

# Diagnostic Issues and Breaking the News

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# Aims of workshop

- **To think together about the often complex process of establishing the diagnosis**
- **To think together about what the diagnosis means for the person with ID and their family, carer and friends and how this guides our interventions**
- **To think together about how to share the diagnosis in a meaningful way**
- **To use a social model of disability and to integrate this with the medical model**

# Developing the evidence base

- In this workshop we will be aware of the available evidence and the need to develop more
- We will mostly be talking about clinical experiences rather than a body of research
- There is lots of scope for research in this area
- We can collate research ideas over the workshop

# Establishing the diagnosis

- **What approaches, pre and post assessment, are most helpful in establishing the diagnosis?**
  - Local care pathway (the Plymouth experience)
  - Multidisciplinary and multiagency coordination
- **Process of the multidisciplinary group bringing the assessment information together and making a diagnosis.**
- **Post diagnostic care pathway link to best practice guidelines for ongoing care planning and care coordination, intervention and support.**
- **What to do when the diagnosis is uncertain?**

# Getting it right

Early diagnosis means:	But what if it is wrong?
Earlier access to medication Psychological therapies Environmental adaptations Surveillance for comorbidities Explanation to service user and carers Training for carers Planning for the future	Distress for service user and carers Inappropriate treatment Stigmatisation and fear of the label Diagnostic overshadowing

- Managing uncertainty
- The role of second opinions
- Initiating interventions prior to formal diagnosis

# Establishing the diagnosis: case study

- Roger is a 60 year old man with moderate learning disabilities of unknown cause
- Recent change in behaviour with increased aggression
- Developed new onset seizures – likely complex partial. Started on carbamazepine. Behaviour change thought to be related to new onset epilepsy
- 1 year later – poor recall of recent information with repetitive questioning; increasingly confused; disorientation in familiar environments; loss of skills; new onset urinary incontinence
- Referral for dementia screening

