Legal and financial
• Lasting Power of Attorney
• Wills
• Future care planning
• Benefits and entitlements
• Registering as a carer
• Driving
• Living !!
Work

The law requires employers to avoid discrimination and make reasonable adjustments to ensure people with dementia and their carers are not disadvantaged in the workplace.

If you have received a diagnosis and are still in work, consider whether reasonable adjustments to your workplace and the way in which you carry out your role might enable you to continue working for longer, should you wish to do so.

• Occupational Health
• Legal advice
Wellbeing and Empowerment

*It is equally important to know what ‘disease’ the person has, and what ‘person’ the disease has”*

- Can do list?
- Needs adaptation list?
- Personal choices
- Enjoying your hobbies or discovering new ones

*Not Meaningful Activities!!!*
Local and National

Partnership working provides the ‘tag team’
• Alzheimer’s Society/Mind etc Dementia Support Services
• Carers Centre
• Age UK
• Community Groups
• Sports Clubs
• Activities
• Local Health and Social Care Teams
Support for Health Professionals

https://www.raredementiasupport.org/education/

Online Dementia Course - The Many Faces of Dementia (futurelearn.com)

Do I see what you see? - Rare Dementia Support

RDS Cascaders

Health Professional correspondence via Zoom/phone/email
If you are interested please email contact@raredementiasupport.org