HINTS AND TIPS JUNE 2013 from Roland Lewis Editor 01923 720198

Items for sale from The News

We offer a free advertising service, but we cannot accept responsibility for the condition of the items advertised.
Arrangements for collection of items for sale should be made directly between the buyer and seller. Where specialised or lifting equipment is concerned, you are strongly advised to seek advice from your occupational therapist and the manufacturer as to suitability and health and safety requirements.
To advertise send details to Debbie Philip, on 01604 611874 or debbie.philip@mndassociation.org. Adverts will appear in one edition of The News. Please contact us if you would like your advert to re-appear.

Mercedes Vaneo ambiente 2005. 5 door, 4 seater, excellent condition, silver. 1.9cc Brotherwood conversion for wheelchair access electric and manual winch. Fold down ramp good space and headroom for all size wheelchairs. MOT and tax until July 2013. Full service record. 30,200 miles.
Price: £9,750 or nearest offer. Contact: 01189 714158 any time.

13 foot stair lift attaches to stairs and not wall.
Area: Collect from Preston area.
Contact: Gloria on 01772 626723.

Willowbrook Electric Riser-Recliner Chair.
Dual motor, massage setting, brown draylon. Petite size. Only used for 10 months. Good condition.
Price: Free.
Area: Collect from Bracknell area.
Contact: Kevin Joyce on 07973 786775.

Ceiling hoist. BHM manual Transverse V5 Duo system. 2 tracks, one approx 137 inches, one approx 118 inches.
Area: Collection near Narberth in Pembrokeshire.
Contact: 01437 541543 or isobel@beresfordjames.com

Elap manual rotating passenger car seat. Dark grey and navy blue. Was fitted new in a Nissan Note in 2007.
Price: Any offer considered.
Area: Collection from Crosby, Merseyside.
Contact: Janice Jump on 0151 931 5513.

For details of these items for sale, contact MND Connect on 08457 626262

MNDA : Unproven treatments

The only 'proven' treatment for MND is Riluzole. There are, however, many organisations offering 'unproven' and 'alternative' treatments for MND.
Unproven treatments have not undergone rigorous testing for their safety and effectiveness. They are also often not supported by any reliable evidence. The only drug proven to slow the progression of MND is riluzole. People, or organisations offering unproven or 'alternative' treatments suggest that they will work better than riluzole. They often claim they can cure MND or significantly slow disease progression. These remarkable claims are not supported by any reliable scientific evidence.

Importance of clinical trials

To become proven, a new treatment must undergo a rigorous clinical trials process. The process not only tests whether a treatment works, it also ensures that the treatment
is safe.

A treatment that has not undergone proper clinical trials:

· Lacks reliable evidence to support its effectiveness
· May have unacceptably serious side effects
· May be unsafe, or even speed up disease progression
· May not have a plausible reason for how it works in MND.

Some clinics offering unproven treatments may claim that they have performed clinical trials. Find out how to tell the difference between a good clinical trial and a poor one. We would encourage anyone with MND who is considering embarking on an unproven treatment to discuss all the implications with their neurologist before making a decision.
http://www.mndassociation.org/Resources/MNDA/Research/Documents/C-%20Unproven%20treatments%20Nov12.pdf

ALS untangled

ALSUntangled helps patients with amyotrophic lateral sclerosis (ALS) to review alternative and off-label ALS treatments. Instructions for using ALSUntangled, as well as our published and active reviews can all be found on this website.
http://www.alsuntangled.com/index.html
Report on Low dose Naltrexone:
http://informahealthcare.com/doi/pdf/10.3109/17482968.2010.544386
Deanna Protocol :
http://informahealthcare.com/doi/pdf/10.3109/21678421.2013.788405

What is Progressive Muscular Atrophy?

PMA is a disorder of the lower motor neurones. In comparison, the more typical forms of MND have both upper and lower motor neurone involvement.

Lower motor neurones are a group of nerve cells in the spinal cord or in the brainstem that control muscles of the limbs or body. The lower motor neurone is at the bottom of the chain of command, but damage results in a loss of muscle control, weakness and muscle wasting (atrophy).

In PMA there is gradual loss of the lower motor neurones, so the muscles become steadily weaker and more wasted, causing weakness in the area they serve. This results in progressive muscle weakness, fasciculation's (rippling effect under the skin), and shrinkage in muscle bulk and weight loss.

PMA affects 5-7% of all people living with MND. Life expectancy, although variable, is generally longer than the average for all cases of MND, averaging 5 – 10 years.

PMA is characterised by:

- Muscle weakness
- Muscle wasting
- Fatigue
- Fasciculations
- Cramps
- Muscle twitching
- Loss of reflexes.

PMA starts most frequently with weakness in one hand/arm, although it can be in one foot/leg and very rarely the tongue. Weakness spreads to other muscles as the disease progresses.

Cramps usually precede weakness and muscle twitching also occurs at an early stage. Both cramp and muscle twitching occur in normal healthy individuals and therefore by themselves do not indicate any cause for concern.

Not having upper motor neurone involvement means that people living with PMA do not have the stiffness (spasticity) in their muscles, nor the very brisk reflexes and the uncontrollable emotions seen in other forms of MND.

he first noticeable effects depend on where the disease starts.

If the initial presentation is in the legs, then stumbling or difficulty climbing stairs may be noticed. If the initial weakness occurs in the arms, then loss of dexterity or an increase in dropping things may be the first signs. Cramps, twitching in muscles, aching muscles and general fatigue, can precede obvious weakness.

For a tiny percentage, PMA doesn't spread from the initial area affected and although disabled, such individuals have a relatively benign course to their disease. An example could be bi-brachial amyotrophy (the so called 'flail arm syndrome') which affects the arms, but often nowhere else for a prolonged period. However, it must be remembered that progression of PMA can be very variable.

For the majority, PMA continues to spread causing increasing disability and speech and swallowing can also become difficult. As breathing muscles are controlled by lower motor neurones, they can also be affected.

The final pathway for PMA is much the same as for other forms of MND, but without major upper motor neurone involvement and usually at a slower rate of disability progression.

However, as with all MND, PMA follows a different time course in each person.

For more information visit the MNDA website information sheet:
www.mndassociation.org/Resources/MNDA/Life%20with%20MND/Information%20Sheet%2017%20-%20Progressive%20Muscular%20Atrophy.pdf