Birmingham and Solihull NHS
Mental Health NHS Foundation Trust

YOUNGER PEOPLE WITH DEMENTIA, and the work of the RARE DEMENTIA SERVICE

Jeremy Smith, Occupational Therapist
Mel Walwyn Martin, Clinical Psychologist
Rare Dementia Service,
Mental Health Services for Older People,
Birmingham and Solihull Mental Health Foundation Trust

Contents

- What is the Rare Dementia Service?
- Working age dementia and rare dementia
- Prevalence of dementias in under 65s
- Impact of having working age dementia
- Fronto-temporal dementia
- Differing needs of younger people with dementia
- Fictionalised case study – “Jim”
- How to refer to RDS

Rare Dementia Service

- Working Age Dementia Service (WADS), covering Birmingham (but not Solihull) – diagnosed and case managed all under 65s with degenerative amnesic conditions
- There is now a Memory Assessment Service covering diagnostics, in Birmingham and Solihull
- Community teams have taken over the care co-ordination of under 65s with dementia on Care Programme Approach
- The Rare Dementia Service care co-ordinates people with rare dementias, nearly all of whom are under 65. This is because members of WADS were seen to have particular experience with these dementias, particularly Fronto - Temporal Dementia (FTD)

Our team

- 2 nurse care co-ordinators (1 + 0.7 staff)
- 2 clinical psychologists (1 + 0.4 staff)
- 1 associate specialist (psychiatrist) – Dr Williams, under supervision of consultant Dr Bentham (0.5 staff)
- 1 occupational therapist
- 2 support workers, one (0.8 staff) who can do one-to-one work as well as groupwork, and one (0.2 staff) who assists in groupwork
- Speech and language therapist (0.2 staff)
- Physiotherapist (0.2 staff)

Definitions

- **Rare Dementia**: low prevalence illness. “Which is generally recognised as being fewer than 5 per 100,000 in the community”

- **Working Age Dementia**: a dementia illness diagnosed before the person is 65 (sometimes called “early onset”, “pre-senile”, not to be confused with EARLY STAGE)

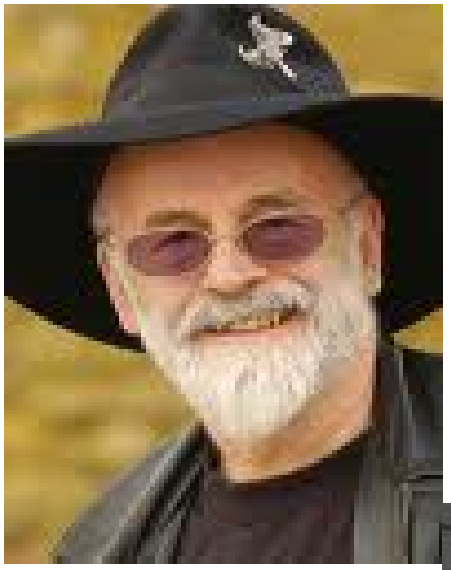
What is “rare dementia”?

- A “rare” illness is one experienced by fewer than 5 in 100,000 people
- Typically the delay between presentation and diagnosis is longer when people have rare illnesses.
- Rare dementias are **not** Alzheimer’s, vascular, mixed, Lewy Body or alcohol-related dementias

What are they then?

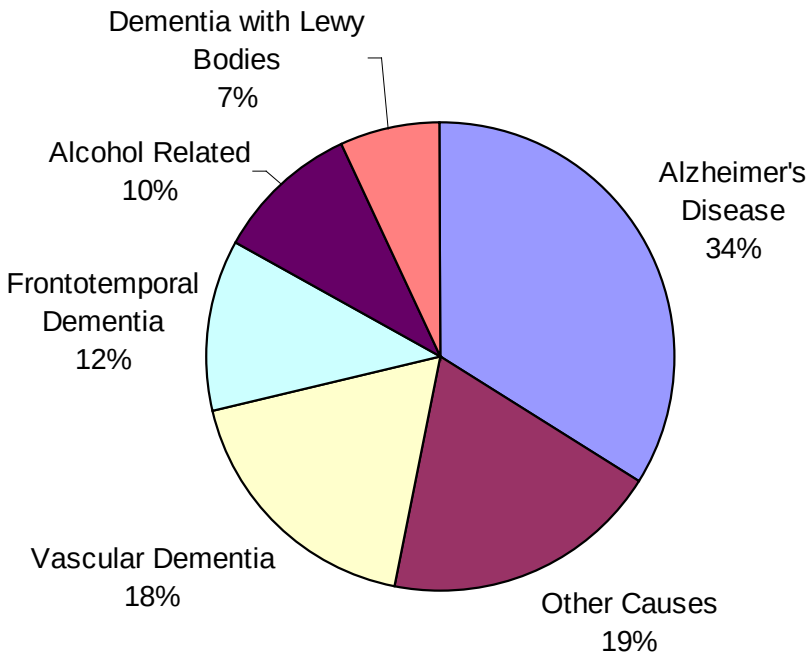
- The biggest sector is fronto-temporal dementia (FTD)
- We also work with familial Alzheimer's, where there is a genetic link
- There are unusual forms of Alzheimer's, such as PCA, which are considered rare dementias
- Movement disorders like progressive supranuclear palsy, motor neurone disease, multiple sclerosis, cortico-basal degeneration
- Leukodystrophies
- CADASIL (a progressive vascular illness)
- HIV, syphilis, Huntingdon's – however, these have other teams to care co-ordinate them

