

Holistic management of upper limb weakness in MND: optimising quality of life and minimising risk - 25 June 2026



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Aims and Objectives

- Increased understanding of upper limb weakness in MND and implications on function
- Share practical techniques and equipment ideas focused on optimising safety, independence and comfort.
- Opportunity to share ideas of best practice with each other
- Produce an 'upper limb quick reference guide'



Outline of Session

- Overview of upper limb weakness in MND
- Outline different areas of daily living and practical ideas to address upper limb weakness
- Presentation from the Electronic Assistive Technology Service (EATS)
- Role of orthotics for upper limb weakness
- Break out rooms for further discussion



Understanding Upper Limb Weakness in MND

Upper limb weakness in MND occurs as a result of dysfunction within:

- Upper Motor Neurones (muscle weakness, spasticity, hyperreflexia).
- Lower Motor Neurones (muscle weakness, hypotonia, atrophy, fasciculations, hyporeflexia).
- Changes in upper limb function can be experienced as the primary symptom of MND. Equally it can be a symptom experienced as the disease progresses.
- It often begins unilaterally but usually progresses bilaterally affecting both upper limbs to varying degrees.



Understanding Upper Limb Weakness in MND

- Weakness to the proximal muscles (shoulder girdle) can result in 'flail arm'. This can severely limit a person's reach and ability to position their hands to support function
- Weakness to the distal muscles (hand) can result in difficulties with hand grasps and fine motor function
- Many experience a combination of both of the above to varying degrees
- Sensory function is preserved



Assessment of function

- Measurement of active and passive movement and range
- Functional and psychological impacts of upper limb weakness
- Develop person centred goals in relation to upper limb function

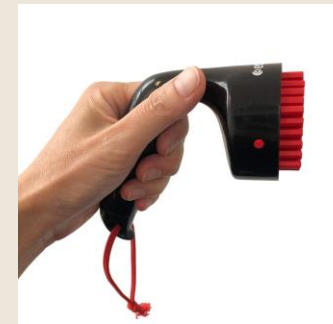
Mobility, Falls & Safety Considerations

- Minimise distractions when mobilising
- Remove trip hazards and obstacles
- Non-slip flooring
- Extra consideration when turning - due to reduced balance reactions
- Consider placement of arms/hands (eg in pockets to avoid swinging and overbalancing)
- Physiotherapy – balance work
- Falls sensors, telecare, alarm systems
- Consider minimising risk e.g. stair lift
- Well-fitting clothing of appropriate length
- Well-fitting shoes to avoid trips, slips



Access

- Adaptive key/knob turners or handle extenders with wider longer handles to help with opening or locking the door
- Lower where key and lock is - more accessible and not reliant on lifting arm against gravity
- Double hinged/sliding doors (internal)
- Removing doors (internal)
- Video doorbells or similar intercom systems
- Key safe
- Door openers - automatic door latch/openers
- Ensure emergency services are aware that there is difficulty/ inability to open the door - particularly if carer not present.
- Request fire safety check/telecare/falls detector in place to inform emergency services.



Transfers

- **Chair** - Chair raisers, Uplift seat assist or riser-recliner chairs to aid sit to stand due to reduced bilateral upper limb support
- **Toilet** - Raised toilet, Uplift commode (with sprung seat) to help with sit to stand
- **Bed** - Bed lever/bed ladder if enough upper body strength. Profiling beds to support both lying to sitting and sit to stand
- **Turning in bed** - Satin pyjamas to reduce friction and aid function (these may cause sliding, so assessment required), in bed systems – e.g. base sheet of Wendylett/Etac, bed cradle to relieve the weight of bedclothes, lightweight bed clothing
- **Bathing** – Bath lift to reduce difficulties getting right down into/out of the bath without upper limb use
- **Environmental controls** - adaptations to support independent operation of bed, chair controls



Bathing, Showering & Oral Hygiene

Oral Hygiene

- Thicker handle – hold with both hands to support
- Long Handled toothbrushes/flosser
- Three-sided toothbrush
- Electric toothbrush
- Automatic toothpaste dispenser
- Rest elbows on sink/hold toothbrush and use head movement to brush
- Potentially use of collar to support neck weakness
- Consider seating/positioning to maximise UL use

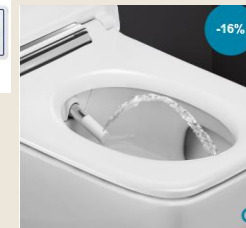
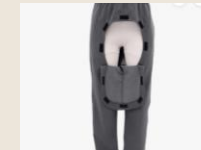


Bathing/Showering

- Use of seating for balance/fatigue
- Swivel bathers
- Bath lifts
- Long handled sponge
- Wash mit
- Automatic shampoo/soap dispenser

