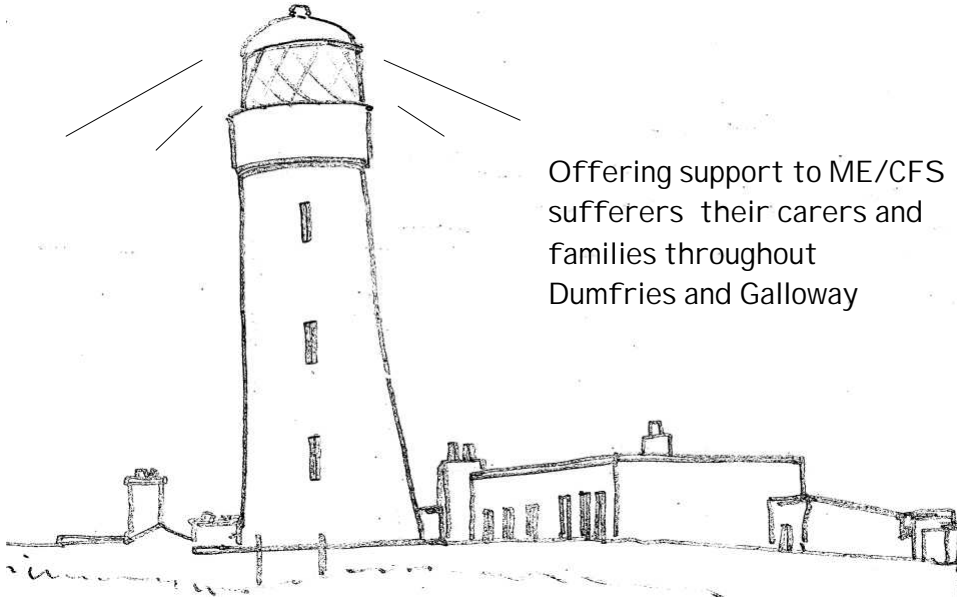


Dumfries and Galloway M.E. Network

Registered Charity SC30641

Issue No. 45

Spring 2008



Offering support to ME/CFS
sufferers their carers and
families throughout
Dumfries and Galloway

Visit our Website - www.dgme.co.uk

Awareness Week

May 7th - 13th

Poster Campaign pg 2 and pg 23

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Dear Member

Most members I have spoken to over the last few weeks seemed to have been going through a bad patch. We hope that you are starting to pick up and looking forward to the summer.

If you would like to help with research please read page 11

This year for Awareness Week we are holding a 'Poster Campaign' and we are asking you to get involved.

On page 23 you will find a poster to cut out. You could even print several copies, then if you cannot manage yourself, ask family, friend or neighbour to put it/them in prominent places -GP's surgery, Dentist, Library, Shop, Supermarket, or the office they work in.

Thanks in anticipation to you all.

Best wishes and take care

Norma



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Challenging your Condition



Sylvia McCracken

The meeting at Lochthorn Library had a disappointing turnout, even so it was a very good meeting. The speaker Sylvia McCracken from 'Arthritis Care' gave an excellent Presentation. It was clear, interesting, informative and easy to follow. The pain management part was very good. ME/CFS/FM sufferers could relate to it.

To end with Sylvia gave us a visual exercise. She took us on a wonderful walk through meadows and gates past gentle falling streams. We all enjoyed the experience and found it very relaxing.



Our other speaker on the day was Jim Richardson from 'Building Healthy Communities'. This is a project set up to tackle health inequalities, through support, volunteering and capacity building, under the governments healthy living centre concept.

The photo above shows Jim (centre) discussing issues with some members



You will find details of the book that goes with the 'Challenging Your Condition' course on page 19.



Question Time ?

With Answers from Dr Gregor Purdie

Medical Adviser to Our Network



Q. It is our understanding that fibromyalgia is to come under the same umbrella as ME/CFS as a number of our members suffer both conditions it would be interesting to know if the Scottish Good Practice Statement for GP's on ME/CFS will include some guidelines on FM?

A. The edition of the Scottish Good Practice Statement that we are working on at the moment is primarily for ME /CFS. My aspiration is that this is the first document in a series that will in time give guidance to other professional groups e.g. physiotherapists, occupational therapists as well as nurses.

Certainly, there will be relevance in the document to fibromyalgia, especially in the assessment for diagnosis - I use the Canadian Guidelines rating scale for both ME/CFS and Fibromyalgia. There are certainly overlaps in management. Future editions could again be expanded to include more fibromyalgia tailored advice.

Q. Is the Network nearer to getting a support worker. Have you any idea on the time scale?

A. Thank you Norma and Denis for your work on the job description - this is now at Human Resources. Once they have worked it up, we should be able to advertise for applicants. Should be at that stage in the next few weeks.

Concerns about the RSM Conference on 28th April 2008 on "CFS"

Although this has past (there was only three weeks notice about the event) we felt it important to inform you all. More about it in the next newsletter.

There is international concern about the forthcoming conference on "CFS" (chronic fatigue syndrome) to be held at the Royal Society of Medicine (RSM) on 28th April 2008 because there can be little doubt that the conference is a "Wessely School" initiative that is intended to promote the psychosocial model of "CFS" and to "educate" GPs accordingly. The psychosocial model denies the reality of myalgic encephalomyelitis as a distinct neurological disorder and subsumes it within "CFS/ME" as a behavioural disorder.

