

# ME & YOU

NO. 65, JUNE 2006

THE NEWSLETTER OF THE  
MID & WEST WALES  
ME GROUP

WWW.MIDWALESMEGROUP.ORG.UK

## National ME Week

### Media Coverage

There was good, positive coverage in newspapers and on websites, as well as items on radio and television news bulletins between May 9th and May 23rd. The Times, The *Daily Telegraph* and *The Daily Mail* all carried long articles. So did The *Norwich Evening News*, which had a piece by their health reporter under the headline "We must end 'yuppie flu' myth". The emphasis in these reports was on the extent of the illness and its impact on people's lives, especially in the case of the severely disabled. Attention was drawn to the fact that the vast majority of people have to leave their jobs and that about 25% of those who give up work are sacked or dismissed. There was a focus, too, on current research and on efforts to find a diagnostic test and effective treatment.

Radio and television bulletins picked up on the AfME report. They used its facts and figures to show how

widespread the illness is and how badly it affects people.

One website, *This Morning*, provided a helpful guide to symptoms and management. Others used information from the AfME survey, but also gave space to individual cases. *Midlands Online* posted a piece by a man who gave a very vivid and effective account of how the illness has affected him. He lost a very good job. He was advised to sue his employers because they had harassed him and aggravated his condition, but he felt too ill to do so. His relationship with his wife was fundamentally altered when he was no longer 'the male breadwinner'. He could no longer go for long walks, but had to sit close to the family car. All this is very familiar to people with ME, their families and carers. And he is not the only person who has not had the energy to take hostile employers to court.

If you would like to look at the newspaper reports and websites in more detail go to the AfME website ([www.afme.org.uk](http://www.afme.org.uk)), click on *Newspapers and Campaigns* and then on '...latest news...'. Scroll down and click on *ME Awareness Week Press Coverage*.



### North Ceredigion:

**Wed. July 19th at 2pm**

Meeting at Derryan's at Penrhyncoch. Ring 01970 828896 for directions or a lift.

**Wed. Sep. 20th at 2pm**

Meeting at John & Marjorie's at Ysbyty Ystwyth. Ring 01974 282691 for directions. Ring Derryan to ask about a lift.

### S. Ceredigion/N.Pembs

These normally take place at Huldah George's in Cardigan. Phone Huldah on 01239 613246 to discuss possible events and dates.

### Carmarthenshire:

**Sat. Aug. 13th & Sat. Oct. 14th at 2pm**

Meetings at Gwendraeth Day Centre, Pontiets. Ring John James on 01267 233793.

## Welcome! New Members



Charley Young



Charity number: 1085348

## **National ME Week 8 - 14 May 2006.**

### **Campaign**

On Thursday 11th May Action for ME (AfME) presented a new manifesto to 10 Downing Street on behalf of people with ME. They are asking for:

1. Better understanding of the condition
2. Appropriate support for people with ME, including benefits
3. Effective health services
4. Better access to health and social care, education and training
5. An end to health and social inequalities

AfME has stressed that ME devastates people's lives. It can undermine and destroy not just their work, but their relationships, their social life, their leisure and their interests.

### **This is how AfME describes ME.**

*"ME is also known as Chronic Fatigue Syndrome (CFS). It is sometimes diagnosed as Post Viral Fatigue Syndrome"*

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

### **'More than You Know'.**

This is what AfME had to say in presenting their campaign.

"ME is a painful and debilitating illness, affecting around one in every 250

people in the UK.

The illness affects many body systems and their functions, particularly the nervous and immune systems. In 2002 the British Government gave formal recognition to the illness.

It is also recognised by the World Health Organisation as a neurological condition." The findings of a survey carried out for the campaign indicate that 240,000 people in the UK have ME. Of these people about 77% have lost their jobs as the result of the illness, at a cost to the nation of £6.4 billion a year. 55,000 people are severely affected. These people are bed-bound or housebound. They are too ill to visit doctors' surgeries and suffer severe pain, something which few people associate with the illness.

