Welcome to Rari-tea

Explaining rarer types of dementia experienced by younger people

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Content

Welcome and introductions
Rare Dementia Support whistle-stop tour

Lived experiences:

Posterior Cortical Atrophy – Martina
Familial frontotemporal dementia – Paul and Pippa
Semantic dementia – Geraint and Jacqui

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Rare Dementia Support
Warning!

Acronyms!
Rare dementias

• Between 5% and 15% of people living with a dementia receive a diagnosis of a rare or young onset dementia

• 30% of people living with a rare dementia first receive an incorrect psychiatric diagnosis, and vice versa

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

• The diagnosis of a rare dementia brings with it a set of unique and complex challenges and it is vital that people are correctly diagnosed
Rare dementias

• Often occur at a younger age (under 65)
• Symptoms that are not always memory-related
• Include difficulties with vision, language, movement and behavioural changes
• RDS Support Groups support seven rarer types
• Isolated with lack of knowledge
• Meetings attracting over 100 people each time from all over the world
Frontotemporal dementia

• Frontotemporal dementia (FTD) is actually a group of disorders that **overlap** with each other

• Usually starting with behaviour or language and sometimes develops into movement problems

• Varies greatly from person to person
FTD – behavioural (bvFTD)

• No insight
• Sweet tooth
• Obsessions, compulsions and routines
• Loss of empathy
• Excessive money spending
• Personality changes
• Disinhibition
• Changes in sexual behaviour
Language (PPA)

Primary Progressive Aphasia (PPA) affects language and speech

FTD - Semantic dementia and Progressive non fluent Aphasia

Atypical Alzheimer’s disease – Logopenic Aphasia

* The importance of specific diagnosis for medication appropriateness
Progressive non fluent Aphasia (nfvPPA)

- Slow, hesitant speech
- Difficulty finding the right word to say
- ‘Telegraphic’ speech
- Producing the wrong grammar
- Saying the opposite word to the one they mean to say
- Problems with reading and spelling
Semantic dementia

• Difficulty finding the right word
• Losing the understanding of the meaning of words
• Difficulty understanding what people say
• Problems with reading and spelling
• Talking in a vague manner
Logopenic Aphasia (LvPPA)

- Mispronunciations
- Pausing in the middle of conversations
- Difficulty finding the right words
- Difficulty understanding more complex messages or retaining information
Posterior Cortical Atrophy

Usually, an atypical Alzheimer’s disease that mainly affects the parts of the brain that process visual and spatial information.

- Problems with reading
- Visual problems
- Issues with recognition
- Managing co-ordination
- Issues with judging distances
- Light sensitivity

“My head tells my hands what to do, but they just don’t behave themselves”
Lewy body dementia

• Problems with concentrating and staying alert
• Fluctuations in thinking and memory problems vary from day to day or even hour to hour
• Visual hallucinations – often of animals or people
• Slower of stiff movements. Some people have problems with falling
• Problems with bladder or bowel function
• Sleep disturbances
Familial Frontotemporal Dementia (fFTD)

- Genetic mutations extremely complex and variable within the subsets of FTD
- Main genes
- Tau / MAPT
- Progranulin / GRN
- C9orf72
- Risk factors will involve family history and often at an early age
- The person with FTD has the genetic test. If tested positive, children will carry 50% risk and can then be tested
Familial Alzheimer’s disease

- Familial Alzheimer’s disease probably accounts for less than 1% of cases of Alzheimer’s disease
- Faulty genes - presenilin 1 (PSEN1), presenilin 2 (PSEN2) or amyloid precursor protein (APP) genes or APP duplications
- Individuals with familial Alzheimer’s disease usually have a strong family history of the illness, which means that they know of cousins, aunts / uncles, parents and grandparents who were affected at a similar age
Paul and Pippa
Geraint and Jacqui
Do you have any questions?
Thank you for joining us