Oxford University Hospitals NHS
NHS Foundation Trust

Equipment

"When and what? - Possible equipment solutions to common challenges for people living with MND“

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June 2023

Why use Equipment?

- Equipment is a means to an end.
- Question is: How can we help someone continue to do the activity/occupations they need/want to do?
- PLUS retain sense of self; control; dignity and quality of life.
- Some of the solutions will be equipment alongside technique and creative thinking and dependent on environment.

Equipment and Adaptations – What are the Challenges?

- It’s a progressive condition – it won’t stand still – some equipment will become redundant
- It won’t be confined to just one area of weakness
- Unpredictability: Doesn’t follow a pattern or a set timescale.
- Level of uncertainty about changes and when they will come?

(There’s a reason regular review is recommended (NICE Guidelines NG42)

- Individuals have different coping strategies and approaches and views of equipment might mean.

Timing – the great balancing act

- Timing of equipment – It needs to feels relevant and timely to current situation.

- The equipment needs to be provided and useable within the required timescales (e.g. especially if grant applications/ finance/ quotes/ planning permission needed).

- The person feels a sense of control over the situation wherever possible.

Scenario 1

- Jim
- Respiratory onset MND
- Developing weakness in legs. Wants to keep walking – even though falling regularly. Arms and hands weak – walking aids therefore difficult
- Wheelchair has been discussed. Need to address ramp issues as steps up to property.
- Doesn’t feel the need of a wheelchair “just yet” and wants to keep going.

Scenario 2

- Mary
- ALS - MND – started in arm. Only symptom at present is limited grip in right hand.
- Wants to be prepared – has been thinking about the future and knows she wants to stay in her own home till the end
- Wants to know fully what to expect; and how best she should prepare

Potential Equipment Solutions

- It is so difficult to anticipate exactly what someone will need.

- What is the most frequently used item of equipment provided and used by people with MND?

- Next section – breaking down equipment solutions by impairment and basing on common Activities of Daily Living.

Upper Limb

Equipment

- Sensor activated technology
- Managing falls risks e.g. lifting cushions/pendant or other sensor alarms*
- Adapted grip (cutlery/pen/toothbrush)
- Orthotics (fingers/hand/wrist/shoulder/neck)
- Mobile Arm supports/ Aids for eating/drinking (e.g. neater/obi/camelbak)*
- Kitchen adaptations/ carrying options/
- Seating – support for the upper limb
- Bed mobility aids – slide sheets; bed levers; turning aids; profiling bed*
- Bath boards/lifters/shower stools/
- Raised seats/ riser chairs
- Dressing aids – adapted clothing

Adaptations

- Wash dry toilet
- Automatic door openers
- Sensor activated technology/ Environmental controls/ Home Automation

Lower Limb

Equipment

Walking aids – walking poles; sticks; walkers; forearm support walkers

Orthotics – AFO's

Wheelchairs – manual/folding/electric/scooters*

Transfer aids – raised heights/rising equipment/standing aids/ hoists

Riser recliner chairs

Profiling bed; bed turning equipment (see previous page)

Perching stools

Adaptations

Handrails and grab handles

Access/ramping

Level access showering facilities

Possible ceiling track hoist

Stairlifts/Through floor lifts/ Stairclimbers*

Bulbar region

Equipment

- Communication aids – mobile phone/tablet – text to speech apps/ Boogie board/ paper and pen
- Voice amplifiers
- (Cough Assist/Suction)
- (Medical procedures PEG etc)

Respiratory

Equipment

- Profiling adjustable bed/wedges
- Upper limb support
- Fan
- (Breath stacking/Cough Assist/NIV)

Trunk and Neck weakness

Similarities to upper and lower limb weakness

- Equipment

Orthotics – Collars; shoulder/ core supports

Walking aids

Seating options/postural support

Profiling bed

Wheelchair - headrests – use of tilt/recline

Adaptations:

Home Automation

Cognition

- Equipment
- Reminders/Prompters with explanations
- Sensors to support care/risk management
- Automatic alarms for those living on their own e.g. falls alarms or movement sensors so that if routine is changed/disturbed someone is aware.