Such is the concern that many representations have been made to the Dean of the RSM, Dr John Scadding. People have expressed dismay that the Royal Society of Medicine should be providing a platform for a group of psychiatrists who are committed to eradicating ME as a distinct medical disorder and who persistently dismiss the substantive evidence that it is not a primary mental disorder but a serious and complex multi-system organic disorder.

In addition to countless postings on the internet, a postcard campaign has been organised for people to write to the Dean; there have been letters to the press; a demonstration outside the RSM has been organised to take place on the day of the conference, and one medical practitioner (himself a Physician-in-Waiting to the Royal Family) has written to Her Majesty the Queen suggesting that such is the outrage, she may wish to consider withdrawing the Royal patronage from the Society. Most of the UK ME/CFS charities have expressed profound disapproval of the undeniable psychiatric bias of this RSM conference.

Margaret Williams 24th April 2008

IN THE NEWS

Counterfeit medicines: the pills that kill Extracts from an article in a recent Saturday Telegraph Magazine

Britain is on the front line, both as Europe's prime target for counterfeiters (medicine prices are high compared with most other EU countries) and as a staging post between producers in the Far East and the medicine-hungry buyers of the United States. But most people in the UK are largely unaware of the scale of the problem: a study last year by the University of London's School of Pharmacy found that only 19 per cent of Britons felt there was a growing risk from counterfeit medicines, compared with 74 per cent of Europeans as a whole. The Medicines and Healthcare Products Regulatory Agency (MHRA) intelligence and enforcement unit, a small specialist group that seeks to keep Britain free of illegal and counterfeit medicines - a multi-billion-pound worldwide trade that is estimated to lead directly to the deaths of more than a half million people a year across the globe.

Although the World Health Organisation (WHO) began collecting data on counterfeit drugs in the early 1980s, until about 10 years ago they were regarded as a problem only in countries such as China. The situation has changed quickly: by 2001 counterfeit versions of major prescription medicines were appearing all over Europe. The WHO estimates the business to be worth £18 billion, a figure that some forecasts will more than double in the next two years, to represent about 10 per cent of all pharmaceutical sales worldwide. The WHO also believes that up to 30 per cent of medicines in Russia and in some countries in Africa, Asia and Latin America are counterfeit. In wealthy nations the figure is one per cent - but in the UK that equates to more than eight million packs of medicines worth about £425 million a year. Internet security experts believe that nearly 25 per cent of all emails - 15 billion messages a day - are spam advertising drugs. According to the WHO, more than 50 per cent of medicines offered by websites that conceal their physical addresses are fakes. But it is no longer only the developing world that is being duped.

In Canada, 58-year-old Marcia Bergeron died just after Christmas 2006 after buying fake Zolpidem, a prescription sleeping pill, on the internet. The pills had been laced with traces of a medley of dangerous metals including uranium, strontium, selenium, arsenic and aluminium.

In 2004 in Chicago, Craig Schmidt, a salesman, bought the anxiety drug Xanax and the painkiller Ultram. He took one of each, and woke up in hospital three weeks later. The 'Xanax', it was found, contained quadruple the usual amount of active ingredient. He suffered a heart attack, coma and brain damage.

Mick Deats, a former detective chief super-intendent who heads the MHRA's intelligence and enforcement unit, says, 'There is far less risk [than with cocaine and heroin] and when you look at the money you can make you are going to make more out of this.' Steve Allen, a former officer with the National Crime Squad (now the Serious and Organised Crime Agency) and senior director of global security at Pfizer, the world's biggest pharmaceuticals company says, 'The chances of detection are pretty low.'

Rarely are dubious internet sites trading from where they claim to be. In one operation the US Food and Drug Administration found that 85 per cent of the drugs that buyers believed were coming from Canadian pharmacies were actually coming from 27 other countries. In one case, original spam messages originated from an address licensed to someone in Russia, the website server was in China, the credit card payee phone number was in the UK, the card payment was processed in Australia and the drugs were mailed from Chicago.

Despite the size of the threat, not all pharmaceutical companies are willing to talk about counterfeits. Dr Paul Newton, an expert on tropical medicines and on fake drugs, said in *The Lancet*, 'There is a serious conflict of interest within the pharmaceutical industry, concerned that making information on specific counterfeits public will reduce public confidence in the product and reduce sales.'

Pharmaceutical companies and health agencies argue that the wrong message could provoke panic and that the whole credibility of the healthcare system could be harmed. Mike Deats agrees: 'It's an emotive subject. If there's an unbalanced message it can frighten patients into not taking medicines that in 99.9 per cent of cases are safe.'

A significant number of chronic headaches are caused by overuse of everyday pain medications, experts say.



IN BRIEF

As many as one in four chronic headaches is believed to result from the overuse of common pain pills. Both over-the-counter pain pills and prescription drugs cause medication-overuse headaches.

Signs of trouble from overusing pain pills include headaches that occur 15 or more days a month and have grown worse with the regular use of pain medication. Sometimes, the cure is worse than the disease.

Four percent of Americans suffer headaches daily, and scientists have suspected culprits as diverse as undiagnosed jaw disorders, genetic susceptibility and stress. But according to recent research, a sizeable and growing number of headaches are being caused by the very medications taken to alleviate them — and the problem is far more common than scientists had realized. Half of chronic migraines, and as many as 25 percent of all headaches, are actually “rebound” episodes triggered by the overuse of common pain medications. Both prescription and over-the-counter drugs may be to blame.

