UNIVERSITY OF
PLYMOUTH

Dementia voices: stories and science in conversation

The University of Plymouth and Rare Dementia Support are hosting a series of free public events to raise awareness of dementia

We wanted to let you know about our next event

Our Third Event!
📅 **Date**: Thursday, 26th February 2026
🕓 **Time**: 11:00 am – 1:00 pm
🏠 **Venue**: The Box, Plymouth – Foulston Room
Refreshments provided

Everyone is welcome!
Registration will open in the New Year.
You can hear about it on our website.

Use the QR code below to access the website (website is also at the bottom of this flyer)

For any questions, contact us:
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Krithika Anil at krithika.anil@plymouth.ac.uk

https://www.plymouth.ac.uk/talks/dementia-voices-stories-and-science-in-conversation

Rare Dementia Support

Advice Community Learning

Rare Dementia Support

Karen Tapson

22 January 2026

RDS Specific Groups

Frontotemporal Dementia
FTD

Young-onset Alzheimer’s Disease
YOAD

Lewy Body Dementia
LBD

Posterior Cortical Atrophy
PCA

Primary Progressive Aphasia
PPA

Familial Alzheimer’s Disease
FAD

Familial Frontotemporal Dementia
fFTD

Between 5% & 15% of people living with dementia receive diagnosis of rare or young-onset dementia

Diagnosis of rare dementia brings unique & complex challenges

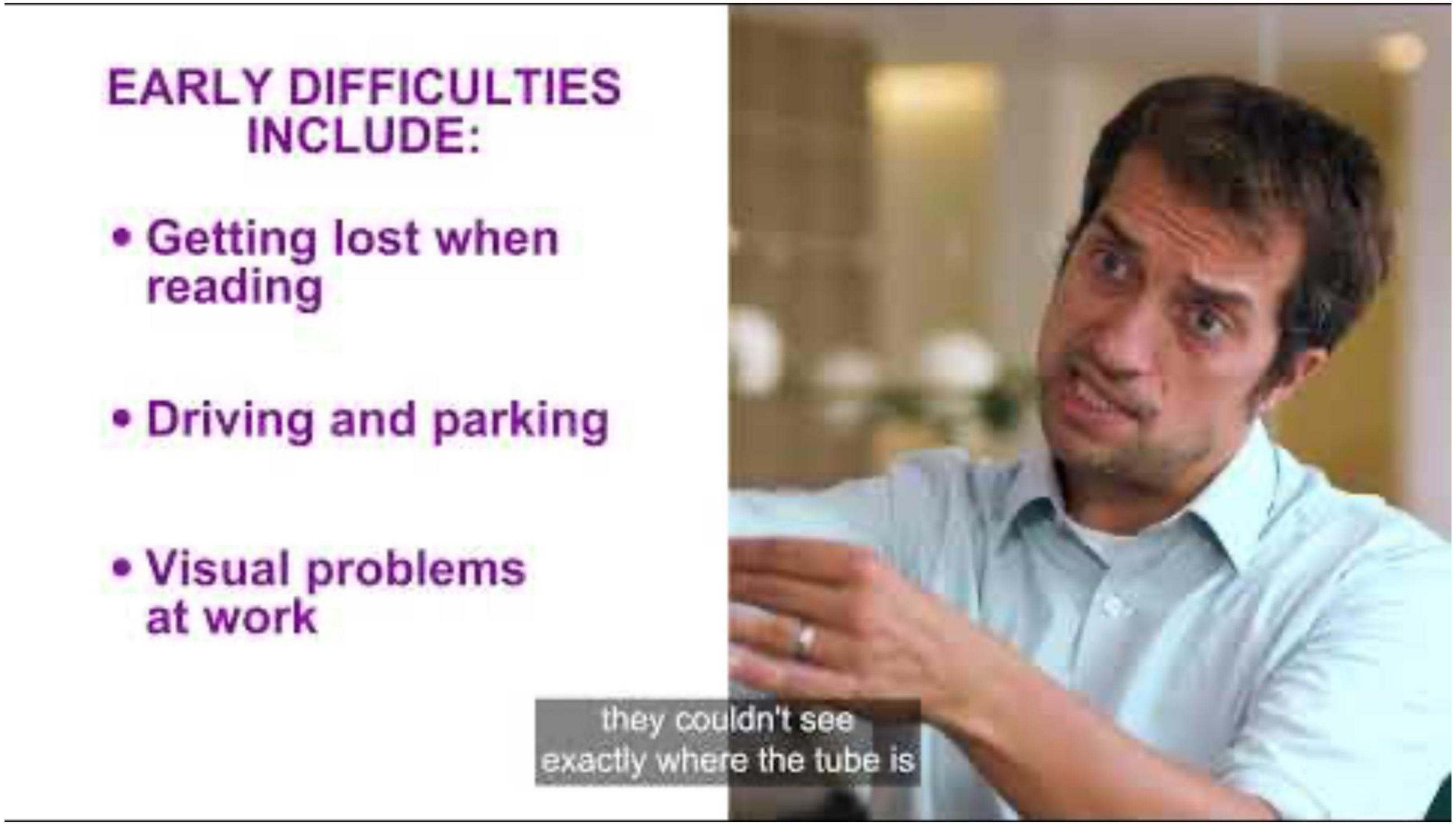
30% of people living with rare dementia first receive incorrect psychiatric diagnosis

