OT and Motor Neurone Disease

Adjusting and adapting to an ever moving target.

Motor Neurone Disease is an incurable but not untreatable progressive neurological condition. It can be a challenging, demanding and confronting area of practice for Occupational Therapists.

Best Practice Model of Care for Occupational Therapy

MND is an umbrella term for different disease subtypes.

These subtypes are characterised by rapid and varying physical presentation and subsequent functional difficulties which may in turn impact on the selection and timing of Occupational Therapy interventions.

Understanding of phenotypes assists in making informed decisions regarding choice and timing of OT interventions.

1. Base clinical reasoning on knowledge of phenotype - For each subtype it is important to understand disease characteristics, physical and cognitive presentation and subsequent functional difficulties.
2. Use knowledge of phenotype patterns to predict an individual’s likely equipment requirements.
   - Trial and provision of required equipment – ask, advocate, loan and fund.
   - Bulbar phenotype clients are unlikely to require large home modifications.
   - Flail UL/Cervical onset phenotype clients will need quick access to ECU’s and alternate computer access, splints and UL supports.
   - Lumbar onset phenotype clients will require quick access to wheelchairs, home mods, ELR chairs, adjustable beds and hoists.
   - PLS phenotype clients will require everything!
3. Client Centered Proactive care
   - Introduce items early to allow time for adjustment.
   - Make clients aware of options to assist with informed decision making.
   - Allow client to decide what is important.
4. Home Modifications - Base decision on individual situation however it is important to consider the following:
   - Prognosis and length of life.
   - Psychological impact of permanent home modifications to family and friends after end of life.
   - Consider timing and cost of large permanent modifications and be strategic with funding.
   - Consider non-permanent, cheaper and flexible solutions – rubber shower inserts and wedge ramps, portable ramps.
   - Sensible negotiation, flexibility and willingness to compromise and experiment with practical alternatives is essential.
5. Understand impact of respiratory involvement on function and role participation.
6. Focus on Individual goals and find out what is important.
7. Embrace Technology – Environmental Control systems, Eye Gaze, AAC, alternate computer access, integrated systems.

MND Phenotypes and Presentation

Global MND/ALS – 75% of cases

Average survival: 2-5 years from symptom onset.
Displays both UMN and LMN signs with rapid global deterioration.
Phenotype defined by onset location – bulbar, cervical or lumbar.
Most patients become totally dependent.
Respiratory deficits require Non Invasive Ventilation (NIV)
Flail Limb Variant /Progressive muscular atrophy – 10% of cases
Average survival: 5-6 years from symptom onset.
LMN signs only – wasting in UL muscles groups.
Slow to develop LL and respiratory weakness.
Unique challenges with ambulant individual with no UL movement.
Familial MND – 10% of cases
Same presentation of functional deficits/life expectancy as global MND.
SOD1 gene mutation on chromosome 21.
Primary Lateral Sclerosis (PLS) – 3% of cases
Average survival – 10+ years from symptom onset.
UMN involvement only – global spasticity, stiffness, joint discomfort.
Significant dysphagia and dysarthria.
Progressive Bulbar Palsy – 1-2 % of cases
Average survival: 6 months – 3 years from symptom onset.
Brainless affected with rapid progression of symptoms.
Difficultly with head and neck control and often excessive saliva.
Lower limbs affected less – may remain mobile.

Challenges for Occupational Therapists

- Clients with MND require a flexible, responsive and ongoing OT input.
- MND can progress so rapidly that functional capacity may deteriorate from week to week.
- The rapid progression of this disease results in significant functional decline.
- Limited time to adjust to loss before next loss occurs.
- Vast array of presenting deficits depending on phenotype and onset location.
- Individual reaction to diagnosis may differ greatly - introduction of changes need gentle discussion.
- Large challenges for funding equipment and supports in a timely manner.
- Huge psychological adjustment to neuro-palliative diagnosis.

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