Specific Activities

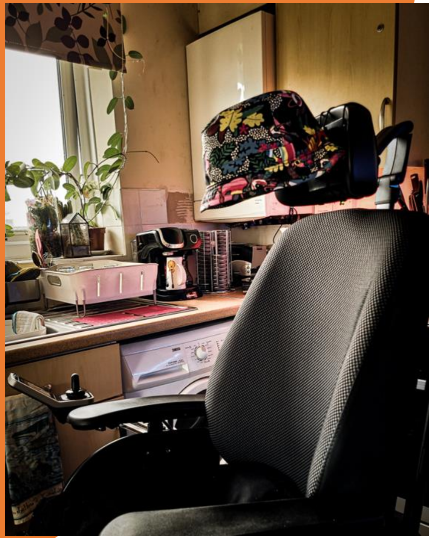
- Computer Access (eye gaze/voice activated/dictation/keyboards/mouse/chair
- Golf – adjusted grips
- Sex – aids and toys
- Painting – adjustable grip/holders/ipad
- Fishing
- Photography
- Writing

Thoughts and questions to consider

- All of this equipment – it's a lot. Some of it will need to be changed/upgraded within short time periods. Should we skip some steps? OR ……
- Disease can change quicker than people are anticipating or able to adjust to – both pwMND and professionals. How can we make sure that equipment is available in a timely way?
- People may reject equipment or not see the need of it "just now" – how do we enable people to be supported with equipment in a way that is acceptable but timely.
- It will change someone's home environment and how they use it. Alter sense of self and aesthetics of what they see everyday.

HOW DO WE HELP SOMEONE REMAIN IN CONTROL; HAVE CHOICE; ANTICIPATE NEED and SUPPORT PEOPLE IN MAINTAINING THEIR FUNCTION

My Reflections



- Know site of onset of Disease – might give you clues.
- Develop trusting relationship early on – Be approachable and responsive. Give them a contact so if needed they can call you and feel able to do so.
- Be pro-active and plant seeds early – E.g. at early signs of leg weakness – if someone is starting to cut down on walking due to weakness/fatigue I'll mention powered wheelchair. You feel like the "bad guy" but it's important that people have information about what is available to them.
- Think about how we use words "Hospital Bed" – what does this mean to someone? Can we offer more choice?
- Be creative – Not all our answers and solutions will come from a stock catalogue. People will want to privately purchase/try different things – e.g. folding powered wheelchairs

Some articles that might be of interest….

- Huub Creemers, Anita Beelen, Hepke Grupstra, Frans Nollet & Leonard H. van den Berg (2014) The provision of assistive devices and home adaptations to patients with ALS in the Netherlands: Patients’ perspectives, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 15:5-6, 420-425, DOI: 10.3109/21678421.2014.920031
- Taylor B. The Impact of Assistive Equipment on Intimacy and Sexual Expression. *British Journal of Occupational Therapy*. 2011;74(9):435-442. doi:10.4276/030802211X13153015305637
- Connors, Karol, Mahony, Lisa, and Morgan, Prue. ‘Variation in Assistive Technology Use in Motor Neuron Disease According to Clinical Phenotypes and ALS Functional Rating Scale – Revised Score: A Prospective Observational Study’. 1 Jan. 2019 : 303 – 313.
- Young HM, Kilaberia TR, Whitney R, et al. Needs of persons living with ALS at home and their family caregivers: A scoping review. *Muscle & nerve*. May 2023. doi:10.1002/mus.27849
- Ando H, Williams C, Angus RM, et al. Why don’t they accept non-invasive ventilation?: Insight into the interpersonal perspectives of patients with motor neurone disease. *British Journal of Health Psychology*. 2015;20(2):341-359. doi:10.1111/bjhp.12104
- Caron J, Light J. “My world has expanded even though I’m stuck at home”: experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication and social media. *American Journal of Speech-Language Pathology*. 2015;24(4):680. doi:10.1044/2015_AJSLP-15-0010