Patients begin by popping too many pills to deal with a migraine or a simple tension-type headache. When the medications stop, another headache follows, similar to a hangover. Sufferers race again to the medicine cabinet, and before long they are locked in a cycle of headaches and overmedication.

At any given time, more than three million Americans are suffering from headaches they are inflicting on themselves, according to Dr. Stephen D. Silberstein, a professor of neurology and director of the Jefferson Headache Center at Thomas Jefferson University in Philadelphia. “If a patient’s headaches have grown markedly worse or more frequent, the problem is almost always medication overuse,” Dr. Silberstein said.

The International Headache Society last year published revised criteria to help doctors recognize and treat headaches from medication overuse. Signs of trouble include headaches that occur 15 or more days a month, according to the society, along with the heavy use of pain medications for three months or more. Overuse is defined as taking pain medication for 15 or more days a month.

“Overuse has less to do with how many pills you take to relieve a single headache than with how often you take them,” said Dr. Robert Kunkel, a headache specialist at the Cleveland Clinic Headache Center. “If you get more than two headaches a week and take pain pills for them, you’re at risk.”

The only way to know whether medication is contributing to your headaches is to stop taking them. Unfortunately, it can take as long as two months for medication-dependent patients to see an improvement.

Migraine sufferers seem to be especially susceptible to rebound episodes. Many doctors begin weaning these patients off Painkillers by prescribing drugs to help prevent attacks, then gradually reducing doses of the painkillers used to treat acute episodes.

Tension headaches can frequently be prevented with stress reduction techniques and avoidance of certain triggers. With close attention to prevention, sufferers should not need to resort to painkillers often enough to risk rebounding.

Yet almost any kind of pain pill can cause rebound problems if used to excess. Among over-the-counter drugs, those with caffeine, like Excedrin, are the likeliest villains, studies show. Among prescription drugs, triptans are most commonly associated with rebounding, Dr. Silberstein said.

The more technical name for this class of medications is selective serotonin receptor agonists. Triptans are not pain medications as we traditionally think of them. Traditional pain medications don't end the pain. They simply increase our tolerance to it -- temporarily. Unless the Migraine attack has run its course while a pain medication is working, the symptoms will return when the pain medication wears off.

Triptans are termed abortive Migraine medications. They cannot prevent Migraines. They are used to abort a Migraine attack, to stop the attack itself and the associated symptoms. Drugs in this class need to be taken early in the Migraine attack to be most effective. In addition to Migraine attacks, triptans are also sometimes helpful for cluster headaches.

But in terms of both rebound and dependence, the most problematic drugs are those containing butalbital, a barbiturate. Two such medications, Fioricet and Fiorinal, have been banned in Germany because they so often led to medication-related headaches. Both are still prescribed in the United States, but not in the UK - one similar drug is only available as a controlled drug in the UK. Only available for people who cannot get off it.

Now that research has begun to spotlight the extent of the problem of medication overuse headaches, more and more doctors are on the lookout for signs of trouble. "Believe me, a lot of patients don't want to hear that they have to stop taking their pain pills in order to get relief," Dr. Kunkel said. "But for these kinds of headaches, that's really the only solution."

Once weaned from medicine, most patients show significant improvement after three months. They also learn their lesson and steer clear of overusing pain pills, research shows. In one study, 87 percent continued to report significant improvement two years after stopping overusing painkillers. Many headache sufferers have been praying for a miracle cure. Now it's here, though it may not be what they expected.

BITS 'N' PIECES

Big Red Bus coming your way!

Questions about your
Medicines?



The prescribing support team are going on the road to spread the message of safe use of medicines and reducing medicines waste to the people of Dumfries and Galloway!

They will be providing opportunities to ask about medicines, the minor ailments scheme at your local community pharmacist and helping you take good care of your medicines.

There will be lots of activities laid on for young and old - for example, colouring sheets, word searches, medicine quizzes as well as a design a poster competition (with prizes).

There will be opportunity to ask pharmacists questions about medicines and there are a whole bunch of goodies to give out which all emphasise the message of taking good care of medicines. Posters are currently being distributed with details of where we will be and when:

Tuesday 6th May: am Lockerbie, Tesco car park, pm: Annan High St

Wednesday 7th May am: Castle Douglas Market Hill car park,
pm: Kirkcudbright Harbour Square car park

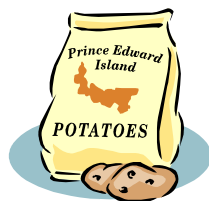
Thursday 8th May: Stranraer, South Strand St

Friday 9th May: Dumfries High St

Saturday 10th May: Dumfries Tesco Extra



WEEKLY EXERCISES.



Begin by standing on a comfortable surface, where you have plenty of room at each side. With a 5-lb potato sack in each hand, extend your arms straight out from your sides and hold them there as long as you can. Try to reach a full minute, and then relax.

Each day you'll find that you can hold this position for just a bit longer.

After a couple of weeks, move up to 10-lb potato sacks.

Then try 50-lb. potato sacks and then eventually try to get to where you can lift a 100-lb potato sack in each hand and hold your arms straight for more than a full minute. (I'm at this level)

After you feel confident at that level, put a potato in each of the sacks.

Anti-Candida – Not Worth the Bother?

Long advocated by many alternative health practitioners, no-sugar, low-wheat, anti-candida diets do nothing to help people with M.E. a recent trial has found.