AfME also released the results of a separate Ipsos Mori survey in Great Britain, designed to find out how much the general public knows about ME. A third (35%) had never heard of ME, although there are three times as many people with ME as MS. Only 5% of people questioned knew how widespread ME is. A third (34%) thought that there were fewer than 50,000 sufferers in the UK.

On Monday 15th May Edward Davey MP tabled an



Early Day Motion in the House of Commons congratulating AfME on their campaign. The purpose of this motion is to draw attention to the issues raised and to canvas support by asking other MPs to sign the motion.

### **Benefits**

On Sunday, 21st May *Radio 5 Live Report* featured the problems faced by disabled people claiming benefits in an item entitled *Computer Says No*. *Radio Times* billed the report like this. "With up to 28,000 disabled people every year wrongly accused of making bogus applications for benefits, Geoff Adams-Spink hears from those left humiliated and poverty-stricken by the claims-assessment methods of a French IT company hired by the British Government". *Radio Times'* radio editor, Jane Anderson, highlighted the case of a man with severe back problems. His disability was questioned because a doctor ticked a box saying that he could watch TV for one hour, without explaining that the man watched TV lying on the

floor. She commented "This [report] is a shocking exposé of the ludicrous injustices imposed upon disabled people when "the computer says no".

People with ME are also suffering from DLA guidelines which emphasise the belief that ME is a 'psycho-social' or imaginary illness. These guidelines have been severely criticised by the ME Alliance, which has insisted that they must be re-written to reflect the levels of disability caused by the illness. They have also challenged the view that the guidelines should incorporate unproven views about the nature of an illness.

On Monday, 15th May *The Daily Telegraph* ran a long article on ME. They interviewed (among others) Professor Peter White, professor of psychological medicine at Queen Mary School of Medicine, London, who heads the trial into CBT and GET "Pacing, Activity and Cognitive Behaviour Therapy" funded by the Medical Research Council. He is quoted as saying "I do not believe that ME is a psychological illness. It is one that affects the mind and the body - and which illness does not? We do a disservice to patients if we try to separate the two."

We hope the Department of Work and Pensions will listen both to the ME Alliance and to Professor White. We also hope the media will continue to highlight the injustice and irrel-



evance of a tickbox system of assessing disability

*Derryan Paul*

### **National ME Week Young People with ME**

The Association of Young People with ME (AYME) ran a campaign during the week to highlight the plight of children and young people who are severely affected. Their survey revealed that:

1. One third were offered no medical services
2. One third were refused a home visit, even though they were too ill to leave the house
3. Half could not access the services they were offered because they were too disabled.

AYME estimate that 25,000 children and young people have ME, an average of 1 in every secondary school. So a very large number are not getting the right kind of help. AYME has found that where they do get the right kind of professional help, it makes a huge difference.

This survey was featured in

*Community Practitioner* (*The Journal of the Community Practitioners' and Health Visitors' Association*, May 2006, p.139) It was also featured in *The Daily Record* in Glasgow on Wednesday, May 10th.

## **NOTICES**

### **Last call for subscriptions**

If you would like to continue receiving ME & You by post, please send your sub to Derryan by 31st July [see back page]. It is £5 for 2006, if you have lost the form

## **Thanks**

Our sincere thanks to Loraine West for undertaking the production of this newsletter, and to Derryan Paul for editing it. Very much appreciated

## National ME Week

The Wales Association of ME Support (WAMES) sent out a DVD issued by MERGE and an information pack to organisations involved in training for medical staff. They hope that this will help to promote and improve training at primary care level, which is the level at which most people with ME in Wales currently receive treatment and guidance on the management of the illness in the NHS.

MERGE is a national UK charity funding biomedical research into ME/CFS. Their main aim is "to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of ME" Their chairman, Dr. Vance Spence has said "A highly successful fundraiser for cancer research told me that in the 1960s, when she began, the word 'cancer' could barely be whispered. But over years ... there was a sea-change in awareness ... we have to do the same - it is ground-level, back-breaking work, but only with data, data, data will we be able to answer our critics AND solve the enigma of ME/CFS."