Widespread lack of understanding & shortage of dedicated resources

Young-Onset Alzheimer’s Disease (YOAD)

- Around 5% of people with Alzheimer’s Disease are under 65
- Usually people in their 40s, 50s & early 60s
- Often still working at time of diagnosis, are physically fit & may have dependent children or parents at home
- Likely to have major financial commitments like rent, mortgage & all living costs

Posterior Cortical Atrophy
PCA



EARLY DIFFICULTIES INCLUDE:

- Getting lost when reading
- Driving and parking
- Visual problems at work

they couldn't see exactly where the tube is

Posterior Cortical Atrophy
PCA

Atypical Alzheimer's Disease

Progressive **visual impairment** in absence of eye changes

Usually **50s** & **60s**

AD most common cause, despite initial sparing of memory

Early Signs:

Problems with reading – not following dancing words

Difficulties with coordination & spatial awareness e.g. picking up objects, dressing – misjudging distances

Visual problems – including perceiving objects amongst clutter, double vision, difficulty focusing

Light sensitivity

> "An ordinary eye test said my eyes were fine, but I couldn't see. We didn't think that not being able to see was anything to do with dementia."

Living with PCA

> "My head tells my hands what to do, but they just don't behave themselves."

Living with PCA

Strategies

“When the pavement and the road rises up… I know it hasn’t, I get a chocolate bar out of my pocket or pat the dog because I know they are real” **Denise**

