

Serving ME/CFS patients, carers and interested parties in Glamorgan



### **Richard Hazelwood's cycle challenge**

To cycle 300 miles in four days between London, Amsterdam and Brussels. I'm doing so in aid of the ME Association, a charity now close to my heart after my wife Rachel was diagnosed with ME last September.

Like many people, until recently I knew little about ME. In the coming months I'm determined to do my bit to raise awareness and improve people's understanding of this terrible illness. The best way I know how is to get on my bike.

**Read more about Richard's story on page 4.**

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## MESIG Committee Positions

The committee is responsible for making sure that the organisation sticks to its aims and objectives as detailed in the Constitution. It has overall responsibility for the management of the organisation's affairs. It is important to meet regularly and make sure that the correct information comes to meetings so that all committee members can make informed decisions.

Committee members are required to attend committee meetings on a regular basis and submit apologies in the event that they will be unable to attend a specific meeting and are required to make themselves available for members to contact either by email or telephone or both. They are also required to contribute ideas and assist with events.

Following the resignation of our Secretary Rebecca Williams and our Chair & Website Facilitator Gemma Phillips (who will continue to serve in position until this years' AGM) we have three vacant committee positions to fill. Post descriptions are as follows:

### **Chair** is responsible for:

- > Assisting with the managerial direction of the organisation
- > Planning and running meetings
- > Acting as spokesperson/figurehead
- > Delegating tasks to other committee members dependant on skills, responsibility and work load
- > Addressing any Grievances in strict accordance with the Grievance policy
- > Assisting new committee members in their post and ensuring that they are provided with the support they require
- > Ensuring all committee members are able to manage their workload and if not re-delegate the work
- > Attending and facilitating all MESIG events and presentations when possible. If attendance is not possible this responsibility will be delegated to the Vice Chair.
- > Attending all ME related events where possible to represent the organisation.
- > Regular correspondence with the secretary to arrange and plan meetings and events
- > Providing an annual report on the activities and achievements of the organisation at the end of each financial year

**If you feel you could offer your services in any of these three positions or as a general committee member please contact any of our current committee members.**

### **Secretary** is responsible for:

- > Taking minutes during committee meetings and providing each committee member with an electronic copy of the minutes prior to the next meeting and hard copy of the minutes at the meeting
- > Corresponding with the Chair prior to committee meeting to arrange the agenda, and providing a hard copy of the agenda for each committee member at the meeting
- > Assisting the Membership Secretary with advertising for any events
- > Liaising with the Website facilitator to keep him/her up to date with the latest news for inclusion on the website
- > Checking agreed tasks by members have been carried out and sending reminders in relation to these tasks
- > Sending reminders to committee members with regards meetings and noting any apologies to be presented at the meeting.
- > Making purchases on behalf of the organisation

### **Website facilitator** is responsible for:

- > Updating the website with all relevant news as it is received
- > Provide a summary report at each committee meeting with regards to the current operation of the site
- > Arrange for the annual payment in March for site rental
- > Ensure the aesthetic look of the website remains in keeping with the site content
- > Ensure the site content complies with all policies and the constitution
- > Report any improper of the site immediately to the committee

### **New Counselling Service for members**

As previously detailed in the chair's report earlier on in the newsletter, MESIG soon hopes to be able to offer a counselling service to it's members. Gemma is in the process of completing a counselling Diploma and plans to offer her services within reason on a voluntary basis to the organisation once qualified.

Anyone wishing to take advantage of the service will be offered 3 free one hour sessions. Should the individual decide they would like additional sessions they can arrange these independently with Gemma, but there will be a small charge for these.

We will clarify the exact date this service will commence at a later date.

## Richard Hazlewood's Cycle Challenge continued



**“It’ll be a challenge, but knowing my efforts can make a difference to the understanding of ME and the support for all those living with the illness will be incentive enough to keep me going.”**

Last year I cycled 1,300 miles or so for no particular reason other than to keep fit. It’s roughly the equivalent distance of London to Lisbon and I’m pleased, if rather surprised, to have gone so far when work commitments meant I only got out once or twice a week.

Later this year I’m setting myself a big and very personal challenge – to cycle 300 miles in four days between London, Amsterdam and Brussels.

I’m doing so in aid of the ME Association, a charity now close to my heart after my wife Rachel was diagnosed with ME last September.

Until recently Rachel was fit and healthy, worked full-time, and led an active life. Then she fell ill and life changed for both of us.

It’s incredibly hard to watch someone go through ME. You feel helpless

and very frustrated. We both find we’re adapting our lives to deal with ME. And this is by no means an exact science. There are days when for Rachel walking up and down the stairs or getting out of the bed in the morning are a challenge. I know there’s not much I can do to make it better other than to just be here.

Like many people, until recently I knew little about ME. In the coming months I’m determined to do my bit to raise awareness and improve people’s understanding of this terrible illness. The best way I know how is to get on my bike.

In 2010 I cycled 300 miles between London and Paris in aid of the Kidney Wales Foundation. Every penny raised motivated me to go that little bit further when every muscle in my legs urged me to stop. When Rachel was diagnosed with ME I knew I could do something

similar again. I’ll embark on London-Amsterdam-Brussels in September. Before that I’ll be doing a few shorter rides as part of the training. I know that for me the fatigue will be temporary and I have to remind myself just how fortunate I am to be well enough to do something like this.

It’ll be a challenge, but knowing my efforts can make a difference to the understanding of ME and the support for all those living with the illness will be incentive enough to keep me going.

I’m raising money for the ME Association by cycling from London to Brussels via Amsterdam in September 2012.

You can support me at [www.justgiving.com/Richard-Hazlewood](http://www.justgiving.com/Richard-Hazlewood)

Also you can follow Richard’s progress on Twitter at @rjhazlewood

## 'Voices From The Shadows' by Invest In ME

It was a great privilege to go to the British Library in London on Wednesday 7th December to attend a meeting organised by INVEST IN ME and to watch the very moving film 'Voices from the Shadows'.

This film is remarkable, telling the story of people with ME, showing them in the times before they were ill, living very normal, happy and active lives and how, when they became ill, the changes that occurred. It tells of the stress they experience, the lack of diagnosis, or misdiagnosis and the 'treatment' they received. This often pushed them backwards rather than assisting them.



The people with ME are interviewed in the film, if well enough, which gives an insight into their lives and the illness. Dr Nigel Speight comments during the film and he was present on the night to answer questions from the audience. He was a Consultant Paediatrician in Durham for over 25 years and considered to be one of the most experienced ME Consultants in the UK. It was made clear that the film has been made, not for people with ME but to educate others about the condition. It is planned that the film will be shown on TV through contacts in the USA, meaning that it will then obtain world coverage. If this is not

possible it will be released as a DVD and distributed far and wide.

The film is difficult to watch but hits home to those who have misconceptions about the illness. At the end of the film we sat in the semi darkness for a short while followed by low lighting before the full lights came on, giving time for us to 'recover' from the impact of the film. This was much needed.

**Invest in ME is one of the founding members of the European ME Alliance formed in 2008, with representatives in Belgium, Denmark, Germany, Ireland, Norway, Spain, Sweden, Switzerland and the UK. They accept that ME is a DEBILITATING NEUROLOGICAL ILLNESS classified as such by the World Health Organisation under ICD-10 G93.3. They are pushing for funding for Biomedical Research for treatment and the cure of ME and fund raising for a research, diagnostic and treatment centre in Norwich.**

**"I think that we have not cared for people with ME to a great enough extent. I think it is correct to say that we have not established proper health care services for these people, and I regret that."**

Research done in Norway was discussed during the programme. This was ground-breaking research from Haukeland University in Bergen where the use of the drug Rituximab for the condition was studied on a group of people with excellent results. As a result the Norwegian Health Directorate made an apology to ME patients for the way in which they have been treated. It is the first time that a statement like this has been made:

"I think that we have not cared for people with ME to a great enough extent. I think it is correct to say that we have not established proper health care services for these people, and I regret that."

The next event organised by Invest in ME is in Westminster, London on the 1st June 2012. It will be the 7th International ME Conference. Details will be released later but we need to make sure that someone from the Welsh Assembly attends and that our GPs are invited as it will count towards their Continuing Professional Development and be very enlightening for them in their understanding and treatment of ME patients.

You can read more about Invest in ME on their website.

Review by Miriam Wood

**Voices from the Shadows (£6 each plus a flat rate of £2 for p&p for any number of disks.**

**Visit [www.voicesfromtheshadowsfilm.co.uk](http://www.voicesfromtheshadowsfilm.co.uk)**

# I Never Imagined My Sister Would Die

The Irish Times - Tuesday, January 24, 2012

**MY HEALTH EXPERIENCE: RÓISÍN WILSON** Sophia's nervous system had been ravaged by ME

BEFORE MY sister Sophia got Myalgic Encephalomyelitis (ME), I had subconsciously developed a disparaging view of the disease. The little I knew about ME at the turn of the century was from how it had been portrayed in the tabloid press.

ME had been painted as some kind of luxury illness, labelled "yuppie flu". It seemed a very boring disease and I can't say I had any interest in it.

I had got the impression ME was kind of a sabbatical illness, an excuse for a few weeks off work to re-charge the batteries. So when my mum told me Sophia had ME, I wasn't that worried.



