

HINTS AND TIPS DECEMBER 2013 from Roland Lewis Editor 01923 720198

Barbara recommends: Shoes

My feet are hopelessly unreliable. Depending on the weather, how well I slept, how many cups of tea I've had, they can range from a modest size 6½ to a pair of balloons that scarcely any shoe will fit. If you are anything like me I have found these wonderful shoes that are actually stretchy. They come in several colours: red, blue, black, beige and purple, and you can actually wash them in a washing machine! (Haven't tried that yet). I suspect they are intended as slippers, but as you can see, they have quite a decent sole so are fine for outdoors (not that I do any walking).

They're from <http://www.pavers.co.uk> reference code Plumex | Item Code: 125054

Ken W writes:

Judy and I are in the chalet, where we have Wi-Fi. This means that I can access Google on my iPad, without disappearing behind a computer screen. Once I'm on Google, I use the "More" option to choose "Translate". I can then type in the English for whatever I want to say in French to whoever is with us. I guess that the translation is OK because the conversation flows naturally. Now for the clever bit. Just below the translation is a loud speaker; tap this and out comes the translation in a human voice! My neighbours are very impressed.

Obviously, to make this work, I need wi-fi access. However, it seems to me that this is rapidly becoming ubiquitous, and certainly exists in hotels. So, when we go to Tenerife next month, I'll try "speaking" Spanish at our hotel. I'll let you know how Google and I get on.

Jean says: I have been put off having an iPad because of the fear of dropping it. Now there is a solution for those of us with weak hands:

Logan technologies have The Gripcase is made from a lightweight and durable shock-absorbent foam body that gives you the convenience, control and peace of mind you've been looking for. It features a "crumple zone," between the body and the bumper corner. This crumple zone absorbs the energy created during an impact and directs it away from your iPad. The handles are easy to grip too.

Cost is from £35 <https://www.logan-technologies.co.uk/shop/bagscases>

Jean recommends:

RAIN-WAVE.COM

for waterproof ponchos that are easy to put on and have no zips or fasteners

New Information Sheet 18

Understanding and coping with bereavement (Information Sheet 18) has been revised to improve our support for carers and families after the death of someone close with MND.

"I thought that the content was excellent in every way and wished that I had had access to material like this during and after my late mother's illness and death." Ex-carer for a person with MND.

You can download this sheet from our website:

www.mndassociation.org/publications or order printed copies from Care Admin 01604 611685, care.admin@mndassociation.org

MND Diaphragm Pacing Clinical Trial

MND clinical trial to test the safety and effectiveness of diaphragm pacing in the UK. Part funded by the MND Association in collaboration with the [National Institute for Health Research \(NIHR\)](#) this is the first randomised controlled trial of diaphragm pacing in the world. Ethically approval has been granted by appropriate bodies to ensure the safety of participants.

The trial is now seeking people who have MND with newly identified breathing problems to take part.

This trial aims to provide the level of evidence that will be required for diaphragm pacing to receive approval from the [National Institute for Health and Care Excellence \(NICE\)](#) for it to be made accessible to everyone in the UK who has MND with respiratory insufficiency.

Dr Chris McDermott from Sheffield University and colleagues will rigorously test whether diaphragm pacing provides benefits for people with MND, in terms of survival and quality of life, over and above those provided by current standard respiratory care, which includes NIV. The results of the trial are due early 2016.



“NIV is good but not perfect! We want to improve the management of breathing problems in MND.

Using diaphragm pacing and NIV together may lead to more benefits in terms of improving breathing, than using NIV alone.”

Dr Chris McDermott, Sheffield University

What is diaphragm pacing?

Diaphragm pacing is a way of maintaining the strength of the diaphragm (the main breathing muscle) by providing it with regular pulses of electrical stimulation, supplementing the deteriorating signals coming from diseased motor neurones.

Who can take part in this trial?

People with MND who have newly identified breathing problems (ie those who do not already use NIV) and would be able to travel to one of the trial sites on a regular basis may be eligible to take part in the trial.

The following MND Association Care Centres are recruiting participants for the Diaphragm Pacing clinical trial:

Sheffield
Oxford
Newcastle-upon-Tyne
Manchester (Salford)
Plymouth
Leeds
Royal Free Hospital London.

Other trial eligibility criteria include:

- Use of riluzole for at least 30 days
- Forced vital capacity (the amount of air that can be forcibly blown out of the lungs after the deepest possible in-breath) greater than 50% of the normal predicted value for your age, gender and size.

Each centre will recruit suitable patients gradually over a number of months. The total trial recruitment target is 108 people with MND.

What does it involve?

In this clinical trial, participants with MND are randomly assigned to have either diaphragm pacing or to receive standard respiratory care. If a participant is randomly allocated to receive diaphragm pacing, small electrodes are inserted into the diaphragm muscle during a minor operation under general anaesthetic and are connected via fine wires to a small box that can be easily carried about.

