

HINTS AND TIPS APRIL 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 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.

Solite 4 Section fully Profiling single Bed – no mattress.

Lifting Pole Strap & Handle Grab Rail

Area: Buyer to collect / transport London E1 area

Bisa 50 Straight Stairlift

Power swivel seat, four months old

Price: Cost £1,200 new.

Donation to cover costs of removal and any extra will be given to charity.

Area: Hampshire area for collection

Contact: Jane Bovey, 07501 161619

Stannah Stairlift. Straight run

Area: Collection from Waltham Cross area

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

MORE ON BENEFIT CHANGES

People who receive Disability Living Allowance (DLA) may recently have received information about the introduction of Personal Independence Payment, which will eventually replace DLA.

Anyone who currently receives DLA doesn't need to do anything at the moment. People living with MND who are under 65 and not yet receiving DLA should consider claiming it before PIP is introduced, as it may be easier to qualify for DLA than PIP in the early stages of MND progression. In the south of England, DLA closes for new claims on June 10.

Anyone under 65 not already receiving DLA should consider claiming it before then.

Although DLA may be somewhat easier to access than PIP, we still expect PIP to be available to all people of working age. For people making a claim aged over 65, Attendance Allowance remains available and is not being changed.

Eventually everyone receiving DLA will be required to claim PIP instead, but this will be a slow process and take several years. From October 2013, those who need to report a change in their condition to move to a higher rate of DLA will see their claim changed to a claim for PIP. Those who have a fixed-term DLA award that ends in February 2014 or later, will be asked to claim PIP when it comes up for renewal.

Apart from people in those situations, nobody receiving DLA needs to take any action until they are contacted by the Department of Work and Pensions (DWP) about claiming PIP.

The DWP has committed to contact people with terminal illnesses only towards the end of the programme to transfer DLA recipients over to PIP, so anyone with an indefinite DLA award is unlikely to have to take any action this year, or even in 2014.

Please note that those who are asked to apply for PIP need to complete the form and send it back as there is no automatic transfer from DLA to PIP. The process may involve a face-to-face assessment, although we would anticipate most people with MND will be able to have their claims processed without this.

If you would like further information, please contact MND Connect on 08457 626262.

Progress in the Oxford BioMOx project

MND Association funded researcher Dr Martin Turner at University of Oxford has identified a pattern of degeneration in the brains of people with MND that is linked to the level of disability.

The study's exciting findings were published in the prestigious journal *Neurology*.

These are the third results to be published from the ongoing Oxford Study for Biomarkers in MND/ALS (BioMOx).

This finding brings us closer to identifying a biomarker that can be used to speed up the diagnosis of MND, which can be delayed on average by a year since first symptoms.

Dr Martin Turner was awarded with an MND Association / Medical Research Council funded Lady Edith Wolfson Clinical Research Fellowship in 2008 for his BioMOx project.

Using an advanced brain scanning technique called 'whole-brain magnetic resonance spectroscopic imaging', Dr Turner and colleagues found that the levels of a chemical found in the brain called N-acetylaspartate (NAA) decrease when the functional capabilities of people with MND decrease.

Dr Turner said, *"This type of MRI scan can be thought of as producing a 'chemical' picture of nerve damage. We knew that NAA was quite a sensitive marker in MND, but until now we were not able to study the whole brain at once in a standardised way."*

"It's also another example of the enormous value of research that involves the actual patient living with MND, and healthy volunteers. This type of research is fundamental to translating the really exciting findings emerging from the laboratory test tube."

Dr Brian Dickie, the MND Association's Director of Research Development comments, *"These latest findings from the BioMOx group adds the finding of alterations in brain chemistry to their previous research on structural and functional changes occurring in MND."*

"Together, they are building up a clearer picture of the pattern of degeneration during disease progression, linking what is happening on the 'inside' which the physical changes happening on the 'outside'"

By [Kelly Edwards](#)

MND stem cell study identifies TDP-43 astrocytes as not toxic to motor neurones

Funded by the MND Association, international researchers have used stem cell technology to learn more about the relationship between motor neurones and their support cells.

These findings highlight the potential of stem cell technology as a tool to create new human 'in a dish' cellular models of disease to learn more about the causes of MND. The research group included MND Association funded researchers Prof Siddharthan Chandran and Sir Prof Ian Wilmot from University of Edinburgh, Prof Chris Shaw from King's College London and Prof Tom Maniatis from Columbia University in America. This important finding was published in the scientific journal *PNAS* on 11 February 2013. This new finding follows on from previous work published by this research group in 2012 where they demonstrated the proof of principle of [creating human motor neurones with MND in a dish](#).