Sophia, two years my junior, had had meningitis before and malaria twice. What was ME compared to those bad boys? My feisty sister could easily whip this lily-livered ME.

I was living in New York at the time and on transatlantic phone calls with our Irish mum, she would tell me how my sister had had to leave her London life because she was too ill to look after herself. She told me Sophia was getting worse and that nearly everything hurt my sister. I thought my mum was exaggerating; how can everything hurt Sophia?

Light hurt my sister, noise, smells, vibrations, the list went on. My then 26-year-old sister had almost zero energy and had to lie in a blackened room day and night, wearing a blindfold and earplugs, in constant pain.

If that wasn't bad enough, the doctors treating her said this disease was a mere "wrong belief", despite doing no physical tests on their patient. And just for good measure they called my mum an enabler, for believing her youngest child was genuinely ill and threatened to remove her as Sophia's carer.

I listened to what my mum told me, but I couldn't really take it in. How could Sophia be so desperately ill for months on end? The ME my mum described was like nothing I had read about on the net. ME is often referred to as Chronic Fatigue Syndrome (CFS) and the information my Google searches revealed at the time did not correspond with what my mum was describing about Sophia. I believed my mum, but I could not grasp just how ill my sister was.

By the time I came back to Britain, I was still none the wiser, but I was more clued up about telling people about my sister's disease, or rather not telling people about it.

Upon hearing of my sibling's ME, people's reactions ranged from "Is that all? I thought you were going to say something serious from your tone of voice", to polite "humour-her" nodding and baffled, sympathetic faces, and then the slam dunk of some responses.

"Maybe your sister has got issues with your mum/dad/whoever," or words to that effect. "Issues!" I snapped at the last person who suggested that, "Issues! If you got ME from having f\*\*\*\*ing issues, then the whole b\*\*\*\*\*d country would be down with it!"

Not long after I returned to Britain, 9/11 happened. My then husband was in the Twin Towers that day, and

## I Never Imagined My Sister Would Die continued

with hindsight, I can see I over-reacted to 9/11, because it was on the strength of that, that I decided to become a nurse.

Throughout my three years of nurse training, I didn't tell a soul about Sophia and the ME. I don't think I even mentioned I had a sister. I saw how ME was viewed from the other side of the fence and it wasn't good or accurate. One day during my second year of training, I was on my cardiac placement and telephoned my mum on my break.

She was distraught, because at that very time I was calling her, the police were breaking down the door so Sophia could be sectioned into a mental hospital. I didn't know what to do, so I called my brother Shane, who went straight down to help mum and Sophia. I then went back to the ward and couldn't say anything to anyone.



And it was around that time I nearly cracked. I very nearly told my personal tutor about my fears and concerns for my sister. I was about to blurt it out once when my tutor mentioned that our confidentiality could be broken if somebody was at risk or over something illegal.

Confiding about Sophia could have me seen as an enabler, it could have jeopardised Sophia even more; I couldn't risk it. I stayed schtum and blamed my tears on PMT and the stress of course work.

Visits to Sophia were rare and precious, they had to be in the dark with only a smidgen of light. Her body may have been torturing her, but Sophia's mind was still all there. Those 13 days in the mental hospital had done irreparable damage to my sister, though, she went downhill from there.

I never imagined Sophia would die from ME, I thought she would outlive the lot of us, by years. But my sister became the first person in England to officially die from ME, a dubious honour indeed.

Sophia was 32 and had been bedridden for the last six years of her life. I was in shock and grief-stricken for months after her death, but in among all the pain, there was a tiny part of me that felt lighter; that tiny light was one of relief, relief my sister was not suffering so unbearably anymore.

The post-mortem revealed the physical evidence of Sophia's ravaged nervous system, proof at last her disease was of physical origin. Sophia's death from ME made news around the world, but it hasn't changed how people with ME get treated in Britain – well not yet it hasn't.

When Sophia got sectioned, the event was tape-recorded. This profoundly moving audio is included in the award-winning documentary *Voices from the Shadows*, a film made out of sheer desperation by the family of a girl who suffers with severe ME.

This documentary includes the stories of other ME sufferers and carers, as well as expert medical opinion and facts. This film needs to be shown to as wide an audience as possible. *Voices from the Shadows* will literally save lives and spare much unnecessary suffering and bring much-needed understanding about the reality of ME. This documentary urgently needs a way to be seen by the masses. Please go to [Voicesfromtheshadowsfilm.co.uk](http://Voicesfromtheshadowsfilm.co.uk) for more information.

Sophia suffered and died from ME, but nobody else should have to.

## Do you know of any Children or Young People Suffering with ME? TYMES TRUST may be able to help.



Registered Charity  
1080985

Tymes Trust is the longest established national UK service for children and young people with ME and their families. It is a respected national charity whose entire professional team give their time free of charge. They work constantly with doctors, teachers and other specialists, and played a major role in producing the children's section of the Dept of Health

Report on CFS/ME (2002).

**Lord Clement-Jones CBE**

**Founder Patron**

### Our Ethos

We are the longest running national organisation supporting children with ME.

We realize that much distress is experienced when a young person is diagnosed with a serious and disabling illness. Members tell us that our friendly, personal approach, coupled with the provision of reputable information supplied by a professional and experienced team, makes us a 'lifeline' and a 'port in the storm' of controversy surrounding ME. We hope that we shall be able to help you too.

### Advice Line

The Trust provides an Advice Line manned by our own trained and experienced Advice Line Team, all of them with personal experience of ME. Most are parents of children with the condition and some have also had ME themselves.

Advice Line hours are Monday to Friday, from 11.00am to 1.00pm and 5.00pm to 7.00pm.

Outside Advice Line hours or when the line is busy you may leave a message and one of our Team will call you back.

### Education in Young People

- Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home tuition, distance or virtual learning) can maximize achievement whilst protecting health.
- Social contact can be preserved through visits from school and friends and through making new friends who understand the limitations imposed by the illness, for example, through the Trust.
- Children with ME are legally entitled to education suited to their medical and special educational needs.

### Contact Us

**[www.tymestrust.org](http://www.tymestrust.org)**

**0845 003 9002**

**PO Box 4347**

**Stock**

**Ingatstone**

**CM4 9TE**



## Homeopathy Helped My Family.....

At age 12 my daughter suffered several throat infections soon after she was unable to fight off any bugs and became progressively more exhausted. After several months she was constantly aching and had headaches all the time, her temperature was erratic and her sleep pattern disrupted, she was missing lots of school. She was referred to a consultant who diagnosed ME/CFS. Treatment involved giving long-term antibiotics and antidepressants. We didn't think that depression was the cause of her illness and antibiotics had always upset her system, it seemed wrong to give her something that made her feel rotten and might not help. I was at college at the time; a fellow student, a midwife, mentioned that she worked alongside a homeopath who had success in treating people with ME. I was wary, but I checked with my GP who felt it would be worth a try.

The homeopath asked questions to get a clear idea of how the illness affected me. At the end of the session she gave one tiny white pill and said she would see us again in a month. After a week when my daughter slept almost all the time she gradually became more energised, her pain was decreasing and her sleep pattern improved. Within a few weeks my daughter was back in school part-time, and over the next year gradually recovered. Ten years on she is a qualified doctor, and although she is still aware of her energy levels she enjoys life to the full. She recognises when she needs a boost and occasionally visits her homeopath for a check-up - mostly she's absolutely fine.

My youngest son became unwell in his early teens, but his symptoms were so different that we didn't even think about ME/CFS. He had always been sports mad and played cricket at every opportunity. His illness began with extreme vertigo, he couldn't stand without holding on to some-

**"Within a few weeks my daughter was back in school part-time, and over the next year gradually recovered. Ten years on she is a qualified doctor, and although she is still aware of her energy levels she enjoys life to the full"**



thing. He also collapsed on a number of occasions – not fainting, but rather going down face first like a felled tree. The GP suspected an ear problem and gave antibiotics then several kinds of sea-sickness medicine. Nothing worked so we were sent to an ENT consultant. His checks found nothing so he ordered an MRI. This didn't show any organic cause for the problems so we were passed on to a neurologist. His assessment was that my son had been ignoring normal tiredness for so long that he had stopped recognising it so his body had given him a symptom he couldn't ignore – the only way to stop him. He said he had seen this before in sportspeople, and in his view it was a type of CFS. He was puzzled by our relief at this diagnosis until we explained that we had already had a good result with my daughter using homeopathy. He was very positive about my son trying some treatment. It took months of part-time school, but on the whole his progress was steady- less patient than his sister he had a few setbacks along the way from overdoing it. For the past year he has needed no treatment at all, he's off to University in the Autumn and really enjoying his life.

Our experience showed me that everyone's illness affects them in a very individual way regardless of medical diagnosis. Each person has their own specific set of symptoms and are they affected differently. I discovered that homeopaths look for exactly that – how the symptoms affect the individual. Rather than treating the named disease they work on treating the particular symptoms and the way the patient FEELS

I became totally fascinated by this system of medicine and enrolled in a course of study to become a homeopath. I studied at The British School of Homeopathy and I am now in practice in the local area. Given our family history it will come as no surprise that I have a special interest in ME/CFS.