Scientists at St Bartholomew's Hospital followed 52 sufferers and found no difference in the levels of fatigue, mood or quality of life after a 6 month period. The ME Association comments "This study shows that the anti-candida diet isn't worth the bother and should be discarded as a treatment for ME or chronic fatigue syndrome"

Craig's comment: I suspect that candida is a problem for many people, particularly those with a poor diet, but that it is a separate condition from M.E. Once again a widely available, definitive diagnostic test is badly needed.

Sick and Tired of Sick and Tired

The article about the anti-candida diet trial results appeared in The Times under the long over-used headline "Sick and Tired". The Times is far from being alone in using what appears to be the default heading of any article featuring M.E. in the National Press. On a more pleasing note though, reporting on Miles Brookson's combined health and Gretna F.C. troubles, The Times mentions that he suffers from "the neurological illness, M.E." This is a major step forward for a paper with a formerly sceptical medical advisor, Dr Thomas Stuttaford. The change in the tone of their reporting appeared to follow an article, including Dr Stuttaford's comments, on Dr Gow and Dr Kerr's genetic findings.

Neurological Pandemic Consumes Population

Drug resistance has mutated a virus. "The Dying" are desperate, paranoid and violent. In the hills above Auldgirth a "seriously affected" blindly staggers slowly, but menacingly towards the last of survivors. Thankfully the above is fiction and is the synopsis of *The Dead Outside*, a Horror film which was shot in the Hills above Auldgirth in March this year.



I auditioned to be an extra and was chosen to be one of the "seriously affected". So early in my career already I'm being typecast! It was my first experience as an extra, and despite it being an unexpectedly long night, most of it spent waiting to be called, and then spending time on an exposed hillside in wind and rain at 3am, it was good fun and a great experience. I should take this opportunity though to apologize to anyone who caught me in their headlights in the small hours as I drove home. The make-up artist had gone to bed so I drove home with the "blood" still pouring from my mouth. It did cross my mind to stop off in the 24hr Tesco on the way home, but I thought better of it!

Like all good horror films, the story is close enough to fact to be frightening. We all know the, less dramatic, but all too true horror of living with a neurological illness.

Craig Woods

The Wigtownshire FM/ME Support Group

We are a recently formed group of people with FM and/or ME. Spouses, carers, family and friends are also welcome. To date, we have about 15 members, although we hope more will join in the near future.

The group is based in Stranraer but we have members from both the north and south Rhins as well. If there is sufficient interest, we will hold additional meetings in other areas, such as Newton Stewart.

Our objective is to assist those with Fibromyalgia (FM) and Myalgic Encephalomyelitis (ME), their families and friends by providing information and support as well as promoting public awareness in the area.

In the last few months we have developed a small lending library of 24 books on FM/ME and related subjects. I subscribe to the FM Association of the UK monthly magazine "Family" and the quarterly magazine of the Fibromyalgia Network, "Fibromyalgia Network Journal" which provides information about new research and drug trials, etc. in the US. Both are available for loan. We also have numerous journal articles, brochures and other publications which might be of interest.

The Wigtownshire FM/ME support Group maintains close ties with our associates in the DGME Network which supports people with both ME and Fibromyalgia.

Most of our members also belong to DGME. We feel it is important to keep in touch with other organizations in the region. Through DGME we keep abreast of new developments in government and the NHS.

Future plans for our group include demonstrations of alternative therapies and talks from specialists on benefits, etc. We are also considering developing a website.

Occasionally we receive inquiries about holding evening meetings for those who are still able to work or for convenience. This may be considered as an option if sufficient interest is shown. When, from time to time, Fibromyalgia or ME conferences are held in the UK, we hope to be able to support the attendance of one or more members.

Membership is free but we do appreciate a donation of £1.00 at meetings towards the cost of refreshments.

We hold meetings on the last Thursday of each month at the Stranraer Public Library 2:00 - 4:00 pm. Our next meetings are scheduled for:



Thursday, 29th May
Thursday, 26th June
Thursday, 31st July

If you require more information, or would like to join us at one of our meetings, please feel free to contact myself

Janet Graham
Newton Stewart
01671 403 577

seonaid51@googlemail.com

Or

Jayne Murphy
Stranraer
01776 703871

jaynemurphy@topmail.co.uk

Blood samples wanted for ME/CFS

Genes Expression Study

The search is on for volunteers to supply blood samples to the ME/CFS genes expression study being conducted at Glasgow Caledonian University by Professor John Gow and his research assistant Dr Suzanne Hagen.

The Glasgow research group - that was set up by Professors Peter and Mina Behan over 20 years ago - now have a list of candidate gene markers which they would like to test out on a larger number of samples from patients with ME/CFS.

It is necessary to test the potential diagnostic test under strict research criteria before a robust diagnostic tool becomes generally available.

It is emphasised that samples are required at this stage for inclusion in an ongoing research project. A diagnostic test is NOT being offered.

The group require blood samples from patients with ME/CFS who have been diagnosed by a clinician familiar with the condition.

All details will be kept confidential and ethical permission from the appropriate authorities has been obtained for these studies. You will remain anonymous. But you will need to sign a consent form, available on line or from the address below

You can ask either your GP's (practise nurse) to take the samples. The bottles to be used are standard bottles that will be used day to day at our Health Centre. Ideally they would like a 5ml sample of blood in an EDTA tube (not heparin) and a 5ml blood sample in a clotted plasma tube together.