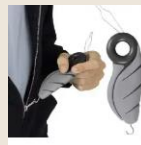
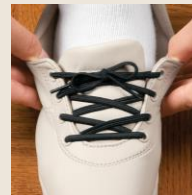
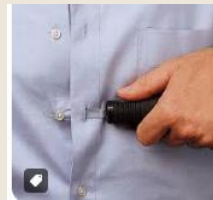
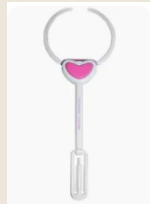
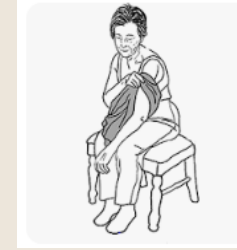
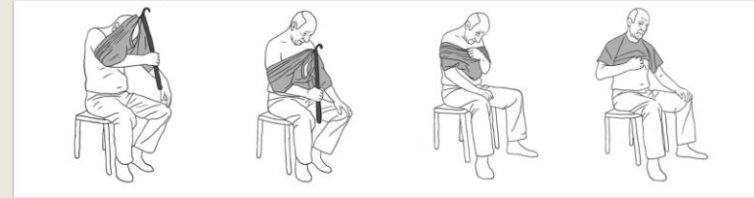
Toileting

- Consider equipment for transfers
- Clothing – e.g elasticated waist, braces for leverage, rear opening dresses/gowns, front opening trousers.
- Long handled wipers
- Bio-bidets
- Wash/Dry Toilets



Dressing

- Dressing techniques (e.g. dressing the weaker arm first)
- Positioning when dressing e.g. in seating



- Dressing aids
- Clothing choices (e.g. Velcro and magnetic fastenings, slip on shoes, elastic laces)

Grooming

- Techniques for supporting weaker arm
- Positioning e.g. seating/elbows supported on table
- Thicker handles e.g. for combs
- Zero arm supports to deweight ULs
- Wall mounted hair dryers
- Hot brush comb
- Eazyhold



Sex and Intimacy

- Body mapping or sensate focus can help
- Consider positioning – e.g. a more upright positioning may free up weak upper limbs against the forces of gravity
- If in separate beds explore ways to be intimate at different times – i.e. sofa during day, cuddle chair/bed
- Partner assists person to take their hands and stroke their body to support the intimacy of touch



Eating and Drinking

Eating

- Lightweight and/or large handled cutlery
- Universal cuffs - straps cutlery to palm of hand
- Consider positioning – e.g. curved table to support forearms, or reduce distance between plate and mouth
- Mobile arm support or electronic feeder such as a Neater eater (robotic option)

Drinking

- Neater straw, one-way valve straw
- Hydrant bottles with one way valve, Giraffe bottle
- Cup/bottle clamps for wheelchairs/tables
- Neater straw mover



Meal Preparation

- Hot water dispenser or tap instead of kettle
- Kettle tipper, filling kettle with lightweight jug
- Electric jar openers and tin openers
- Use of pre-cut food, meal kits or ready meals
- Use of meal delivery services
- To support a family member/carer to prepare meals completing achievable tasks within the process or sharing meal preparation knowledge



Shopping

- Use of small trolley even for a small shop to avoid carrying
- Use of the Hidden Disabilities Sunflower Scheme to let staff know you may need extra support
- Shop with a friend, family member or personal assistant for help to pick and pack
- Use Click and Collect option at superstore, or book an accompanied shop
- Complete an online shop, most companies will bring the items into the house and off-load them for you upon request