Maggie Wilson – [maggiewilson@sky.com](mailto:maggiewilson@sky.com) 07803 205226

## MESIG's AGM and Awareness Event

When : **Saturday 19th May**

Time :

Where : **Ararat Baptist Church,  
Plas Treoda,  
Whitchurch,  
CF14 1PT**



**4pm-5pm** AGM / Presentations  
**5pm-6pm** Food, Browsing stalls  
**6pm-7pm** Guest Speaker

Guest speaker Naturopath Emma Jones- 'Change your life and your symptoms forever' with the healthy Jones naturopathic nutrition approach.

Emma had ME herself and is now fully recovered and full of energy. She lives and breathes the treatment that helped her. Emma is well known for her work throughout Cardiff and beyond, running workshops and retreats. Her talks are always so full of useful tips and information and very uplifting. If you have an interest in what goes into your body, this talk is a must for you.

Your support for AGM would also be appreciated and if anyone would like to come on board in any capacity please let us know. Contact : 02920 762347 or Email : [christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)

## ME Awareness Week

M.E Awareness Week takes place from 6th-12th May 2012.

Held each year, the week aims to improve awareness of ME and raise funds for research into this painful condition. Throughout the awareness week, Action for ME will be organising fundraising events and asking you to get involved too.

Ways to get involved include:

Campaign for change— although much has been achieved since Action for ME was founded in 1987, there is still a lack of understanding of the illness. **'We campaign for the widespread recognition of ME, better services and support and more research into the causes, faster diagnosis and more effective treatment.'**

Raise Funds— this may include runs or walks, treks or challenges, organising your own event or easy giving.

Tell your story— We want to hear about your experiences of life with ME, whether you have the illness or care for or work with someone who does. Sharing your story can help others who find themselves in a similar situation.

Raise Awareness— The more people that know about ME, the more understanding and support people with ME will get. Putting up posters and giving out awareness leaflets about M.E. in your local community is a great way to get people thinking about M.E. and what it's like to have it.

For more information please visit [www.actionforme.org.uk](http://www.actionforme.org.uk)

Or contact Action for ME on 0845 123 2380

## Laughter Corner

### QUESTIONS YOU JUST CAN'T ANSWER

Why doesn't Tarzan have a beard when he lives in the jungle without a razor?  
 Why do we press harder on a remote control when we know the batteries are flat?  
 Why do banks charge a fee on 'insufficient funds' when they know there is not enough?



\*\*\*\*

Why does someone believe you when you say there are four billion stars, but check when you say the paint is wet?  
 Whose idea was it to put an 'S' in the word 'lisp'?  
 Why is it that people say they 'slept like a baby' when babies wake up every two hours?  
 If the temperature is zero outside today and it's going to be twice as cold tomorrow, how cold will it be?

\*\*\*\*

Do married people live longer than single ones or does it only seem longer?  
 How is it that we put man on the moon before we figured out it would be a good idea to put wheels on luggage?  
 Why do people pay to go up tall buildings and then put money in binoculars to look at things on the ground?



### DID YOU EVER STOP AND WONDER...

Who was the first person to look at a cow and say, 'I think I'll squeeze these pink dangly things here, and drink whatever comes out?'

Who was the first person to say, 'See that chicken there... I'm gonna eat the next thing that comes outta it's bum.'

Why do toasters always have a setting so high that could burn the toast to a horrible crisp, which no decent human being would eat?

\*\*\*\*

Why is there a light in the fridge and not in the freezer?  
 Why do people point to their wrist when asking for the time, but don't point to their bum when they ask where the bathroom is?  
 Why does your Gynaecologist leave the room when you get undressed if they are going to look up there anyway?

\*\*\*\*

If quizzes are quizzical, what are tests?  
 If corn oil is made from corn, and vegetable oil is made from vegetables, then what is baby oil made from?  
 If electricity comes from electrons, does morality come from morons?  
 Do illiterate people get the full effect of Alphabet Soup?

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Did you ever notice that when you blow in a dog's face, he gets mad at you, but when you take him on a car ride, he sticks his head out the window?  
 Does pushing the elevator button more than once make it arrive faster?

## Making Cycling Accessible To All



Pedal power is a wonderful organization whose aim is to get disabled people out and about, having fun, and exercising!

It came about in 1996 when the founder, Sybil, was working at Ely hospital as a physiotherapist and wanted her patients to get some exercise and enjoy it! So she took twelve of her adults with disabilities to the Forest of Dean as a trial to see if it would be beneficial for them to be out in nature and riding a bike. The trail was very successful and made such a difference for those of the people who just went from their homes to the hospital and nowhere else. Now Sybil has the two set ups in Cardiff, one in Pontcanna, which building was funded by the lottery, and one at Cardiff Bay, so there are two beautiful situations to choose from, lush green park or stunning coast line.

Pontcanna has a lovely cafe, run by volunteers, that serves good food and even herbal tea! They have a huge range of bikes to choose from for all different disabilities, the ones that would be the best for those with M.E are either the electric bikes, so you don't use up too much precious energy or the double side by side bikes that you can share with a healthy person, so that if you need to rest, they can do all the hard work and you can sit back and enjoy the nature around you.

They provide multiple courses for unconfident riders of all abilities and ages, so no one is excluded and can be included, no matter what. For an annual membership it's just £12. If you do not want to commit you can hire as you go or bring your own bike.

In addition they also hold many events throughout the year, including a Vintage Fair and lots of other intriguing things.

This really is a blessing we should all take advantage of.

Becca Williams



### Contact

**[Www.cardiffpedalpower.org](http://www.cardiffpedalpower.org)**

**Cardiff Office -07775616411**

**Pontcanna Office- 02920390713**

**Email- [info@cardiffpedalpower.org](mailto:info@cardiffpedalpower.org)**

## Friends Reunite To Give Singer A Video Success

**South Wales Echo– Thursday 16th February 2012**

TWO long-lost school friends were reunited– and produced a music video that has been picked up by a major music magazine’s website.

Singer Tiffany Aubrey, forced to use a wheelchair after being struck down with ME as a teenager, and student John Rees worked together on song 9 years.

It was inspiring by Tiffany’s long battle with illness. And after the video earned the attention of NME, the 27 year old is hoping to land a record deal.

Tiffany, who was diagnosed with the condition aged just 14 said: “Because of ME my life hasn't gone the way I planned at all, but I've adapted to deal with the constraints of the illness. I have to pace myself for everything I do, including writing and singing, which is really frustrating.”



Cardiff-based Tiffany wrote the song four years ago. “It was the first song I wrote and recorded. Its about my struggle with ME and wasn’t hard to write because I knew exactly what I wanted to say and how I wanted it to sound. “To sing those lyrics and for people to hear the song was a bit daunting at first but I’m proud of the song and of how honest those lyrics are so I wanted people to hear it.”

But Tiffany did not know a filmmaker who could produce a video for the song until she and John got in contact again. The pair lost touch ages 11 when they left Marlborough Junior School in Roath, but got back in touch last year through Facebook.

“We started a conversation over Facebook and we thought we had similar interests so we decided to meet up,” said John, 26.

Tiffany added: “We started chatting and he told me that he makes films and that he wanted to make a video for one of my songs. I said Yes straight away.”

The video was shot one day late last summer, but was not uploaded to the internet until the turn of the year. And within weeks the video was picked up by the website of iconic music magazine NME.

Tiffany said: “I've read the magazine for years so to have my song on the website is really exciting.” John, a creative industries student at the university of Glamorgan said, ‘I was very pleased with the publicity and I was happy for Tiffany.’

**To listen to Tiffany’s music, visit [www.myspace.com/ildeclectic](http://www.myspace.com/ildeclectic)**

## Changes to Housing Benefit

The government in Westminster is making some important changes to Local Housing Allowance from 4 April 2011. These changes will affect people getting Housing Benefit who pay rent to a private landlord.

Shelter Cymru is working with a number of partners in Wales – the Welsh Assembly Government, local authorities, Citizens Advice, Community Housing Cymru and Jobcentres - to try to mitigate the effects these changes will have. A large number of people will be affected and if you are one of them, it's important to seek advice as soon as possible to ensure you don't get into difficulties paying for your housing.

### Help for disabled people

There will be additional help for disabled people who are getting certain benefits towards the cost of an extra bedroom if they have a regular non-resident overnight carer. They must have a room available in their home for this. If you think this applies to you, let your Housing Benefit section know as soon as possible.

### What you can do

There is a benefits checker on the Turn2Us website ([www.turn2us.org.uk](http://www.turn2us.org.uk)) or on the DirectGov website ([www.direct.gov.uk](http://www.direct.gov.uk)) which can help you find out how you will be affected. Note that you will need to have information about your income and outgoings to hand to answer the questions you will be asked. You should answer fully to get a real picture of how you will be affected and if you are still unclear you should seek further advice as soon as possible.

### Further changes from 2 April 2012

There are a number of further changes due to start on 2 April 2012. These changes are not yet law and the information about these is based on government details. More can be found on the DirectGov website ([www.direct.gov.uk](http://www.direct.gov.uk))

### Turn2us



This service from the charity Elizabeth Finn help people to access the money available to them in welfare benefits, charitable grants and other financial help. It brings together an easy-to-use benefits checker and a grants search, giving access to over 3,500 charitable funds.

