How can we reduce the impact of MND on everyday life?

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Summary

- The impact of MND
- How can this impact be reduced?
- Relevant research
Psychological & Emotional Impact

Cognitive Disability

Physical disability

Environmental impact: Relationships, finances, accommodation, etc

Person with MND

Person with MND
Time
Challenges of reducing the impact of MND

- Important to acknowledge that it’s difficult
- Time factor makes a huge difference
- Number of services involved is important
- Variety of age of onset has an impact
Variability in age of onset


Figure 1 Line graph of age- and gender-specific incidence of MND for all-Ireland, 2004–2005.
What does research tell us?

- pw MND develop experience of living with the condition, what works and what doesn’t
- Concentrate on present day and tend to face each issue as it arises
- Professionals’ knowledge of MND, coordination and delivery of service may be inadequate
- MDT clinics appreciated but can be challenging and tiring due to too many different professionals

- Not having control over the disease but having control over one’s life

- As condition progresses finding it harder to engage in meaningful activities and maintain valued social roles

- Modify notion of desired self and engage in a continual process of adapting to change

- Cannot trust their body, therefore take control of life in different ways
How do we reduce the impact?

- Making services coordinated and timely
  - MDT clinics
  - Copying in correspondence
  - Phone contact
  - Specialist nurse role
  - Limiting number of professionals involved
  - Timed review
  - Health, social services and MNDA working together

- Each person has their own role to play

- Not preferential treatment but responding to needs of condition
How do we reduce the impact?

- Thinking ahead – at same time as respecting the person’s needs to not be overwhelmed

- Incremental information giving – at same time as not giving same message at each encounter
Taking different ages of onset into account

- Onset can be from 20’s to 90’s

- Knowing the person’s life circumstances extremely important for an individualised response

- Factors include:
  - Work
  - Roles carrying responsibility
  - Leisure activities
  - Family relationships

- Services and benefits available will differ
**Physical disability**

- **Impairments:**
  - Swallowing *
  - Speech *
  - Respiratory muscle weakness *
  - Cervical weakness
  - Upper limb weakness
  - Trunk weakness
  - Lower limb weakness
  - Neurogenic bowel
  - Neurogenic bladder
  - Fatigue
Movement disabilities

- Optimising ability
  - Exercise within limitations
  - Range of exercises
  - Focus on specific activities, e.g. climbing stairs, transferring, avoiding falls, activities associated with occupation

- Adapting to disability
  - Equipment for mobility and posture
  - Different ways of moving and thinking about movement
Ambulant participants
Endurance & resistance training (23) compared with usual neurological rehabilitation (15)
Daily for 5 weeks
Submaximal isometric contractions using therabands, low repetitions with recovery +65% of maximum HR cycle ergometer or treadmill for 15–20 minutes
Usual – 1 hour of ‘stretching, mobilisation and muscle reinforcement’

Table 4. Functional and cardiopulmonary changes after training.

<table>
<thead>
<tr>
<th></th>
<th>ALS-EP n=23 mean±SD</th>
<th>ALS-SNT n=15 mean±SD</th>
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</thead>
<tbody>
<tr>
<td>FIM</td>
<td>4.56±1.16*</td>
<td>1.8±1.37*</td>
</tr>
<tr>
<td>FSS</td>
<td>1.29±0.21*</td>
<td>-0.21±0.16</td>
</tr>
<tr>
<td>Resting heart rate, bpm</td>
<td>-5.7±1.29</td>
<td>-0.53±4.47</td>
</tr>
<tr>
<td>Oxygen Consumption, ml/min/kg</td>
<td>-4.16±1.71*</td>
<td>0.10±1.53</td>
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<tr>
<td>Ventilation, L/min</td>
<td>-3.59±4.73</td>
<td>0.34±4.64</td>
</tr>
<tr>
<td>MRC Sum Score</td>
<td>7.83±1.80*</td>
<td>1.53±1.13</td>
</tr>
<tr>
<td>Right Biceps, kg/min</td>
<td>9.26±13.17*</td>
<td>-0.73±1.10</td>
</tr>
<tr>
<td>Left Biceps, kg/min</td>
<td>8.18±10.09±</td>
<td>-0.54±1.35</td>
</tr>
<tr>
<td>Right Tibial, kg/min</td>
<td>9.28±12.96</td>
<td>-0.13±1.46</td>
</tr>
<tr>
<td>Left Tibial, kg/min</td>
<td>8.44±17.27</td>
<td>-1.00±1.41</td>
</tr>
<tr>
<td>Six Minute Walk Test, mt</td>
<td>71.56±50.72</td>
<td>2.90±5.48</td>
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</tbody>
</table>

* Significant effect of time, p<0.05; ° Significant difference between groups, p<0.05
Upper limbs

Equipment

- Mobile arm supports and Neater Eaters
- For writing, eating, keyboard use, etc
- To assist with washing and dressing
- Use of electronic assistive technology
Trunk and neck

- Neck supports
- Supportive seating
- Bed adaptations
- Core exercises
Cognitive disabilities

- Severe cognitive impairment affects a small proportion of those with MND
- Mild executive dysfunction in a greater number
- Affects the way in which information should be given and the time allowed for processing information
- If a dementia is developing then making decisions known and/or knowledge that will inform best interests decisions is important
ALS–specific cognitive and behavioural changes associated with advancing disease stage in ALS. Crockford et al. Neurology 2018
Activities

- Exploring the leisure and sports activities a person wants to continue with or learn
- Enabling the person to modify the way these are done
- Assists in maintaining sense of self and self worth
- Can reduce isolation
Psychological and emotional impact

- Impact on pwMND and family, especially those who develop caring roles
- Grief, acceptance and adjustment

- Every professional encounter can incorporate an emotionally and psychologically sensitive approach

- Further assistance:
  - Hospices
  - IAPT
  - MND service psychologist or counsellor
Environmental impact: relationships

- Changes in role:
  - Carer to cared for
  - Worker to unemployed
  - Fixer to increasing dependence
  - Diminished role as parent, grandparent, etc

- Importance of carer support

- Signposting to sources of assistance
  - Carers Association
  - Psychological therapies
Environmental impact: practical help

- Finances, employment, accommodation affected
- Signposting to support for these from MND clinic
  - Voluntary sector
  - Benefits
  - Social services
  - Housing
  - Access to work
- Talking through decisions that may need to be made
The impact of MND can be reduced, but requires coordination, effort and resources.

Health, social services and voluntary sector have a large role to play.