More information

Download the [diaphragm pacing trial information sheet](#), created by the MND Association to provide a background to the use of diaphragm pacing in MND as well as information on who can take part in the trial and what it might be like to participate.

If, after reading our information sheet you think you may be eligible, please contact [Chin Maguire](#), who is co-ordinating the trial. Full contact details for Chin can be found in the information sheet, or a direct email can be sent

[Unproven treatments: Have you really got nothing to lose by trying it?](#)

The only 'proven' treatment to slow the progression of MND is Riluzole. There are, however, many organisations offering expensive 'unproven' and 'alternative' treatments for MND.

We have worked with the organisation [Sense about Science](#) to help produce their '[I've got nothing to lose by trying it' information booklet](#) so that people living with MND can make up their own minds about unproven treatments.

What is an unproven treatment?

Unproven treatments are treatments that have not undergone rigorous testing for their safety and effectiveness by means of a clinical trial. Also, they are often not supported by any reliable evidence.

People or organisations offering unproven or 'alternative' treatments may 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 scientific evidence.

ALS Untangled

ALS Untangled

The MND Association co-funds an international group of scientists and clinicians, collectively known as [ALS Untangled](#) to investigate unproven or alternative treatments for MND. This group look for the evidence behind these unproven treatments for people living with MND concluding with their own recommendations.

These reviews are freely available and are published Open Access. You can download the most recent review on [propofol here](#).

"Thank you for your support of ALSuntangled! Dr Bedlack et al. are doing wonderful work on behalf of people living with MND everywhere!" – Doug Hetzel, USA

A neurologist's point of view

Association-funded researcher Prof Ammar Al-Chalabi explains his views on unproven treatments:

Prof Ammar Al-Chalabi

Many people with MND seek out unproven treatments because of the very difficult situation they

and their families are in. My advice is that this is generally OK if the treatment is not harmful, is not expensive and is not obvious quackery. The difference of opinion between medical staff and people with MND mainly comes in the first part - whether the treatment is harmful. As doctors we are taught, "first do no harm", whereas someone with MND will often say they are dying anyway so it makes no difference if the treatment is harmful because there might be a benefit. This is a powerful argument that can only be countered by the point that someone may have a slow form of MND and be shortening their life significantly or may greatly reduce their quality of life.

"I see people who are desperate, spending tens of thousands of pounds on treatments that are definitely pointless, like stem cell therapy consisting of giving an unknown substance intravenously at an unlicensed clinic. I see others who shun conventional medicine because they believe in alternative therapies, even though conventional treatments have a known side effect profile and alternative treatments do not. As medical staff we have an ethical obligation to provide clear advice in these situations, but I have not had a life threatening illness before and cannot say how I would react, so there is always a seed of doubt in my mind about whether I am doing the right thing."

A person living with MND's point of view

Charlie Fletcher is living with MND and explains her point of view on unproven treatments after reading the new [Sense about Science](#) booklet:

Charlie Fletcher

"Having been diagnosed with MND and confronted by the stark reality that there is no cure and incredibly limited medications available, was a hard pill to swallow. To then be bombarded by the media with advert after advert of extraordinary treatments and radical cures was overwhelming. Those with long-term illnesses tend to have a heightened sense of impending doom and a desperate need for hope so it is not surprising that many are swayed by these claims. I will admit that at times the little voice in the back of my mind suggests I might be overlooking the answer I'm after, but as a natural sceptic I am not likely to be tempted unless there is substantial evidence to support these theories.

"Whilst I can appreciate the draw of untested drugs and alternative therapies, I am not about to start licking trees on the off chance. However, medical research is an integral part of the search for possible treatments for diseases like MND and I am fully supportive of the incredible work being done. In my opinion, participating in clinical trials of drugs and methodologies is beneficial in the development of our knowledge of the disease and eventually a cure, and therefore, is something for which I would willingly offer my assistance.

"It is often difficult to separate the head from the heart, particularly for family and friends who are naturally driven by their need to make things better. The passing on of unlikely remedies and anecdotes for seemingly successful treatments, in my personal experience, is more of a hindrance than a help. Following all this advice can be exhausting, time-consuming and expensive, but more importantly it can create false hope, which can have a devastating effect especially when something doesn't work.

"To my knowledge there is only one drug available and it is not even close to a cure; as far as I'm concerned, if the only drug that has passed its clinical trials and can be prescribed barely makes any difference, I am not likely to be convinced by the promises made by the latest, untested 'miracle drug'.

"I find the [information presented in this booklet](#) an accurate and in-depth view of the realities of long-term, degenerative conditions and for this reason felt moved to add my contribution."