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%

Miller et al 2009
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

Miller et al 2009
Cognitive change in MND / ALS

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

Goldstein 2006; Merrilees et al 2010
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

Goldstein 2006; Merrilees et al 2010
Conclusion

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