

HINTS AND TIPS OCTOBER 2012 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 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.

Peugeot Expert Tepee. Diesel.
Wheelchair converted with ramp. Dark grey. Taxed until end of Nov. MOT till end of Jan 13. 29,000 Miles. Reg 2008.
Price: £11,500 ono.

The Neater Eater feeding aid.
Smooths out tremors. Retains independence and works extremely well.
Price: Free for someone with MND.

Gewa automatic page turner BLV-6
New in 2006 and never used.
Price: £1,200
Area: Bridestowe, Okehampton, Devon

Electric Powered Wheelchair. Marbella Model – P200. Left or right hand joystick control.
Price: Cost £1,800 when new. Offered for free but buyer collects.
Area: Uckfield, East Sussex

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

New Care information

The Caring and MND: quick guide launches this month, as the second stage of our information for carers.

A summary version of the full carer's pack, the quick guide is designed to help people new to the caring role after someone close has been diagnosed with MND.

This lightweight A5 booklet explains what they may need to consider and the types of support available, with the focus on their needs as the carer. As the care demands increase and become more complex, the full pack Caring and MND: support for you provides more comprehensive support.

Various information sheets have also been revised:

7 – Motoring and MND

8 – Choosing the right vehicle for you

22A – Benefits and entitlements

11 – PEG and alternative feeding – making the decision.

The Respiratory Checklist card for health professionals has also been rebranded and revised to follow the NICE guidelines for NIV.

To order copies of our care information provision, please contact regional admin 01604 611812

regionaladminservices@mndassociation.org

or MND Connect 08457 626262 mndconnect@mndassociation.org

These items will also be available to view and download from our website

www.mndassociation.org

Choices and Control when you have a life- shortening illness

FINDINGS have been published from **Choices and control when you have a life-shortening illness**, an important Association commissioned study researching the views of people living with MND.

The findings show that while the study participants are appreciative of the support from the Association's volunteers and staff, we should consider doing more to help those people with MND who want to talk about end of life issues to do so.

The research involved in-depth interviews with 34 people living with MND, and showed that many people with MND want to talk about issues and choices related to death and dying, but do not feel they are always given the opportunity to do so.

We are committed to exploring further and addressing this gap – both in our own services and also in our educating and influencing work with the health and social care sector and Government.

Working jointly with Picker Institute Europe, the independent research experts who carried out the study on our behalf, we are calling for:

- improved training and guidance for professionals;
- more specialist palliative care to be commissioned; and
- clearer government guidance to support health and social care professionals to have conversations within the law.

In terms of our own services, we will be reviewing the report's content with everyone involved in delivering services and support to people with MND, looking at what it means for the training and development of Association visitors, plus the role of MND Connect, regional care, care information and education.

We know death, dying and end-of-life decision making are sensitive subjects, and that some people may find reading the study report a distressing experience. We're grateful for any support you can give to people affected by MND in your area, including advising them on the report's contents to help them decide whether they wish to read it. Finally, thank you to the Association visitors who took part in a focus group exercise with Picker last autumn, to help them prepare to undertake the research sensitively. To view the full report and also an executive summary version, go to

www.mndassociation.org/choicesandcontrol

I took part in the survey and found it very thought provoking. I believe that end of life issues should be discussed.

Roland Lewis