Your Doctor will only have to write a very brief note on how long you have had M.E., you must have been ill for 6 months or more, also a symptom list and medication you are on.

The researchers would be happy to pay the postage for any samples sent from surgeries or clinics if required.

The blood samples can be bubble wrapped and placed in a strong jiffy bag and the address to send the samples too is:

Dr Suzanne Hagan, Room C223A, B1 O, Charles Oakley Laboratories, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA.

email: suzanne.hagan@gcal.ac.uk

tel: 0141 331 8615; fax: 0141 332 3208.

The ME Association has been funding Dr Hagen's salary.

The results of these studies will be made available by presentation at appropriate conferences and by publication in a peer-reviewed journal.

Any further questions GP's need answered, can be emailed or telephoned to Dr Hagan. Dr Hagan and Dr Gow are hoping for 50 samples, lets aim to double that for them!! Please help them to help us as much as possible!

Petition to the Prime Minister

The following is the response to the e-petition you may have taken part in.

You signed a petition asking the Prime Minister to "get the Health Service and medical profession to accept the WHO classification of ME/CFS as an organic neurological disorder and not as a psychosocial syndrome."

The Prime Minister's Office has responded to that petition -:

There is no established cause of chronic fatigue syndrome/myalgic encephalopathy (CFS/ME). A number of different potential aetiologies including neurological, endocrine, immunological, genetic, psychiatric and infectious have been investigated, but the diverse nature of the symptoms can not yet be fully explained. The World Health Organization classifies CFS/ME as a neurological illness, but we recognise that many others working in the field of CFS/ME believe that until research further identifies its aetiology and pathogenesis, there is a risk of restricting research into the causes, mechanisms and future treatments for CFS/ME. What is important to recognise that CFS/ME is a genuine and disabling illness and health professionals must recognise it as such.

As with all serious illnesses, it is important that patients, their families and the healthcare professionals looking after them have the best scientific information available and the PACE trial has been designed to help them decide for themselves what treatment is likely to be best from them. There is currently very little information about the relative benefits of cognitive behaviour therapy (CBT) and graded exercise treatment and a scientific trial is the only way to find out which is the most effective approach.

The aim behind CBT is to support a sustainable improvement in functioning and adaptation to illness, via gradual steps that are mutually agreed and regularly reviewed by patient and clinician. Applied appropriately, CBT can help the patient cope confidently with their illness and help them adjust to some of the consequences of being unwell and to feel more in control of their illness. In common with other illnesses such as cancer where it has been successfully used, its use does not imply that the cause of the illness is psychological.

As with any treatment, an explanation of the benefits and possible harmful effects of CBT should always be provided before decisions are made to offer and accept the treatment. It is important that health professionals recognise that people can vary in response to the treatments available and that it is appropriate to review therapy if symptoms appear to worsen as a result.

The Medical Research Council's support for the PACE trial does not mean that money is not available for biomedical research and the Council remains committed to funding scientific research in all aspects of CFS/ME. Nevertheless it is important to maintain high standards in funding decisions and the MRC maintains a rigorous decision making process, only funding research that is likely to make a significant contribution to knowledge and is a good use of tax payers' money. The decision to reject proposals is taken on the grounds of scientific quality and whether the research proposed would be likely to inform the knowledge base.

Tea Time Recipes



Gluten Free Scone Recipe

These gluten free scones aren't just gluten free, they're egg free and dairy free too.

525g gluten free self-raising flour

3 teaspoons gluten free baking powder

Sea salt

80g dairy-free margarine

1 tablespoon caster sugar

325ml gluten free rice milk (you'd think all rice milk would be gluten free but it's not.

Rice Dream's cartons carry the warning that they may contain barley protein).

1 teaspoon xanthan gum

Preheat the oven to 220C. Sift the gluten free flour, baking powder and a pinch of salt into a bowl. Rub the margarine into the flour until it looks like fine breadcrumbs. Add the sugar. Add the rice milk and mix until the dough forms.

On the other hand, you can just stick it all into a blender - it's a reliable way to make good dough quickly.

Turn out onto a floured surface and knead if extra mixing required. Roll out to about 2 cm thick. Cut rounds with a cutter (about 5cm wide). Bake for 12-15 minutes.

Gluten free scones don't keep terribly well, so it's recommended you eat them on the same day. A good way to perk them up on the second day is to cut one in half and place in the microwave for 15 seconds (tested, this is the best length of time).

White Oven Scones (Not Gluten Free)

Preparation time: 20 minutes

Cooking time: 9 minutes

Ingredients:

One cup each of all-purpose and self-raising flour

1.5 tsp baking powder

0.25 tsp baking soda

0.25 tsp salt

1 tbsp sugar

0.25 cup butter (60 gms)

1 large egg

2/3 cup buttermilk or mix of milk and yoghurt

Method:

Mix dry ingredients and work in butter. If adding dry ingredients (e.g. currants or raisins) add them now.

Add egg to buttermilk (or milk mixture) and beat lightly.

Pour into dry ingredients and mix thoroughly.

Turn out onto floured surface and form into a round about 1/2 thick. Cut into 8 segments and place onto baking tray.

Cook at 220 C for 9 minutes

The scones are best eaten ASAP but if required can be frozen and reheated in a microwave (e.g. 20 seconds on medium) Serves: 8 scones

Tips to help ME to help you

The American CFIDS Association regularly receives tips from CFS patients and authorities on various ways to manage challenges common to the illness.