Visit us on [www.turn2us.org.uk](http://www.turn2us.org.uk)

#### Contact

**Shelter Cymru-**

**0845 075 5005**

**[Sheltercymru.org.uk](http://Sheltercymru.org.uk)**

**Email- [hb@sheltercymru.org.uk](mailto:hb@sheltercymru.org.uk)**

**Citizens Advice Bureau-**

**08444 77 2020**

**[Adviceguide.org.uk](http://Adviceguide.org.uk)**

## Updates

### **NOTE:**

**There will be NO support group meeting in May due to the AGM/Awareness event on the 19th May.**

### **ME Calendars 2012**

Thank You for all your entries.

CONGRATULATIONS to Rachel who had best entry (January entry).

Rachel won a £10 voucher as a prize.



How I felt during and after my first MESIG meeting- I know that I don't have to face this alone!

**ME Calendars 2012 are now reduced to £3 if anyone wishes to purchase any please contact us. Details are on the Contact Pages at the back of newsletter.**

### **Speakeasy (January 9th 2012)**

Ben, from Speakeasy Advice Centre, talked about help with Fuel Bills. Speakeasy offer help with:

- Applications for grants
- Referrals for free insulation



Advice on fuel debt and how to save energy

Contact- 029 2045 3111

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

Email- [speakeasyenergyadvice@gmail.com](mailto:speakeasyenergyadvice@gmail.com)

### **Bowen Treatment (February 6th 2012)**

Guest speaker Margaret Woodley gave an interesting talk about Bowen Technique.

For more details contact Margaret on 029 2088 2955 or 07970 317 531

### **Art Workshop with Sian Williams (March 5th 2012)**

Members joined in and produced some really lovely pieces.

The atmosphere was very calm and therapeutic.

Website- [marged-sian-artist.com](http://marged-sian-artist.com)

Email- [mail@marged-sian-artist.com](mailto:mail@marged-sian-artist.com)



## MESIG Christmas Party December 2011

We got up early on the day of the Christmas Party, and I quickly made some sandwiches and set them aside. Then I gathered up my pots of cyclamen to be sold etc. and found some festive table clothes to decorate the tables. When we were ready to go, Peter (my partner) bundled everything in the car together with the raffle prizes, and off we went.

Meanwhile, Chris, Irene, Gemma and Liz along with others, had been hard at work preparing the bulk of the food, and we met up at Ararat before 2pm whilst Peter and a couple of the others set about putting out tables. Then they were laid with colourful cloths. The girls brought in the rest of the food and set it all on the tables, and the room looked quite festive. Linda and Julie set up drinks in the kitchen and we were open for business.

People started trickling in and all of a sudden we were all chattering away, so pleased to see our friends.

When everyone had finally arrived, the drinks were served and we all took our plates and set upon the food. Chris had an assortment of the Raffle prizes put in the corner, a big colourful knitted clown peeping out forlornly at the back.



Then after we had finished eating, Gemma asked us to 'listen', and then told us that she had a quiz for us to try. That was a new idea indeed for us! She put us in groups and gave us pencil and paper and started her twenty questions. Now, I'm not very good at quizzes, but we did get a number of questions right, thanks to the other members in the group. However we didn't win, but there was lots of laughter from around the room, and the team opposite won.

Every year each of us take a gift to put in the bran tub. Then later, we take it in turns to have a 'dip' and that way, everyone has a Christmas gift to take home. This went well with lots of 'oohs' and 'ahs' - and only one or two doubtful sighs, when exchanges were made. The raffle was a great success, and after a few of the prizes were won, at last the clown was claimed by Mavis, and after a cuddle, he looked much happier, that he was going to a good home. What?!-

Very soon, it seemed, it was time to start packing-up. Many hands made light work, and this was soon done. We had made too many sandwiches, so these were given to Chris for their journey to Ffald-y-Brenin the next day. We made a mental note, not to make quite as many sandwiches next time. People started saying their reluctant 'goodbyes' and everyone slowly trickled out to their cars. Everything had gone well and it had been a great party.

Dee Penny



# Bulletin of the IACFS/ME

A Quarterly Publication of the International Association for CFS/ME

## Multi-tasking: A challenge for patients with CFS

Gudrun Lange, PhD

Pain and Fatigue Study Center, UMDNJ-New Jersey Medical School

As a researcher and a practicing clinical neuropsychologist my task is to assess cognitive function in CFS patients. Once the test measures given are scored and the results interpreted, I provide feedback about my findings. Very often the findings are consistent with decreased information processing speed and poor working memory while overall intellectual function is usually intact. These results are not uncommon in CFS and are supported by increasing research evidence (1,2). During feedback sessions, I aim to explain the deficits found, but are frequently asked the question: "How do these findings relate to what I am experiencing in my daily life and what, if anything, can I do about it?" I will use this brief essay to begin to address these questions.

Many of the *Bulletin's* readers who are CFS patients may have experienced a version of the following scenario told to me by one of my patients:

**"Since coming down with CFS, food shopping has become an increasingly difficult task for me. I used to be so organized and enjoyed going shopping once a week for all my family's needs; it made me feel good. I am not able to do this anymore and now go whenever I feel up to it physically and mentally. I generally make a shopping list and try to at least get some of the crucial items, because I never know how long I am able to stay in the store, sometimes I don't even make it there. I get so confused and exhausted if there is a lot of traffic, I have to stop and then turn around. Once I could not remember where I had to turn and even got briefly lost. I just sat in my car and cried.**

**When I actually get to the supermarket, parking is very difficult for me due to cars and pedestrians crossing my path, I get confused. I try to park next to a shopping cart carrel, so I can grab a cart to help me walk to the store. Once in the store, the sights, sounds, and smells common to supermarkets, bother me. I try to focus on shopping list, but although I try hard, I cannot concentrate on figuring out what I need most. I become anxious, upset, and frustrated and start pushing through one aisle after another, hoping the sight of a product may jostle my memory. But now everything feels like it is washing right over me and nothing sinks in. Not even half way through the store, with only a few items in my cart I think I needed, exhaustion overwhelms me forcing me to cut shopping short. I exit the store relieved to escape the noise and the people, but – where did I park?"**

This CFS patient describes an event that most people, healthy or sick, consider an everyday, commonplace activity. We do not generally think of all the separate steps or sub-goals involved to accomplish the overarching goal which is to "go food shopping". Most of us, if healthy, achieve the goals of the sub-tasks involved successfully, because task execution is performed almost automatically. For instance, most individuals do not tend to spend much focused attention on the mechanics of driving a car while monitoring traffic and thinking ahead to the next goal, which they fully expect to achieve once initiated after they navigated the well-learned road to the store and parking the car. Many individuals even manage to simultaneously rehearse their shopping list while driving, listen to the radio, and answer their phone plugged into their ears.

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In terms of cognitive science, the ‘everyday’ food shopping event described above is anything but simple. For successful completion, it requires an individual to ‘multi-task’, a term nowadays familiar to almost any adult and an activity coveted as necessary to perform successfully in today’s society. Multi-tasking requires top down control by what some cognitive scientists theoretically call the supervisory attentional system (SAS)(3) or the central executive (4). These executive control systems are thought to provide assistance in doing multiple tasks simultaneously, promoting one, while inhibiting action on another, screening out irrelevant distractions, all the while integrating streams of new information and updating online an individual’s ‘mental computer’. Doing this assures successful completion of subgoals, while delaying the initiation, execution, and completion of future goals ultimately contributing to a successful completion of a larger event, such as food shopping. A smooth functioning executive control system results in an individual’s perception of being able to perform the “food shopping” event effortlessly and almost automatically. Importantly however, for this to occur, information processing speed and working memory have to be intact. This is not the case for many CFS patients. If the ‘executive system’ is not effectively supported by these essential cognitive components, it will not be able to do its job. Effortless tasks become effortful, interfering events and stimuli are not screened out successfully, setting priorities appropriately becomes difficult, overall task execution and completion is jeopardized. Less effortful top down processing turns into more effortful bottom up processing.

While many papers have been published about cognitive dysfunction in CFS, the issue of difficulties with multi-tasking has not been taken explicitly under consideration in CFS yet and is an area for future research consideration. While many cognitive studies have developed paradigms to address task switching and performing dual task, a laboratory paradigm based on the real life perception of patients that they “have lost their edge” or “cannot do even routine tasks at the same time” has been difficult to translate into a quantifiable paradigm. Based on the framework proposed by Norman and Shallice (3), key components for successful multi-tasking are the ability to prioritize, organize, and execute “a number of different tasks within a given period”(5). In 1991, Shallice and Burgess (6) operationalized this concept and developed the “Multiple Errands Test” (MET) and the “Six Element Test” (SET). The MET is a real life task where participants are given some money and a sheet with instructions and are told to buy a set of specific items operating under specific rules told to them (i.e., you must buy tomatoes before you buy potatoes, but you cannot go through the same aisle to get either of the items). The SET is a laboratory task addressing the same concept under more quantifiable circumstances. Patients with neurological disorders affecting frontal lobe function performed these tasks and showed a variety of similar errors including difficulties with sequencing of events according to the rules, being susceptible to internal and external stimuli interfering with task execution, leaving tasks unfinished, forgetting to carry out tasks they wanted to carry out at some future point. Shallice and Burgess considered patients with these everyday life problems “poor multi-taskers”. Since then either the MET or the SET have been used in a variety of patient populations. Based on these tests, Burgess and co-workers also developed the standardized Behavioral Assessment of Dysexecutive Function Battery (BADs) (7). It is a lengthy neuropsychological assessment tool that includes the “Modified 6 Elements Test” a version of the original SET that is rarely used in clinical practice.

