



May 2014, no. 7

# me voice

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The WAMES Magazine

**WAMES**  
Welsh Association of ME & CFS Support

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## ME voice

*me voice* is published 5 times a year. You can subscribe to the paper copy for £10 p.a., or receive it free by email, or read and / or download it from our website [www.wames.org.uk](http://www.wames.org.uk)

### Contact:

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WAMES Subscriptions  
The Coach House, Frongôg  
Aberystwyth, SY23 3HN

We welcome news items, articles, cartoons, jokes, poems, suggestions etc. We will include them whenever it is appropriate. Send them to: [admin@wames.org.uk](mailto:admin@wames.org.uk) or to the WAMES Subscriptions address in the previous column.

## The WAMES information exchange

Offers a number of ways to share news and views which interest and entertain people with ME who live in Wales (and carers and family):

- [newsblog on website](#)
- [magazine](#)
- [facebook](#)
- [twitter](#)
- [e-group](#)

## Making the web links in me voice work in your Browser

### Internet Explorer

When you click the *me voice* link, this opens your default pdf reader. The hyperlinks and the email addresses all work.

Google Chrome, Opera, Torch Hyperlinks and email addresses work correctly.

### Mozilla Firefox

If '*This pdf might not be displayed correctly*' appears top left under the bookmarks toolbar, click on the box to the right 'Open with a different viewer'. Choose your favourite pdf reader and tick the box 'do this automatically for files like this in future'. The hyperlinks and email addresses will now work correctly.

### Read the magazine full screen:

In Foxit Reader click F11 to increase an decrease the size of page.

In Adobe Acrobat press Control+L

### Copy dates for the magazine:

24 June 2014, 22 September 2014

## News from the AGM

### 2014 Committee

**Chair:** Jan Rusell

**Secretary:** Vacant

**Treasurer:** Liz Chandler

**Youth & Care Officer**

Sylvia Penny

**Young People's Contact:**

Michelle Penny

**Website & Publicity:**

Tony Thompson

### 2013 Finances

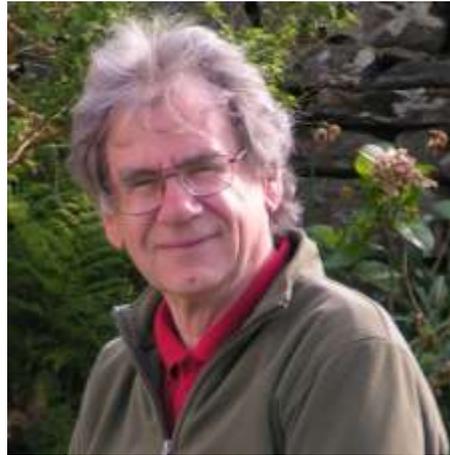
Opening balance	£3353.75
Income	£1390.09
Expenditure	£ 2011.24
End of year balance	£ 2732.60

### From the Treasurer

The bulk of the income we received last year comprised of money from MWWMEG when it merged with WAMES. We also received money from magazine subscriptions, donations and online fund raising.

WAMES has enough money to fund our activities for 2014, but we need to look for some major funding sources, donations and fundraising volunteers to ensure we can continue to campaign and provide information in the future.

### From Tony, the retiring chair



“My tenure as chair was short but I have been working for WAMES on the website and publications since the beginning in 2001. I am also retiring as newsletter publisher but will continue to support WAMES in a number of ways as I am impressed by how much has been achieved in the last 13 years. It has been a team effort and it has been good to see new volunteers joining us, enabling us to develop our services. The backbone of WAMES however has been Jan, now Chair of WAMES, who has had ME for almost 30 years, and Sylvia who cares for her two adult disabled children, one with severe ME, and an ageing mother.

Yet despite this, they have kept campaigning and refused to be deterred by inaction from the government and the NHS. In addition they have answered many requests for help and information from people from all

## about wames

over Wales, and have developed an effective information service.

While we should all be grateful to them for the entirely voluntary and dedicated work they do on our behalf, they need more help if WAMES is to develop further. We are grateful for the volunteers who have joined us over the last few years but WAMES needs more long term committed help, even if it is just a few hours a week, or even a month.

Many of you have special skills that would be of value, can you please ask yourselves if, despite your illness, you could manage to give a little of your time to help yourself and other people with ME and their carers in Wales by contributing to the WAMES campaign in some meaningful way. PLEASE contact Jan if you feel you can help – PLEASE.”

### From Jan, the retiring secretary

I have stepped down from the secretary's post because I need more time to campaign and planning our publications. We have reached an exciting crossroads in the health services

campaign when there is a real possibility services can improve if we can foster good working relationships with the Health Boards.

It was decided that the role of Chair was more in keeping with my increasing activities as the public face of WAMES. With more effective pacing(!) and a new secretary, I want to ensure WAMES continues to represent people with ME in Wales and keep WAMES working for a health service that recognises the physical and serious nature of ME. Without a secretary WAMES cannot continue to function as a charity, but all the admin roles in WAMES do not need to be done by the secretary, so we will be looking at ways that many people can get involved without overloading any one person.

When I became secretary I knew nothing about administering a charity. I learnt on the job and made my mistakes behind the scenes. Looking back I can see how important, if unglamorous the job was! So my message to anyone wondering if they could do the job is: a willingness to learn is the main requirement.

# about wames

## ME Awareness Week 11-17 May

Join WAMES in raising awareness and fundraising during May.



### Need ideas...

- Write your story – we'll help you distribute it.
- Wear blue ribbon and/or blue clothes
- Wear pyjamas or dressing gowns when out
- Add a WAMES twibbon to your FB site (URL to come)
- Supermarket collectin
- Collecting tins in local shops etc
- Display posters in libraries, community centres etc
- Sponsored event at school, work etc – raise money online for us at [www.charitychoice.co.uk](http://www.charitychoice.co.uk) or [www.btplc.com/mydonate/](http://www.btplc.com/mydonate/).
- Shop online through [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk)
- Sell unwanted goods on Ebay in

aid of WAMES Paypal giving fund at [www.missionfish.org.uk](http://www.missionfish.org.uk)

### More information...

Contact Sharon Price, our Awareness Week Contact (last year she 'lay down for ME' in public places and the previous year she wore a blue wig! Find out about this year's sponsored walk on page 5. She can help with ideas, publicity and planning. She can provide posters, leaflets, gift aid forms, sponsorship forms. [sharon@wames.org.uk](mailto:sharon@wames.org.uk) 078551 28647

Tell Sharon what you're planning and we will advertise it on FB, Twitter and the Newsblog.