Driving and Travel

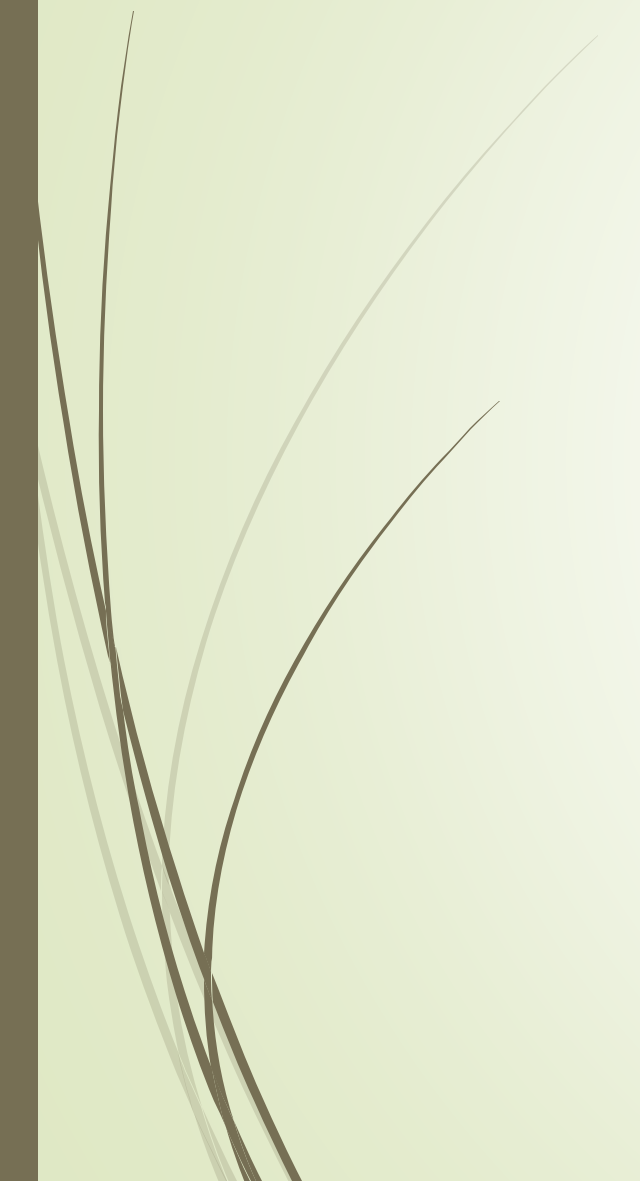
- Inform the DVLA of diagnosis
- Consider a drivability assessment – driving adaptations, w/c hoist
- Adaptations for car transfers – e.g swivel seat, handle
- Blue Badge Scheme
- Plan ahead for journeys e.g. booking accessible taxis (uber assist), arranging assistance
- Consider equipment needs when travelling – supportive travel companies, hiring equipment in advance, portable transfer equipment



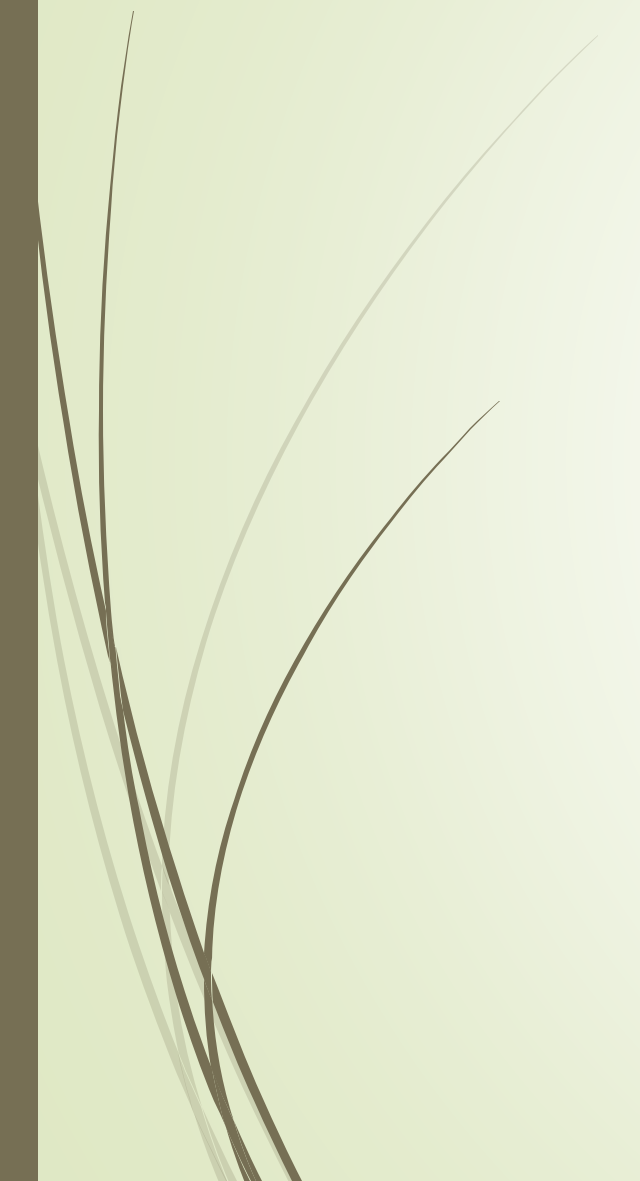
Work

- Liaise with Occupational Health
- Have support from Occupational Therapy for a reasonable adjustments report e.g. task modification
- Complete a workstation assessment
- Consider travel to/from work – access to work scheme
- Equipment – e.g. appropriate seating, arm supports, voice activation, eye gaze, hi-low table
- Consider fire evacuation plans
- Consider environmental adaptations





Q & A



Electronic Assistive Technology Service (EATS)

- Environmental controls -



What is EATS Environmental controls?