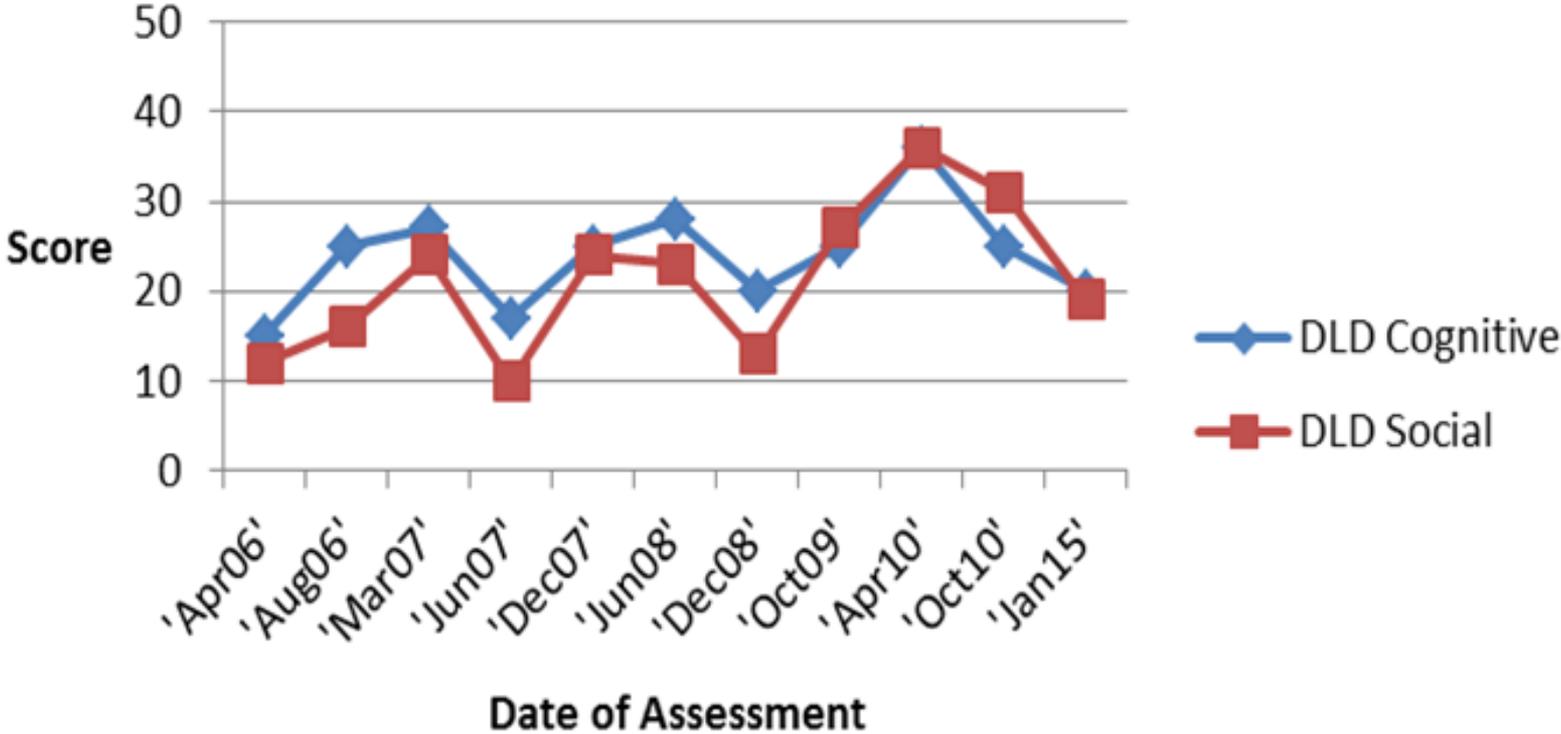
# Case study continued

- Baseline DMR repeated 6 monthly

	Baseline	+ 6 months	+ 12 months
Cognitive	15	25	27
Social	12	16	24

- CBZ reduced at 9 months due to concerns re: toxicity. Vast improvement in presentation
- “Probable Alzheimer’s” diagnosis stuck for a number of years
- Fluctuating picture from ongoing testing
  - Impact of epilepsy, medication, mood, anxiety, physical health concerns, environmental changes

# DLD Scores Over Time (The Lower the Score the Better)



# Multi-agency and Multidisciplinary working

- **An individual with a diagnosis of dementia needs coordinated multi-disciplinary and multi-agency intervention.**
- **Our responses to the person's needs have to change as dementia progresses through early, middle and late stages**
- **Other agencies to engage with and integrated working:**
- **Provider agencies-supported living, residential, day opportunity projects, respite**
- **Primary care, hospital services, liaison nurse, older adults mental health, palliative care**
- **Commissioners (of social care and health to ensure suitable services develop)**

# **Your own case material and discussion**

- **Please go into groups of 3 and for 5 minutes discuss a clinical case one of you has worked with.**
- **Look at how you might consider and act upon the issues we have looked at today, including how to establish the diagnosis in an MDT setting, who to involve in process, agencies to engage with and individual profile of interventions adjusted to stage of dementia**
- **Think about your local care pathway – discuss what works well and what improvements are needed**
- **Feedback to wider group and discussion**

# What to develop

- **Partnership between the person, the family, paid carers and health and social care professionals needs to be developed from diagnosis onwards**
- **Joint working with other services**
- **A palliative approach needs to be developed from diagnosis onwards**
- **Local arrangements need to be developed**

# **Sharing the diagnosis- the dilemmas and challenges**

- **Everyone should be told their diagnosis**
- **Dilemmas and challenges concerning sharing the diagnosis with the individual with intellectual disabilities, their family and carers and their friends**
- **Group discussion of your experiences**
- **Developing local practise guidelines**
- **Risks of not sharing the diagnosis-increased marginalisation and distress**

# Understanding ID and Health Risks

- **People can be given opportunities to understand the nature of the intellectual disability and any associated health risks from an early point in their life and particularly from transition to adulthood onwards**
- **Implications for changing our practise**
- **Context of lifelong health risks and addressing these**
- **Understanding that early identification means more effective and person-centred interventions**

