

# Swanfield Monthly

**It's a packed newsletter this month**—hints and tips from members are pouring in, and we've included as many as we can fit in. Keep them coming!

Each issue we're keen to illustrate how our members help themselves to reduce their symptoms, whatever their condition, because here at the Therapy Centre we have a collection of 'experts' (all of you!) on MS. Last issue we carried a story of how HBO (or O<sub>2</sub>T, as

we're supposed to call it now!) can help with crash injuries. This issue we have focused on diet, featuring first-hand experiences from two members who have successfully reduced their symptoms through excluding certain foods from their diet.

There's an update on planning for development, which includes a survey (see P3) plus plenty of other activity.

Fundraising is continuing—there have been some successful

activities, and you can read about them on P4. See the box below for details on [easyfundraising.org.uk](http://easyfundraising.org.uk)—this is a way everyone can raise funds with NO EFFORT and NO EXTRA COST!

Finally, check out the dates on P8 for the next fundraising events, the **Christmas party**, and other activities. The Centre will be closed for some days over Christmas, and operating reduced hours for others. All details on P8.



## Update: [Easyfundraising.org.uk](http://Easyfundraising.org.uk)

So far this year the Centre has received **£80.11** when members and their friends bought goods from the following shops through [easyfundraising.org.uk](http://easyfundraising.org.uk):

**Amazon, Tiso, John Lewis, Argos,  
 Flybe, Sainsbury's**

*It's so easy—to support the Therapy Centre when you shop visit [www.mstc-lothian.org.uk](http://www.mstc-lothian.org.uk) and click on the [easyfundraising.org.uk](http://easyfundraising.org.uk) button on the right hand side*

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## **Development Activity**

The Committee are currently working on various strands of activity:

**Design of the new logo:** with the generous help of graphic designer Lucy Boyd of LBD, a new logo has been developed. It reflects the Centre as a positive place where members support each other. Striking colours make it stand out, and it is immediately obvious to anyone that the Centre is for MS. At time of writing, it has been approved by the Advisory Group, and will be finally ratified at the next Committee meeting, when the launch date will be set.

**Research:** it became clear that before any more work was done, it was necessary to assess why so many people with MS do not come to the Centre. Do they know we are here? Can they not get here? Do we not offer what they want?

A survey has therefore been launched (*see box*), to run until early December. We are very fortunate to have Anna and Chris, who both have significant experience in this area, and who have designed it for us, with the

## **Survey of people with MS**

The MS Therapy Centre Lothian is currently conducting a survey of people with MS in the local area. This has been developed with the support and input of Dr Weller and is being distributed by the **MS Clinic** at the Western General, **KICC** (Keeping Fit with and Chronic Condition) and by the **MS Society**. The purpose of the

generous help of Best Consulting. The results will be available in early January.

**Support:** following the first Committee Strategy Day, many actions and developments were suggested. The challenge is to ensure that the Business Plan contains realistic targets and timelines, and so the Centre has enlisted an independent external 'mentor'. Tracy Thomson, a relationship manager at RBS, is over-seeing the planning process.

**Umbrella group:** The member Centres of MSTC (Scotland) voted in Sept to disband, and for all the Centres to apply to join MS National Therapy Centres. MSNTC already provides support to the Scottish centres, through bulk purchasing of oxygen, insurance

survey is to assess the level of local awareness of the Centre, and to assess what the barriers to accessing the therapies are. For these reasons it has not been distributed to all members, but members are definitely encouraged to take part if they receive a copy. It can also be accessed through our website, and copies are available in the Centre.

and medical support. They have developed and funded a purpose-built database for therapy centres, which will be installed at our Centre in December.

**Community Jobs Scotland:** The Scottish Government has provided funding for charities to create six-month jobs for long-term unemployed people, to help them back to work and gain skills. The Centre has been awarded funding for a receptionist and is receiving applications now.

**Investors In Volunteers:** The Centre has been awarded the Investors In Volunteers accreditation. During preparation, the recruitment, training, and support of volunteers has been scrutinised and improved.

*For details, please speak to Alice*

## **High Fuel prices**

If you are worried about high fuel prices, contact [www.turn2us.org.uk](http://www.turn2us.org.uk). They can check (in confidence) if there are any benefits or charitable grants that you may be entitled to.

