

OT AND MOTOR NEURONE DISEASE

Adjusting and adapting to rapidly changing function

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Motor Neurone Disease (MND) is an incurable but not untreatable progressive neurological condition. Working with people who have been diagnosed with MND can be a challenging, demanding and confronting area of practice for clinicians.

Diana – my Mum.

***Diagnosed with MND
April 2012***

10/6/43 – 28/9/2012

**Lived in Manjimup –
Western Australia.**



Motor Neurone Disease (MND) is an umbrella term for different disease subtypes.

MND subtypes are characterised by often rapid and varying physical presentation and subsequent functional difficulties.

Sound understanding of MND phenotypes assists in making appropriate decisions regarding choice and timing of OT interventions.

WHAT DO OT's DO?

Occupational Therapists enable people to participate in the activities of everyday life by providing adaptive equipment, modifying the environment & exploring alternate ways to complete activities.

In people with MND, the focus is on compensating for changes in function with equipment, home modifications and adaptive strategies.

TIPS FOR OT PRACTICE

- ✓ Understand the **phenotype** and the likely **progression** for the individual client.
- ✓ **Be PROACTIVE!** Plan ahead for the **next stage** and the **long term**.
- ✓ Smart and strategic use of funding.
- ✓ Close to perfect solutions may need to be good enough.
- ✓ Be **creative** not **prescriptive** and put recommendations in **writing**.
- ✓ People with MND require regular, **long term** input and support.

- Clients with MND require flexible, responsive and ongoing OT input as rapid progression results in significant functional decline.
- There is limited time to adjust to functional change before next change occurs.
- People present with a vast array of deficits depending on phenotype and onset location.
- Individual reactions to diagnosis may differ greatly.
- Large challenges for funding equipment and supports in a timely manner.
- Huge psychological adjustment to neuro- palliative diagnosis for the individual and their significant others.

FUNCTIONAL SPLINTS

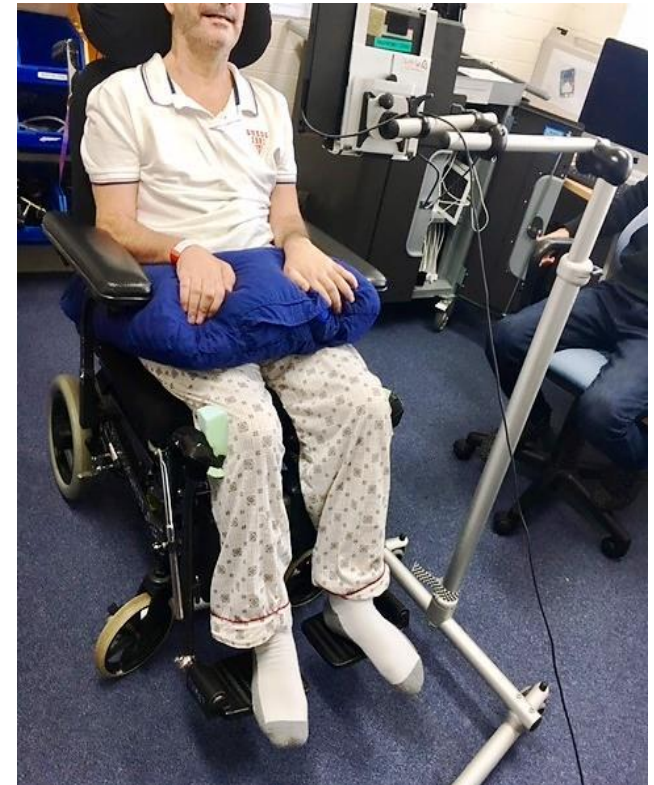
If a splint is indicated we:

1. Aim to improve grip and/or opposition of finger/thumb
2. Support wrist to allow function



UL MANAGEMENT

It is very important to support upper limbs for comfort, shoulder care and to support posture/respiratory function.



ELECTRONIC ASSISTIVE TECHNOLOGY (E.A.T)

Advancing technology is continually providing more options for engagement and independence for people with MND.

We need to keep up!

ELECTRONIC ASSISTIVE TECHNOLOGY (E.A.T)

The process of identifying what E.A.T is appropriate for each client takes time.