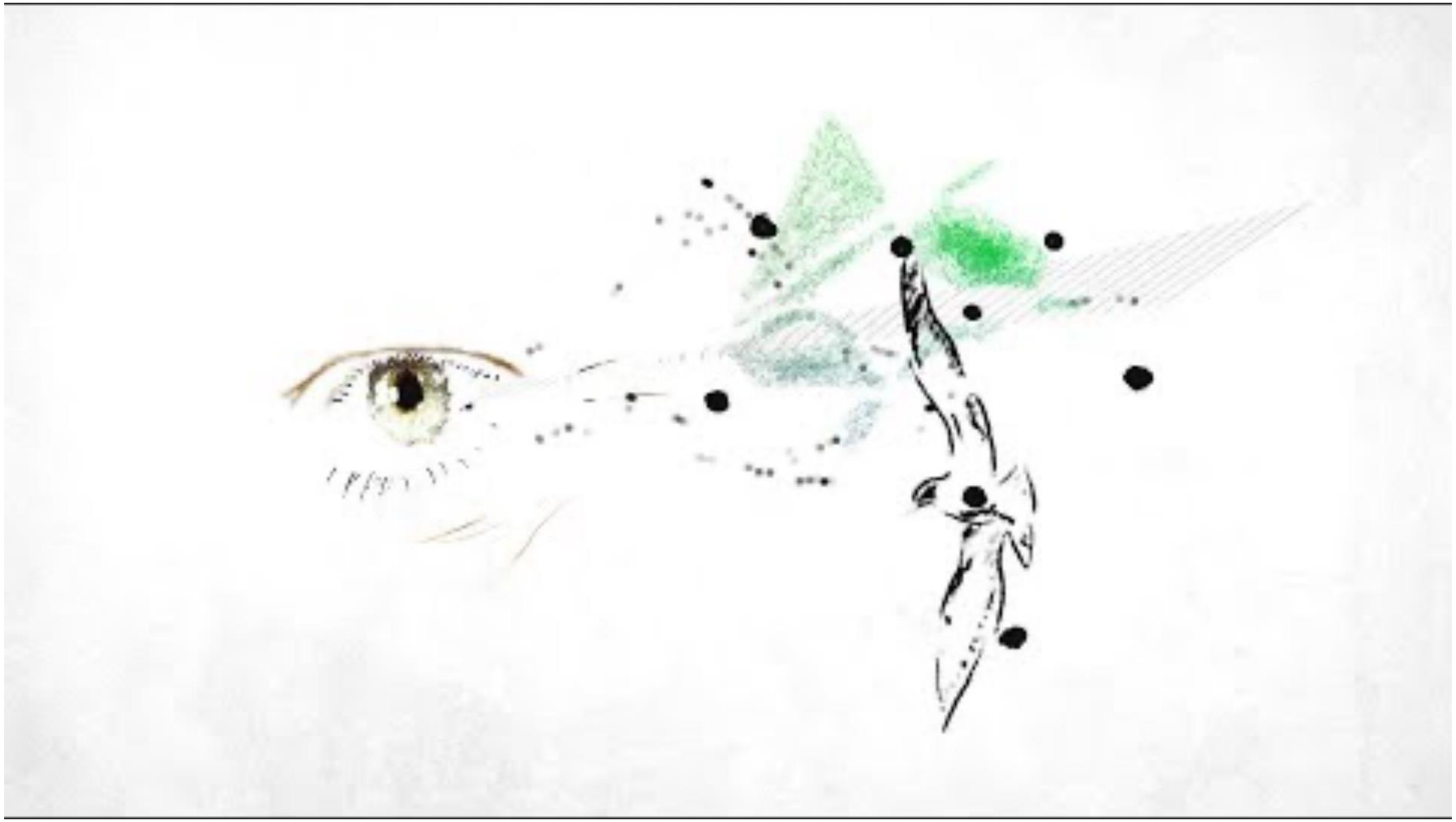
Living with PCA

Strategies

Martina I wear my sunglasses in the supermarket and style it out like a film star

“Reading, writing and arithmetic, they were the first sign something was wrong ” **Michael**

Do you see what I see?



PCA Living with Peer Support Group

Empowerment in groups

When - Third Monday of each month

How - Via zoom for 75 minutes

Three group 11am, 1.30pm and 3pm

Criteria – to have a diagnosis of PCA and be a member of RDS

Referral Pathway – email contact@raredementiasupport.org

PCA Living with Peer Support Group

Empowerment in groups

“For me this is the only group I speak to about PCA, I don’t know anyone else, it was lonely. It is very freeing as everyone else has the same condition… it is amazing how important this group is to me”   **Victoria**

“When you first come to the group it is very scary…but we can now all laugh together“ **Felicity**

“We are not judged – someone always has a solution or a trick ”   **Michael and Alice**

PCA Carer's Peer Support Group

Empowerment in groups

Second Wednesday of each month at 2pm on zoom
Two groups one of early to mid and one for mid to late stage

"Listening to the other members of the group each month makes me feel that my life is 'normal' " **Val**

"People at different stages gives you a better map of where you might be in 12 months time" **Ian**

"I don't need the perfect solution – I just need it to be a little bit better" **Geraldine**

Useful links

Envelope guide
https://shop.rnib.org.uk/products/envelope-guide-address-outline?_pos=12&_sid=82688dd65&_ss=r
Signature guide
https://www.partsight.org.uk/signature-guide
PCA factsheet
https://www.dementiauk.org/wp-content/uploads/dementia-uk-pca-leaflet.pdf
https://www.alzheimersresearchuk.org/wp-content/uploads/2023/10/PCA_0423_0425_WEB.pdf
This is me! – for any hospital admissions
https://www.alzheimers.org.uk/sites/default/files/2020-03/this_is_me_1553.pdf
John's Campaign – for any hospital admissions - https://johnscampaign.org.uk
Sunflower lanyard - https://hdsunflower.com/uk/shop.html
Dementia Research network – https://www.joindementiaresearch.nihr.ac.uk/

contact@raredementiasupport.org

How to contact us?

