



July 2013, no. 3

# me voice

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The WAMES Magazine

**WAMES**  
Welsh Association of ME and 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 [tony@wames.org.uk](mailto:tony@wames.org.uk)

WAMES Subscriptions  
The Coach House Frongôg  
Aberystwyth SY23 3HN

## the wames enformation exchange

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

- newsblog on website
- magazine
- facebook
- twitter
- e-group

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.

## 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 and decrease size of page. In Adobe Acrobat press "control" and "L" together.

## Copy dates for the magazine:

1 Oct., and 1 Dec. 2013

# about wames

## AGM report

The AGM took place on 17th April and the following were re-elected:

Acting Chair: Dr Tony Thompson  
Secretary: Jan Russell  
Treasurer: Liz Chandler  
Youth & Care Officer: Sylvia Penny  
Young People's Contact: Michelle Penny

The valuable contribution of the growing number of volunteers was acknowledged but there are so many opportunities that we need to recruit more. A dedicated volunteer coordinator would effectively recruit, arrange training and mentor, and ensure a fulfilling experience for both volunteers and WAMES.

### Finances for 2013

We have enough money to cover running expenses but not for specific projects or to develop existing ones. All income during 2012 came from donations and so applying for grants and encourage fundraising needs to be a priority. The account balance at the end of 2012 was £3353.75.

We have now registered with 2 online fundraising sites: Mydonate [www.btplc.com/mydonate/](http://www.btplc.com/mydonate/) and Charity Choice [www.charitychoice.co.uk](http://www.charitychoice.co.uk) which will

enable people to raise money for us and give businesses the opportunity to link with us.

We have also registered with the Paypal giving fund [www.missionfish.org.uk](http://www.missionfish.org.uk) which will enable people to raise funds for WAMES when shopping, selling or fundraising on eBay. We have also registered for Gift Aid enabling us to reclaim 25p for each £1 donated by tax payers.

### Online activities & publications

The use of the website and newsblog has continued to increase steadily but there is a need to add more information to the website to increase its usefulness and increase the amount of Welsh on the newsblog. Numbers of people involved in our FB and twitter activities are also slowly increasing.

2 issues of the magazine have been published and comments so far have been positive. There are plans to improve the balance of articles and news.

### Helpline

The number of people calling and emailing continues to increase, with problems accessing specialist health-care and Benefits being the most common topics.

### Media & publicity

It remains difficult to find people willing to do media interviews, especially in Welsh, but Sylvia and Michelle step up when necessary.

### Campaigns

The Health Services campaign is progressing slowly. Hywel Dda is the most responsive of the Health Boards. Aneurin Bevan and Abertawe Bro Morgannwg have failed to appoint a lead for ME pathway development. Jan needs people from each HB area to assist in the campaign.

### Memberships and Alliances

WAMES continues to extend its memberships and alliances so we are well informed and can campaign more effectively.

We get a lot of support and information from the WCVA (Wales Council of Voluntary Associations) and local Associations of Voluntary Organisations (AVOs).

Alliance activities:  
WNA (Wales Neurological Alliance)  
Wheelchair service review and  
Neurophysiotherapy inquiry

LTCAC(Long Term Conditions Alliance Cymru). Self Care Action Plan for Wales and the Primary and Community Care Delivery Plan.

WAMES is now a member of all the local alliances and has taken part in

their reports and awareness events: MANGO, WWNA, SWWNA, SGLTCA and provides the secretariat for MANGO.

Disability Benefits Consortium & Hardest hit campaign: campaign on PIP.

## Volunteer opportunity

Could you be the WAMES secretary?

We need someone to take over the administration of the managing committee, so the current secretary can devote more time to campaigning. The job entails:

- Minutes
- Administration related to meetings
- Ensure policies and constitution are up to date
- Ensure the charity operates legally
- AGM once a year, March/Apr, currently in South Wales
- General meetings held by teleconference or email
- All paperwork related to the operation of the committee
- Share oversight of the work of WAMES with other trustees

For more info contact Jan.

In response to the observation that volunteers are too often seen as amateurs: "Just remember: Noah's Ark was built by amateurs. The Titanic was built by professionals."