(The DVD, containing a lecture by Dr. Spence, on 'Energising Biomedical Research on ME/CFS' can be borrowed from our postal library. Please contact Derryan - see back page).



Radio Cymru broadcast an item on ME on Post Cyntaf on Tuesday, 9th May. They drew facts and figures from the AfME Survey and took clips from an interview with a sufferer describing the effect the illness had had on her and how it had changed her life. They also included clips from interviews with two doctors. One viewed the illness as one of a group of conditions characterised by chronic fatigue. The other drew attention to the complexity of the illness and the problems that this causes for doctors and patients.

### **From S.W. Wales: a petition**

On Wednesday 10th May a petition with almost 7,000 signatures was presented to the National Assembly of Wales demanding a new clinical service for sufferers. The petition was presented by the campaign group Help ME Wales, led by Christine Llewellyn and Alison Lenihan. Christine is a former chair of the ME Association and a member of Mid and West Wales ME Group.

Their initial aim is to get a clinic for S.W. Wales. They hope that this will be the starting point for setting up clinics throughout Wales. The campaign has the support of MEPs Glenys Kinnock and Jonathan Evans and of Stephen Crabb, MP for Preseli Pembrokeshire.

### **In Pembrokeshire**

Group member, Ruth Roberts of Llanteg, wrote an article to draw attention to the work of Mid and West Wales ME Group and to explain how widespread the illness is and how badly it affects people. This was published in The Tenby Observer and The Narberth and Whitland Observer.

### **In Ceredigion: £337.50**

On National ME Day, Friday May 12th, members of Mid and West Wales ME Group living in Ceredigion held a collection at Morrisons in Aberystwyth, with family members, carers and friends. We raised a grand total of £337.50, one of our best collections ever. We send our warmest thanks to Morrisons, their customers and to everyone who helped to organise the rotas and to collect and count the money.

*Derryan Paul*

## **Community Transport**

Community Transport arrangements within our catchment area vary from one local authority to another, so it can be difficult to know who to ask. Here are starting points.

If you live in Carmarthenshire, Ceredigion, Pembrokeshire or Powys and you have internet access, you can start on our Group website

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

Click on *Local help* and follow the links.

If you live outside these areas or if you do not have internet access, here are contact details.

### **CARMARTHENSHIRE**

Country Cars, ( WRVS), will take you to medical and hospital appointments or to shop. There is a limit of one journey a week. Contact WRVS National Service Centre on 029 2073 9000.

Other schemes are being considered. For the latest information contact Carmarthenshire Council's Community Development Officer, Philip Thomas. Phone: 01267 224314. E-mail: [pdthomas@carmarthenshire.gov.uk](mailto:pdthomas@carmarthenshire.gov.uk)



### **CEREDIGION**

Several schemes exist. Contact the Community Transport Development Officer, Alan Davies, at Ceredigion Association of Voluntary Organisations on 01570 423232.

### **MERIONETH**

Transport for disabled people in Gwynedd is provided through the Red Cross. Contact Helen Williams on 01286 677830.

### **NEATH PORT TALBOT**

Contact Community Transport on 01639 646969.

### **PEMBROKESHIRE**

Contact Pembrokeshire Association of Community Transport Organisations. Booking and General Enquiries: freephone 0800 783 1584. Community Transport Development Officer: 01437 776550.

## **POWYS**

There is a range of schemes, many of them local, based in towns and larger villages. Contact Powys Association of Voluntary Organisations on 01597 824494.

## **SWANSEA**

Contact the Mobility Helpline on 01792 474477.

### **Cars for Carers : Ceredigion**

The Cars for Carers scheme, which has been running successfully in Pembrokeshire for 3-4 years, is due to be extended to Ceredigion.