**Use the computer at the Centre—ask for assistance at any time.**

## **MS Register**

**Don't forget to sign up for the UK MS Register.**

“At the moment, researchers, policy makers, and healthcare professionals do not have a complete picture of MS across the UK. At present, there is not even an accurate estimate of the number of people with MS in the UK, or of what forms of MS they have. More importantly, we do not know the details of how MS impacts on people's everyday lives.”

**You can help to change this by taking part:**

[www.ukmsregister.org/Portal/Home](http://www.ukmsregister.org/Portal/Home)

## Chairman`s note

### **We are a self-help charity.**

When I was first diagnosed I joined the M.S. Therapy Centre, Lothian because I was attracted to the idea of self-help. It meant I was actually going to do something to help myself and not just lie in my house and leave it to others to provide for me. My greatest worry as Chairman is that this self-help ethos appears to be misunderstood and I want to ensure everyone knows what membership of the Centre really means.

1. **We are a self-help charity**, set up by people with M.S. to assist and support people with M.S. The only thing you need in order to qualify to be treated at the Centre is to have a diagnosis of M.S.
2. There are over 2000 people with MS in the Lothian area, and the Centre serves a fraction of that number but is aiming to improve on this by promoting the services and hopefully encourage people to access the services they need to help them maintain their health.
3. We will treat everyone on an **equal basis**, whether they are first time attenders or have been coming since the Centre first opened in 1984.
4. We have a Member's Code of Conduct that is given to all new members which sets out our 'good manners' guide. This is the behaviour and welcome you should

expect from everyone when you visit the Centre and what will be expected from you in return.

### Entitlements:

- ⇒ As a member of the Centre you are entitled to access our range of therapies and treatments
- ⇒ You will receive a monthly newsletter keeping you up to date with new developments or services
- ⇒ You will also be invited to attend the Annual General Meeting and to vote for the new committee

### Responsibilities:

Alongside those entitlements are some responsibilities for members i.e. contributing time, energy and resources to ensure the Centre can continue to deliver services into the future, to people with MS:

### **Cost**

We welcome everyone to the MS Therapy Centre *regardless* of their ability to pay. However, we do ask all members to make regular donations towards the running costs of the Centre according to their genuine ability to do so.

### **Fundraising**

Funds raised through member donations exceed £40,000 per year but the organisation needs £160,000 in order to continue offering services. This is why, as a Committee, we took the decision to employ someone who would take specific responsibility for fundraising activity. However, having a dedicated Business and

Funding Manager does not mean we can be complacent or think that it's solely this person's job to raise all of the funds we require in order to remain in business. Our main costs are premises, staffing and oxygen which is why we need to maintain and expand fundraising activities.

For example, our annual raffle which was drawn at the coffee morning in August raised approximately £2,500 which was excellent news. However, this money was raised by approximately 30% of the membership. Imagine how much more could have been raised had every member sold (or purchased) a book of tickets costing £10? Next time we have a raffle, please try to help us to improve on the money raised this year by increasing the response to 100%!

### **Taking part**

A very important part of our ethos is that we are run by people with MS, so all members are encouraged to consider sharing their skills and abilities by taking a turn on the Committee.

We are a **SELF-HELP CHARITY** and we need everyone to help particularly in the economic climate we now find ourselves.

I would love to hear from you on this article. So please write to me at the Centre. You have my undertaking that your letter will be published in full in the next newsletter.

Bruce Laidlaw

## £ Fundraising update

### Donations:

Very many thanks to the following for their kind support:

Pumpherstons Bowling Club, and Grant Management (dress down day).

It was with sadness that we learnt of the death of Lesley Hampton, and the Centre is very grateful to her family and friends who held a collection in aid of the Centre.

The Donation Board on the website is up-to-date—have a look to see who is supporting the Centre.