# news from wales

## ME Group events round Wales

**Clwyd ME Support Group Saturday 10th August – the group's 21st Birthday.** AGM: 12 noon, all are welcome, with lunch following at 1 pm at the Beaufort Park Hotel, New Brighton

**Summer Picnic:** Greenfield Park, Holywell on Saturday 20th July 12.00. Meet by Basinwerk Abbey. Bring a chair and picnic - there is a cafe nearby too which should be open.

### Swansea valley

Contact Kayleigh Jones for more information about a get together in the Swansea valley area (Ystradgynlais, Ystalyfera, Pontardawe, Clydach)  
[kmejones73@hotmail.co.uk](mailto:kmejones73@hotmail.co.uk)  
07429617002

### Carmarthenshire ME Group

Meets on 10th August, 12 October at Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James [pm] for further details.

### North Ceredigion Group

meets at 11 Nant Seilo, Penrhyn-coch, Aberystwyth. Next meeting

September 10th. Contact Dr Derryan Paul on 01970 828896  
[edpaul@phonecoop.coop](mailto:edpaul@phonecoop.coop)

### North Ceredigion Yoga Class

Meets at 11 Nant Seilo, Penrhyn-coch on Thursdays 2.30-4.00pm. Contact Derryan [above] for more information.

### ME Support in Glamorgan (MESiG)

2 Sept at Llanishen Community Shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

Wednesday 14th August 2.00pm **tea in the park** @ Roath Park Cafe Terrace. look out for the 'MESiG' sign at one of the tables.

'gentle pilates for m.e.' - course starts 4th september 2-3pm in Bethel church hall, Llanishen, CF14 5BL free to members (limited spaces only). Book now!

Contact Christalla 0292976 2347  
[christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)  
[www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk)

### Pembrokeshire

Meets in Haverfordwest SA 61 1LB Contact Tina Norman for more information.  
01437 454359, [tretiul@talktalk.net](mailto:tretiul@talktalk.net)

## Health Services meeting in West Wales

Hywel Dda LHB (Local Health Board) is planning a stakeholder's event on the afternoon of Sep 12th at the Police HQ near Carmarthen. Professionals, patients and carers from Ceredigion, Carmarthenshire and Pembrokeshire are invited to discuss service provision and the development of a care pathway for West Wales. Please contact Jan for more information if you would like to attend.

## Welsh government challenged about ME services

When asked for a comment on the lack of recognition and care for people with ME in Wales the Welsh Government told ITV during ME Awareness Week that "*progress has not been universal across Wales*" since it published a care strategy for the treatment of patients with ME in 2011."

"*The Welsh Government requires Health Boards to put in place measures to ensure prompt diagnosis and treatment for patients with ME. A care pathway was set out in 2011, with the involvement of the Chronic Fatigue Syndrome Task and Finish Group commis-*

*sioned by the Minister for Health and Social Services in 2010.*"

*Last year, the Welsh Government asked all Health Boards for updates on service developments since the publication of this guidance. The responses received show that there have been some improvements, but that progress has not been universal across Wales.*

*Therefore the Task and Finish Group will be reconvened this year to consider how services can be further developed to meet the needs of people with CFS and ME in Wales.*"

According to the government's Dept of Health & Social Services the Task and Finish Group will be reconvened in the latter part of the year and WAMES will be invited to take part. In the meantime WAMES will continue to encourage Health Boards to set up discussions within their areas with professionals and patients about developing services and local pathways for care.

## ME Awareness

Well done to everyone who got involved to raise awareness of ME and raise funds in Wales this year! **Chris & Ken Bailey** from MESiG (ME Support in Glamorgan) gave a radio interview.  
<http://tinyurl.com/l6rtzvc>

# news from wales

**Caru James** gave interviews to the Llanelli Star and S4C's *Prynhawn Da* about her experience of ME and the difficulty of finding a diagnosis and healthcare.  
<http://tiny.cc/r7yyzw>

**Michelle Penny** gave an interview to ITV  
<http://tiny.cc/u8yyzw>  
<http://tiny.cc/u9yyzw>

The chair of the Wales Neurological Alliance spoke in support of the need for an equality of services between neurological conditions and the Government spokesperson acknowledged the need for faster improvement in services.  
<http://vimeo.com/66055569>

**Sharon Price** 'lay down for ME' in a book shop and camping shop.

**Julie** raised £32.59 from a collecting tin in her local pub and £324.61 by baking biscuits for her husband's work colleagues.