I hope I have addressed how poor processing speed and working memory can manifest in daily life and what the hypothetical reason is for this to happen. But the question that remains to be answered is possibly the more important one for CFS patients who have to deal with these problems: “What can I do about it?” Following are some tips I usually advise my patients to consider: (See next page)

# Bulletin of the IACFS/ME

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## **Tips I usually advise my patients to consider:**

1. Do not continue to try and complete 'everyday' tasks, such as food shopping, the same way you did before you became ill. A paradigm shift is in order.
2. Unlike the perpetuated myth that multi-tasking saves time, it does not for patients with CFS: instead unsuccessful multi-tasking takes more time, adds anxiety and frustration, thus compounding the problem. Many CFS patients encounter difficulties multi-tasking. Instead of continuing to try and do multiple things at the same time, do them serially. It will enhance the number of reasonable goals you can achieve successfully.
3. Instead of developing a shopping list in one sitting trying to remember all the things you thought you or your family needed, write them down in a dedicated notebook that sits on a dedicated spot on a shelf or counter, as you think of them. Your notepad should have 3 categories to help you prioritize your list to facilitate shopping when you get to the store, taking into account that you may just feel up to getting the most urgently needed items. These categories are: RED (urgent need), YELLOW (needed in near future), GREEN (stock item, long-term need).
4. Depending on how you feel once you get to the supermarket, prepare yourself mentally that you might only get the items in one category. This counts as a successful trip to the store.
5. Do not push the cart through every aisle, it will interfere with your goal-oriented approach and tire you out unnecessarily; shop selectively for the items you need. If you are not familiar with the store, try and figure out a select way of shopping by studying the aisle designations. If all else fails, sit down and ask a store attendant to get you the items in a select category that is written in your notebook.
6. Do not drive to the store during rush hour; avoid any additional distractions while driving. The action of driving and monitoring traffic is not as automatic as it used to be and thus requires more attention and more effort. Do not hesitate to ask someone to drive you to the store.
7. Remembering where the car is parking on a big parking lot is a concern that comes up frequently. Try and park your car in the same parking lot area every time you go optimally next to an easily recognizable landmark on the lot. This will reduce the need to rehearse the location while shopping and further enhance a successful shopping experience.

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## The Real ME

I have been involved in a Midland ME Support Group for many years. Two things in particular stick out in my mind and I'd like to share these with you.

First I was fortunate to get a chance to talk to an eminent doctor working on profiling the DNA of ME sufferers. He was giving the keynote speech at the AGM of one of the National ME Groups. During the course of the conversation I asked him "How confident are you that all the people you are testing really have full-blown ME?"

His response astounded me. He said that "Of all the people referred to my hospital for testing—less than half!" Now these people had been diagnosed by a GP or a specialist and referred specifically for this trial. He went on to say "we admit all the referrals for a three day screening process to eliminate other possible explanations for the Chronic Fatigue". Maybe, like me, you are shocked that so many of these professionals, doing the referring, had got I wrong. The again maybe you are not so surprised!

**"Of all the people referred to my hospital for testing—less than half!" Now these people had been diagnosed by a GP or a specialist and referred specifically for this trial. He went on to say "we admit all the referrals for a three day screening process to eliminate other possible explanations for the Chronic Fatigue".**

Well it got me thinking: if are actual ME sufferers, research findings in the many of the participant in passed the three day since many of the PACE against what, I believe, to the Oxford. It is not my in-bate about the reliability but it IS my intention to en-selecting the participants in



less than half of those referred how does that reflect on other ME field? In particular how the PACE trial would have screening? All the more so panels were self selecting be a very low criterion namely tention here to reopen the de-and the creditability of PACE: courage a much better way of future trials.

The second thing that stays with me is all the people who came to our support group who said something like "You don't know how good it is to talk to somebody who actually understands ME; my GP doesn't even believe ME exists". Now this is actually another manifestation of the first problem I covered—namely the inability of many GPs to correctly identify ME. Could it be that it has something to do with the low level of exposure the average GP has to people with ME? I believe the average GP has about 1500 patients on his/her books. Further statistics suggest that between a quarter and a half of one percent will have ME :ergo each GP can expect to encounter between 3 and 7 cases. Maybe it is not so surprising that all too often they seem to be poorly equipped to understand ME.

Further weight is given to the lack of clarity amongst GPs, by the experience of a fellow Trustee. He was a GP, who was appointed as the ME Specialist for his PCT area. He found a very significant number of the referral to his clinic were NOT suffering for ME (Chronic Fatigue Syndrome) but were suffering from some other manifestation of Chronic Fatigue. Further he said that the quality of the referral letters and information given by the referring GPs was often poor and suggested a lack of confidence in diagnosis and understanding of ME.

## The Real ME continued

As a Trustee of Resumecfs (the clue is in the last five letters!) I was very pleased when we embarked on two projects to address these issues

- 1) The expansion of a Disease Register specific to ME
- 2) A GP Awareness Campaign

The aim of the Disease Register is to provide a data bank of people, whose ME has been assessed against the highest criteria, willing to take part in future Research projects into ME. The plan is to supplement this further by creating a Biobank holding blood (and maybe later post-mortem tissue samples) of the participants in the Disease Register. These together should ensure quicker and much more reliable groups for research into ME.

The aim of the GP awareness is to provide GPs with a check-sheet (developed by my colleague who was the GP ME specialist) which sufferers can complete and take to their GP as a basis for discussion on their symptoms. Allied to this is a set of basic Guidance Notes which might be of use to the sufferer and especially to his/her GP.

There is much more detail of this on our website [www.resumecfs.org.uk](http://www.resumecfs.org.uk) This covers, amongst a lot of other information :

- The various criteria used to define ME
- An application form to download and send to offer yourself for inclusion on the Disease Register
- The symptoms check sheet for the GP Awareness and the Guidelines

Our chairman, Professor Derek Pheby gave a presentation on all this and for those with internet access this film is available on our website. It is also available on YouTube (enter resumecfs) and indeed your ME Support Group should have a DVD copy in your library.

But if we are to make progress on these important fronts we need the active support and the engagement of People with ME—that probably means you.



### Contact Us

[www.resumecfs.org.uk](http://www.resumecfs.org.uk)

**RESUME CFS Charity**  
**22 Lower Street**  
**Harnham**  
**Salisbury, Wilts**  
**SP2 8EY**

**Email: [info@resume-cfs.org.uk](mailto:info@resume-cfs.org.uk)**

Wednesday 21st March 2012

We all (the MESIG committee) had great expectations after lots of planning, putting together of ideas, and presentation practices for this important meeting with the Welsh Assembly. The day dawned fine but over-cast. We arrived at the Majestic Grey Assembly building on the shoreline just after 11am. There was quite a 'presence' of police security in and around the entrance, and we had to queue to go through security and the X-ray equipment inside the reception area. The place felt so strange, with no place to hide, as all the walls are made of glass?!

When we finally got to the conference room downstairs, we met the other members of the committee and also welcomed other members of our group that had arrived. A little later Julie Morgan AM came in and chatted to us, and slowly the

room began to fill up with other M E members, journalists and about twelve AMs. Julie explained that there would be a bit of 'coming and going' during our meeting, due to AM's other commitments - and this is what happened.

**'Even a couple of the A Ms were not dry-eyed, and later, as a result, several of the A M's present said they would be writing to the Health Minister on our behalf.'**



Finally, when most had arrived, Julie was able to open the meeting, and Gemma, as Chair of our group, gave her introduction speech, then Ken gave us all the facts about the illness in a clear concise way, while Irene worked wonders managing the technical support of the explanatory slides on screen.

Previous to this meeting Julie and some of the other Assembly Members had been sent a DVD 'Voices in the shadows' depicting the lives of people with M E.

Chris gave a spontaneous and passionate speech explaining the difficulties that sufferers go through - the desperate need for specific services of a specialist doctor and clinic for people with ME/Fibromyalgia, that are not available yet in Wales - and we were moved to tears - even a couple of the AMs were not dry-eyed, and later, as a result, several of the AM's present said they would be writing to the Health Minister on our behalf.

After this, Miriam gave a moving and very detailed talk of her very difficult experience as a carer of a dear young friend with ME, and again voiced her frustration with the ongoing and unresolved difficulties in getting support for her caring, and her medical and benefit needs.

Lastly, Dee gave her talk about a twelve year old boy - giving a mothers' perspective, on how difficult and harrowing it is to watch your child getting inappropriate treatment and very little support from the medical profession in general. She explained that ME can strike at any age and that children are particularly vulnerable. This illness now causes the most absenteeism amongst children in schools.