### Grants:

Received with thanks from:

**Hugh Fraser Foundation** (£2,000)

**Bank of Scotland Foundation**

(£4,800 to cover 4 months rent)

**Royal Caledonian Ball Trust**

(£2,120 to cover the purchase of oxygen)

### Fundraising:

**Can Collections** raised £597 at the Gyle on 15th October and £807 at Sainsburys, Blackhall on 24th/25th September. Thank you very much to Gordon, Colin, Cynthia, Linda, Caronne, Danny, Margaret, Bruce, Hazel and Eileen who rattled the cans so successfully. **Many hands make light work:** Janice is recruiting for the next collection at **Ocean Terminal on the 26th November**—please let Alice know if you can help out.

Saturday volunteer **Neil Comfort and the 'Midgical Mountaineers'** raised £627 doing the Great Highland Hike! Fair weather and midge-free, along 23 miles of the West Highland Way.

**Leigh McColl and colleagues** at Standard Life raised a phenomenal £2,230 through a sponsored walk

and bake-a-thon. With gift aid, this is £2,630!

**Ben Moran** completed his swim of the Firth of Forth on 22nd Sept. It took just over 35 minutes. This is a real challenge as it can only be done at high or low tide, so he only had 50 minutes to get across or the wind and tide would sweep him away. He raised £3,200 for the Centre and the MS Society (and the mankini pictures are on our Facebook page!)

A successful **car boot sale** raised £100. Many thanks to Sheila, Cynthia, Mary, and Bruce.

The **Christmas cards** are selling well, with approximately £800 raised so far in the Centre. Particular thanks are due to Anne, who has single-handedly raised at least 25% of this sum through selling to colleagues and friends! Please take catalogues and encourage yours to purchase them likewise. Orders can be posted.

### A Day Out:

#### Visit the newly-refurbished Museum of Scotland

As you will know the Museum in Chambers Street recently re-opened after a multi-million pound refurbishment. I thought I would pay a visit to see what its disabled access was like, besides wanting to see the many new displays there.

I must tell you, I was pleasantly surprised and impressed by the efforts they have made to ensure easy access for disabled visitors. My wife and I visited, with me in a wheelchair due to a recent accident that left me with several

cracked ribs.

On our arrival at the Museum, we were able to gain easy access through a new street level entranceway on Level 0. There is a Restaurant & café on this level and two disabled toilets. There are two lifts to take you to other floors. On the first level there are eight lifts and three disabled toilets. You will find similar on floors 1, 3 and 5. There are also disabled toilets on floors 2 and 4, and these floors have a limited amount of display space.

The Museum is really worth a visit, we should be very proud of the wonderful collections that are on display there. Children are also looked after very well, with

interactive displays on every floor. The catering, which we sampled, is very good, if a bit expensive, but since there are no admission fees you should treat yourself to a meal there.

I have given Alice a copy of the National Museum Map, which is free to all entrants, to give to anyone who would like to look.

Have no fear about visiting the new Museum. As a disabled person you can be assured that your needs are really well taken care of. It's a great day out, and although you won't see it all on your first visit you will have no fear about making other visits.

Rob Parker

## Gadget News

MSTC Lothian has looked into some equipment which may be of interest to members. We have found various cups and straws which make it much easier for someone with limited mobility to drink:

### The Neater Drinker:

The **Neater Drinker** is a special long straw in a special sturdy ceramic mug with a lid.

- ⇒ The tough straw can be bent and positioned so that it can be reached easily.
- ⇒ A non-return valve at the bottom keeps the drink in the straw and so makes sucking easier.
- ⇒ The mug is very stable with a non-slip base, and a lid holds the straw in place as well as keeping drinks warm.
- ⇒ Cost: £39.00 for mug and straw, plus £8.00 p+p,
- ⇒ The straws are also available separately, as 60cm (£8) or 120cm (£12)
- ⇒ From **Neater Solutions**: Email: [info@neater.co.uk](mailto:info@neater.co.uk) / [www.neater.co.uk](http://www.neater.co.uk) Telephone: 01298 23882



### Cheaper alternatives:

**Thermal cups** can be purchased at any outdoor activity shop. I have given an example from Amazon: the Thermos Thermocafe 2060 Steel Travel Mug, **£4.97**:

- ⇒ Splash resistant, drink through lid
- ⇒ This can be used together with the Neater straw as it has a drinking hole in the lid.
- ⇒ Fits most car cup holders; keeps hot for up to 2 hours



**One-way straws** can be used. This straw has a non-return valve at the base keeping the straw filled with liquid. Packs contain two sizes: 10 inches and 7 inches. The straw is attached to the cup via a plastic clip. From **One Stop Mobility**: [www.onestopmobility.com](http://www.onestopmobility.com)  
Tel: 0800 028 24 76 . Cost £8.34



## The Radar Key

When out and about are you ever caught short? Find it more than difficult to access disabled toilet facilities when on arrival you are faced with a locked door? Well here's the answer. **"The Radar Key"**.