- EATS provides environmental control systems and alternative means of computer access for people with complex disabilities.
- We use a person's most reliable and consistent access method (e.g. direct touch, switches, head movement etc) to operate our equipment.
- We can provide simple or more complex systems to enable people to control as little or as much as they want in their home environment dependent on their goals.
- We can support access to:
 - Leisure devices: such as TV, Ipad, Laptops, Computers, Mobile phone, DVD players, CD players etc
 - Communication: such as landline phones, intercoms
 - Comfort: such as fans, lamps, control of bed/chair (if compatible and risk assessed)
 - If above EC is provided we can also support with access to Security: such as pagers, interfacing with care alarms
- We match the person's functional ability to technology to increase independence
- EATS is an NHS England Specialist Service and we are funded directly from NHS England.



What we don't offer:

- We are unable to provide readily available equipment such as tablet/phone stands, Alexa, Google Home, Hive, smart bulbs/smart home systems etc.
- We are unable to assess for Access to work or educational ICT equipment as this falls within the remit of other services.
- We do not make alterations to people's wheelchair controls – this is the remit of the local Wheelchair Services.
- We are unable to assess/fund for any works that would be funded via a Disabled Facilities Grant or minor adaptation such as:
 - Door openers
 - Curtain openers
 - Electrical or joinery work
 - Equipment for monitoring health needs (ie monitoring diabetes)
 - Telecare equipment (although we can interface with it if in situ)
 - Pager Turners
 - Neater Eaters



Derbyshire and Nottinghamshire EATS

- Our Service covers environmental controls for Derbyshire & Nottinghamshire only and is made up of:
 - 1.3 WTE Occupational Therapist
 - Clinical Technologist
 - Rehab Technologist
 - Medical Secretary
- Derbyshire and Nottinghamshire AAC (Communication) is covered by Lincoln EATS.



Other EATS services



- All areas of England have an EATS service commissioned to support that area. The service covering your area can be found at: [NHS Service Finder | Ace Centre](#)
 - Although work is being done on updating this tracker as the information is out of date in areas, such as our service is not showing.
- Other EATS services are much larger than ours in regard to staffing and geographical areas covered.
- Other EATS Services also have Speech & Language Therapists working for them if they provide Assistive Technology for AAC.
- Arrangements of EATS services are different in Wales, Scotland and Northern Ireland.

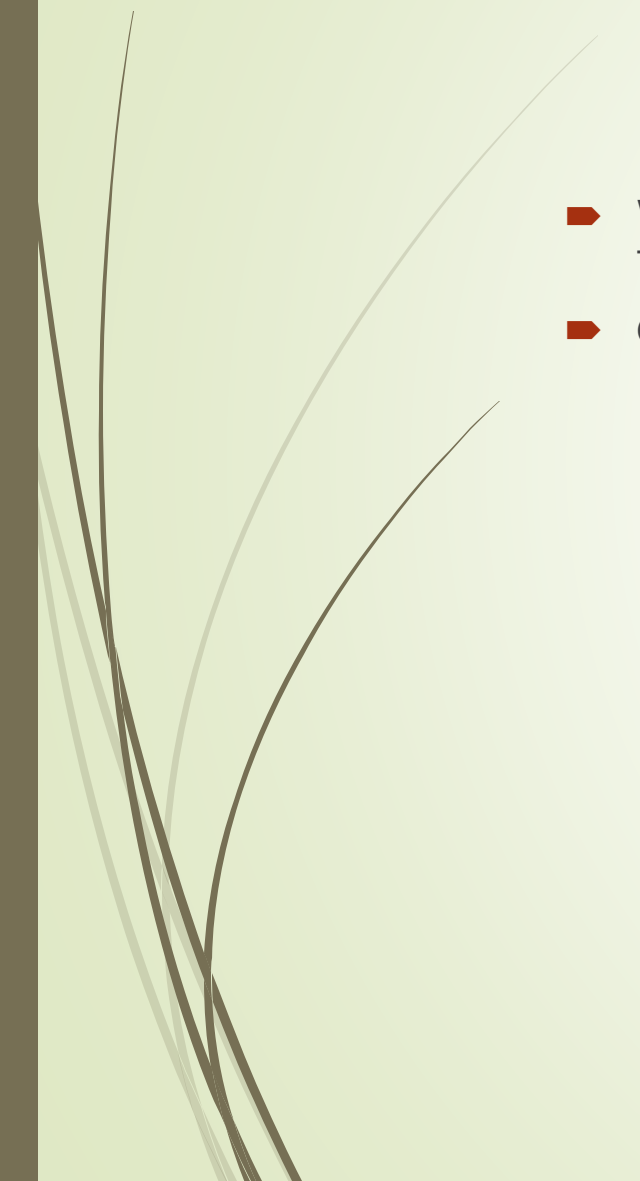


Who is eligible for our service?

