

## **HINTS AND TIPS APRIL 2014 from Roland Lewis Editor 01923 720198**

### **GET TOGETHERS FOR PEOPLE LIVING WITH MND**

These are informal gatherings in a place where people living with MND and their carers and family members can meet in privacy, and chat together informally in a calm and safe setting

The venue is the Box Moor Trust centre, London Road, Hemel Hempstead, HP1 2RE.

If you need transport or any more information, please contact Jenny Fellas on 01582 621387 or [chris\\_jennyfellas@hotmail.com](mailto:chris_jennyfellas@hotmail.com)

The meetings start at 2pm, and will be held on Wednesdays, April 9, May 7, June 11, July 9, August 6, September 3, October 1, November 5, December 10.

### **DIET and MND**

**A high-carbohydrate, high-calorie diet could delay the progression of Amyotrophic Lateral Sclerosis (ALS), also known as motor neuron disease or Lou Gehrig's disease, according to a phase 2 study published in The Lancet.**

ALS is a rapidly progressive, fatal neurodegenerative disorder affecting the nerve cells that control muscle movement (motor neurons). Patients gradually lose the ability to control the body's muscles, including the muscles which control breathing. This leads to respiratory failure and death on average about 3 years after patients are diagnosed.

Loss of weight, both muscle and fat, is common as ALS progresses, and patients experience more difficulties eating, swallowing, and maintaining their bodyweight. Recent work suggests that these problems might also contribute to the course of the disease: patients who are mildly obese are more likely to live longer, and mice carrying a gene which causes ALS lived longer when they were fed a calorie-rich diet high in fat.

The new study, funded by the Muscular Dystrophy Association, was performed at 12 ALS centres and led by Dr Anne-Marie Wills at the Massachusetts General Hospital, in Boston, USA. To participate in the study, patients with advanced ALS had to already have a feeding tube (known as PEG tubes, or percutaneous endoscopic gastrostomy tubes), which allows food to be delivered directly into the stomach. Twenty patients were split into three groups, each with a different diet plan -- a control group (to maintain weight) and two high-calorie (hypercaloric) groups: one high in carbohydrates, the other high in fat. The diets lasted for 4 months, and data on safety and survival were collected from the beginning of the study for a total of 5 months.

This study was primarily intended to assess safety and tolerability of the diets for ALS patients: patients given the high-carbohydrate/high-calorie diet experienced fewer adverse events (23 vs 42), and significantly fewer serious adverse events (0 vs 9) including deaths from respiratory failure than the control group.

Patients given the high-carbohydrate/high-calorie diet also gained slightly more weight than the other groups (an average of 0.39kg [about 0.86lbs] gained per month, compared to an average gain of 0.11kg [0.24lbs] per month in the control group, and an average weight loss of 0.46kg [1.01lbs] in the high-fat high-calorie diet group).

According to Dr Wills, "There is good epidemiological evidence that, in ALS, survival is

determined by nutritional status. This pilot study demonstrates the safety of a novel, simple, low-cost treatment for a devastating disease where currently, very few treatment options are available. The adverse outcomes that we feared might result from weight gain, such as diabetes or heart disease, were not observed in our study period of five months."

Nonetheless, the authors point out that the findings should be interpreted "with caution," and call for larger trials, with similar nutritional interventions tested at an earlier stage in the disease for ALS patients.

"Although the sample size was small, we are optimistic about these results, because they are consistent with previous studies in ALS mouse models that showed that hypercaloric diets improve survival," says Dr Wills. "Not only could this type of nutritional intervention be a novel way to treat and slow down the progression of ALS, it might also be useful in other neurological diseases."

Writing in a linked Comment, Dr Ammar Al-Chalabi, of King's College London, UK, states that, "I will not be changing my advice to patients on the basis of this study, but I am eager to see the results of a large Phase 3 trial. Wills and colleagues have taken the first steps needed to provide evidence for a robust, non-pharmacological treatment that is well tolerated and easy to administer. We must finish the work they have started."