In 2006, a series of "Solutions for Daily Living" that shared 8 to 10 tips on a given topic that many people face. This sampling of tips is taken from the topics that got the most positive feedback from readers.

Making the most of medical interactions

With CFS, good health care can be like the Holy Grail. Yet in today's fast-paced world and overloaded health care system, the process can be daunting. Here are three tips to help you make the most of your medical interactions.

Medical Visits Tip 1:

Fatigue is one of the most frequent medical complaints that health care workers hear—yet the fatigue of CFS is distinct in its severity. Instead of just saying you feel fatigued, be specific in your description. Illustrate the severity of the fatigue using concrete examples and contrasting them with your pre-illness state. Use similar methods for describing pain and cognitive problems.

Medical Visits Tip 2:

When trying a new supplement or medication, keep a record of your scope of symptoms before and throughout the treatment so you can accurately track any changes.

Improvement may be subtle over time. In other cases, a treatment may alleviate one symptom but bring on other side effects. Tracking your progress can help you and your doctor more effectively decide if the treatment is worth continuing.

Cognitive Tip 1:

cognitive difficulties such as memory lapses and trouble processing information. Here are some tips to help clear the fog.

Distractions are the enemy of concentration. Background noise, conversation and attempts to multitask can get in the way of focus. Try to keep the TV off when working on something that requires attention. Avoid doing two things at once or having a conversation while working on a cognitive task. And don't feel guilty about having to pare things down.

Many people experience better cognitive performance during certain times of the day. For instance, some people have concentration problems in the early morning. Others experience higher capacity first thing in the morning and wear down mentally as the day progresses. Try to determine the times you experience mental peaks (and valleys) and plan your activities around them.

Productivity gurus are now advising businesses that multitasking actually impairs work quality. If the corporate world can recognize the value of pacing tasks, so can you. One member reports coping with her worst days of brain fog by writing important tasks for the day on individual, loose-fitting rubber bands that she wears on her wrist. As she completes a task, she removes the corresponding band.

Cognitive Tip 2:

Memory aids abound, from PDAs and elaborate planners to sticky notes and calendars of all sizes. But not all of these items work equally well for everyone. Find what works for you and use it. Generally speaking, the simpler the better.

For example, many people report that colour-coding their calendars for medical, household and social activities helps them keep better track of tasks and engagements. The key is to keep the same tool close at hand and write things down immediately.

Reducing isolation

CFS can be very isolating. Lack of energy, lack of understanding, physical pain and limited mobility can significantly limit the chance to connect with others. Here is some practical advice that could help.

Isolation Tip 1:

Make it as easy as possible for you to reach out to others by streamlining the social outlets that remain open to you.

For example, keep a list of friends' and family members' phone numbers right by the phone so you don't have to look them up when you have the energy to call. One member describes feeling less inhibited about reaching out when she's easily able to choose different people to call rather than leaning heavily on one or two contacts.

It also pays to learn what community centres, support groups and activities exist in your area. Knowing what's available and how to get there can make it that much easier to take advantage of those resources when you're able. Then, when you've got the energy or the need to venture out, you're not wasting any of it wondering where to go or what to do.

Isolation Tip 2:

With modern technology, you can commune with people across the globe without ever leaving your home. It's no wonder that people with CFS and Internet access are using it to connect with each other.

CFS weblogs (or blogs) are sprouting up in abundance. The "bloggers" use their sites to talk about CFS and exchange messages with visitors. CFS bloggers often describe how much more connected they feel from having the outlet to use.

Isolation Tip 3:

Certain medications can contribute to feelings of depression. If you're feeling isolated or anxious, ask your doctor about the medications you're taking and whether they could be part of the problem. For example, some tranquilizers, narcotic painkillers and even steroid treatments can affect your mood or intensify depression. Your doctor may be able to adjust your medications or advise you on ways to counter or mitigate the effects.

On the flip side, there are also medications that help with feelings of isolation associated with disorders such as social phobia and depression. If you suspect your sense of isolation may be a sign of a more urgent problem, ask your doctor about treatment options. Together you can determine if medication may be appropriate.

CALLING ALL YOU CARERS

CARERS WEEK 9-15TH JUNE 2008

Carers Week' this year is being held from the 9th to 15th June
The Theme is 'Carers can't afford to be ill'

Here is a flavour of the activities in your area !!

ANNANDALE & ESKDALE

PERSONALISING YOUR OWN NOTEBOOK

9th June Kings Arms Hotel, High Street Lockerbie 12pm to 4pm £4:00 including lunch

CARERS INFORMATION EXHIBITION

10th June The Buccleuch Centre Langholm 1pm to 6pm

Telephone Lindsay 01387 248600 for both of the above events

WIGTOWNSHIRE

BUS TRIP TO CASTLE DOUGLAS AND NEW GALLOWAY

12th June Leaving Stranraer [Hanover Square] 9:15am
Newton Stewart 10am
Returning home to Stranraer for 5pm

To book contact Fiona Barr on 01671 401152

STEWARTRY

THREAVE GARDENS

9th June Arrive any time between 10am and 4pm Stroll through the
Gardens a snack in the Restaurant

SANQUHAR FUN POOL

All week To suit yourself—Try out the facilities - Pool - Sauna - Steam Room -
Fitness suite

For both of the above contact Margaret Sharp 01644 430005

DUMFRIES

GARDEN OF COSMIC SPECULATION

11th June Visit to Garden of Cosmic Speculation 1pm to 3pm

BODY SHOP PARTY

13th June Body Shop Party at the Careers Centre 2-6 Nith Street, Dumfries
7:30pm £3:00 to include refreshments.