- Both Children and Adults
- Profound and potentially complex physical disabilities where they are unable to operate standard controls (i.e. TV remote) for functioning independently in their home due to very restricted arm function.
- Where the Community OT has ruled out alternative and simpler equipment to resolve the issues, a referral can be made to EATS.
- Patients need to be cognitively able to understand, learn and operate our equipment consistently.
- Patients need to demonstrate sustained motivation to use the equipment.
- Own home, care homes, units (i.e. brain injury units).
- Referral Process – completion of referral form (which can be sourced from the appropriate EATS service); completed by a professional involved with the patient.

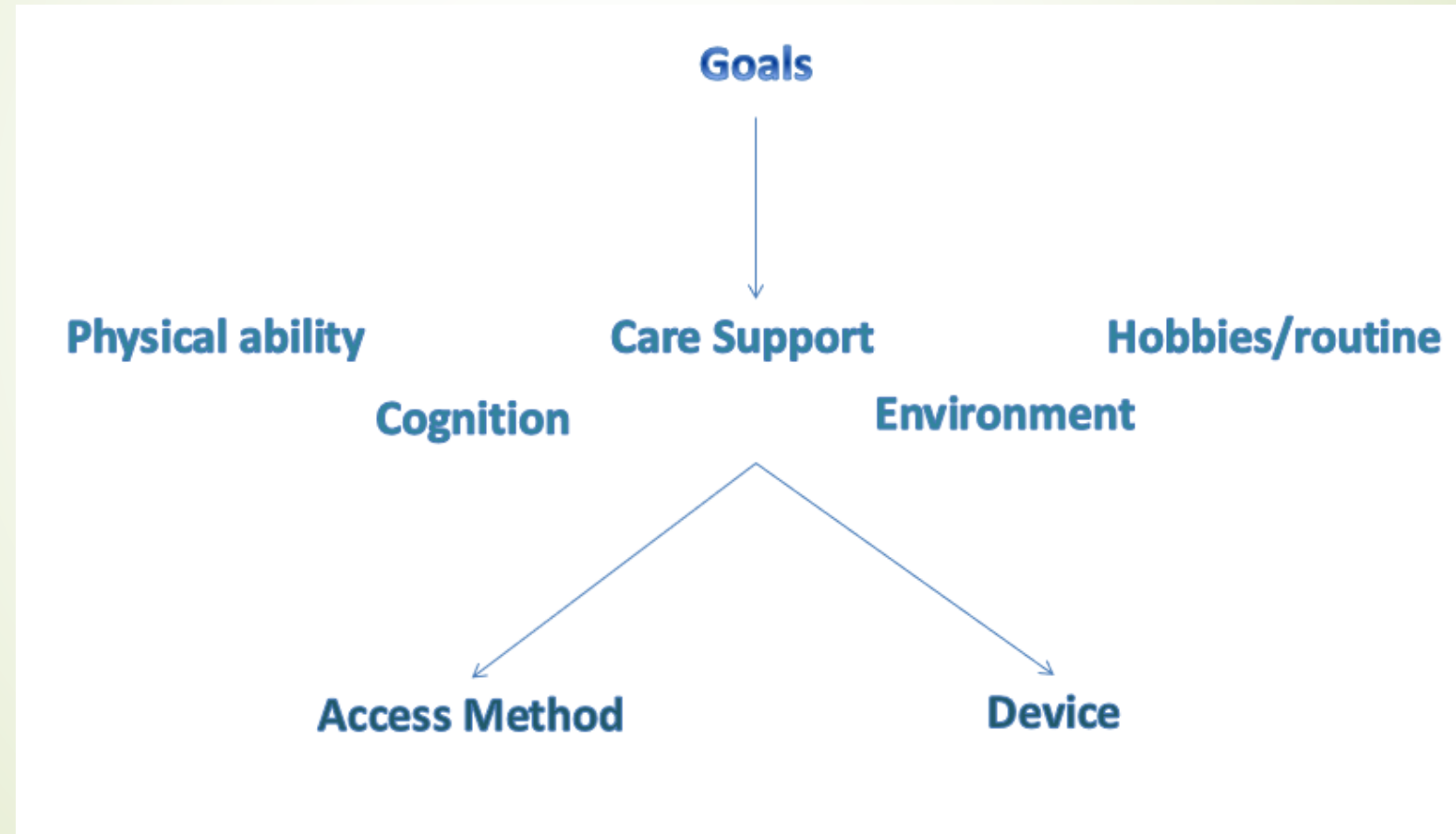


Conditions



- We provide a service to anyone who has a condition that impacts on their upper limb function.
- Our caseload is made of up people with conditions such as:
 - MND
 - MS
 - Cerebral Palsy
 - Head Injury
 - Spinal Injury
 - PSP
 - Muscular Dystrophy
 - Stroke
 - Any many more...