All three speakers, asked the Assembly Members to act, and use their influence to help get services into place.

The audience gave every speech loud applause, and then Julie thanked everyone for coming and asked for questions from the audience.

## The Meeting at the Welsh Assembly continued

Concern was voiced at the UK Coalition Government's Incapacity Benefit Medical Checks process, which it was said, placed an intolerable burden on ill and vulnerable ME sufferers. Also issues were raised about what is available now - not much improvement in the last twenty years, and each new case (ME) being sent to a different consultant, with no planned treatment.

All too soon, time had run out, and Julie had to close the meeting.

She said, "I was delighted to welcome both ME sufferers and carers to the Senedd today and to listen to their very moving accounts of dealing with this very serious illness. I intend to do all I can now to help take

their calls for improved services forward".

We really appreciate the ongoing support that Julie has given us since her visit to our members meeting last year. It is invaluable, and we have been told that we will be invited back every six months for a progress report.



Photos were taken by various people, and then we were able to chat and catchup with friends there at the event. When we finally emerged from the Assembly Building, we were greeted by a brilliant sun shining brightly over the Waterfront. It lifted our spirits and I am sure was a very good omen.

Action for M E have been in touch, having heard of our Assembly Meeting and will be covering it in their next issue.

### PRESS RELEASE

#### M E SUFFERERS PUT CASE TO AM'S FOR BETTER SERVICES AND RECOGNITION

CARDIFF NORTH ASSEMBLY MEMBER, Julie Morgan today (Wednesday 21st March) welcomed ME sufferers and carers to the Senedd to hear at first-hand the case for better health and support services.

Julie was joined at the event by members of the ME Support in Glamorgan Group as well as a cross party group of Assembly Members, who all heard calls for better awareness and treatment of the illness. Sufferers complained about the ignorance of the illness that exists, with many people, including doctors believing it was all in the mind. They asked for Specialist Services with understanding of the illness.

During the meeting, concerns were also expressed at the UK Coalition Government's Incapacity Benefit Medical Checks process, which it was said, placed an intolerable burden on ill and vulnerable M E sufferers.

Julie Morgan AM said:

"I was delighted to welcome both ME sufferers and carers to the Senedd today and to listen to their very moving accounts of dealing with this very serious illness. I intend to do all I can now, to help take their calls or improved services forward."

## RELAX!

**Relaxation CDs and tapes can really help you to cope with the persistent pain. Helpline nurses Janet Bowman and Niki Gonty look at some of the options available and explore some useful relaxation**



Everyone will experience physical pain at some stage in their lives, but individual experiences differ widely. Most pain improves once the injury or condition that caused it has healed, but there are a number of people who develop persistent or chronic pain that never fully goes away.

As so many people with chronic pain know, medication alone is often not enough to relieve their pain and a combination of treatments and therapies will generally be more effective than any single approach. In this section we look at the use of relaxation CDs as an aid to help with persistent pain.

It is not unusual for those who suffer from chronic pain to feel stressed or anxious at times and for

sleep to be disrupted. Learning relaxation techniques can help some people to reduce their pain to a more manageable level and encourage peaceful sleep at bedtime.

There are a variety of resources available that can help in the relaxation process, in the form of music, spoken word and peaceful sounds. Relaxation CDs and digital downloads are available from the high street, internet stores, libraries and some organisations such as the Pain Relief Foundation and Arthritis Care.

**The following is a review of a small selection of relaxation and meditation CDs that have been recommended by member if the Charity, health professionals and other organisation involved in pain relief.**

### Types of relaxation techniques

**Meditation:** There are different types, but essentially they all focus on calming and clearing the mind of jumbled thoughts to help to promote inner peace and wellbeing. Sometimes this is done by silently repeating a calming word or phrase (mantra) or by focusing on you breathing.

**Guided imagery or visualisation:** Use of mental images of places or situations that you find relaxing, and using as many of your senses as possible to induce a deep sense of relaxation.

**Deep-breathing technique and breathing exercises:** Used to help the body relax; can be particularly helpful when you are feeling tense or anxious.

**Progressive muscle relaxation:** A deep relaxation techniques based on the practice of tensing up a group of muscles and then relaxing them. Usually performed by starting at the feet and working up the body to relax the muscles and to relieve tension.

Relaxation techniques and just one approach to pain relief and can be effective in helping with the stress and anxiety that often accompany long-term pain. Although they do not address the actual cause of the pain, techniques such as visualisation and deep breathing can distract a person's attention away from their pain for a while.

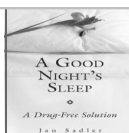
Most relaxation techniques can be self taught and incorporated into an individuals day-to-day life. Some are very simple to do and others may take a little longer to master, but any relaxation technique will be of most benefit when practiced regularly.

We have sampled only a small selection of relaxation CDs for this review but there is a vast array of similar resources available for purchases. Our selection of relaxation CDs and the use of relaxation techniques generally, may not appeal to everyone and, as always, it is a matter of finding an approach or a specific CD that works best for you.



## *A Good Night's Sleep*

Jan Sadler



Deep relaxation to achieve a peaceful sleep at bedtime.

**Website:** [www.painsupport.co.uk/](http://www.painsupport.co.uk/)  
[www.perfectrelaxation.com](http://www.perfectrelaxation.com)

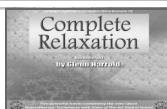
**Cost:** CD £10 (plus p&p). Book plus CD £14.99 plus p&p.

**Description:** Relaxation and deep breathing techniques are used alongside short positive statements to help still the mind and to relax the body at bedtime. Guided imagery takes you on a walk in a secret garden, leading to a beautiful house with a bedroom containing the most comfortable bed imaginable.

**User's view:** 'I found the techniques a great help before going to sleep. Using this CD taught me easy ways to get off to sleep.' Bob Rees.

## *Complete Relaxation*

Glenn Harrold



Hypnotic relaxation to help manage stress levels and to aid relaxation.

**Website:** [www.glennharrold.com/](http://www.glennharrold.com/)  
[www.hypnosisaudio.com](http://www.hypnosisaudio.com) Tel 01732882057

**Cost:** CD £11.95 plus p&p. MP3 download £10.95 (available commercially e.g. via Amazon)

**Description:** Complete relaxation uses hypnotherapy techniques with subtle background music and an echo panning from left to right to enhance the relaxation effect. Track one uses slow breathing techniques and hypnotic relaxation to calm the mind and body. Track two guides the listener to step slowly down some steps into a garden and into deeper levels of relaxation. At the end of both tracks the listener is returned to a fully awake state.

**User's view:** 'Picturing flowers, birds and so on does help to give you more focus to relax, but the echo of the words fading doesn't really work. This is a relaxation CD but is more about how to empower yourself and positive thinking.' Deb Dormer

## *Living with Chronic Pain*

Neil Berry



Provides information and strategies to help people manage their long-term problems.

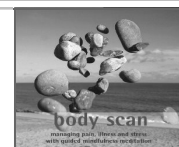
**Website:** [www.paincd.org.uk](http://www.paincd.org.uk)

**Cost:** CD £3; includes booklet and p&p in UK (£4.50 overseas). MP3 download— free. Listen online— free.

**Description:** This CD gives a good summary of the experience of chronic pain that is easy to understand and presented in a way that people can relate to. It covers approaches to help you to regain control of your body and runs through sleep problems, diet, the role of medication and the effects of inactivity. There is also a section on the emotional effects of pain. It ends with a 20-minute relaxation exercise.

**User's view:** 'I attended a pain management course in 2004 and this CD reiterated what I was told then. It was good to have a CD to use to remind me of the techniques.' Bob Rees.

## *Body Scan: managing pain, illness and stress with guided mindfulness meditation.*



Vidyamala Burch and Sona Fricker

One of a set of three meditation CDs for anyone experiencing pain, stress or ill health.

**Website:** [breathworks-mindfulness.org.uk](http://breathworks-mindfulness.org.uk)

**Cost:** CD £10 (plus p&p) MP3 download £8

**Description:** 'Mindful awareness' involves focusing your mind in the present and cultivating greater awareness of your thoughts, emotions and physical sensations (including pain). After a brief introduction and discussion about posture, the CD follows two guided body scan meditations. The leader asks you to 'scan' through the whole of your body and focus on the sensations in each part of it and then, by using the breath, let go of areas of pain and tension.

**User's view:** 'The concentration on relaxing the body in the kind of detail distracted me from my current worries and thoughts. I became involved in following the instructions.' Patricia Ireland.

## Chair Report

Greetings to all! It has been another jam packed and eventful twelve months, during which time I am proud to say, we have made some significant breakthroughs in raising awareness of M.E/CFS and Fibromyalgia, and taken many steps towards becoming a more professional organisation.

We kicked off the year with our annual AGM event, held in conjunction with M.E Awareness week on May 14<sup>th</sup> 2011. Just a few weeks later on June 3<sup>rd</sup> we launched the re-design of our newsletter which was very well received.

July was indeed a fruitful month, which saw great benefit when the group made the decision to purchase the Amethyst Bio, acquired using funds that were raised through two fundraising events held in the latter part of 2010 and following a generous donation from Arlene, in memory of her beloved son Huw. I would like to take this opportunity to again thank Arlene for her generosity.