For both of the above - Contact the Careers Centre to book 01387 248600

X-Party Group on ME.

Holyrood



At a lengthy meeting on the 23rd April 2008 among items discussed were The Managed Clinical Network and GPs Guidelines on M.E.

The following item shows how the new draft for the Scottish Good Practise Guide (GP's guidelines on ME) is being formulated

The Way Ahead

9. Schedule. The Scottish Government Health Directorates have asked Dr Purdie and Action for M.E. to lead the project jointly over the next six to nine months placing a renewed emphasis on wide consultation especially with patients and their representative groups as well as with relevant health professionals.

10. Although the timescale allowed for comment on the draft circulated in Jan 08 regrettably precluded many people with the illness from responding, a great deal of valuable information was gathered. This will assist the drafting of the next iteration. It is envisaged that a new document of about 8 to 10 pages will be ready for the next circulation by the end of June. Six to eight weeks will then be allowed for written comments to be sent in by all interested parties. The need for another circulation and any other form of consultation in the light of the responses received.

11. Dr Purdie will in addition set up a working group of GPs to assist in shaping the final product in a manner which reflects the working practices and environments of Scottish GPs in both urban and rural areas.

12. Source Documents. Core documentation which will be consulted for good clinical practice comprises the Action for M.E. Guidance to GPs, the MEA Guidelines for GPs and the Canadian Guidelines [Carruthers]. These will all be critically appraised against evidence based principles in order to identify and capture best practice wherever possible and feed it into the new Guidance for Scottish GPs.

13. Other Documents. In order to maintain credibility with the wider NHS, the NI CE Guidelines on CFS/M.E. issued for use in England and Wales will be appraised in developing the advice to GPs in Scotland. However it is emphasised that the NI CE document has no formal status in Scotland and its NI CE recommendations are expected to be strongly challenged during the Scottish process.

14. Published research papers will be trawled for evidence that contributes to our knowledge of how to manage this illness.

Continued on page 18

X-Party Group on ME—continued

15. Consultation Process. The consultation process will involve the three major groups that have already been identified viz:

Lay group of people with M.E. and their cares and supporters

GP Group

Specialist group – medical consultants and representatives from other disciplines such as nursing, physio, occupational therapy etc.

Consultation will be open and contemporaneous so that all stakeholders may be confident of being involved in a meaningful iterative process.

16. Other participants. The RCGP and the BMA will be consulted as the professional bodies which represent the interest of the GPs. Bearing in mind the longer term desirability of expanding the advice given to GPs into more substantial guidance for all relevant health professionals in Scotland, there are several organisations that may also be invited to make an input to the good practice guide as it develops. These bodies include NHS QI S and FINE for example.

17. Benefits. The immediate benefits that will be derived from this document are better and more consistent standards of care for patients with M.E. including quicker and more reliable diagnosis of the illness. It should also help to develop care pathways for patients within the NHS in Scotland and lay the foundations of a basic training package for health professionals. In addition, the Guidance would also be expected to form part of the evidence base of the M.E. managed clinical networks which are currently under consideration.

18. The Guidance for GPs will be a living document that will be regularly updated in the light of emerging evidence. In this way patients will benefit from the latest knowledge of best GP practice as our knowledge improves over time.

Conclusion

19. It is evident that the production of this urgently needed guidance for GPs in Scotland has been delayed for too long. Every effort will now be made to expedite completion without compromising the consultation process which is considered to be essential.

Dr Gregor Purdie
M.E. Lead Clinician
NHS Dumfries & Galloway

Peter Spencer
Chief Executive
Action for M.E.

Garden Wise

Dates for Garden Wise get-togethers :

Sat June 7th

Sat July 5th

Sat August 2nd

Sat Sept 6th



Library



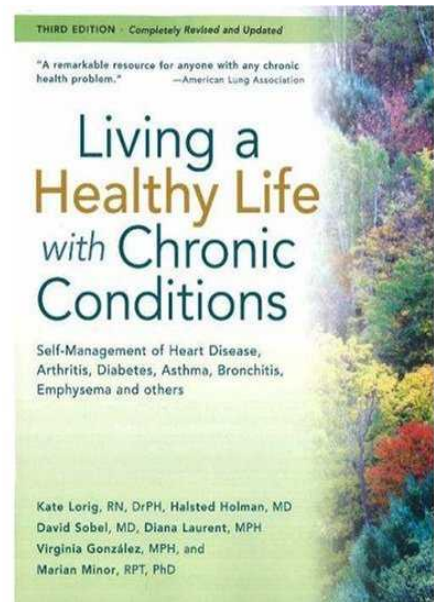
We have a small selection of books about ME/CFS/FM for members to borrow. Janet Graham with the help of husband Chris brings them to the Garden Wise get-togethers. There is no charge and books may be borrowed for up to a month.



Living a Healthy Life with Chronic Conditions:

Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and Others:

Filled with hundreds of tips, suggestions, and strategies, this guide explains how to develop and maintain exercise and nutrition programs, manage symptoms, determine when to seek medical help, work effectively with doctors, properly use medications and minimise side effects, find community resources, discuss the illness with family and friends, and tailor social activities for particular conditions. Written by six medical professionals, this book encourages an individual approach to the process, with the ultimate goal being greater self-management.