We hope that Rachel Evans, the project officer will be able to come and tell us about the scheme at one of our North Ceredigion meetings. Full details will appear in the newsletter as soon as we have them.

## ALL MEDDLED UP!

### What I saw

Rattle of Britain  
successful poisoning  
not all breasts hibernate in winter  
uninformed groups  
through whom the book was tripped  
a marketable voice  
moisturised tailgate  
please deliver gently  
in the Dartmoor fridge-magnet of  
doormat perennials

### What it said

Battle of Britain  
successful sponsoring  
not all beasts hibernate in winter  
uniformed groups  
though whom the trip was booked  
a remarkable voice  
motorised tailgate  
please deliver urgently  
in the Dartmoor fringe-hamlet of  
dormant perennials

**L. Mair Jones**

---

### M.E.

Miserable  
You can't do this, you can't do that  
Angry  
Lonely  
Grumpy  
Irregular heartbeat  
Counselling

Energy, where's it all gone?  
Nothing to do except sit about  
Cross and confused  
Education gone to pot  
Pace yourself  
Horrible  
Activities-they've all stopped  
Long, slow recovery

Oh why me!  
Muscles aching all the time  
Yawning all day through  
Empty tummy, too tired to eat  
Lethargic  
Irritable  
Tragic  
It's not fair  
Sleepless nights

(by Molly)

(thanks to NI MEA Newsletter)

---

## Group Contacts

### Chairman, Membership & Website

Tony Thompson  
The Coach House Frongôg  
Aberystwyth SY23 3HN  
Tel./fax 01970 636515  
[Tony@midwalesmegroup.org.uk](mailto:Tony@midwalesmegroup.org.uk)

### Secretary

Derryan Paul  
11 Nant Seilo  
Penrhyncoch  
Aberystwyth SY23 3HD  
Tel. 01970 828896  
[Derryan@midwalesmegroup.org.uk](mailto:Derryan@midwalesmegroup.org.uk)

### Librarian, Campaign Coordinator and WAMES Rep.

Jan M Russell  
Tel./fax 01970 636515  
[Jan@midwalesmegroup.org.uk](mailto:Jan@midwalesmegroup.org.uk)

### Listening Ear & Publicity

Sharonrose Ellis  
Tel. 01970 820788 (inc.  
answerphone)  
[Sharonrose@midwalesmegroup.org.uk](mailto:Sharonrose@midwalesmegroup.org.uk)

### Local Contacts

**Brecknock & Radnor, & WAMES  
Rep.** Richard Jones  
Tel 01874 622310  
[richard.gj@virgin.net](mailto:richard.gj@virgin.net)

### Carmarthenshire

John James  
Tel 01267 233793  
[johnjames@glangwil.freesev.co.uk](mailto:johnjames@glangwil.freesev.co.uk)

### Pembs & South Ceredigion

Huldah George  
Tel 01239 613246  
[tmelfyddgeorge@welshnet.co.uk](mailto:tmelfyddgeorge@welshnet.co.uk)

### Tregaron area

Martin Dixon  
Tel 01974 299265  
[mh.dixon@btinternet.com](mailto:mh.dixon@btinternet.com)

## MWWMEG Activities

- Meetings in different venues - details on front page. Everyone is welcome.
- Information and understanding from our listening ear.
- *ME & You*, every 2 months
- Postal Library - books, audio and video tapes about ME. Lists available from Jan or Derryan.
- The Group has wheelchairs for members to borrow. A small donation is requested for their upkeep.

## Subscriptions

These are now due - please see the notice on the front page. Remember, most back issues are available on our website.

MWWMEG is a partner group to The Young ME Sufferers Trust  
[www.tymestrust.org](http://www.tymestrust.org)

## Group Website

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

We are happy for articles and news items to be quoted or copied, provided the intended meaning is preserved and the author/source and *ME & You* is properly acknowledged.

**Next issue August 2006. Contributions, please, to Jan, Derryan or Tony by 1 August 2006**