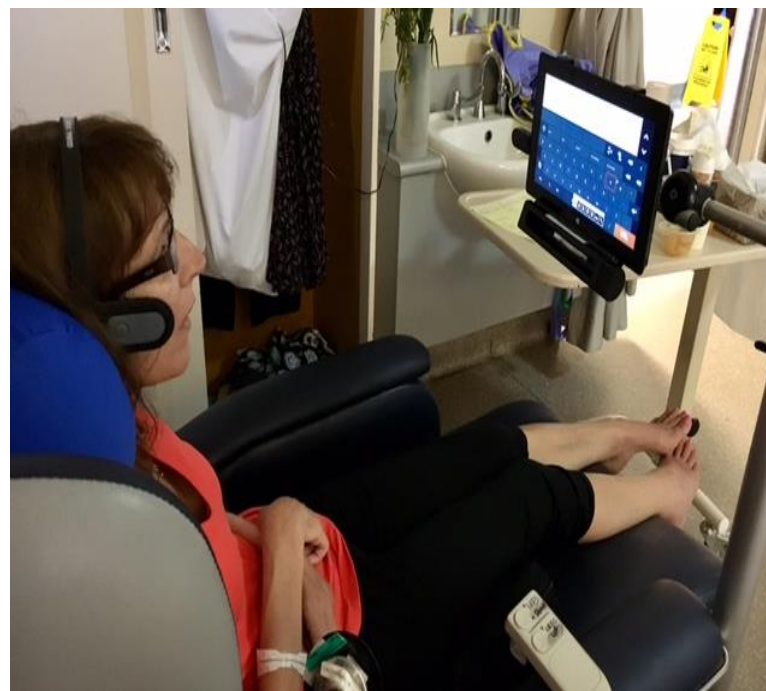
There is no MAGIC SINGLE SOLUTION!

1. WHAT do they want to DO?
2. WHAT are their GOALS for using E.A.T?
3. ASSESS access options — head mouse, gyroscopic mouse, eye gaze, switch scanning, direct touch.
4. WHAT combination of hardware and software is required to achieve their goals?
5. WHERE do they want to use – mounting and positioning
6. Trial and PRACTICE!

Early access to E.A.T leads to better outcomes.



Hospitality
Healing
Stewardship
Respect





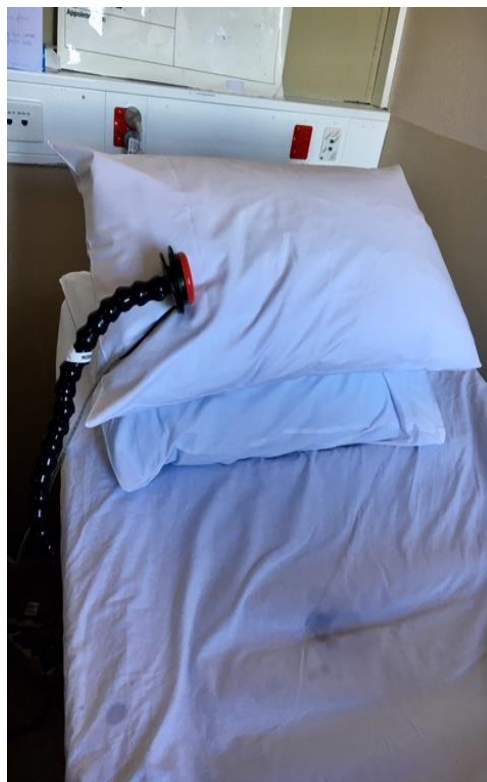
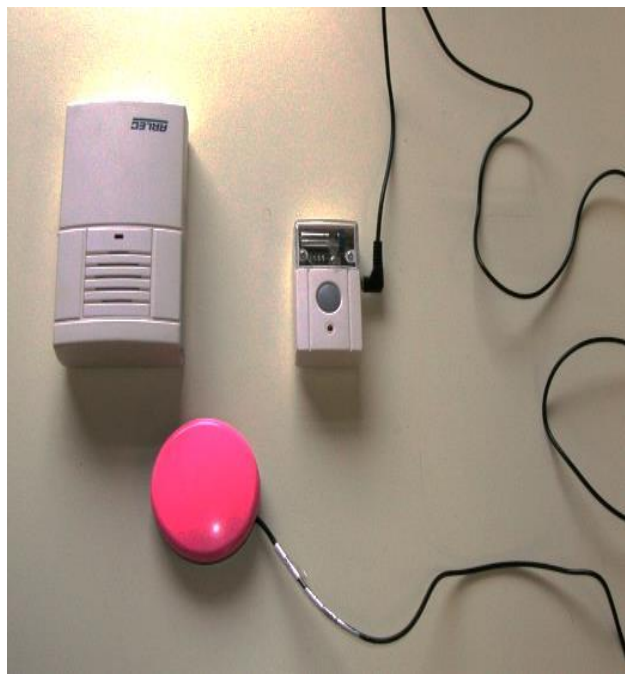


- Assistive technology provision is providing people with options!
- Introduction of Assistive Technology (Aids and Equipment) can be viewed as a symbol of loss and a reminder of the progressive nature of the condition
- There are a HUGE variety of aids and equipment available.
- We use our knowledge of onset patterns to predict a patient's requirement for equipment to allow for proactive introduction of equipment
- Some equipment may only be useful for a short period of time – that's ok.