Originally based on a five-year study conducted at Stanford University with hundreds of volunteers, this work has grown to include the feedback of medical professionals and thousands of people with chronic conditions all over the world.

An excellent guide for anyone with any chronic condition

This book is the standard text for our self-help management group. It covers most chronic conditions and is suitable for all people of all ages and abilities. It aims to help you to get and then keep a positive outlook regardless of your condition. Although an American text, all the sections are applicable wherever you live.

Available from Amazon. Third addition price £8.42 plus postage

GIVING SUPPORT TO EACH OTHER

YOUR SHOUT YOUR SHOUT

These days you could be forgiven for thinking that as a society everyone has the ability to accept people for who they are, but this is not the case.

There are many people out there suffering from illnesses who feel isolated and alone because society sets them aside.

I have suffered from illness all my life and have encountered barriers wherever I go. From school right through growing up, I have suffered knock backs and set backs from everyone. In 2001 I was diagnosed with Fibromyalgia and have been in constant pain ever since.

In 2007 I heard that there were a group of people that met up at Garden Wise on the first Saturday of the month for people with M.E. and Fibromyalgia and their carers, we all have a cuppa and a blether and we are all there for each other and enjoy each others company.

So, whatever you do don't suffer in silence, come along to Garden Wise for support, we are all there to support each other from 2pm till 3pm, I for one and my husband both benefit from the meetings, Thank You

Denise Cochrane

In the kitchen, my brother was trying to hit a moth with the newspaper, "I don't like moths", he cried. "I am a moth", I said. He caught the moth twixt paper and glass and whilst grinding it into the window pane, turned and glared at me saying, "I hate moths!", then walked away. I carefully took the empty body, the broken, crumpled wings, never to feel the freedom of flight again, into the garden and cried.

I got the ME Blues, so don't turn out the lights - feel so spaced - don't wanna go on anymore - heart is so sore - I just wanna go home.

I heard someone crying, weeping pitifully. I looked outside - no-one - so I looked inside and discovered it was me.

When alone, I can take off the invisible cloak that hides the real me from the ravages of life outside - my armour of steel, my blocks of stone that hide my vulnerable fragility and pain and loneliness deep inside. I fight two battles - the one outside and the ongoing illness inside. I get so tired of "putting a brave face" when all I want is to curl up and hide - but fight on I must, otherwise all is lost. My reason for being will not exist. I will not allow this illness to win.

Author Unknown



YOUR SHOUT YOUR SHOUT

A FLYING LIMERICK



There was a young
man from Skye
Thought he would learn to fly
So he got himself wings
Which were tied up with string
Hoping to give it a try

But he couldn't get off the ground
Maybe his shape was too round
He thought he would diet
Then he did try it
Losing 5 stones and 2 lbs

Into the wind he did lead
This requirement he really did need
But his clothes were too slack
They were holding him back
Unable to reach any speed

The clothes have got to go
They were making him far too slow
So dressed in a thong
What could go wrong?
His excitement was starting to show

Taking off from a hillside
Thermals he's hoping to ride
Now he's streamlined
Take off was fine
All he's to do is just glide

He fell like a lead balloon
The ground was coming too soon
It was a great shock
When appeared a great rock
Like something in a cartoon



A tribute inscribed in the rock
Wasn't put there for people to mock
But never to venture
Into an adventure
There's always a chance of a shock

INSCRIPTION

He came from up at the top
Down here is where he did drop
Not much of a saving
He helped with the engraving
It was his nose that made the full stop"

A G. Dumfries



HELP

LOCAL COMMITTEE CONTACTS
D&G ME NETWORK

If you are worried, stressed, feeling alone or fancy a chat don't hesitate to call any of the following :-

- Craig (Lochmaben) 01387 811082
e-mail craig@dgme.co.uk
- Norma/Denis (Lockerbie) 01576 204129
e-mail dennor@btinternet.com
- Janet (Newton Stewart) 01671 403577
e-mail janetg_uk@yahoo.co.uk

ME RESEARCH UK

The Gateway, North Methven Street
Perth PH1 5PP, UK

Tel 01738 451234

E-mail meruk@pkavs.org.uk

Website enquiries editor@meresearch.org.uk

ACTION FOR ME

Information service and general enquiries, publications and information for young people.

TEL ; LO Call **0845 123 2380**
9.30am-5pm Monday to Friday
www.afme.org.uk

WELFARE RIGHTS HELPLINE

01749 330136

9-1PM Mon, Tues, Thurs
9-12.30 Fri

Website for children and young people

www.a4me.org.uk

ME ASSOCIATION

TEL 08707 443011

FAX 01280821602

www.meassociation.org.uk

25% ME GROUP 01292 318611

The views expressed in this newsletter are not necessarily those of the D&G Network. We do not recommend treatments, but may express opinions.

**CLOSING DATE FOR SUBMISSIONS FOR
SUMMER NEWSLETTER
28th APRIL 2008**

ME AWARENESS WEEK

May 7th –13th 2008

**Do you or a member of your
family suffer from**

ME/CFS/FM?

Are you a carer for a sufferer?

**Contact us for support and
more information**

**Dumfries & Galloway
ME Network**

www.dgme.co.uk

Phone 01387 811082 or 01671 403577



IF I GET LOST OR YOU CANNOT DELIVER ME PLEASE RETURN TO ;

**TURNER
LEAFIELD.SOUTH HAYRIGG.LOCKERBIE.DG11 1BJ**