Derivative of [File:TANDBERG E20.jpg](http://File:TANDBERG E20.jpg)

### Our May Telehealth Poll

Would you be happy to use technology at home to improve medical care and reduce travel?

The Health Minister has announced £9.5 million to

develop telehealth and health technologies services to improve patient care in Wales. £2.87 million of that will be for 'developing remote devices and connectivity to link clinicians and patients together'.

Health technologies can enable long distance consultations between patient and professionals by phone or video. They can also send data from machines in the home to clinics anywhere which measure and monitors temperature, blood pressure and other vital signs. All these and personal alarms allow people to live independently and safely in their own homes and reduces expensive and tiring travel.

Let us know if you would be happy for technology to be used to help provide health care for you and your ME.

<http://wames.org.uk/cms-english/2014/05/3044/>

### Facebook Vacancy

A big thank you to El Jones for setting up and coordinating our FB site. She will soon be leaving Wales to travel overseas so we are looking for a volunteer to take over from her. You don't need to be a social media expert. El is happy to pass on her expertise and provide back up until she leaves.

[www.facebook.com/WAMESMECFS/](http://www.facebook.com/WAMESMECFS/)

Contact El to discuss what is involved [facebook@wames.org.uk](mailto:facebook@wames.org.uk)

## Welsh Awareness Events

### Sharon's Sponsored Walk

After 2 decades of ME, Sharon Price is going to attempt to walk 5km in Pembrokeshire for WAMES on 11<sup>th</sup> May - a big undertaking! She will walk round Dinas Head near Newport.

Please check out her fundraising page for more details and donate to make it worth the effort. (She promises to rest along the way so she doesn't make herself ill and her boyfriend Gareth will accompany her.)

[www.charitychoice.co.uk/fundraiser/sharonpricewameswalk](http://www.charitychoice.co.uk/fundraiser/sharonpricewameswalk)

If you wish to sponsor her or find out about her route you can also contact her at [sharon@wames.org.uk](mailto:sharon@wames.org.uk) 07855128647 and send cheques to 23 Wordsworth Avenue, Priory Park, Haverfordwest, Pems, SA61 1SN

### Gwyn's 7 Day Sponsored Walk

Recovered ME sufferer Gwyneth Hopkins will walk round Pembrokeshire for 7 days from May 11<sup>th</sup> – 17<sup>th</sup>. She plans to start



at Haverfordwest at 10am Sunday 11<sup>th</sup> May, then go around the top of Cleddau estuary to Lawrenny, then Lydstep, Tenby, past Narbeth and over the Preseli hills to Newport, St. Davids and back to Haverfordwest. She expects to walk approx. 125 miles

She wishes to raise awareness of ME and money for research (for [www.mereseach.org.uk](http://www.mereseach.org.uk)).



Also to let people know about the ME Group in Haverfordwest (for details contact Tina 01437 454359)

## news from wales

Donate at [www.justgiving.com/Gwyneth-Hopkins](http://www.justgiving.com/Gwyneth-Hopkins) or contact Gwyn on 01646 636683 email [gwyn@gwynhopkins.co.uk](mailto:gwyn@gwynhopkins.co.uk)

During the walk you may contact her on 07950160389 for updates and if you want to join in for a few miles you're welcome.

### Withybush Hospital

The West Wales group are planning an awareness display in the hospital to provide information about ME to patients and staff.

### Awareness Film Show in Penarth

MESiG is showing a moving one hour documentary about severe ME in Penarth Pavilion at 2pm on May 12<sup>th</sup> Tickets £4. Suitable for age 16+

#### More info:

[voicesfromtheshadowsfilm.co.uk](http://voicesfromtheshadowsfilm.co.uk)  
[www.penarthpavilion.co.uk/cinema](http://www.penarthpavilion.co.uk/cinema)  
[www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk)  
<http://bit.ly/1Y8sKK>

MESig have also launched an e petition calling for an ME clinic, specialist and team in SE Wales, and will have an awareness display in Heath hospital on the 13<sup>th</sup> May.

### Hywel Dda Health Board

Hywel Dda Health Board and WAMES are planning to distribute posters and information about ME to staff.

### Mid & West Wales Info Engine

The Powys Info engine is expanding to cover Ceredigion, Carmarthenshire and Pembrokeshire.

The website enables anyone to find out which public, voluntary and statutory sector organisations and services are available in their area.

Add your group to the hundreds of Powys organisations already there by contacting Claire Powell PAVO on 01597 822191 or email [claire.powell@pavo.org.uk](mailto:claire.powell@pavo.org.uk) [www.info-engine.org.uk](http://www.info-engine.org.uk)

# news from wales

## Local ME get-togethers

Here are some forthcoming meetings and events to be held by support groups. Contacts for all groups in Wales can be found on the back page.

## Carmarthenshire ME Group

Meets on June 14th at Caemaen Day Centre, Coleshil Terrace, Llanelli, SA15 3BT. Please ring John James [pm] 01267 233793 to confirm dates.

## North Ceredigion Yoga Class

Meets in Penrhyncoch on Thursday afternoons, 2.30-4pm at 11 Nant Seilo. For more details contact Derryan on 01970 828896 or derryanpaul@gmail.com or Cathy on 01570 421144 or 07748 031614 or cathycrick@hotmail.co.uk

## ME Support Glamorgan (MESiG)

Meets 2nd June, 7th July at

Llanishen community shop, Llangranog road (off Templeton Ave) Llanishen CF14 5BL

## West Wales ME/FM Group

Meets 4th Monday every month. 11am until 1pm at 65 Tudor Gardens, Merlin's Bridge, Haverfordwest, Pembro SA61 1LB

**Next meetings:** 28 April & 26 May

Transport can be arranged from the bus or train stations. Parking is available.

Contact [Tina tretiul@talktalk.net](mailto:tina.tretiul@talktalk.net) or phone 01437 454359.

## Haverfordwest Carers Meeting

Open to all Parent Carers of all conditions, not just ME, and all ages of 'child'. Meets on last Wednesday of month, 11am – 1 and again 7 – 9pm, as many carers work. Next meetings: 30<sup>th</sup> April, 28<sup>th</sup> May. Contact Tina [tretiul@talktalk.net](mailto:tretiul@talktalk.net) or phone 01437 454359.