Assessment process:



Access Methods:

- Assess for consistent and reliable movement
- Could be any part of the body – hand, head, foot, eyes, elbow, toe, chin.
- There are lots of different switches that have a range of sensitivities – some switches don't actually need to be pressed as they have proximity sensors.
- If we are providing a switch, we would consider the appropriate placement of this switch and provide mounting for this if required.



Devices

- We can provide environmental control devices with varying levels of complexity.
- We can support patients if they want to remain on their mobile phones/tablets, or can provide a separate Environmental controls device.
- We can support patients to remain on their mobile phone/tablets/computers, however they must have these devices already. We do not provide computers, mobile phones and tablets.
- Any equipment we provide is free of charge, provided on a loan basis. Once the equipment is no longer required for whatever reason, the equipment is collected, decontaminated, refurbished and reallocated if safe to do so.





Installation & Review Process:

■ Installation:

- Equipment is installed by our Technologists.
- Training is given to patients and their family/carers on installation (and post installation as required/requested).
- On-going maintenance of our equipment is provided via fault calls and/or annual service visits.

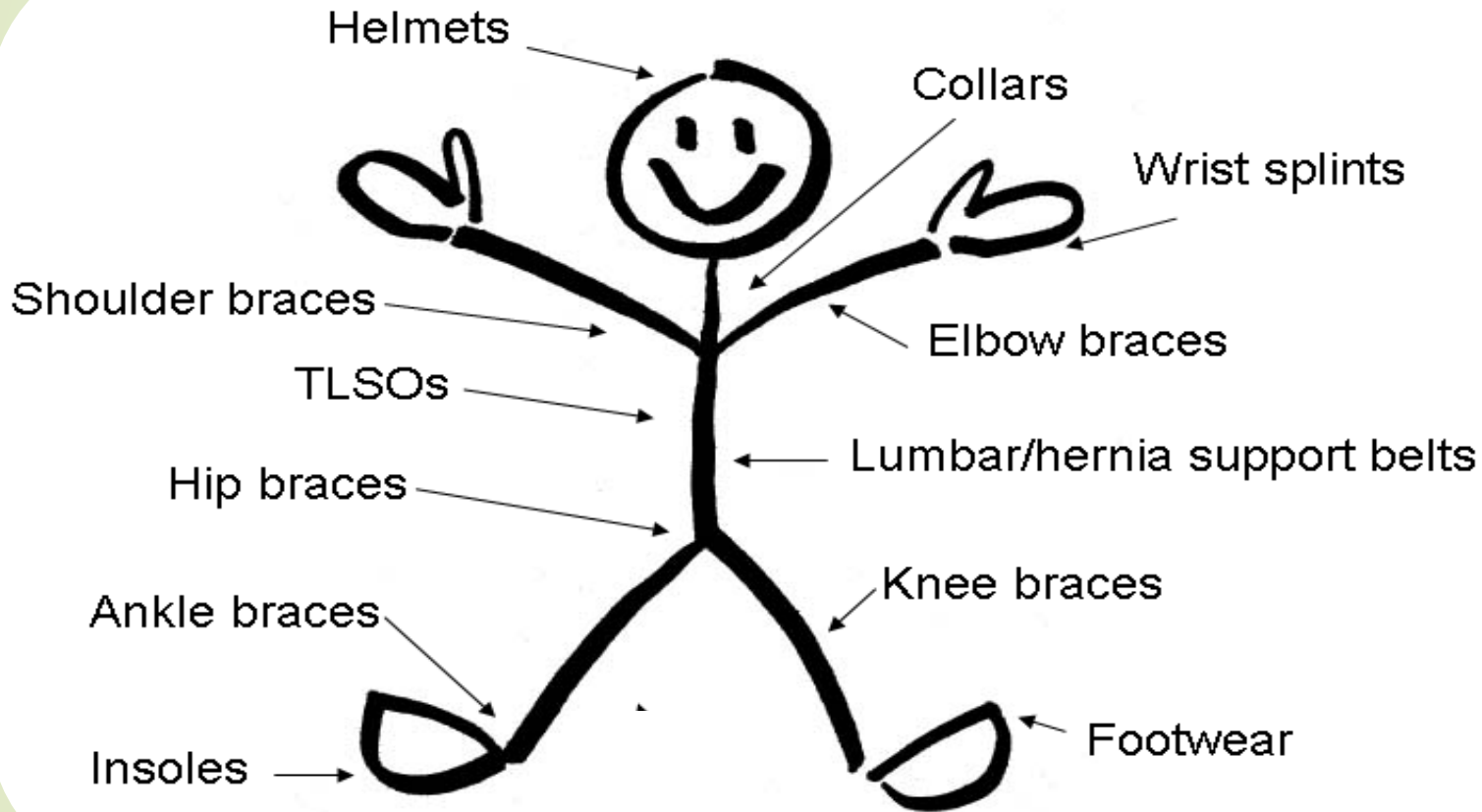
■ Reviews:

- Post installation reviews are completed by the allocated OT to ensure the equipment provided is suitable for the patient. Any alterations and revisions can then be made if needed.
- Reviews are completed as clinically required i.e. 1 months, 3 months, 6 months, 12 months however we do ask the patients/family to contact us if their condition changes, if further EC is requested etc.



Role of Orthotics in Upper Limb Weakness

WHAT IS AN ORTHOSIS?



“An externally applied device used to modify the structural and functional characteristics of the neuromuscular and skeletal system.”

ISO 8549-1:1989

EVIDENCE BASED SUPPORT OF ORTHOTICS

NICE Guidelines (NG42):

- Early assessment for mobility aids and orthotic support to maintain function
- Emphasises orthotics in managing foot drop and posture

Systematic Review: Orthotics in ALS/MND (Ivy et al., 2015):

- Highlights improved function, pain relief, range of motion from use of orthotics

Study: Neck Support in MND (MND Association 2023):

- Neck collars like Headmaster and HeadUp provide essential head support
- Prioritise comfort and allow safe swallowing
- Tailored selection improves compliance and daily function

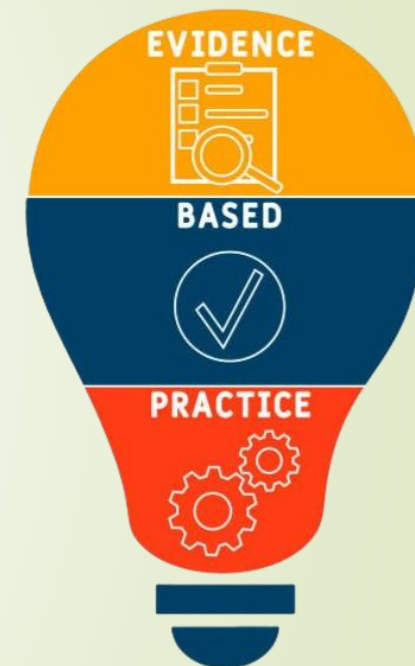


Image from
istockphoto.com

WHY ORTHOTICS MATTERS?

- Compensate for weakened musculature
- Enhance postural control
- Reduce fatigue by improving biomechanical efficiency
- Ensure safe pressure distribution
- Prevent or delay development of joint contractures
- Improve comfort and independence in daily activities
- ➡ Reduce pain and protect joints
- ➡ Provision of control to unstable joints or against abnormal muscle tone



Image from
istockphoto.com

CLINICAL CONSIDERATIONS IN ORTHOTICS

- **Progressive disease** – Reviewing regularly
- **Fatigue** – Use lightweight, energy-efficient devices
- **Skin integrity** – Monitor pressure areas, breathable materials
- **Compliance** – Prioritise comfort and ease of use
- **MDT review** – Coordinate with PT, OT, SLT and neuro team
- **Psychosocial factors** – Respect emotional impact, involve patient in decisions

WHAT TO TRY FIRST?

- Could try alternatives to orthoses first to assess tolerance and compliance
- Prior to orthoses, try:
 - Flannel
 - Stress ball
 - Soft toys



SHOULDER ORTHOSIS



Images from Blatchford and DMO

Indications

- Shoulder subluxation with pain
- Upper limb heaviness due to reduced muscle support
- Reduced proximal stability impacting function
- Fatigue during upper limb use

Advantages

- Provides external support to improve shoulder alignment and comfort
- May reduce pain from subluxation
- Supports limb positioning for function and rest
- Can reduce effort and fatigue during activity

Disadvantages

- Often requires assistance to apply/remove
- Tolerance may reduce as condition progresses
- Must balance support with comfort and ease of use
- Requires regular review due to disease progression

Clinical Feedback

- Reduced pain
- Improved comfort and limb awareness
- Decreased heaviness sensation
- Reduced fatigue during functional use

WRIST-HAND-ORTHOSIS (WHO)



