Week 5 Case Studies

- This activity is a reflection on the presentations of MND and the role of the MDT.
- **Purpose**: To compare and contrast the response to patient need in variously constructed multidisciplinary teams. This is an opportunity to see if there are lessons to be learned from differing practice.
- For **each of the three** case studies, note your answers to the following:
- what do you believe are the 2/3 main issues?
- what needs to happen next?
- who to involve?
- how you would organise those next steps?
- what is the key information you would pass on to other MDT members and how?

Case Study 1: Jacob

Introduction

Jacob is a 38-year-old married man who lives with his wife. They have no children or close family in the UK and describe themselves as having a very full and active social life enjoying coastal sports and outdoor activities.

His original diagnosis of probable MND was made by a neurologist in clinic 6 weeks ago. Jacob sought a second opinion and subsequently received a confirmed as limb-onset motor neurone disease (ALS) during a hospital admission under the care of another neurologist 3 weeks ago. Jacob describes the diagnosis as "a death sentence".

He has been referred to the MDT Clinic and is due to attend next month. He has, however, been seen at home by the care co-ordinator since his discharge from hospital and was assessed by both the physiotherapist and occupational therapist whilst on the ward.

Case Presentation

Jacob describes a year long history of tripping over his left foot, reporting that he felt that his ankle had become "wobbly" and he was always catching his toes. Following a second stumble 10 months ago (sustained whilst walking along a pebble beach) he attended the Physiotherapy Walk-in Clinic at his local hospital. He was treated for a lateral ligament sprain; provided with exercises and given reassurance that he could return to surfing and paddle-boarding within 4-6 weeks. This has not been the case and Jacob is extremely frustrated by this.

- The following investigations were performed during his hospital stay:

- MRI of the brain and spinal cord noted to be unremarkable
- Nerve conduction studies are normal in the upper & lower limbs with fully preserved sensory responses. There are no demyelinating features.
- EMG is abnormal in all muscles sampled with a mixture of active and chronic denervation changes associated with frequent fasciculations in his limb and abdominal muscles.
- Loss of muscle bulk in the left leg was observed but not quantified.

- Physical examination whilst on the ward 3 weeks ago identified:

- Weakness in his left ankle dorsiflexors (MRC 4/5)

- Brisk tendon reflexes on the left (tendo-achilles and patellar tendon)
- A positive Babinski sign on the left
- Modified Ashworth Scale of 1 in ankle plantarflexors

The ward physiotherapist noted a slight limp with "stiffness during the swing phase of gait" on the left. Jacob declined the offer of a walking stick. Orthotic devices for the foot and ankle were not discussed. He was noted to be independent; climbing stairs with minimal use of a right ascending handrail. Descending stairs he was noted to be more cautious and reliant on the handrail.

The occupational therapist on the ward reported no difficulties with personal Activities of Daily Living and noted that Jacob chooses to sit down to dress his lower half. Jacob lives in a privately owned modern 3 storey town house. Noting the findings from his stair assessment and his insistence that he has no difficulties ascending or descending stairs, a home visit was not performed.

Jacob expressed that since having his "death sentence" of a diagnosis he had performed an internet search and is becoming more accepting. He understands the disease course to be variable and suspects he may have Primary Lateral Sclerosis.

Management and Outcome

Jacob has only just been diagnosed with MND and is struggling to come to terms with it. He is angry that the diagnosis was not suspected when he attended Physiotherapy Walk-In Clinic 10 months ago.

During his initial home visit from the MND Care Co-ordinator his ALS-FRS score was noted to be 45/48:

ALS-FRS scoring		
Speech	normal	4
Salvation	normal	4
Swallowing	normal	4
Hand writing	normal	4
Cutting food & handling utensils	normal	4
Dressing & Hygiene	decreased efficiency	3
Turning in bed and adjusting bedclothes	normal	4
Walking	early difficulties	3
Climbing stairs	slow	3
Dyspnoea	None	4
Orthopnea	None	4
Respiratory insufficiency	None	4
	Total	45

Jacob has not yet undergone respiratory assessment, however denies any symptoms of respiratory insufficiency.

- what do you believe are the 2/3 main issues?
- what needs to happen next?
- who to involve?
- how you would organise those next steps?
- what is the key information you would pass on to other MDT members and how?

Compare your answers to those of 2 other MDTs by watching these videos:

Oxford Group Case One: https://youtu.be/ngokyMdpTgA

Physio Case Study One: https://youtu.be/5TmJQgxSHjc

Case Study 2: Ameena

Introduction

Ameena is a 43-year-old woman, originally from Iran. She sought asylum in Britain 7 years ago when her husband was executed for speaking out against the government. Ameena lives with her partner Janet in a one-bedroom social housing flat in Liverpool. She has no family in the UK and is unable to visit her family due to the danger to her if she were to return to Iran.

In Iran Ameena was a drama teacher, she is still passionate about the arts and enjoys going to plays when she is able. Since receiving asylum 2 years ago Ameena has been working as an assistant at a children's nursery. Ameena and Janet have limited social support, but are close with their neighbour James.

Ameena was diagnosed with MND six months ago. Her presenting symptoms were breathlessness, disturbed sleep and morning headaches. She has found these symptoms and their sudden onset distressing. She is happy to attend her neurology appointments and accepts that she will continue to experience rapid change with her condition. Janet is very concerned with how quickly Ameena's breathing has been affected.