## Welsh Better Journey Card

The Better Journey card is designed to give those with disabilities a way of easily and discreetly making the bus driver aware of any special assistance they may need.

It contains 10 messages ranging from 'Please help me find a seat' and 'Please count out my change with me' to 'Please face me and speak clearly, I lip read' and 'Please be patient, I have a hidden disability'. The cards can also be customised to the users' individual needs as there is space for people to write in their own message.

Safe Journey and Better Journey cards can be downloaded for free from the First website: [www.firstgroup.com/safejourney](http://www.firstgroup.com/safejourney) or [www.firstgroup.com/betterjourney](http://www.firstgroup.com/betterjourney). A limited number of pre-printed, folded, wallet-sized cards are also directly available from First.

All their buses will be low floor and disabled friendly by 2015-16 and will carry mobility scooters safely.

## The Welsh Dads Survey

ALL fathers, grandfathers, step-dads and father figures are invited to help *FnF Both parents matter Cymru* to get a better picture of your experience of support for your crucial role as a dad in Wales. Recent research has shown that many services want to reach out to more male carers. Your experience will help us work with them to make that a reality.

The survey asks you about experience of dealing with Children's Services, Families First, Flying Start as well as more universal services such as health and education. It's all completely anonymous so you can share your stories without fear of being identified.

For help with child contact problems visit their website. Complete the survey online: [www.surveymonkey.com/s/PTPDBPV](http://www.surveymonkey.com/s/PTPDBPV) or go to the website [www.fnf-bpm.org.uk](http://www.fnf-bpm.org.uk) and follow the link to Dads Survey or call the Helpline on 08456 00 4446 61 Cowbridge Rd East, Cardiff, CF11 9AE



# regional news

## North Wales

### Make Friends with a Book

A free, weekly shared reading group at Bangor Library Friday 10.30-12pm. Everyone is welcome

#### For further details:

[jeanettewooden@thereader.org.uk](mailto:jeanettewooden@thereader.org.uk)

0781 223 8411

[leahedge@thereader.org.uk](mailto:leahedge@thereader.org.uk)

0781 223 8413

### Patient Stories Wanted

The North Wales Community Health Council (CHC) has now started recording Patient Stories. This is an excellent way to capture personal experiences of patients/carers/members of the public when using NHS services in North Wales. They want both 'good news' stories as well as 'suggestions where improvements can be made'.

#### For further details please contact:

Mrs Chris Jones, Deputy Chief Officer, North Wales CHC  
11 Chestnut Court, Ffordd y Parc, Parc Menai, Bangor  
LL57 4FH

[admin@bcchc.org.uk](mailto:admin@bcchc.org.uk) /

01248 679 284

## Mid Wales

### Volunteer Pain Mentors

During 2014-2015 Powys teaching Health Board (PtHB) will be piloting a project designed to support people living with pain, delivered by volunteer peer mentors who also live with pain. The role will involve:

#### Some informal social support

Supporting participants to set commitments designed to help them manage their pain and improve their quality of life

#### Monitor progress and follow up with solutions.

Operational support and supervision will be available. The peer mentors will work with a variable caseload size with an average placement length of 4-6 sessions. Full training, will be provided.

Anticipated commitment: one day a week for an initial 12 month pilot period. To apply or for an informal chat please contact: Sarah Cronin, Development Manager, Long Term Conditions, Powys teaching Health Board,

Pain & Fatigue Management Centre, Bronllys Hospital, Bronllys, Brecon LD3 0LU  
Tel: 01874 712507 Mobile: 07920 528387

[sarah.cronin@wales.nhs.uk](mailto:sarah.cronin@wales.nhs.uk)

### Neurological Conditions Delivery Workshop

Do you or someone you care for have a neurological condition?

If so, would you like to be involved in the way Powys Teaching Health Board develops the services they offer in your community?

#### A workshop is being held to hear your views on:

Tuesday, 13th May 2014  
10:00—12:30

Powys Association of Voluntary Organisations (PAVO) office, Unit 30, Ddole Road Industrial Estate, Llandrindod Wells, Powys, LD1 6DF

If you would like to attend please confirm your attendance with Bertha/Kath on 01874 712652 or via email

[Pa.dothsandwod.POW@wales.nhs.uk](mailto:Pa.dothsandwod.POW@wales.nhs.uk) ASAP.

Crossroads Care might be able to offer carers replacement care and help with transport costs (bus or train ticket;

mileage). Please give advance notice. Contact Ingrid Bernathova at Crossroads Mid & West Wales on 01874 610900 or email:

[ingrid.bernathova@crossroadsmw.w.org.uk](mailto:ingrid.bernathova@crossroadsmw.w.org.uk)

If you aren't able to attend but wish to have your views represented, please contact Bertha, Kath or Gayle at Neuro Voice Powys. (see above)

## Neuro Voice Powys

Neuro Voice Powys helps people in Powys who have, or who care for someone with a neurological condition.

The Project Co-ordinator Gayle Pearson is available to meet with patients, carers or support groups to find out about the issues that affect you and help you to resolve them. She wants to work with you to help improve your quality of life.

She will then work to influence government, health boards and charities to improve local services and support.

#### Find out more

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

[nvp@neurovoicepowys.org.uk](mailto:nvp@neurovoicepowys.org.uk)

01686 626220 07918 077 721 c/o MANGO, Plas Dolerw, Milford Rd, Newtown SY16 2EH

## West Wales

# regional news

# news

## West Wales Neurological Alliance

The next meeting of the WWNA will be 14<sup>th</sup> May in Haverfordwest and will be discussing involvement with the Neuro Delivery Plan. Contact Jan for more information.

## Carmarthenshire Transport Plus

The Royal Voluntary Service are currently piloting their 'Transport Plus' scheme. This offers transport (obviously) but also seeks to befriend clients and support them a little more. If this would be of interest to you please contact Jan so she can liaise with the RVS

## South West Wales Community Road Shows Swansea

The overall aim of the Patient and Carer Participation Project is to enable patients and carers to be more involved in and able to influence the design and delivery of health and social care services (including primary care, social services and the voluntary sector), ensuring that the services provided meet local (community network based) needs.