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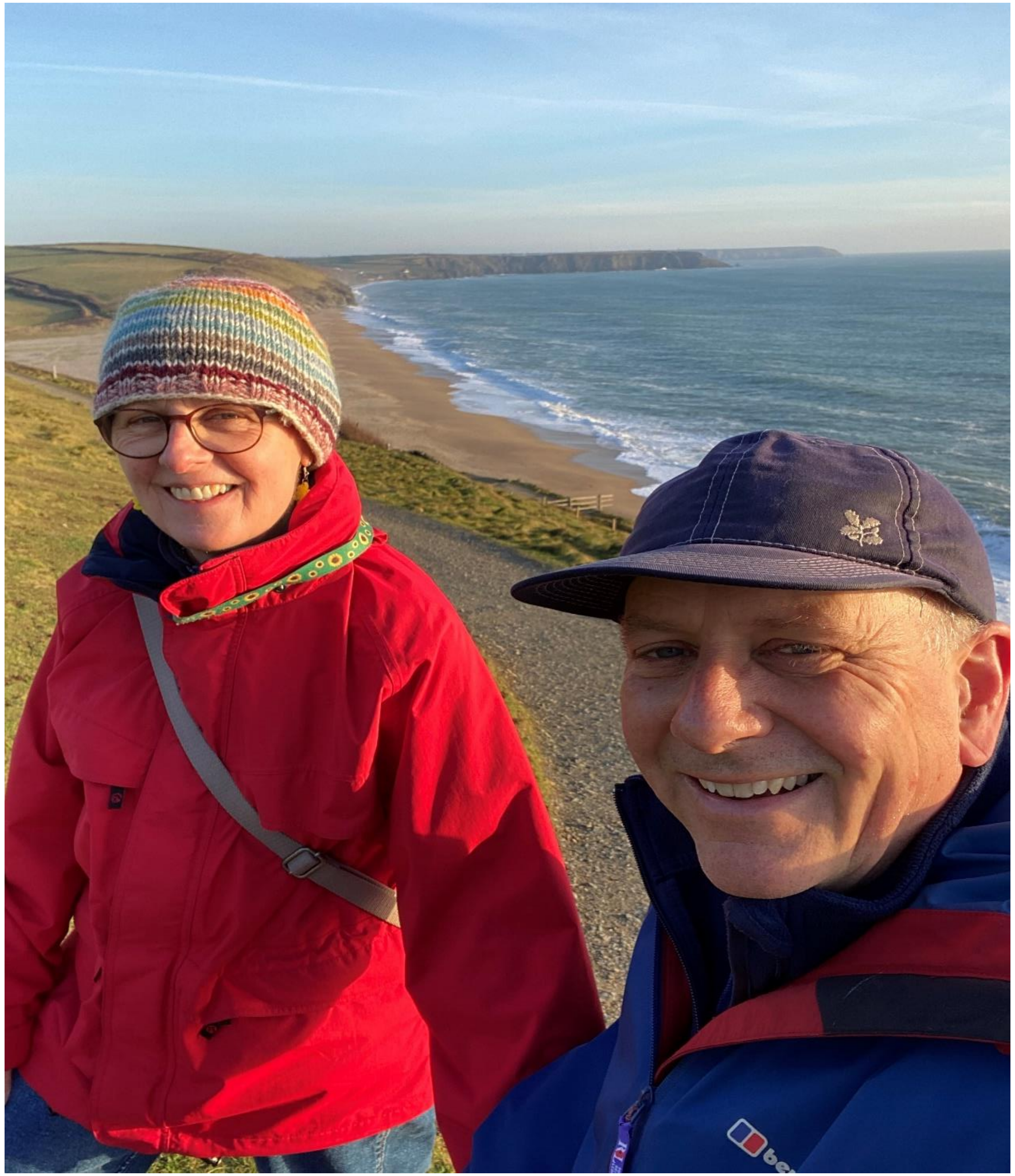
Expert by experience Living with PCA



Tim and Jane

Rare Dementia Support - Become a member

Rare Dementia Support
Advice Community Learning

Funded by
The National Brain Appeal

contact@raredementiasupport.org