**El and Hazz** wore blue at the beach!

**Wayne (Diggy) Duigan** raised over £400 on June 30th by completing the Merlin bike Ride. This was a 105 mile ride from the National Botanic gardens near Carmarthen. His online fundraising page:  
<http://tiny.cc/gbzyzw>



**Natasha Trew-Burns** held a fundraiser for WAMES and FMUK on 7 July in Bassaleg, Gwent and raised over £800.

Article about Natasha in South Wales Argus: *Bassaleg woman in constant pain with Fibromyalgia and ME* <http://tiny.cc/qezyzw>

## Want to improve health & social care services in your area?

There are a number of ways you could get involved in your local area. By joining with others who are already campaigning, volunteering or monitoring services you could make a difference:

- ◆ Local neurological alliances gather information and campaign for change

- ◆ Community Health Councils monitor the quality of services and help people with complaints
- ◆ Focus groups bring together patients, carers & staff to discuss adult, carer or children's services
- ◆ WAMES is working with Local Health Boards to improve services for people with ME & CFS
- ◆ The NHS and Social services have opportunities for a wide range of volunteers to support services

You could help by providing your experiences, attending meetings, distributing publicity or volunteering your time regularly. Contact Jan to find out more.

## Call for advocacy

WAMES was one of over 70 organisations who sent a joint letter to the deputy Minister for Social Services asking that the Welsh government include a clear commitment to professional independent advocacy in the new Social Care Bill.

Age Cymru's research into advocacy provision for older people in Wales found that there was only

one paid advocate per 17,000 older people in Wales.

The Children's Commissioner for Wales's 2011 review of advocacy found that children and young people do not get equal access to services in Wales, and too many remain unaware of their entitlement to an advocate.

*Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. (Action on Advocacy)*

*Advocacy = 'someone on your side' (meic:advocacy and advice helpline for young people)*

Gwenda Thomas, Deputy Minister for Social care responded by announcing plans to extend provision for statutory advocacy:

- ◆ for people with complex needs without other support;
- ◆ for people at risk or abused;
- ◆ requiring local authorities to inform people of their right to advocacy;
- ◆ requiring registered care home providers to inform residents about the availability of advocacy services.

# news and welfare

This does not guarantee people's access to advocacy services but it is a step in the right direction.

## More information:

Written Statement - Social Services and Well-being (Wales) Bill – Statutory Framework for Advocacy  
<http://tiny.cc/qr0yzw>

## Free legal advice

The Disability Law Service provides a casework service, and support at any level of the legal system.

It also provides advice and information in these areas of the law:

- ◆ Community Care
- ◆ Disability Discrimination
- ◆ Special Educational Needs (SEN)
- ◆ Employment
- ◆ Goods and Services
- ◆ Welfare Benefits

Adviceline:

Mon to Fri 10.00am - 5pm

020 7791 9800

Minicom: 020 7791 9801

Fax: 020 7791 9802

[advice@dls.org.uk](mailto:advice@dls.org.uk)

Disability Law Service, 39-45  
Cavell Street, London, E1 2BP  
<http://www.dls.org.uk/>

## PIP consultation

The DWP (Department of Work & Pensions) has launched a six week consultation on PIP (Personal independence Payment), looking solely at the enhanced mobility component.

The move comes after protestors launched a judicial review of the DWP's failure to consult on changing the qualifying distance from 50 metres down to 20 metres.

The DWP could ignore the findings, but it is important that they are forced to admit that the changes to PIP have nothing to do with improving the methods of assessing disability and everything to do with cutting costs.

In addition, they think it is vital that support is given to the brave campaigners who have forced the DWP to make this embarrassing concession. Also, the judicial review is likely to be stayed whilst the consultation takes place, but may be restarted once it is over.