Case Presentation

Ameena went to her GP because of recurrent headaches in the morning and difficulty catching her breath. There was a delay in her being referred to a specialist at first and her GP suggested over the counter painkillers. Ameena returned to her GP 4 weeks later when she had become visibly more short of breath. Initially the GP was concerned that she may have sleep apnoea and this was investigated at first.

Ameena was referred to the respiratory team and a neurologist. The neurologist suspected MND but a referral was made to a specialist neurologist for confirmation. A definite diagnosis of MND with respiratory type symptoms was then made following a full neurological examination.

Over the past six months Ameena has:

- Experienced disturbed and reduced amount of sleep
- Increasing breathlessness

- Decreased exercise tolerance, she previously enjoyed running, but now struggles to climb the stairs.
- Periods of confusion and loss of concentration
- Increasing fatigue
- Lost a significant amount of weight
- Has reduced coordination and motor control
- Relies on a walking frame to walk around the flat, and a wheelchair when outdoors
- She has recently developed a chest infection for which she is on her second course of antibiotics

Ameena and Janet report noticing that Ameena's condition is changing on a weekly basis. Ameena is now relying more heavily on a wheelchair and requires non-invasive ventilation throughout the day and night.

Management and Outcome

Ameena's condition is rapidly deteriorating and she requires regular specialist input to manage these changes. Ameena has been referred to the local hospice, she is also seen by the respiratory team, a neurologist, dietician and speech & language therapist (SLT).

Ameena is accepting of her condition and continue with the non-invasive ventilation, but has declined further intervention such as a feeding tube. Ameena and Janet reached a crisis point when Ameena's condition changed rapidly over a period of two weeks and she was no longer manage her personal care.

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Compare your answers to those of 2 other MDTs by watching these videos:

Oxford Group Case Two: https://youtu.be/4Kr_5qVN9_0

Physio Case Study Two: https://youtu.be/U4jC8-LkRc0

Case Study 3: Faisal

Introduction

Faisal is a 70 year-old man, originally from Turkey. He is now a British citizen and has lived in London for the past 20 years. He was widowed five- years ago and now lives alone in a small rented third floor flat. He has the support of his two sons and a daughter, all of whom live in London and the South East. Faisal has a degree in the history of art but has spent most of his working life as a builder. His one main social interest remains visiting art galleries.

Faisal was diagnosed with MND two-years ago. His presenting symptoms were slurred speech, coughing on drinks, occasional word finding problems and losing track of finances and day-to-day planning. Currently he is happy to attend

neurology appointments but sees little value in seeing other professionals. His family are very concerned about his speech, swallowing and his ability to manage life at home. They also feel that he has become more short-tempered. Faisal, however, sees no problem in these areas.

Case Presentation

Faisal's family initiated investigations by taking him to his GP. They were concerned about his coughing on drinks, difficulties in making decisions, problems 'remembering words' and responding to new situations. His GP referred him to speech & language therapy (SLT) to investigate his swallow and to a local memory clinic to consider his decision making and planning. He attended the SLT appointment but declined the memory clinic.

Faisal's SLT observed fasciculations (involuntary muscle movements) on his tongue, as well as obvious word finding problems, and suggested to the GP that a referral to a neurologist would be helpful. A few months later Faisal saw a general neurologist at his local hospital. The neurologist suspected MND but a referral was made to a specialist neurologist for confirmation. A definite diagnosis of MND with bulbar type symptoms was then made following a full neurological examination. Throughout this process Faisal has been very reluctant to attend appointments, regularly complaining that 'there is nothing wrong – I'm just getting old'.

Over the past two years Faisal has:

- Lost a significant amount of weight
- Reduced his oral intake to soft foods
- Experienced an increasing number of falls, particularly in accessing his flat
- Become breathless on exertion, particularly when climbing the stairs
- Relied increasingly on his children for shopping and some personal care
- Become unintelligible except to his close family
- Displayed unpredictable behaviour towards family and professionals, including inappropriate laugher and crying.
- Experienced problems in understanding what others are saying to him
- Remained very reluctant to participate in any decision making about his future care or treatment
- Complains that nobody wants to be with him and that he has nothing to do during the day.

The family now feel that Faisal is unable to cope at home. They are very worried about his unpredictable behaviour and signs of disinhibition (e.g. swearing at strangers in the street).

At his last MND clinic visit he underwent an Edinburgh Cognitive and Behavioural ALS Screen (ECAS). This revealed a clear frontotemporal dementia (FTD).

Management and Outcome

Faisal has attended his local specialist MND clinic (every three months). His SLT and dietician have made recommendations regarding appropriate consistencies and have mentioned the availability of a feeding tube (gastrostomy) and a computer through which he can communicate (an augmentative and alternative communication system), it is recognised however, that his word finding problems could present additional problems. Faisal has not wanted to engage in these discussions.
It has become apparent that his cognitive function has deteriorated. He

becomes confused in new surroundings, is resistant to change, finds understanding complex language difficult, and cannot easily understand or recognise other people's emotions.

- what do you believe are the 2/3 main issues?
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Compare your answers to those of 2 other MDTs by watching these videos:

Oxford Group Case Three: https://youtu.be/SlvsARatSk8

Physio Case Study Three: https://youtu.be/0zdN1mYE13k