People under 65 with dementia



Types of dementia in under 65s populations

Figure 1. Causes of Dementia In Younger People (Harvey, 1998)



Working Age Dementia Impact

- COGNITIVE (memory, understanding, planning)
- INTERPERSONAL / BEHAVIOURAL (social inappropriateness, risk)
- MOVEMENT (in some cases, like MND or Parkinson's)
- COMMUNICATION / LANGUAGE / SENSORY (word-finding problems)
- MOOD / NON-COGNITIVE (may appear depressed, agitated, anxious)

Fronto-Temporal Dementias: A spectrum of illnesses

- Behavioural variant FTD (BvFTD)
- Primary Progressive aphasias (difficulties producing and understanding speech)

I. Progressive non-fluent aphasia
II. Semantic dementia

Language variant forms of FTD

Clinical subtype	Common symptoms
Progressive non-fluent aphasia	Expressive language difficulties with effortful, halting speech and grammar errors
Semantic dementia	Loss of knowledge of word and object meaning, difficulty finding words

BvFTD: Clinical Features

Rascovsky et all (2011) Brain, 134(9):2456-77

- Disinhibition – acting inappropriately or riskily
- Apathy / inertia – no motivation or drive
- Loss of empathy – inconsiderate, unfeeling, hurtful behaviour
- Perseverative / compulsive behaviour – repeated phrases or actions
- Hyperorality – “mouthing” things, cramming, sweet tooth
- Dysexecutive neuropsychological profile – problems with planning

AD and BvFTD compared

	Alzheimer's disease	BvFTD
Presenting features	Cognitive change	Behavioural , personality change
Cognitive features	1. Memory impairment 2. Language difficulties 3. Spatial disorientation	1. Concreteness of thought 2. Impaired problem solving 3. Difficulty "shifting sets"
Social interactions	Preserved social skills	Impaired social awareness and skills
Insight	Maintained	Disrupted
Mood and Emotion	Often anxious, worried, concerned,	Unconcerned, blunted, lacking empathy ?depression

Person Centered Perspectives (Tom Kitwood)