# Case study “Selina”

- **Family lack of awareness of risks**
- **Late diagnosis**
- **Elderly carer**
- **Accommodation not appropriate to needs of individual with ID or family carer**
- **Fear of change, fear that interventions will not be culturally appropriate**
- **Family meetings alongside MDT interventions**
- **Local Older Adults Care Home with specialist support**

# The personal context when sharing the diagnosis

- **Think together how a wide range of personal factors, including culture, personal history and current relationships, can be taken into account.**
- **Think together about what psychological interventions people with intellectual disabilities and their families and carers may need to feel emotionally supported and to begin to understand the diagnosis**
- **Group discussion**

# Breaking the news to the person with ID is an ongoing process

- **Generic breaking-bad-news models do not meet the needs of people with intellectual disabilities so we need to communicate information over time and based on “chunks”.**
- **A Person-centred approach aims to support the person to understand and cope with their changing experiences**
- **We want to help them be involved as much as possible in decisions about their support and care and medical treatments, including future care.**
- **These chunks need to be appropriate to the person’s current and changing framework of knowledge and lived experience and they need to take into account disturbed encoding and roll-back memory.**
- **Working with the Speech and Language Therapist**
- **Specific resources: The Journey of Life and About Dementia; What is dementia**
- **Discussion**

# Case study “Lilian”

- **Fun-loving woman with Down Syndrome who lives in supported living and is a talented leader in all activities at day service.**
- **She developed dementia at 54 years.**
- **Staff teams given training and ongoing support including concerning how to support other service-users to support Lilian which is a change in role.**
- **Brothers who live at some distance invited for 3 sessions. After initial concerns expressed, they agree Lilian needs to be told.**
- **Regular individual sessions with Lilian in first year post-diagnosis to talk about her changing experiences and how to alleviate stress and continue to enjoy life.**
- **Move to specialist residential care because of mobility problems. Positive transition, and reassurance and emotional support ongoing. Attends same day service until a few weeks before death. Lilian remains calm. Dies at residential care home, brothers have visited in last week.**

# Supporting families and carers

- **How can we help family and carers understand how dementia is affecting the person so that they can understand and cope with the changing situation and give appropriate support?**
- **How can they be involved in management plans and be given opportunities for education and learning?**
- **QOMID: Quality Outcome Measure for Individuals with Dementia**
- **Whole staff team training**
- **Discussion**
- **Specific resources: Keep Talking about Dementia and Down's Syndrome and Alzheimer's Disease: A Guide for Parents and Carers**

# Supporting friends and peers

- **Different settings: supported living, day and respite**
- **A dementia capable environment means everyone is supported to understand dementia**
- **Stress experienced by friends and peers and consequences of feeling distressed and finding it hard to support person with ID and dementia**
- **Specific resources: About my Friend, Ann has Dementia**
- **Specialist interventions eg groupwork**
- **Lynggaard and Alexander paper**

# Supporting other services

- **How to develop links and provide support and guidance to health and social care professionals in other services concerning the needs of the person with intellectual disabilities.**
- **GP Training, Training to Commissioners**
- **How to develop links and provide support and guidance to provider services**

# Case study “Jennifer”

- **Working with a staff team**
- **Shock and loss**
- **Their sense of disablement**
- **Supporting staff to support service-user when they have to move**
- **Valuing people and relationships**
- **Finding, supporting and involving family**

# Summary-key points

- **Establishing the diagnosis is often a complex process**
- **People with intellectual disabilities, their families and carers need to be given opportunities to understand the nature of the intellectual disability and information about any associated health risks from an early point in their life and particularly from transition to adulthood onwards.**
- **People with intellectual disabilities need to be told about their diagnosis of dementia and given ongoing opportunities to understand their diagnosis and their experience of dementia.**
- **Family members and carers need to be informed about the diagnosis and involved as much as possible in support and management plans and, as appropriate, be given opportunities for education and training.**
- **The person's peers and friends are also important people to involve in giving information about the diagnosis and this will both help them cope and help them support the person affected by dementia.**
- **People with intellectual disabilities and their families and carers may need psychological interventions to enable them to feel emotionally supported and to understand the diagnosis.**

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