### **Scrabble**

If you like scrabble and are either on Facebook or have an Android phone, iPhone or iPad , then think about downloading 'words with friends' , available as a free App. You can play anytime and anywhere you can get internet or 3G.

Sue Oliver and Jean Waters play together which is fun and we always happy to take on challengers.

My user name is jestelia and Sue's is 191pig , so both easy to find.

We look forward to playing with you!

[jestelia@talktalk.net](mailto:jestelia@talktalk.net) [sueoliver409@aol.com](mailto:sueoliver409@aol.com)

### **Sue Oliver says:**

I have just bought a travel mobility scooter from CareCo. It was originally just under £1800 reduced to £399 !

CareCo has a huge range of items for the disabled and it is well worth a look at their web page. I bought it because it will split down to go in our car boot - ideal for us to take on holiday.

My mobility scooter arrived on Thursday and I am delighted with it. I have had a practice run around the drive and it is so easy to use.

[www.careco.co.uk](http://www.careco.co.uk)

[sueoliver409@aol.com](mailto:sueoliver409@aol.com)

### **Sore heels**

Jean mentioned last month that there's risk of damage to the skin on your heels, especially when you raise the end of the mattress.

I've had this problem and my MND Clinic nurse recommended Cavilon Barrier Cream which I have found very helpful. I use it every night, then moisturise the skin in the morning. Whilst it's not foolproof it really has helped.

I have it on prescription so see your GP if you think you need it.

## New NICE MND Clinical Guidelines

This week the MND Association had some fantastic news; NICE is starting the consultation process to produce a guideline for Motor Neurone Disease.

**But what exactly is NICE? And what does it mean to people living with MND and**



**their carers?**

**We thought it would be NICE to tell you more about it, so we asked Alison Railton, our Public Affairs Manager, to explain what the guideline is and how you can get involved...**

The National Institute for Health and Care Excellence (NICE) is the independent body responsible for developing national guidance, standards and information on high quality health and social care.

In a nut shell, NICE provides advice to health, public health and social care professionals to make sure that the care they provide is the best it can be and that it offers value for money. NICE is at the heart of the health and social care system.

Last year NICE announced that it would be producing a clinical guideline on MND. This was great news and something that we as an Association and you as members had been campaigning for over several years.

Because MND is such a complex, rare and often rapidly progressive disease it was vital to get us on the NICE map in this way. Guidance is urgently needed on how best to care for people with this devastating disease.

BUT, while most NICE guidelines include the care people will need from the very start of their symptoms throughout the course of the disease, NICE is proposing to exclude MND diagnosis from the scope of the guideline. We are very disappointed for lots of reasons but mainly because getting a diagnosis of MND can take a long time and be fraught with problems.

An earlier diagnosis means people with MND can have faster access to care, treatments and financial support. We think that people with suspected MND should be fast-tracked for formal diagnosis and healthcare professionals also need support and advice to diagnose a condition which they may come across so infrequently in their career

So, the NICE consultation process (the time we have to influence it) has just started. As an Association we will be making the case very strongly for diagnosis to be included.

NICE is also seeking people living with MND and their carers to join the guideline development group. Your experiences will be key to ensuring the guideline includes the care which is of most importance to people with MND

[If you are interested in finding out more about joining the guideline development group, please visit the MND page on the NICE website.](#)

**If you would like to speak to someone at the MND Association about joining the group please call Alison Railton on 01327 844911 or email**

[alison.railton@mndassociation.org](mailto:alison.railton@mndassociation.org).

We know that NICE guidelines can work. In 2010 NICE published a short clinical guideline on non-invasive ventilation (NIV) for people with MND. Since the guideline has been published many more people with MND have been offered NIV. We hope the full guideline on MND will have a similar positive impact.

We will be working hard to make sure that our MND NICE guideline will be as useful as possible for people living with MND and all those who care for them.