

Patients with cognitive change – the challenge for families and professionals

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Cognitive change in MND / ALS

- 1869 Noted by Charcot
- Mid 20th century - not recognised
- 1980s Increasing awareness
 - Fronto-temporal dementia - 5-10%
 - Cognitive change – up to 75%
- Classification
 - ALS
 - ALSci cognitive impairment 28%
 - ALSbi behavioural impairment 39%
 - ALS – FTD fronto-temporal dementia 15%

Cognitive change in MND / ALS

- ALSci cognitive impairment
 - Frontotemporal dysfunction
 - Deficits in attention / cognitive flexibility / word generation
 - Sparing of memory
- ALSbi behavioural impairment
 - Changes in social interactions

Cognitive change in MND / ALS

- ALS – FTD fronto-temporal dementia
 - Altered social conduct Insidious onset
 - Emotional blunting Language change
 - Loss of insight Poor self care

Miller et al 2009

Cognitive change

- Cognitive loss
- Psychomotor speed
- Fluency
- Language
- Visual memory
- Immediate verbal memory
- Executive functioning

Raaphorst et al 2010

Mr G

- 64 year old retired bricklayer
- Married – wife works as a GP secretary
- On daughter
- Diagnosis
 - 2006 “funny feeling “ in his hand
 - 2007 “hand problem” investigations
 - October 2008 diagnosis of MND / ALS

Mr G

- Continued to work until may 2009
- June 2009 Used wheelchair on holiday
- December 2009 Walking very bad, wife stressed
- April 2010 swallowing more difficult, speech slurred
- May 2010 “Obsessional” behaviour
- June 2010 “Struggling”
- August 2010 1 week respite in nursing home
- Increased obsessional behaviour

Mr G

- Problems with care at home
 - Carers finding care difficult
 - Wife wishes to remain at work
 - Risk of falls / swallowing problems
- October 2010 admitted to hospice
- Died at hospice

Mr MG

- 48 year old man. Married with children of 3 and 1, and 3 children from earlier marriage
- Diagnosis
 - September 2008 slurred speech
 - July 2009 saw neurologist and told MND / ALS
 - August
 - “giggling”
 - “confused”
 - “repeats himself”

Mr MG

- September 2009 walking around the town all day
 - Cannot concentrate through a film on TV
 - “obsessive”
 - Swallowing poorer
 - Walks to bank to deposit small sums of money
- Jan 2010
 - Falling
 - Cough
 - Frustrated
 - Attends day hospice, but wanders out of the building

Mr MG

- February 2010
 - Agitated
 - Angry at the children
 - Angry at neighbours
- March 2010
 - Little communication
 - Incontinent
 - Agitated
 - Hitting out at wife / children

Mr MG

- Decision to admit to the hospice
- Agitated and required medication
 - Increased sedative medication
- Deprivation of Liberty Safeguards
 - Legal documentation that he was not allowed to leave
- Died at the hospice

Wisdom Hospice

- MND Clinical Team
 - Population of 350,000
 - 20-25 patients with MND / ALS at any one time
- From 2005 – 2010 57 patients have died

Wisdom Hospice

- 20 (35%) with cognitive change
 - Fronto-temporal dementia 3
 - Cognitive change affecting 17
 - Quality of life
 - Relationships
 - Overall ability

Issues for patient

- Decision making
- Risk taking
 - Reduced awareness of risk
 - Cannot assess risk
- Frustration
- Forgetfulness

Issues for families

- Decision making
- Day to day coping
 - Frustration
 - Fear of risk taking
 - Language Communication
 - Obsessional behaviour
 - Impulsiveness

Issues for professionals

- Decision making
 - Assessment earlier to make decision – but person may not want to discuss the issues
- Communication
 - Unsure if discussion retained and able to be involved in the discussion
- Assessing symptoms
 - Pain / depression / swallowing problems
- Coping with memory loss / confusion

Issues for professionals

- Maintaining safety
 - Feeding
 - Mobility
 - Restraint
 - Restriction of liberty
 - Medication
 - Sedation
- Multidisciplinary team
 - Variable views on management
 - Conflict

What can we do?

- Increase awareness
 - Family
 - Professionals
- Help in simple interventions
- Acceptance of the issue
- Discussion
 - Family
 - Multidisciplinary team
- Support

What can we do?

- Environmental / Communication
 - Short phrases
 - Stop / think - reduce distractions
 - Reduce and simplify decisions / cognitive load
 - Reduce complexity of communication
 - Diaries / calendars / memo boards

What can we do?

- Behavioural
 - Distraction
 - Diversion
- Pharmacological
 - SSRI antidepressant

Goldstein 2006; Merrilees et al 2010

What can we do?

- Physical
 - Lock doors to reduce availability of risks
 - Car keys kept securely
 - Lock tools away
- Caregiver support
 - Help acceptance of the reality of cognitive change
 - Education for family and carers as to what they can do
 - Support
 - Psychosocial support

Conclusion

- Awareness of cognitive change
 - Families
 - Professionals
- Look for ways to reduce the impact
- Support of all involved
 - Families
 - Multidisciplinary teams
 - Individual carers