**Find out more about the**

## project, local services and how to get involved.

- 9th June (12.30-4.30pm), Scout and Guide Headquarters, Brynmill, Swansea, SA2 0AR.
- 13th June (12.30-4.30pm), The Phoenix Centre, Powys Ave, Townhill, Swansea, SA1 6PH.
- 16th June (12.30-4.30pm), Forge Fach Community Resource Centre, Hebron Rd, Clydach, Swansea, SA6 5EJ.
- 17th June (12.30-4.30pm), Gendros Community Centre, Gendros Avenue East, Gendros, Swansea, SA5 8DE

## South Wales

South Wales programme update

<http://www.wales.nhs.uk/SWP/press-releases-and-updates>

## Invest in ME 9<sup>th</sup> International ME conference

**30 May London**

Speakers to include: Prof Jonathan Edwards, Assoc Prof Mady Hornig, Prof Sonya Marshall-Gradisnik; Prof Julia Newton, Dr James Baraniuk.

[www.investinme.org/](http://www.investinme.org/)

Experts will be speaking and important CPD (Continuing Professional Development) points are available for healthcare professionals. WAMES can 'sponsor' interested professionals to attend and they will receive a discount. Contact Jan

## NICE confirms decision to shelve CFS/ME guidelines

The 2007 clinical guideline on ME/CS, first published in August 2007, has been put on a new 'static list' by NICE (the National Institute for Health and Clinical Excellence) which means it won't

be reviewed for 5 years. WAMES' objections to the guideline being placed on the NICE static list are detailed on pages 90-95 of the NICE report of the consultation.

You can read NICE's response (from p55) to submissions from Action for ME and others at [www.nice.org.uk/media/3F6/9E/ClinicalGuidelineStaticListAndSHCommentsNov13.pdf?dm\\_i=1HO,2C5ZS,A5RHDL,8HQCB,1](http://www.nice.org.uk/media/3F6/9E/ClinicalGuidelineStaticListAndSHCommentsNov13.pdf?dm_i=1HO,2C5ZS,A5RHDL,8HQCB,1)

## **NICE response extract:**

Having considered the criteria again in light of all comments received we still do not feel that the evidence base is substantially evolving in this area at this time. In addition this guideline is not scheduled to form part of a Quality Standard at this time and is therefore not considered a priority for NICE to review.

## Turn your body blue for ME

Julieann Chown is asking people to turn body parts blue for ME in aid of Invest in ME because important research is needed for the illness

<https://www.facebook.com/pages/Turn-your-body-blue-for-ME/298704563611198>

# health services campaign q&a

WAMES has been campaigning for healthcare for **PWME** in Wales since 2001. We are grateful for the support from many people with ME and their carers as we have lobbied for services that will improve our quality of life. We have also received many questions and comments over the years about the lack of progress and how we can change that. We are learning and listening all the time...

## Why is ME still not recognised as a neurological condition?

The WHO (World Health Organisation) classifies ME as neurological and research results confirm that neurological dysfunction causes many of people's symptoms.

GPs and hospitals use other classification codes for illnesses however and many in the NHS would say that for all practical purposes the WHO codes are irrelevant to them. They are more concerned with what they can prove and treat in clinics and so far

there is no consensus on diagnosis and treatment.

## Why are neurologists not interested in ME?

There are a number of reasons. They are not taught about ME in medical schools and so they don't realise they should be interested in it. In addition, there has been a shortage of neurologists in Wales for many years so it has been difficult to provide a service to people with conditions that are widely accepted as neurological, let alone more controversial ones like ME.

Once diagnosed, many neurological patients don't get follow up appointments with a neurologist though their GPs can refer them back if necessary. The lack of accepted diagnostic tests and treatments for ME also make neurologists feel that they have little specialist care to offer people with ME.



## Why don't doctors know about ME research results?

Busy doctors rely on UK publications The Lancet and British Medical Journal to keep them up to date and they rarely include research into biomedical ME. In fact there have been allegations of bias against neurological ME and in favour of psychological CFS.

Although doctors have to show they are continuing to educate themselves (called Continuing Professional Development) they, or their medical practices or hospitals can choose which

topics to cover. Few choose ME, and ME training sessions for doctors are not always well attended.

## More people have ME than have other serious conditions (Parkinson's, MS etc). They have clinics, specialists etc. Why not ME?

There could be 13,000 people with ME & CFS in Wales but that is an estimate based on the formula presented in the CMO's report of 2002 (0.01-0.004% of the population). Nobody knows how many people actually have ME or CFS and Health Boards need hard evidence before developing services. Surgeries and hospitals don't keep records of the number of people with ME they deal with. In fact there isn't a code specifically for ME.

Also until the quality of diagnosis improves, any figures would include people misdiagnosed with ME or CFS, and those with general tiredness, and would omit those who have ME but have been misdiagnosed with another condition like depression.

## Who is responsible for ME in Health Boards?

Good question! For years it didn't fit neatly into any department's work. Non stop reorganisation and reallocation of staff responsibilities over the last 10 years hasn't helped either.

In 2006 the Government started to develop a strategy for the care of long term and chronic conditions which they believed could be applied to all conditions, including ME. The principles have influenced the NHS to some extent but later strategies and delivery plans have taken priority.

When LHBs were told to develop ME services in 2011 WAMES contacted every HB but most had not appointed a 'lead' for ME and didn't know who that should be. Health Boards have different structures so the lead in Hywel Dda is a nurse in charge of the chronic conditions team.

In Powys and Betsi Cadwaladr the leads are clinical psychologists reporting to the Primary Care Boards. The Task & Finish Group have agreed that ME does not

belong in Mental Health so each HB will be told to appoint a 'lead' and find a home for ME somewhere other than in mental health.

## Why haven't you lobbied to close the North Wales & Powys Fatigue Clinics?

We are aware that a number of people have found the rehabilitation techniques practised by those clinics very unhelpful and some feel that they have been harmful.

Others have found them helpful to some extent. Many also reported however that they believed the staff did actually want to help people but were misguided about ME. Staff at 2 of the clinics tell us they accept that ME is a neuro-immune-endocrine condition, not a psychological one, but that rehabilitation can still be helpful.

After listening to both patients and the clinics WAMES believes that the clinics have a role to play for people who have chronic

## health services campaign q&a

fatigue as a major symptom but who don't react badly to exercise.