It's a nationwide service for the disabled fraternity, and you can either purchase it online from [radar-shop.org.uk](http://radar-shop.org.uk) or, like me, you can go along to the Brunton Hall in Musselburgh and purchase one at the reception. Below is a short excerpt from the online service.

### Opening doors to independent living – the Radar key - only £2.25, plus £2.00 Postage & Packing

"The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme (NKS) locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

Order the National Key Scheme Guide 2011 to find out the location of the 9,000 accessible toilets across the UK fitted with the NKS lock. This valuable resource is the only guide of its kind and really does open doors to independent living."



Kath Walker

# FEATURE ON DIET

## Food Intolerances,

By Maureen McGonigle

When I was first diagnosed in 1994, my Neurologist suggested that some patients found a low-fat diet helpful in managing the symptoms of MS. I followed this diet for many years but was not sure if I could notice any difference in my symptoms.

During this time I noticed slight **skin rashes**, my hair and scalp becoming drier and patches of **eczema** on my fingers and sometimes my scalp and neck. My problem with **constipation, gas and bloating** was incremental so that I wasn't sure when it started. I developed **bladder urgency** and needed to go to the toilet frequently. I had often suffered from **stabbing eye pain, double and blurred vision and terrible headaches** often resulting in mental foginess, **forgetfulness and tendency to mental confusion**. These symptoms improved but could resurface without warning. I often felt that my **circulation was poor** and that my upper body was prone to tension on a daily basis with **aching muscles** in my back, neck and shoulders so much so that I often felt like I'd been beaten up. **Sleep** became a problem accompanied by bouts of **low level anxiety and depression**.

All of these symptoms I'd put down to "my MS" but later discovered that they were all symptoms of food intolerance.

### Next steps

It wasn't until after my daughter started to experience problems with her digestion which resulted in her symptoms varying wildly to include double vision and blurred vision that I began to seriously investigate food intolerance. This was an arduous task to begin with as there are no tests for intolerance done on the NHS, only allergies. Food intolerances are not life-threatening and therefore have not been adequately researched or even taken seriously

as they should be.

Unfortunately the tests that are available have not been found to be reliably accurate. One way is to take notes on how each food affects you and eliminate it from your diet for a period and then reintroduce it and mark the results if any. However, food intolerance can be a very difficult thing to pin down.

### It's hard to do on your own

From my research it appears that most people are intolerant to five different things, though the most common intolerances are wheat and dairy. As your tolerance changes every day depending on various factors, you can appreciate that elimination alone of certain foods (even for up to a month) may not be a reliable method of deducing your "food culprits". Food is an emotional issue, but nature of food intolerance is that we become addicted to those foods that are intrinsically bad for us. Maybe you can see why it took me so long to address this issue! After an experience I had with a panini one day when my entire face heated up to a high temperature and I felt as though my central nervous system was being attacked, I finally decided to get tested.

The results surprised me. I was intolerant to **gluten** (which is contained in wheat, oats, rye, and barley), **chocolate, milk, cheese, yeast, rice, apples, bananas, alcohol, caffeine, coca cola and spices**.



I have since changed my diet again to avoid all bread and anything containing wheat, barley, and rye but still eat some oats now and again as I'm less intolerant to them than the others. When I had a relapse, the hospital always asked: "had I done anything differently recently?" The answer was always "no" and yet prior to all my relapses my diet had been high in all the foods that I later

discovered that I was intolerant to. Anything I eat has to be gluten-free, and to be able to eat out I often bring my own bread with me (usually pita bread as it has no yeast in it). It was tricky to begin with but once you know what you can eat it becomes easier. It just takes a bit more organisation.