PERSON with dementia

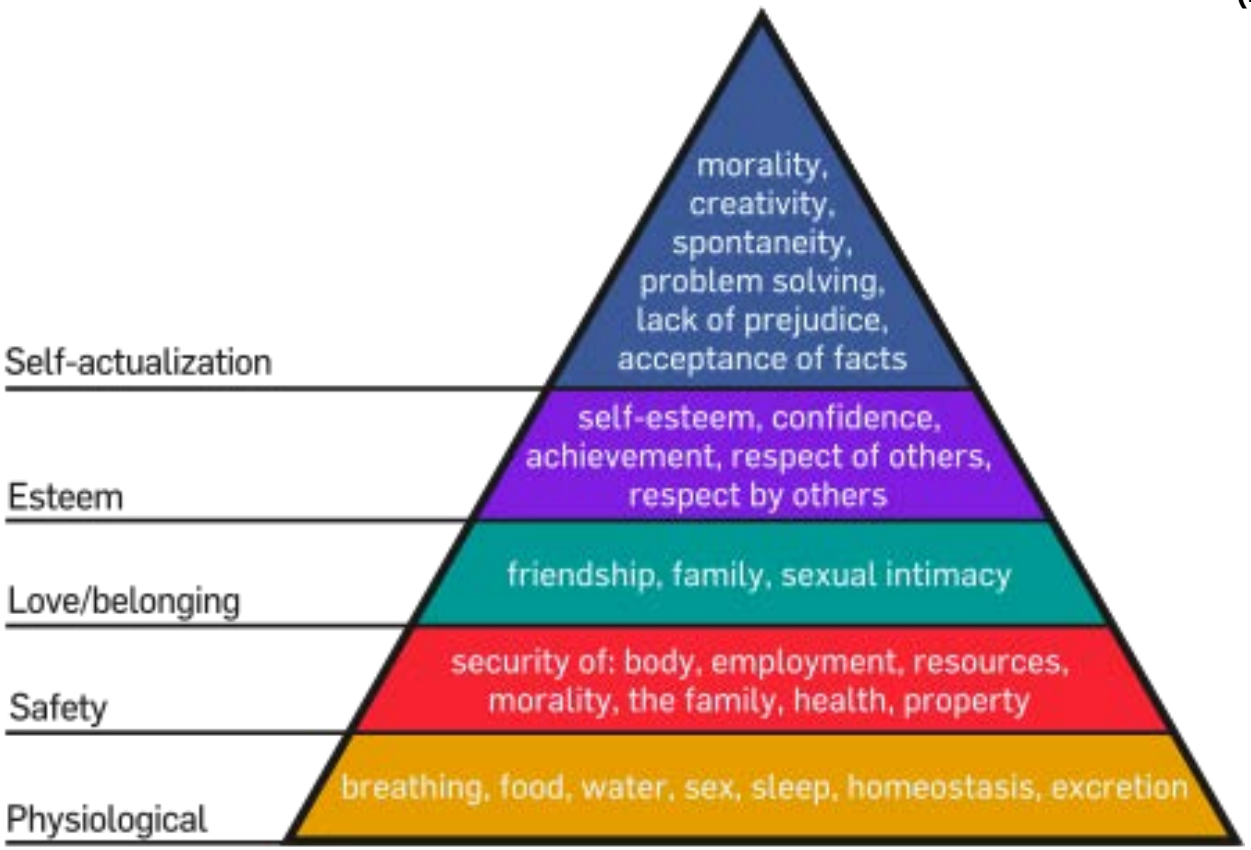
Person with DEMENTIA

D = NI + PH + B + SP

- **NI = Neurological Impairment**
- **PH = Physical Health**
- **B = Biography (life story)**
- **SP = Social Psychology**

Maslow's Hierarchy of Needs

(Maslow, 1943)



Psychological needs of people with dementia

Differing needs of younger people with dementia

- May have a job
- May need benefits, advice, advocacy
- More likely to drive
- May have dependent children
- More energy
- More risks
- Do not “feel old”

Needs

- Timely and accurate diagnosis
- Evidence-based treatment
- Information and advice
- Social welfare
- Social connectedness
- Carer support

RDS interventions

- Medic reviews
- CPA care co-ordination
- Occupational therapy (productivity, self-care and leisure), physiotherapy, speech and language
- Psychology interventions
- Monitoring
- Advocacy/liaison with other agencies
- Carer support
- Groupwork

Fictionalised case study - Jim

- Male aged 47
- Physically well and vigorous
- Behaviour change
- No insight
- Repetitive, stereotyped behaviours
- Driving impulsive and dangerous

Jim (contd.)

- Independent in ADLs
- Persuaded to stop driving – accepted
- Drug use – had been abstinent
- Inappropriate behaviour in public places
- Police
- Psychiatry referral
- Diagnosis of behavioural variant fronto-temporal dementia (BvFTD)

Jim (contd.)

- No pharmacological treatment for condition
- Some evidence for pharmacological management of impulsiveness – was tried
- Risk assessment – increasing risks
- No insight = no mental capacity?
- High level of carer stress

Jim (contd.)

- Needed supervision during the day
- Carer in trouble at work
- Required social care package – but what?
- Risks severe, likely to increase further
- Day centre tried - unsuccessful
- Family not able to cope

Jim (contd.)

- Arrested.
- Some one-to-one monitoring provided
- Monitoring could not prevent the high-risk situations occurring
- Crisis eventually reached
- No availability of suitable safe placement
- Admission under Mental Health Act
- Care home

How to refer

- RDS takes most of its referrals from the Memory Assessment Service
- Referrals to MAS are via Single Point of Access. Pan-Birmingham and Solihull Mental Health Assessment Referral Form.
- If somebody already has a diagnosis but you wish them to be care co-ordinated by RDS, refer to SPOA