They also offer advice other than exercise therapy which could be helpful to people with ME if the service was reorganised, though they only currently cater for mobile patients who are well enough to travel. Such clinics should only be one of the approaches offered by Health Boards to people with ME and CFS however and patients should always be able to choose the most appropriate for them.

WAMES is campaigning to ensure that all patients receive appropriate care, including those who are severely affected, housebound or who cannot tolerate exercise therapy.

## Why won't the government give money to set up new services?

The lack of clinical champions is one reason but there has never been a lot of money available for healthcare in Wales (in

comparison to England). As the current economic crisis has taken hold money is in even shorter supply and priority is being given to conditions that cost the NHS a lot of money - those that require expensive hospital care, cause death and affect a large number of people. These include heart disease, cancer and diabetes. In comparison ME affects a relatively small number of people and hospitalisation and mortality rates are low.

It should also be noted that many specialist nurses and some specialist Occupational Therapists and Physiotherapists are part or largely funded by charities. Unfortunately WAMES does not have the resources for projects like this at the moment.

**"If you can't be a good example, then you'll just have to be a horrible warning."**

# health services campaign Q&A

## Why aren't you asking the government for a specialist clinic?

For 13 years we have been lobbying both the government and the NHS for specialist services. We have been repeatedly told that the key requirement in the NHS for the development of services for any health condition is a clinical champion, usually a consultant or GP who will spearhead and shape the way that services are developed.

No clinical champion for ME has come forward, although a couple of consultants have shown an interest in chronic fatigue. The situation in England has shown that setting up clinics without a strong biomedical foundation has led to inappropriate and unhelpful services. We have therefore been pushing for widespread awareness and training so champions can be encouraged and appropriate services are developed all.

Over the years WAMES has contacted a number of health

professionals when patients have praised the care they have received. Few have wished to let it be known they have an interest in ME or chronic fatigue as they haven't wanted to put themselves 'in the firing line'. A few have even referred to the threats that Simon Wessely received as a concern.

We are pleased that there is now a consultant running a diagnostic service for ME (using the Canadian guidelines). He is an endocrinologist in Hywel Dda who has a small amount of time to spend with ME patients. We hope that this will encourage other consultants and GPs throughout Wales and we will be looking for ways to meet and discuss ME with as many medics as possible in the future.

## Why won't the NHS use the diagnostic tests and treatments we know exist?

The NHS requires services to be 'evidence based'.

<http://www.patient.co.uk/doctor/different-levels-of-evidence>

As part of that, research is assessed and graded according to quality and applicability. The highest grade of research is a systematic review or a number of RCTs (Randomised Control Trials). <http://www.cebm.net/index.aspx?o=1025>

There has been very little research into ME and CFS in comparison to other chronic illnesses. And some of what has been done has questionable selection of participants, methods etc. Many are very small or 'pilot' studies with as few as 5 or 6 participants.

When a number of pilot studies produce similar results it shows that there is a good probability a subject is worth pursuing, but before it can be considered conclusive evidence the findings need to be 'validated' i.e. researched with a larger size and range of participants. If successful this research will then form the basis of treatments and services.

A significant number of research findings are not replicated when further research is done. Not to follow this system of checks and balances could lead to harmful treatments being used and a lot of money wasted, but it does take a frustratingly long time, especially when so little research into ME is being done.

Unfortunately there has been little interest in biomedical research into ME within Wales and WAMES does not have a research programme but we believe it is important, and would support any attempt to take research on to the next stage.

**"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."**

**Margaret Mead (1902-1978) Cultural Anthropologist**

## Why won't the government take ME seriously?

From the beginning WAMES has found AMs very supportive to our campaigns. They have often contacted us when trying to find help for their constituents and have willingly lobbied successive Health Ministers on our behalf and when requested to do so by their constituents, to the extent that the government file on ME was the largest of all health conditions by 2005.

All the Health Ministers and many individuals within the government and civil service have understood the serious and distressing effect that ME has on individuals and their families. Some have set up initiatives to look for champions and start a movement towards greater awareness and service improvement: 2004 Masterclass; 2006 Health & Social Care committee assessment; 2007 ME working group; 2009 Task & Finish Group; 2010 Care pathway development group; 2013 Task & Finish Group.

For a range of reasons these activities have not resulted in huge steps forward, but perhaps it could



be said to be like a slowly dripping tap!

## Is there any sign of progress?

Progress might be slow but people we talk to, and surveys we have carried out, indicate that while there is still a lot of ignorance and disbelief in the medical community, there is a small increase in the number of health professionals who take ME seriously. Perhaps the NICE guidelines have legitimized CFS/ME for the NHS, though they failed to educate them about the true nature of the condition. One good news story is that Hywel

# health services campaign q&a

Dda Local Health Board is close to devising a local care pathway and action plan to improve services.

ME is firmly on the political health agenda. Health Boards have been told to devise a local care pathway and improve services in cooperation with patients and carers (the jargon is 'co-production'). The current Task & Finish Group has given Health Boards an opportunity to discuss the barriers to doing this and create a development strategy. The Health Minister has made it clear he wants to see action in all Health Boards.

## What's next?

The Task & Finish Group should lead to service planning in all Health Boards and WAMES will continue to work with all Health Boards to start developing action plans involving patients and carers in their area. We will also be reporting back to the Health Minister to ensure the government directives are not ignored.

Because no money has been committed to develop new services WAMES will be looking for ways to encourage existing staff and services to provide informed care for people with ME such as nurses, OTs, dieticians, community resource teams, neuro clinics etc.

*Jan Russell*

## You can help us:

### Tell Us Your Story...

so we have the necessary facts to advise the NHS.

### Help us find Clinical Champions

Tell us of any health professional who is informed and/or interested in ME. We can suggest literature and training options, and ensure they are consulted about service development in their Health Board.

### Volunteer for local focus groups...

so that staff can hear from patients and carers what the real needs are in their area.

# carers

## Carers week quest

This year, Carers' Week is 9th – 15th June and centres on the idea of a Carers Quest. In order to help unidentified carers individuals and organisations are asked to point carers in the direction of information and advice.

Will you to pledge your support by telling sharing what you plan to do during the week itself?