- Approach electric bed discussions with care and sensitivity.
- Consider changes to personal relationships, intimacy and sexuality so discuss companion bed arrangements
- Scanning bed controller can provide independence via 'hands free' control.



- Remote door bells with switch adaption are an excellent low budget alert option esp. for people who have dysarthria to allow carer alert with a range of 50-80m.



Personal alarm options- consider the individual need:

- Monitored or unmonitored?
- 3/4G or Landline?
- Impact of NBN
- Switch adapted personal alarm pendants
- Alarm mats/sensors to alert carers to minimise falls risk



<https://livelifealarms.com.au/>

<https://www.carealert.com.au/>

<http://tecsol.com.au/cms123/index.php>

<https://www.personalarms.net.au/>

Base decisions for Home Modifications on individual situations

- Work to manage short term and long term needs
- Home mods may afford prolonged independence and safety at home
- Consider non permanent, cheaper and more flexible solutions.

Permanent or major home mods can be:

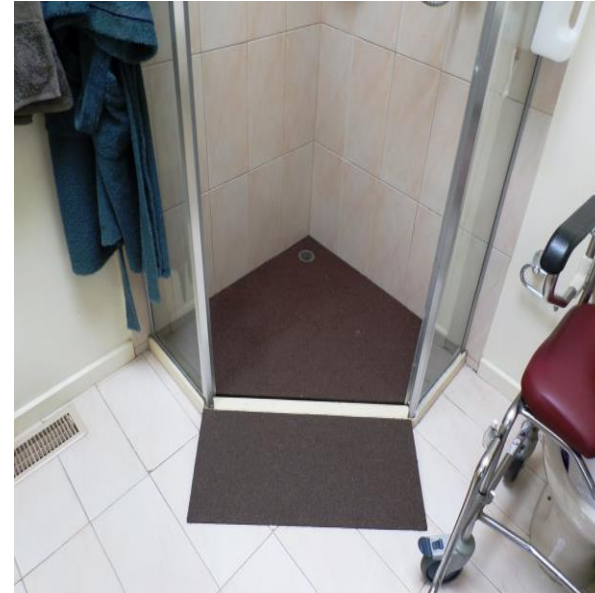
- Confronting – affirms disability & prognosis
- Inappropriate due to timing, disruption and cost
- Psychologically difficult – consider impact of permanent home mods on family and friends



Calvary

HOME MODIFICATIONS

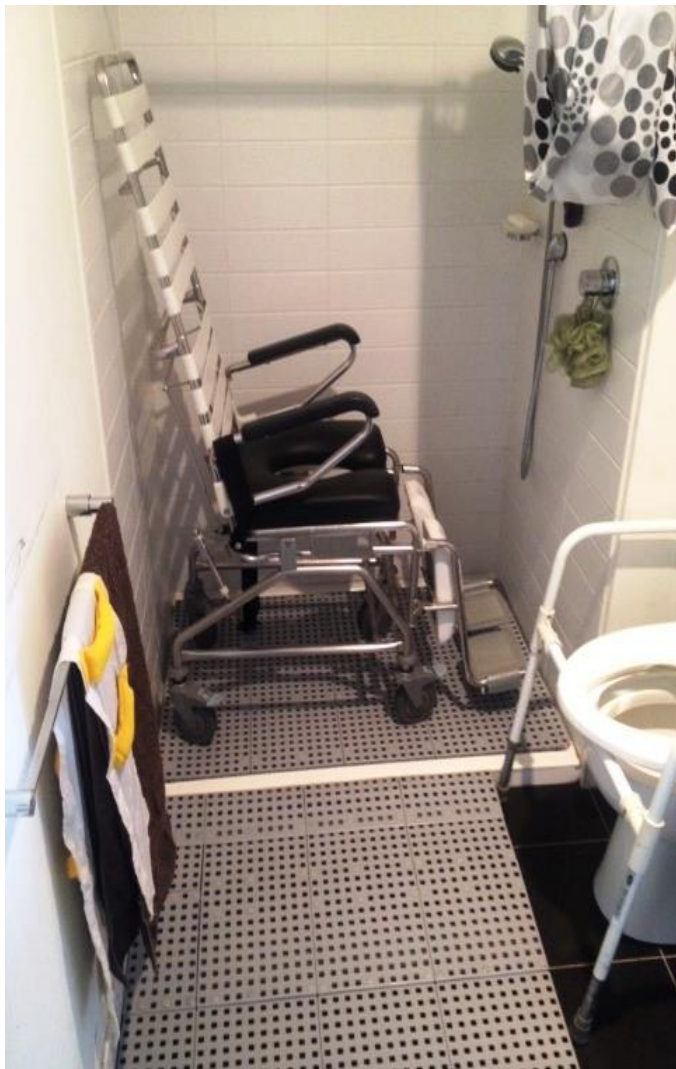
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Recycled rubber shower base insets and wedge ramps.