On 11<sup>th</sup> August; our annual 'Tea in The Park' event took place in the Roath Park café and was thoroughly enjoyed by all who attended, despite the unpredictable weather.

Unfortunately, September saw the loss of 3 of our valued committee members; Linda Tatham, who was our Treasurer at the time; Gareth Price and Gina Fisher. Their resignations called for a reorganisation of the remaining committee positions to better facilitate the group. Many thanks, Linda, Gareth and Gina, for your support and contribution to MESiG during your tenure as a committee member. But this month also brought with it some very interesting events. We were fortunate enough to have Paul Swan from Disabilities Wales speak at our general monthly meeting on 5<sup>th</sup> September in relation to work & benefits and on 22<sup>nd</sup> September Chris, Ken and Dee went along to the Hardest Hit Rally in Cardiff to raise awareness of M.E and join in the demonstration with others to emphasise the difficulties the disabled are facing in the current economic crisis as a result of new laws imposed by the government.

On 5<sup>th</sup> of October I commenced a Counselling and Psychotherapy Diploma course, funded by MESiG; with a view to offering a counselling service to our members once qualified. The course is due to be completed on 5<sup>th</sup> October 2012, however I am pleased to report that I have made great process and passed all examinations to date earlier than scheduled and therefore I am hopeful that this service can be provided at a much earlier date than first anticipated. On 19<sup>th</sup> October, following work completed in unity with Disability Wales in relation to Work and benefits, I was invited to attend their annual AGM event, in which a video interview I completed was presented to all attendees, including the Health Minister and Assembly Member Jane Hutt. This was later published to the web.

On November 18<sup>th</sup> we welcomed 3 new committee members on board; Irene Davies who needs no introduction having served the organisation as a volunteer for many years. Irene accepted the post of Newsletter Editor, allowing myself and Chris to step down as Co-Newsletter Editors. Miriam Wood came on board as our political Liaison Officer and a new MESiG member Rebecca Williams stepped up as Secretary. We were delighted to welcome them on board. Sadly, as a result of a change in personal circumstances, Rebecca had to resign from her position in March. It is hoped that should her circumstances change again for the better she will be able to serve on the committee in the future. On November 22<sup>nd</sup> Chris and myself visited the Health Hospital to make representatives there aware of us and offer our services in an advisory capacity. On November 24<sup>th</sup>, Chris and Rebecca attended a pedal power event to establish cycling services that could be offered to the disabled community.

Our Christmas Party was held this year on 5<sup>th</sup> December at Ararat Community Hall and was a run-away success, enjoyed by all. As well as the usual bran tub, raffle and buffet members took part in a Christmas Quiz, which was a very welcome addition to this year's agenda. 2 days later on December 7<sup>th</sup> Miriam attended a screening of 'Voices from the Shadows' in London. This film is a true breakthrough as it is a marvellous way to raise awareness of M.E and dispel common misconception. December 21<sup>st</sup> saw the publication of our first ever MESiG calendar, which was considered a truly inspirational and moving piece of artwork. Thank you for everyone who sent in images and anecdotes for us to include.

On 9<sup>th</sup> of January we were pleased to welcome Ben to our monthly meeting from the Speakeasy Centre. January 20<sup>th</sup> saw the introduction of a new structure on the committee to ensure maximum efficiency; new policy documents were produced and a decision taken to amend and update our constitution. Subsequently a new constitution was adopted and signed on 6<sup>th</sup> April 2012.

At our monthly meeting in February we welcomed Margaret, who gave a presentation in relation to the effectiveness of Bowen treatment. Later this month on the 20<sup>th</sup> Chris and Ken attend a meeting offered to us by 'VCVS Awards for all' to obtain funding. They represented us very well and as a result the representatives encouraged them to apply for more funding than we originally had.

Our monthly meeting on 5<sup>th</sup> March saw something a little different, with Sian Williams offering an Art Class, which was enjoyed by all who attended. Two days later Miriam and Julie attended a media surgery workshop, which is hoped will greatly benefit us in our marketing campaign. On the 9<sup>th</sup> March Ken and myself were invited to attend a meeting with VAC, which was a tremendous success opening the door to many funding opportunities for us. The biggest event of the year took place on 21<sup>st</sup> March, following an invitation received from AM Julie Morgan in November 2011 when she attended one of our monthly meetings. The MESIG committee, supported by its members gave an influential and hard hitting presentation at the Welsh Assembly; achieving support in relation to the provision of a specialized M.E clinic in Wales. Since the presentation, several AM's have written to the Minister for Health requesting this provision. The event was such a great success that the organisation has been invited to return and give additional presentation at the Welsh Assembly on a six monthly basis.

I would like to take this opportunity to thank every committee member for their hard work, commitment and support during the past twelve months. Ken Bailey (Vice Chair) who actually served as Chair until 5<sup>th</sup> October, Christalla Davies (Membership Secretary), Who also served as Co-Newsletter Editor until November 18<sup>th</sup>, Dee Penny (Treasurer), Irene Davies (Newsletter Editor), Miriam Wood (Political Liaison Officer) and finally special thanks to Rebecca Williams our former Secretary who's time with us was brief but instrumental.

On a final and personal note I would like to take this opportunity to announce that it is with regret that I will not be able to step back up for re-election into either of my current committee roles at AGM. Unfortunately my personal circumstances have significantly altered over the past few months and it is no longer possible for me to offer my time and energy to serve on the committee as a result. I will however continue to support the Group in my new role as Counsellor as soon as I am qualified and possibly in a lesser role as a general volunteer if my other commitments allow. I'd like to take this opportunity to thank each and every one of you for your support and friendship during my brief time as Chair of MESIG.

Best wishes for what I trust will be healthier and happier year ahead from your Chairwomen and Website facilitator, Gemma Phillips



## How does ME/CFS start?

ME/CFS is often reported as having started with a virus or other infection, commonly involving the chest or stomach. However, it can also develop after an accident, operation, vaccination, exposure to crop sprays or sheep dip, or other shock to the system. Alternatively, it may creep on very gradually. The causes of ME/CFS are still unknown.

## What distinguishes ME/CFS from other chronic illnesses?

By far the most widely reported characteristics of the illness, which distinguishes it from other chronic conditions, is exhaustion and malaise following physical or mental activity, the full extent of which becomes apparent only 24 to 48 hours after activity. Recovery from this flare-up of symptoms may be prolonged—days, weeks or even months. Rapid fluctuation of symptoms is a second key indicator.

## What are the other main symptoms?

Abnormal muscle fatigue following activity. Muscle pain and muscle twitching. Sometimes with eyelid tic or twitch.

Failures in attention span. short term memory and concentration.

Other cognitive problems such as tendency to lose track of conversation in the middle of sentences, along with difficulty thinking of the correct word when speaking or writing and difficulty putting ideas into order.

Constantly feeling unwell, with 'flu-like' symptoms (e.g. sore throat, enlarged glands, joint pains) and problems with temperature control and night sweats.

## Other symptoms may include:

Sleep disturbance, especially waking unrefreshed. The disturbance can include sleeping for long periods, perhaps 12 to 18 hours at a stretch, inability to get to sleep, sleeping during the day while staying awake at night, dreams (sometimes nightmares) particularly memorable by their vivid colour.

Pain in one or more joints, but with no signs of swelling, redness or joint deformity.

Feelings of unsteadiness, when walking or standing. Some people report feeling as though they are 'walking on rubber'.

Sudden, unexplained mood swings.

Headaches of a new type, pattern or severity.

Sensations of tingling or numbness, loss of sense of touch.

Over-sensitivity to noise and/or light.

Alcohol intolerance, particularly in the early stages of the illness, and onset of food intolerances.

## Is there a diagnostic test or a cure for ME/CFS?

No, to both. The diagnosis has to be made from the typical pattern of symptoms, with the exclusion of other possible causes. Anyone suspected of having ME/CFS should have a number of routine blood tests

to identify other possible illnesses, and have more specialized investigations if the diagnosis remains in doubt.

## What are the chances of recovery?

### People with ME tend to fall into one of three groups:

People who manage to return completely to normal health, but this may take considerable time. The percentage of people falling into this category is fairly small.

The majority, tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or flare-ups are often triggered by infections, operations, temperature extremes or stressful events.

A significant minority remain severely affected and will require a great deal of practical and social support.

Continued deterioration is unusual. When this occurs, a detailed medical assessment is advised to exclude other conditions.

## How can recovery be helped?

It is important to remain positive about the prospect of recovery. The period of illness varies from person to person and improvements in health can occur, even in people who have been ill for a long time.

## Anecdotal reports suggest two things which improve prospects for recovery. They are:

Taking control early on in the illness (in particular not trying to ignore the symptoms in the hope they'll go away). Youth-younger people seem to make a better recovery than adults.

## Sudden improvement and sustained recovery

Fluctuation in symptoms may lull you into a false sense of security, so do not be tempted to do too much if you suddenly feel better for a short while. Sustained recovery is preferable to a roller-coaster ride of inappropriate activity and relapse.