Your pledges can be as big or small as you can manage, things like:

- I pledge to find out about my local carers services and pass the information to my colleagues/employees
- I pledge to run an event during Carers Week to raise awareness of our services and how we support carers
- I pledge to get information and advice for someone I care about who is a carer

.To find out more visit [www.carersweek.org](http://www.carersweek.org)

To see carers who have already pledged their support [www.carersweek.org/get-involved/pledge-wall](http://www.carersweek.org/get-involved/pledge-wall)

## WAMES has pledged...

To reach out to every carer of a person with ME, CFS and PVFS in Wales and ensure that they are aware of the different ways in which they can get help and support. To ensure that every carer knows that they are legally entitled to receive a 'Carer's Assessment' from their Local Authority and to ensure that they are aware of the different allowances they can claim as a carer from the Government.

## Many events are being planned around Wales including:

**Lampeter (Ceredigion)**  
Thurs June 12th 9.30 to 3.15  
Victoria Hall, Lampeter

**Cardiff & Vale**  
Information roadshow  
The Hub, Gladstone Road, Barry  
Tues 10th June 10 -1  
Cophthorne Hotel, Culverhouse  
Cross Wed 11 June, 2 – 7pm  
Star Centre, Splott

Thurs 12 June,  
1 – 4 pm

### Cardiff

McGill & Brown, Sophia House,  
Mon 9<sup>th</sup> -13<sup>th</sup> June

Free advice from specialist solicitors on wills, power of attorney, legislation that support Carers, support available to Carers etc 02920660188  
[jo@mccgillbrown.co.uk](mailto:jo@mccgillbrown.co.uk)

### Rhondda,

Trehafod - Rhondda Heritage Park Museum, Mon 9th June, 10:00

A course to build confidence and self esteem through creative and visual means.  
01443 668813  
[Claire.L.Meredith@rctcbc.gov.uk](mailto:Claire.L.Meredith@rctcbc.gov.uk)

### Rhondda

Nantgarw - Cole Y Camped, Heol-Y-Coleg Wed 11th June, 10:00  
01443 668813

[Claire.L.Meredith@rctcbc.gov.uk](mailto:Claire.L.Meredith@rctcbc.gov.uk)

### Carmarthenshire

Llanelli - Trostre Retail Park, Thurs 12th June, 10:00 0300 0200 002  
[info@carmarthenshirecarers.org.uk](mailto:info@carmarthenshirecarers.org.uk)

### Pembrokeshire

Wed 11 June 01437

769422 [enquiries@pavs.org.uk](mailto:enquiries@pavs.org.uk)

Contact your local Carers service to find out what is planned for your area.

**Contact your local Carers service to find out what is planned for your area.**

## The Quest Pledge Wall



## Short term Respite for Carers

The Betsi Cadwaladr University Health Board has commissioned Crossroads Care North Wales to deliver a new support service for carers.

The pilot project will cover all North Wales providing practical and emotional support to carers in Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham.

If a carer is experiencing a short term health need, they will now be able to access up to a total of 12 weeks respite support (over a 12month period) in their home to help them carry on with their caring role. 'Health needs' can be wide ranging and include:

- Common Cold/Flu
- Viruses
- Long-term conditions
- Stress/Anxiety
- Support to help carers after they've undergone an operation
- Support to enable carers to attend hospital appointments
- Support to enable carers to attend clinical treatments

The service is available to carers of all ages including parent

carers. Crossroads Care North Wales is registered to provide support (including personal care) to both adults and children.

### More information:

01492 516435

[northwales@nwcrossroads.org.uk](mailto:northwales@nwcrossroads.org.uk)

[http://nwcrossroads.org.uk/?page\\_id=79](http://nwcrossroads.org.uk/?page_id=79)

## Newport libraries carers' collection

This selection of books designed to offer information, guidance, support and advice to all types of caregivers, including those in the caring professions.

The titles available are suitable for carers of both adults and children and cover a wide range of topics including Mental Health, Dementia and Bereavement.

The main collection is held at the Central Library, though you can request any title in the collection from one of the branch libraries, online or via the Book Express service.

Download a copy of the booklist:

<http://www.ageuk.org.uk/cymru/gwent/news--campaigns/newport-libraries-carers-collection/>

## It's mitochondria not hypochondria

A fully revised and updated version of Dr Sarah Myhill's book on CFS/ME is now available.

*Diagnosis and Treatment of Chronic Fatigue Syndrome - It's mitochondria, not hypochondria.* The price, including postage to any UK address is £13

Payment can be made by:

**bank transfer** - to Barclays Bank plc, payee name: Sarah Myhill Limited, Account No. 90234265, Bank sort code 20-61-08. Please give your postal address in a separate email and use the reference CFS BOOK when making a payment.

**online card payment** via a secure payment page - email [hania@doctormyhill.co.uk](mailto:hania@doctormyhill.co.uk) with your postal address and the type

## carers

of card (debit/credit) and you will receive an email message from cardsave with a link to a secure payment page. - £3 charge for credit card.

**cheque** made payable to Sarah Myhill Limited and addressed to Sarah Myhill Limited, Upper Weston, Llanguillo, Knighton, Powys LD7 1SL. Please write CFS BOOK on the back of your cheque or in a covering note and give the postal address to which you want the book to be sent.

## Sheep dig saga at Westminster

A meeting with Andy Burnham, MP and Sarah McKenzie-Ross, Countess of Marr is to be held at Westminster on **May 15**, 2014 at 2 pm.

One of the purposes of this meeting is to show just how many people have been adversely affected by OPs. Farmer Tom Rigby would like sufferers to send him a short message to be read out at this meeting detailing how OPs have affected their health etc. **Photos can be sent to:**

*Tom Rigby, Johnstons Farm, Lowton, Warrington, WA3 1LQ*

# young people

## “Tell me, what is ME?”

Are you brave enough to wear a blue ribbon in ME Awareness week or put a twibbon on your FB page?

Or are you secretly scared that someone might ask you to explain what ME is? After all, just pronouncing encephalomyelitis can be tough on a bad day! Never fear, there are a number of ways you can talk about ME:

### You could memorise a medical definition:

*A complex, acquired multi-systemic disease [with] a pathological low threshold of fatigability... and a prolonged recovery period. (International guidelines)*

But you can't be sure your ME memory won't let you down at the wrong time!