Removal of shower screen door and replacement with curtain.

Can achieve flexible ramp angles.



“Excellent Ramps “shower base insert and ramp.
Recycled rubber shower insert, platform and ramp.



OTHER OPTIONS

Hospitality
Healing
Stewardship
Respect

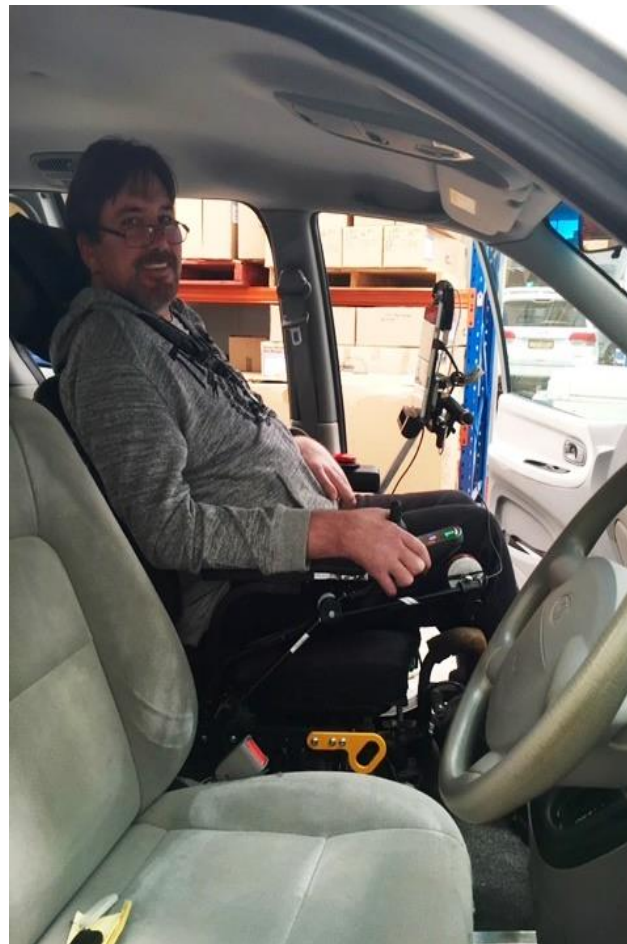


HOME MODIFICATIONS



WHEELCHAIR ACCESSIBLE VEHICLES

- The best long term option is a vehicle that allows the individual to travel in a wheelchair.
- Consideration of choice predominantly depends on the wheelchair size, the driver's abilities and budget.
- Car hoists and lifters may only provide short term benefit
- Avoid car seats that double as wheelchairs
- Remember to investigate taxi and wheelchair accessible vehicle hire
- Work out cost benefit of purchasing a vehicle over non purchase options for occasional need.





- Support people to manage tasks and activities that are meaningful or necessary.
- Task simplification and pacing.
- Reduce load on respiratory system.
- Avoid peaks and troughs of energy and exhaustion.
- Preserve energy for enjoyable activities through saving energy on essential tasks.
- Introduce aids and equipment to reduce effort on muscles during transfers and walking.
- Adapt tasks eg: sitting down, long handled aids.
- Encourage effective resting.

THINGS WE LIKE!

Thinking outside the box!

- Portable Bidets with foot controls
- Chest and leg straps for commodes
- Washette Bathroom aid
- Phone and Drink holders



THINGS WE LIKE!

Thinking outside the box!

Ear cut-out cushions for ear pressure care

Satin sheet panel overlays

Quick release NIV mask adaption

Adapted clothing for comfort



THINGS WE LIKE!

Thinking outside the box!

Cuddle buddy cushions for elbows, hips, necks, heads.

Around chair tables

Using mounts and switches for call bells to ensure reliable and efficient carer alert.



Thinking outside the box!

Working with our Allied Health colleagues to achieve unique solutions for people.



TAKE HOME MESSAGE

**Working with people with MND and
their families is:**

**Confronting - Challenging –
Rewarding**

**MND is still incurable but not
untreatable!**

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Occupational Therapy Department

State-wide Progressive Neurological Diseases service (SPNDS)

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