### Perseverance pays off

The downside is that you have to read all the ingredients religiously.

But the benefits are worthwhile. After starting the diet I immediately found that I had **less flatulence, less bloating and constipation, bladder better, more energy, slept better, and not really any fatigue** unless I'd eaten something I should not have. My **head felt clearer**, without headaches and my **focus was better**. I felt **more relaxed and able to cope** with daily activities. These are to name but a few.

Unfortunately, every time I slip up and think "just a little won't hurt" chances are that it might!

### Final thoughts

If not addressed, food intolerances will ultimately progress into something more serious such as a stomach ulcer, and I've shown the widely varying symptoms which it can produce. Many of these symptoms are similar if not identical to those we experience with MS, or indeed with other auto-immune diseases. In my opinion, the food intolerance may be responsible for making our symptoms worse, so likewise perhaps we can improve them just by monitoring what we eat and the reactions produced. A food diary is a good way of doing this. At least you may be able to work out **why** you're having a bad day when nothing seems to work as well as it did the day before. The answer might be what you had to eat for dinner. If this all sounds like a lot of effort: it is, but it could be worth it for you in the end!

## Useful Details:

### Further reading:

**The Best Bet Diet**—available in the Centre and at [www.msrc.co.uk](http://www.msrc.co.uk)

**My Fight Against MS** by Roger Macdougall—available in the Centre

**Taking Control of MS** by George Jelinek

**Eat Fat Get Thin** by Barry Groves— info, recipes and menus to help manage on a gluten/cereal-free

diet

### For advice and testing:

*Everyone is different, and so it's far easier to make these changes with expert advice:*

**Jan De Vries:** [edinburgh@jandevrieshealth.co.uk](mailto:edinburgh@jandevrieshealth.co.uk), tel: 0131 662 0250, [www.jandevrieshealth.co.uk](http://www.jandevrieshealth.co.uk)

**Napiers:** Hamilton Place 315 2130 (Stockbridge), and Bristo Place 225 5542 (Old Town)

**Herbal Inn:** Ocean Terminal 554 9455 (testing only)

## Following a Gluten-Free Diet By Bruce Laidlaw

When I was first diagnosed in January 1989 a friend of my wife suggested I go to see complementary therapist Jan De Vries, as he had cured her of a serious skin complaint which the medics had given up on and he claimed to be able to treat people with M.S.

I am a bit of a cynic about most things and, at that time, I was especially cynical about complementary medicine, but I agreed to visit Jan De Vries primarily for my wife's benefit, as she was bearing the brunt of my illness while having to bring up two young children so I thought it would be motivational for her.

I visited Jan De Vries at his Troon consulting rooms when he assessed me over three visits before putting me on a gluten-free diet. (also known as the Roger Macdougall diet, as it was he who devised it.)

### **The diet**

Basically this diet involves:-

- ⇒ Eating nothing with gluten in it
- ⇒ Low intake of refined sugar
- ⇒ Low intake of animal fats
- ⇒ Making good any possible vitamin and mineral deficiencies with a pill supplement.

So at age 43, I put myself on a very strict gluten-free diet and have remained on that for 23 years. It sounds a bit complicated and

inconvenient but is really quite simple. **DO NOT EAT ANYTHING WITH GLUTEN IN IT.**

The good news is that today gluten-free foods are quite common. You can buy very good gluten-free bread, cakes, biscuits, etc., in most supermarkets. (Look in the "Free From" Section) Also all food manufacturers are required to label their foods and many of them also put on allergy advice. – **read the labels.**

If you want to eat out most good restaurants can accommodate gluten-free if you give them 24 hours notice.

### **Perseverance**

A few people at the Centre have, in the past, asked me about the gluten-free diet and have even stopped eating gluten for a few weeks. However, Roger Macdougall, who was crippled with M.S. and who devised the gluten-free diet, had to persevere with it for over **four years** before he saw any improvement in his condition. So perseverance is essential. If you are looking for a quick fix.....this is not it! The gluten-free diet will not cure you of M.S. but it may reduce your symptoms to an extent that you can again get on with life normally.