Indications

- Weak wrist extensors
- Wrist joint instability
- Risk of contracture development
- To maintain functional joint position

Advantages

- Maintains wrist alignment and helps prevent contractures
- May be used at night (if tolerated) for prolonged positioning and comfort
- Supports wrist position for comfort and functional hand use

Disadvantages

- Poor fit may cause pressure areas or skin irritation
- Can limit function during ADLs when worn
- Often difficult to don/doff independently

Clinical Feedback

- May feel bulky or uncomfortable
- Compliance can be variable
- Tolerance may reduce with progression

SAEBO GLOVE AND SAEBO STRETCH



Image from
Saebo UK

Indications:

Mild to moderate hand weakness
Inability to extend fingers actively after gripping

Advantages:

Spring loaded tension assists with finger release
Lightweight and low profile
Can enhance motor practice

Disadvantages:

Requires some baseline muscle control
Can be difficult to don independently
Not suitable for contractures/tone

Feedback:

Improved confidence in using hand

PALM PROTECTOR

Indications:

Hand contractures

Prevention of pressure sores and skin breakdown

Advantages:

Provides a soft barrier

Reduce pressure sores in patients with limited hand opening

Disadvantages:

Can be hot and sweaty

Frequent fit adjustments needed

Feedback:

Improves comfort, prevents skin damage, provides security

May be bulky and uncomfortable



Image from Promedics Healthcare

INFLATABLE CARROT

Indications:

Hand contractures

Prevention of pressure sores and skin breakdown

Advantages:

Inflatable

Ideal when not enough range to fit a palm protector

Disadvantages:

Can deflate / poor longevity

Frequent fit adjustments needed

Feedback:

Improves comfort, prevents skin damage, easy to adjust



Image from
KSA



IMPORTANCE OF MDT

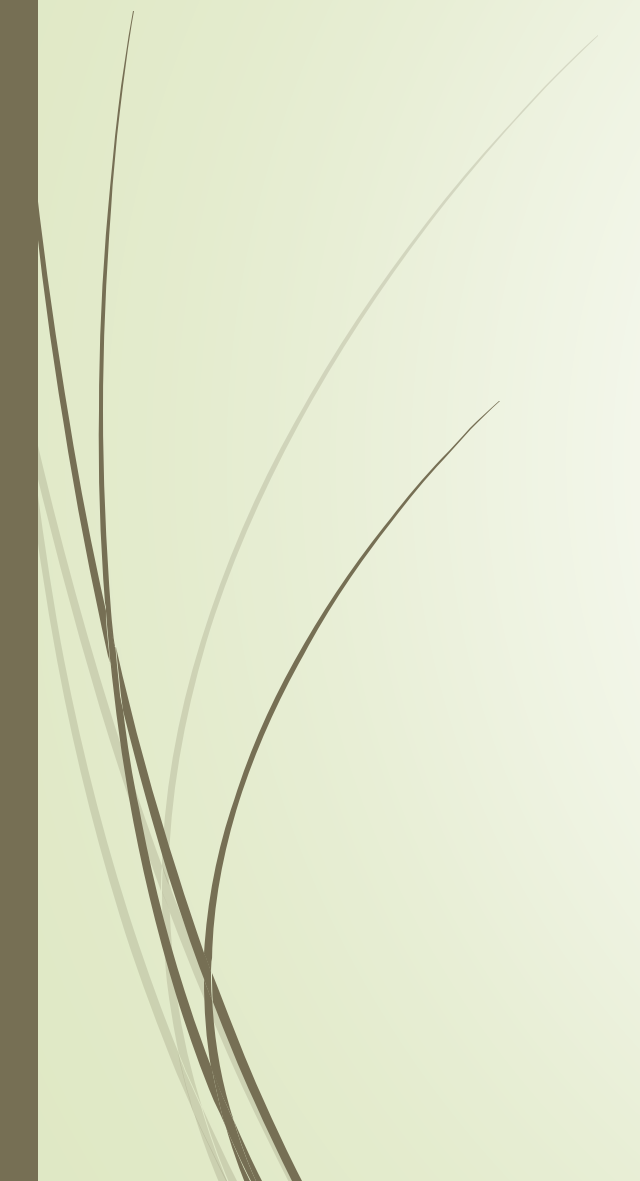
Effective management involves:

- Orthotist
- Neurology team
- Occupational Therapy
- Physiotherapy
- Speech & Language Therapy
- Individual and family/carers

IN SUMMARY

- Orthotics play a key role in maintaining function, comfort, and independence in upper limb MND involvement
- Focus is on supportive, adaptable, patient-centred solutions
- Early and regular intervention improves quality of life
- Best outcomes come from MDT working





Break out rooms