

Rare Dementia Support

Advice Community Learning

Young onset dementia – improving the diagnosis process for people with atypical symptoms



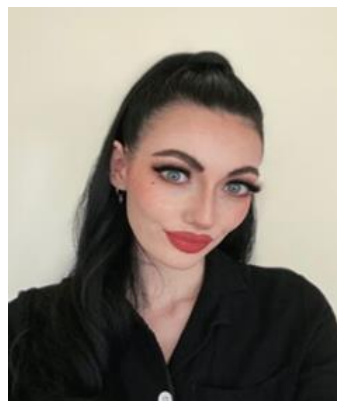
Rare Dementia Support

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

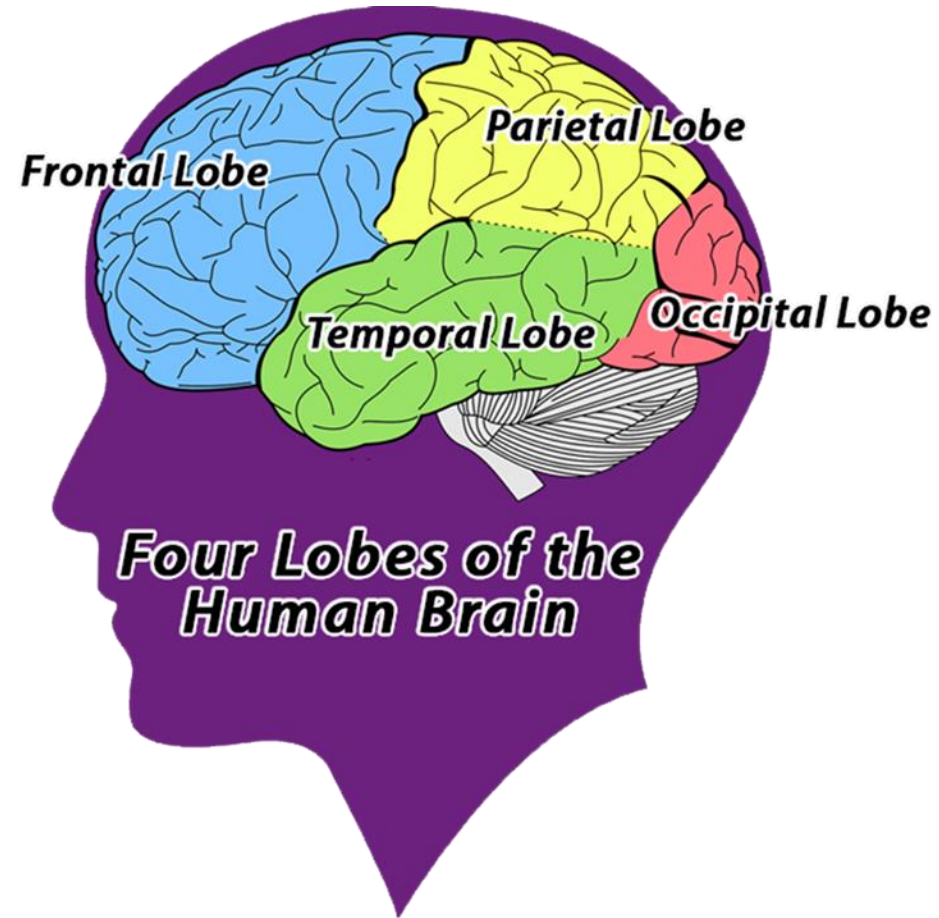
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Post Diagnostic Support



Understanding the diagnosis



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

**Rare
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Funded by
**The National
Brain Appeal**

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