### **What now?**

If you are interested I would suggest you do what I did and make an appointment to see Jan De Vries in Edinburgh. (give him my regards). I don't think he charges for appointments but you will have to pay for whatever medicines he

prescribes. He has also written a book on M.S. which is worth reading.

### **Conclusion**

When I was first diagnosed I vowed to do literally **anything** to stave off disability. I said I'd buy four weasels if drinking fresh weasel urine was a cure!

So within a week of my diagnosis I:

1. embarked on the gluten-free diet;
2. attended HBO; and
3. undertook a strenuous keep fit programme utilising those muscles which still worked. (mainly weightlifting in a sedentary position as my walking and balance weren't great at that time)

I still haven't bought those four weasels!

I am now very fit and there is physically very little that I am prevented from doing by M.S.

Many people, including some highly qualified neurologists, put my current symptom-free condition down to good luck and not diet. However I know for a fact that Jan de Vries has a very fat file of letters of gratitude from other people with M.S. who he has put on the Roger Macdougall diet and have had similar results to mine. So I am not just one lucky case. When you go to see him ask how many others have experienced similar success.

PS: If you embark on the gluten-free diet and need advice on navigating your way through the minefield that is the food industry, then Cathy will give you my contact details and we will be delighted to help.

## Dates for your Diary

**Can Collections:** Sat 26th November: Ocean Terminal

**Christmas gift wrapping** *To be confirmed* Ocean Terminal

**Christmas party:** **Wed 14th December,  
3pm—8.30pm in the Centre**



**Christmas card Sales:** Mon 21 November, St George's West  
(need 1 volunteer) Mon 5 December,  
Mon 19 December

**CLOSED over Christmas:** Sat 24th December  
Mon 26th December  
Tues 27th December

**And closed over Hogmanay:** Mon 2nd January  
Tues 3rd January  
(see box to right for reduced opening hours over xmas period)

**Advisory Group meeting:** 11th January  
**Committee meetings:** Wed 23rd November  
Wed 18th January 2012

**AGM:** Wed 25th April 2012

## 200 Club winners:

3rd Oct Marjory Whigham  
10th Oct Yvonne Rafferty  
17th Oct Sheila Hughes  
24th Oct Dr Alistair Philip  
31st Oct Sandra Laidlaw  
7th Nov Margaret Berry

***Congratulations to everyone!***

**The next £250 draw will be held in November. Watch this space....**

***Want to join the 200 Club and be in with a chance of winning £250? It's open again for entries in March 2012, at the same time as membership renewal. Anyone can join—no need to be a member of the Centre.***

## What's available?

A reminder of the therapies and services available at the MS Therapy Centre Lothian:

- **Oxygen therapy**
- **Physiotherapy**
- **Reflexology:** ring Maureen on 07746 779 525
- **Yoga:** Tuesday 6.30pm, Thursday 4.30pm
- **Group exercise sessions:**
  - ⇒ Monday: **12.30pm**
  - ⇒ Thursdays: **1.30pm** (mild exercises, for high fatigue level), **2.00pm** (moderate exercises), **3.30pm** (wheelchair users) and **4.00pm**.
- Public computer access, with accessible software and a large keyboard
- Publications from MS Society, MS Trust, and local organisations
- General assistance with any questions—please ask anyone!

## Opening hours during Christmas period:

Reduced opening hours will operate on:

**28th Dec:** 11.00—5.30pm

**29th Dec:** 11.00—5.30pm

**30th Dec:** 9.00—2.30pm

**31st Dec:** 10.00—12.30pm

Please be sure to confirm your oxygen sessions in advance as some pressures have been altered to ensure a range of options. There will be no physiotherapy on these days.

**The Centre will be open as normal from Wed 4th Jan**

***If you are not a member and no longer wish to receive this newsletter, please help us save postage by:***

- ***Send an email to [info@mstc-lothian.org.uk](mailto:info@mstc-lothian.org.uk)***
- ***Call a member of the admin team on 0131 554 5384***

***Equally, if you receive it by post and wish to receive it by email instead please email: [info@mstc-lothian.org.uk](mailto:info@mstc-lothian.org.uk)***