### You could use a simpler definition:

*Lots of different systems in the body don't work properly and symptoms get worse a day or 2 after I use my body or brain too much.*

### Or you could explain how ME makes you feel e.g.

*I feel as if I have flu all the time.*

*My body doesn't like standing up and my head is full of fog.*

*I feel ill and weak most / all of the time*

*I used to feel awful all the time but now I'm on the road to recovery and I have good days and bad days.*

### Use a metaphor:

*My mind feels wired but my body is unplugged.*

*I'm like a battery that doesn't hold a charge.*

The Spoon Theory uses the image of spoons to explain the limited energy people have when they have a chronic illness:

*A person living with chronic illness only has a certain number of spoons in their possession each day, and every small action*



*a person takes can result in a lost spoon. Once a person loses a spoon, it is very hard to get that back until after a full night's sleep (not a dead cert with ME). Simple actions like getting out of bed, taking a shower, walking, and driving can require enormous amounts of energy that people don't have. These disabilities can be visible or invisible.*

Read the full story at:

[www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory/](http://www.butyoudontlooksick.com/wpress/articles/written-by-christine/the-spoon-theory/)

### Or share a picture, poem or poster

Check out the WAMES FB page during May. We will post the best

awareness pics on the web for you to share with others.

**So join us this Awareness week: "Let's talk ME"!**

## First Aid Videos

Six 1 minute Red Cross videos show the simple steps you can follow for different first aid situations:

Choking; a burn, bleeding; unconscious person; asthma attack; broken bone

<http://bit.ly/1kCyfWH>

# young people

## Job Hunting Tips

Unemployment is still high, despite the early signs of an improving economy. It can be particularly tricky to get that first step on a career path, particularly if you also have a disability or illness. The website Great with Disability, is a useful source of advice and information for job seeking students.

It includes tips about presenting well in a CV and at interview; how to disclose a disability and ask for any adjustments you need; information about employment opportunities at a range of companies. There seems to be a disproportionate number of banks, but given that it is a banking sector initiative, that is perhaps not surprising. And you can certainly make a case that a more diverse and inclusive workforce would be an enhancement to their somewhat battered reputation!

<http://www.greatwithdisability.com/index.php>

Top tips for demonstrating your strengths through disability-related examples.

- Ensure that what you are saying is relevant
- Highlight the additional strengths you have gained as a result of your disability

- Be positive
- Use a variety of different examples to answer questions
- Do not use disability to answer too many of the questions
- Don't go for the sympathy vote!

Examples of competencies you may have developed as a result of your disability:

### Communication

As a result of liaising with doctors and other professionals about your disability, you may have developed strong communication skills, whether verbal or written.

Managing your disability on a daily basis can require huge amounts of organisation and planning.

### Organisation

Overcoming challenges and

difficulties will be an every day occurrence for anyone with a disability. Draw on this to demonstrate your problem-solving ability.

### Problem Solving

Whether disabled from birth or having acquired a disability later on in life, you will have had to demonstrate resilience in order to overcome the everyday obstacles.

### Resilience

It can sometimes seem like there people are determined to stand in your way and prevent you from doing something, simply because you have a disability. You will have developed an equally

strong determination to counteract this!

### Determination

These are just some of the personality traits that you may have developed as a result of your disability or long-term health condition. There will undoubtedly be many more. Think creatively and then draw upon these to demonstrate to a future employer why you are an asset to their organisation.

See more at:

[http://www.greatwithdisability.com/index.php/GWDtoolkit/disability/your\\_cv#sthash.tAXgHux1.dpuf](http://www.greatwithdisability.com/index.php/GWDtoolkit/disability/your_cv#sthash.tAXgHux1.dpuf)

## Cryptogram

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z
9		22	13				19												17						

			<u>C</u>	<u>A</u>				<u>A</u>	<u>D</u>	<u>A</u>	<u>H</u>							<u>T</u>			<u>A</u>	<u>T</u>			
4	2	1	22	9	18	26	7	9	13	9	19	2	10	5	7	17	2	8	9	17	7	10			
			<u>T</u>					<u>C</u>	<u>A</u>		<u>T</u>		<u>A</u>					<u>T</u>		<u>D</u>					
			23	1	17	4	2	1	22	9	18	18	2	17	21	9	11	7	3	17	13	10	3	18	11

Answers on page 18

# living with me

## Helpful Products

### Non-slip trays

The ideal solution for those who are less steady on their feet or the accident prone among us! Capable of holding a glass at angles of up to 40 degrees, these elegant wooden trays are available in an Oak Wood finish.

### Suction Grab Rails

There is now a range of “stick n stay” grab rails, which use powerful suction to adhere to surfaces such as tiles and enamel.

### Electric Tin opener

Mains operated, this tin opener can be operated with one hand and little effort whether you are left or right handed

### Ablebelt

Leather belt with Velcro to make fastening and removing it easier.

These products and many more are available from:

### The Good Life Guide

1 Pipers Court Thatcham  
Berkshire RG19 4ER  
01635 874323

<http://www.goodlifeguide.co.uk>

## Tips for an Easier Life with ME

This Facebook Page at [www.facebook.com/pages/Tips-for-A-Easier-Life-With-ME/719081154798616](http://www.facebook.com/pages/Tips-for-A-Easier-Life-With-ME/719081154798616) invites people to share useful tips for saving time, effort and money.

## Are you sitting comfortably?

There are a wide range of posture cushions on the market to help you sit more comfortably.

They include simple seat wedges, travel supports, lumber rolls, neck pillows and bean bags.

### Chilli Bean posture cushion by AAT

AAT Posture Cushions mould to the shape of user's body therefore helping to improve sitting or lying comfort. The special structure of the cushions allows you to preserve the shape with various degrees of hardness.

They can be modelled like



plasticine and, if necessary, the shape can be preserved in the form of a hard shell. It can then be adapted to new positions when required.

Available from >>>

### AAT Mobility Solutions

AAT (GB) Ltd, Community Enterprise Centre Office, 3 Well Street, Cefn Mawr, Wrexham, LL14 3AL

01978 821875

[http://www.aatgb.com/posture\\_cushion.html](http://www.aatgb.com/posture_cushion.html)

Other sources:

<http://www.independentliving.co.uk/?s=posture+cushions>

<http://www.back2.co.uk/Back-Cushions-c5/>

## Cerebra Children's Awards 2014

Do you know a child who deserves an award? Cerebra would love to hear from you.

All you need to do to enter is tell them about the child you are nominating and why you think they deserve an award. It could be for their courage or bravery; for something they have achieved at home, school or in daily life; for their sense of humour or simply for being who they are.