Why we need an astrocyte model of MND

Astrocytes, so called because of their star-like appearance, normally act as neurone support cells to nourish and protect motor neurones. They act with motor neurones to ensure that they can continue to function.

From previous studies, we know that when these cells begin to dysfunction, they can become toxic to motor neurones to contribute to MND. Finding out why astrocytes can cause motor neurones to degenerate is an issue of ongoing debate – we recently gave an update on this [from the International Symposium](#).

Being able to grow human astrocytes in a laboratory dish is of importance to be able to learn more about the relationship between astrocytes and motor neurones in MND.

Creating human astrocytes in a dish

Using cutting-edge stem cell technology, the research group reprogrammed skin cells into astrocytes in a laboratory dish. The skin cells were donated by people with MND who have a family history of the disease caused by known mistakes in a gene called TDP-43.

Led by Prof Chandran and colleagues, the research group aimed to identify whether these cells would develop the 'hallmarks' of MND in a laboratory dish.

By studying the characteristics of these human astrocytes with faults in the TDP-43 gene, the research group identified that they shared the same qualities as cells affected by MND. The astrocytes had increased levels of TDP-43 found in areas where it isn't usually found – outside of the control centre of the cell. They also found that the astrocytes didn't survive as long as astrocytes created from skin cells of people that didn't have MND.

This means that the human astrocytes created by Prof Chandran and colleagues using stem cell technology develop MND-like characteristics. This new model can be used to study how motor neurones develop the disease in a system that is directly relevant to people living with MND.

Answering whether faulty astrocytes affect healthy motor neurones

The next question that this research group wanted to answer was whether these faulty astrocytes had an effect on healthy motor neurones.

By growing faulty TDP-43 astrocytes with healthy motor neurones, the research group identified that the survival of motor neurones was *not* adversely affected.

This was surprising as other research groups have shown that when astrocytes have faults in the SOD1 gene (which cause one in five cases of MND with a family history) that motor neurones are compromised, even if the motor neurones were originally healthy.

TDP-43 is found within tangled lumps in over 90% of cases of MND (irrespective of whether it was caused by an inherited genetic mistake). However, when MND is caused by

SOD1, TDP-43 is not found in these tangled lumps.

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This important difference could be leading to the key difference in whether astrocytes become toxic to contribute to causing MND.

These findings will of course need to be verified by an independent research group to determine that they are valid, but the results suggests that SOD1 and TDP-43 could be causing havoc in motor neurones in slightly different ways, both avenues leading to MND. Our Director of Research Development, Dr Brian Dickie comments: *“From a therapeutic perspective this is important because it means that specific treatments targeted at astrocytes may only be relevant and effective, in specific subsets of patients who will have to be carefully selected for drug trials.”*

CLOTHING

Janette asked advice on stopping pyjama legs rolling up in bed as she is unable to pull them down again .

Theresa’s suggestion for Problem Pyjamas: What if you made some sort of stirrup, like ski pants. If you made 2 tiny holes on either side of the leg, within the double layer that is “hemmed” & then use round elastic, knotted on both sides to secure the elastic.

If you have a problem threading the elastic you could always use a plain hair grip, (not as fiddly as threading the elastic through a large needle)

Round elastic is widely available including Supermarkets.

No sewing necessary.

Barbara had similar ideas:

I wondered if you could put up with some soft elastic on the end of your pyjamas, like stirrups. For my part, I really struggle to turn over in bed and I find that skin is the most slippery stuff so I just wear (avert your eyes gentlemen) knickers, or if you prefer something looser, my fashion advisers tell me that men’s boxer shorts are all the rage with ladies. I should think they’d look rather neat with a pyjama top.

Janette also asked how she might get a bra on using only one hand :

Jean suggested the ‘Bra Angel’

The Bra Angel Dressing Aid is a helpful device for women who can only make use of one hand, or who struggle with fiddly bra straps, and who would prefer to put their bra on without assistance. Created by an occupational therapy professional, the Bra Angel is very easy to use. It is placed over the users neck and holds one end of the strap ready and in place, so that the user can bring the other end round to fasten it very easily and with no fuss.

In a similar way, the wearer is also able to remove the bra using the dressing aid to hold one strap in place whilst it is being unhooked.

www.amazon.co.uk/NRS-Bra-Angel-One-Handed-Dressing/dp/B006J7H948

Barbara says: I do relate to this, and when it’s not too cold I’ve given up trying! But I just saw these on Ebay and thought they might be a solution: ‘New Genie Bra 3 Pack White Black Nude Comfort Support Seamless Conform Fabric’ - they have no fastenings. <http://www.geniebra.co.uk>