## If recovery slows or stops

Experience suggests a large proportion of people make a degree of recovery but then reach a point where the rate slows dramatically, becomes sporadic or even stops. We do not know the reason for this. Some doctors suggest this happens because the person develops an incorrect understanding of the illness and so rehabilitation therapy is offered

## Relapses

Relapses are a feature of ME/CFS and may occur through a variety of circumstances: exposure to other illness, sustained physical or mental activity unsuited to a person's capacity at the time, incompatible treatments and therapies, emotional stress, vaccinations, anaesthetics etc. So it may make sense to limit exposure to these situations, except where the consequences of doing so could make matters worse.

## Contact and Support

### **ME Association**

7 Apollo Office Court,  
Radclive Road,  
Gawcott,  
Buckinghamshire  
MK18 4DF

**Tel:** 01280 827070 10am - 3.30pm

**Email:** [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)

**Website :** [www.meassociation.org.uk](http://www.meassociation.org.uk)

### **Brame**

30 Wimmer Avenue  
Winterton-on-sea  
Great Yarmouth  
Norfolk  
NR29 4BA  
UK

**Tel/Fax:** 01493393717

**Email:** [info@brame.org](mailto:info@brame.org)

### **25% ME Group**

21 Church Street  
Troon  
Ayrshire  
KA10 6HT

**Tel: Office** 01292 318611

**Advocacy line:** 01292 312369

**Website:** [www.25megroup.org](http://www.25megroup.org)

### **Action for M.E.**

PO Box 2778  
Bristol  
BS1 9DJ

**Membership/general:** 0845 123 2380 /  
0117 9279551

Mon - Fri: 9.30am - 5pm

**Telephone support:** 0845 123 2314

Mon - Fri: 11am - 3pm



### **ME Connect**

**Helpline** 08445765326

10am-12pm, 2pm-4pm, 7pm-9pm week-days

### **MCS Matters**

*(Multiple Chemical Sensitivity)*

Gordon D McHenry  
UK Co-ordinator

Global Campaign for recognition of MCS

**Tel Helpline:** 01446 794 700

Tues & Thurs 2 –4 and 6—7pm (manned when able)

**Welfare rights helpline:** 0845 122  
8648 (Membership only service)

Monday: 1pm - 5pm

Tuesday: 9.30am - 12.30pm & 3.15pm  
- 6.45pm

Wednesday: 1.30pm - 4.30pm

Thursday: 9.30am - 1pm

Friday: Closed

**Email:** [admin@afme.org.uk](mailto:admin@afme.org.uk)

**Website:** [www.afme.org.uk](http://www.afme.org.uk)

### **STIFF (UK)**

PO Box 1484  
Newcastle-under-Lyme  
Staffordshire  
ST5 7UZ

**Tel:** 01782 562366

### **National ME Centre**

Disablement Services Centre.  
Harold Wood Hospital  
Gubbins Lane  
Harold Wood  
Romford  
Essex  
RM3 0BE

**Tel:** 01708 378050

**Website :** [www.nmec.org.uk](http://www.nmec.org.uk)

### ***Fibromyalgia Association***

PO Box 206  
Stourbridge  
West Midlands  
DY9 8YL

#### ***Helpline:***

***Tel:*** 0844 887 2444 (10am - 4pm Mon - Fri)

***Email:*** fmauk@hotmail.com

### **The Young ME Sufferers Trust**

PO Box 4347  
Stock

Ingatstone  
CM4 9TE

***Tel:*** 0845 003 9002

(best between 11 –1 and 5—7pm week-days)

***Website:*** [www.tymestrust.org](http://www.tymestrust.org)

### ***Welsh Association of ME & CFS Support (WAMES)***

***Tel:*** 029 20515061

***Email:*** [enquiries@wames.org.uk](mailto:enquiries@wames.org.uk)

***Website:*** [www.wames.org.uk](http://www.wames.org.uk)



### ***C.L.I.P.-***

Coping and Living in Pain, support group.

***Tel:*** Richard Goss, 01443 757378

Gloria Edmunds, 029 20530593

Steve Sweetman, 02920214339

***Email:*** [pain.help@ntlworld.com](mailto:pain.help@ntlworld.com)

### **A 4 ME**

Third Floor  
Canningford House  
38 Victoria Street  
Bristol  
BS1 6BY

***Tel:*** Lo-call 0845 123 2380 or 0117 927 9551

***Fax:*** 0117 9279552

***Email:*** [admin@afme.org.uk](mailto:admin@afme.org.uk)

***Website:*** <http://www.a4me.org.uk>

### **Association of Young People With ME (AYME)**

10 Vermont Place  
Tongwell  
Milton Keynes  
MK15 8JA

***Email:*** [info@ayme.org.uk](mailto:info@ayme.org.uk)

***Tel:*** 08451 23 23 89

10am-2pm Mon-Fri

***Website:*** [www.ayme.org.uk](http://www.ayme.org.uk)

### **Welsh Association of ME & CFS Support (WAMES Young People)**

Michelle Penny

***Tel:*** 029 20515061

***Email:*** [michelle@wames.org.uk](mailto:michelle@wames.org.uk)

***Website:*** [www.wames.org.uk](http://www.wames.org.uk)

(Carers—same as above but contact Sylvia Penny—same tel no.)

***Email:*** [Sylvia@wames.org.uk](mailto:Sylvia@wames.org.uk)

## Contact and Support continued

### Travel

#### **National Rail Enquiries**

**Tel:** 0845 748 4950

#### **Disabled assistance**

Advance notice is required by the train operator.

### **Bus and Coach:**

#### **National Express**

**Tel:** 0870 580 8080

#### **Travel Line**

**Tel :** 0870 608 2608

**VEST:** for help with local lifts and transport for the disabled - *Ring* 029 20490325 and ask for an information pack.

### **Carers Line**

**Tel:** 0808 808 7777

### **The Samaritans**

24 hour confidential and emotional support helpline and email service for anyone in crisis.

**Tel:** 0845 90 90 90

**Email:** Jo@samaritans.org

### **Useful Websites**

[www.mereseach.org.uk](http://www.mereseach.org.uk)

[www.butyoudontlooksick.com/the-spoon-theory](http://www.butyoudontlooksick.com/the-spoon-theory)

[www.nice.org.uk](http://www.nice.org.uk)

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

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



## Benefits advice and Support

If you are having problems with your benefits, need some advice or your benefit entitlement checked, you might like to get in touch with one of the three listed below.

### **The Law Centre**

41-42 Clifton Street

Adamsdown

Cardiff

TEL: 029 20498117

Drop in: Monday, Wednesday, Friday  
10-12.30

Tuesday, Thursday 2-4.30

Phone advice: Monday and Thursday

### **Speakeasy Advice Centre**

166 Richmond Road

Cardiff, CF24 3BX

TEL: 029 20453111

### **Riverside Advice**

41a Lower Cathedral Road.

Cardiff

TEL: 029 20341577

### **Useful Telephone Numbers**

A range of useful information leaflets can be obtained from any of the groups.

### **Benefits:**

#### **Citizens Advice Bureau**

**Tel:** See telephone directory for nearest office

**Website:** [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**Dial UK** (Disability Information and Advice Line services)

**Tel:** 01302 310 123

**Website:** [www.dialuk.info/index.asp](http://www.dialuk.info/index.asp)

### **Benefits Helpline**

**Tel:** 0800 88 22 00

### **Social Care:**

#### **Assessment Centre**

Will help with occupational therapy and evaluations

**Tel:** 029 2052 0984

#### **Occupational Therapy:**

**Tel:** 029 2076 7404

## M.E.S.I.G Committee Members

### **Gemma Phillips**

(Chair and Website Facilitator)

**Tel:** 07542 526831

**Email:** [gemmaphillips47@yahoo.co.uk](mailto:gemmaphillips47@yahoo.co.uk)

(Please only telephone me between 2pm and 4pm on Mondays and Wednesdays. Email welcome anytime)

### **Ken Bailey**

(Vice Chair)

**Tel:** 07825702171

**Email:** [kenbailey@talktalk.net](mailto:kenbailey@talktalk.net)

### **Chris Davies**

(Membership secretary)

75 Llanon Road

Llanishen

Cardiff

CF14 5AH

**Tel:** 029 20762347

**Email:** [christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)

(Please only telephone me between 10am and 12noon on Thursdays. Email welcome anytime)

### **Dee Penny**

(Treasurer)

**Tel:** 02920842499

**Email:** [deirdrepenny@yahoo.co.uk](mailto:deirdrepenny@yahoo.co.uk)

### **Miriam Wood**

(Political Liaison Officer)

**Tel:** 07826520959

**Email:** [Miriam\\_melody2000@yahoo.com](mailto:Miriam_melody2000@yahoo.com)

### **Irene Davies**

(Newsletter Editor)

**Tel:** 07891712344

**Email:** [Irenedavies01@hotmail.com](mailto:Irenedavies01@hotmail.com)

*Please send us anything you wish us to submit in next newsletter: poem, recipe, personal story, question etc.*

*or email*

[christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)

[gemmaphillips47@yahoo.co.uk](mailto:gemmaphillips47@yahoo.co.uk)



### **M.E.S.I.G**

(M.E. Support In Glamorgan)

75 Llanon Rd

Llanishen

Cardiff

CF145AH

Tel :02920762347

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

[Email: mesig@hotmail.co.uk](mailto:mesig@hotmail.co.uk)

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