The awards are open to children between the age of 0 and 16 who have been diagnosed with a neurological condition. The closing date for nominations is 1st July 2014.

This year eight lucky winners will be presented with their award at an afternoon ceremony at the prestigious House of Lords in London on 23rd October 2014.

You can download an application form from their website or contact Jessica Bishop by phone (01267) 244221 or email:

[jessicab@cerebra.org.uk](mailto:jessicab@cerebra.org.uk)  
[www.cerebra.org.uk](http://www.cerebra.org.uk)

**Cryptogram:** You can lead a horse to water but you cannot make it drink

## Top tips for surviving on benefits

**Benefits and work asked what advice people would give to new benefits claimants. Over 500 people responded and the suggestions cover shopping, money, dealing with DWP, voluntary work etc.**

"I always recommend 2 bank accounts - one for all bills to be paid from and the other for living expenses such as food and travel. I also recommend clients to use the basic bank accounts website [www.money.co.uk/current-accounts/basic-bank-accounts.htm](http://www.money.co.uk/current-accounts/basic-bank-accounts.htm) to ensure they have a bank account which doesn't charge them for any overdraft facilities and is aimed at people who are on low incomes and/or benefits. I also use comparison sites"

**Read more:**

<http://www.benefitsandwork.co.uk/surviving-life-on-benefits#manage>

## Keep a diary for PIP

For people caught up in the PIP system, Benefits and Work have now published [a set of sample PIP diary extracts](#) and a diary template you can print and fill in by hand or complete on-screen. Not everyone wants to keep a diary of the effects

of their condition, but many claimants do find them useful either to help with completing the PIP 'How your disability affects you' form or to submit as additional evidence.

The sample extracts covering mental and physical health conditions such as arthritis, fibromyalgia, anxiety and depression and the templates will make sure you do the best possible job of keeping a PIP diary.

## Bedroom Tax Loophole

A very curious slant on the [Bedroom Tax](#). As you know, social housing tenants are penalised for perceived under-occupation of their home by losing £14 a week from Housing Benefit. Many disabled tenants use their "spare" bedroom to store essential equipment, or for a carer to sleep in when necessary.

This isn't considered a justification for an extra room – but apparently, setting up a home-based business is.

So anyone with an entrepreneurial turn of mind can gain exemption from the Bedroom Tax by starting a business, provided their landlord grants permission. The loophole was revealed by a Tory peer,

Lord Attlee, who said: "The spare room subsidy encourages people to make full use of their property and to -consider running a small business. I think that is highly desirable."

## Guide to ESA Appeals

Benefits and Works have a guide to challenging an ESA decision and a set of sample submissions. There are sample mandatory reconsideration requests, a sample SSCS1 form and sample written submissions. In addition, the 7 step system allows you to create your own submissions from scratch, whatever the grounds of your appeal. Annual subscriptions cost £19.95

<http://www.benefitsandwork.co.uk/join-us/payment-page>

## ESA & Work Programme Report

Spartacus has released their latest report *Beyond the Barriers, on ESA and the Work Programme*.

They don't just explain what's wrong with the current system

# welfare

and how we know, but also offer a comprehensive alternative to support everyone with illness, impairment or disability.

Please also write to your MP explaining why you think this report is important, and what difference it could make to you. A template letter is on the website. Download the report

[www.spartacusnetwork.org.uk/index.php/esa](http://www.spartacusnetwork.org.uk/index.php/esa)

## ESA Backlog

The latest quarterly statistics show that just 28% of claims for ESA made between 9 and 12 months ago have been assessed. The majority of claimants either get better before the DWP gets round to assessing them or are still waiting up to a year later to actually have their work capability assessment (WCA). <http://bit.ly/ReOIYF>

## Benefits rates 2014 -15

A poster from *Social Welfare Training* giving an overview of Benefits and the weekly rates has been added to the WAMES website

<http://bit.ly/1un2U0N>

# me groups

WAMES would be pleased to hear from anyone who runs a small group, no matter how informal, or from anyone who would like to assistance in setting up local meetings,

**Anglesey & Gwynedd Fibromyalgia / ME Group**  
Contact: Rhian Medi (secretary)  
01248 722184  
[fmsmemonagwy@yahoo.com](mailto:fmsmemonagwy@yahoo.com)

**Brecon Area Contact**  
Richard Jones  
[richardj5@virginmedia.com](mailto:richardj5@virginmedia.com)  
01874 622310

**Carmarthenshire ME Group**  
Meets Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James pm 01267 233793 for further details.

**Clwyd ME Group**  
[clwydme@googlemail.com](mailto:clwydme@googlemail.com)  
01745 822953 [www.clwydme.net](http://www.clwydme.net)

**ME Support in Glamorgan (MESiG)**  
Monthly meetings are held on the first Monday of the month, 11am - 12.30pm at The Community Shop, Llangranog Road, Llanishen, Cardiff CF14 5BL  
Contact: Christalla Bailey,



029 2076 2347  
[christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)  
[www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk)

**Montgomeryshire ME/CFS FM Group**  
Please telephone Mike or Karen on 0796 9665419 (between 2-4pm only please) or email [karen@kandm46.plus.com](mailto:karen@kandm46.plus.com) for more information and the date of the next get-together.

**North Ceredigion Group**  
North Ceredigion contact Contact Dr Derryan Paul on 01970 828896 / [edpaul@phonecoop.coop](mailto:edpaul@phonecoop.coop) to find out about informal get togethers.

**North Ceredigion**  
Yoga Class 11, Nant Seilo, Penrhyncoch on Thursdays 2-30-4.00pm.  
Contact Derryan above for more information.

**Pembrokeshire**  
Get togethers 4th Monday every month at 65, Tudor Gardens, Merlin's Bridge, Haverfordwest SA 61 1LB. Tina, 01437 454359, [tretiul@talktalk.net](mailto:tretiul@talktalk.net)

**Live near the border? An English group may meet closer to you:**  
**Shropshire**  
[www.shropshiremegroup.org.uk](http://www.shropshiremegroup.org.uk)  
Maralyn Hepworth 07516 401097

**Chester**  
[www.chestermesh.org.uk](http://www.chestermesh.org.uk)  
Joan Crawford 01244 370988

## Contact Us

[helpline@wames.org.uk](mailto:helpline@wames.org.uk)  
02920 051 5061

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