The consultation document is available on <http://tiny.cc/ras7zw> and the closing date is **5th August**.  
[pip.assessment@dwp.gsi.gov.uk](mailto:pip.assessment@dwp.gsi.gov.uk)

Or write to:

PIP Assessment Dev.Team  
Department for Work and Pensions  
2nd floor, Caxton House  
Tothill Street, London SW1H 9NA

## You CAN record the ESA WCA

The government has again confirmed their policy that the Work Capability Assessment (WCA) carried out by ATOS can be recorded. A request for this must be made in advance. Some clients wish a recording due to the inaccuracy of past reports.

Any attempt to covertly record an assessment will result in immediate termination of that assessment but you can request in advance to use your own equipment to record their Assessment. The device must use only CD or tape and provide 2 copies of the recording in such a way to ensure that the recording has not been tampered with!!!

## Recording FAQ:

<http://tiny.cc/lfs7zw>

## Blue badge in Wales

Automatic entitlement for a Blue Badge will now be linked to the new Personal Independence Payments (PIP) that have replaced DLA for people of working age, 16 to 64.

The Welsh Government is extending automatic eligibility for a Blue Badge to people who can stand and then move but no more than 50 metres and to those who cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. This includes people with sensory impairments and those with cognitive impairments.

It is not clear yet how those people who cannot apply for PIP as they are not of working age will be assessed.

<http://tiny.cc/eis7zw>

Apply to your Local Authority or online <http://tiny.cc/yjs7zw>

## Social Fund

This has been replaced in Wales by the Discretionary Assistance Fund.

To apply for a grant, call 0800 859 5924 (free from landline) or 033 0101 5000 (local rate).

For more information:

<http://tiny.cc/yjs7zw>

**I like long walks...**

Epecially when taken by people who really annoy me.

## NORTH WALES

### Over 50 in Gwynedd & Mon?

Age Cymru Gwynedd a Mon offer a range of services and activities:

- Befriending
- Benefits advice
- Advocacy
- Forums
- Lunch clubs
- Day care
- Home care
- Age well clubs

### Dolgellau 'Age Well' Open Day

Friday 19th July 9:30am – 2:30pm  
Clwb Rygbi Dolgellau Rugby Club.  
Reaching Out to People Over 50!  
Join them for a cuppa and slice of cake and see what's available for you. Taster sessions in crafts, computers, walking and gentle exercise and much more including benefits advice.

More info about all activities from 01286 677711 [info@acgm.co.uk](mailto:info@acgm.co.uk)  
[www.ageuk.org.uk/cymru/gwyneddamon/](http://www.ageuk.org.uk/cymru/gwyneddamon/)

### Good Health Event Dolgellau

18th of October at the Leisure Centre. An event for everybody!

Drop in at any time between 10 am and 2 pm.

- 40+ organisations to give Advice and Information.
- Blood pressure taking opportunity
- Local Pharmacy on hand to give advice
- Complementary therapies
- Taster sessions
- Memory & Friendship Café
- Light Refreshments
- Entertainment

If you could man a display / stall for WAMES please contact Jan

### South Gwynedd Long Term Health Condition Alliance

Next meeting: Monday September 23rd at the Glan Wnion Leisure Centre, Dolgellau at 10:00 am.

If you would like to represent WAMES and ME on this alliance please contact Jan for more info. [www.southgwyneddltca.org.uk](http://www.southgwyneddltca.org.uk)

### Free computer training in Denbighshire

These free sessions are open to all.

**First Click training:**  
(Booking required) - First Click is a basic 1½ day course that teaches you how to use a computer from

# wales regional news

switching it on, explaining use of the mouse and keyboard, all parts of the desktop and windows, and first steps on the internet and email.

Tues 23rd 10-3pm & Wed 24th July 10-12pm at Open Doors, **Rhyl**

Tues 27th 10-3pm & Wed 28th Aug 10-12pm at Open Doors, **Rhyl**

Tues 24th 10-3pm & Wed 25th Sept 10-12pm at Open Doors, **Rhyl**

#### Drop in sessions:

Come along to any of the sessions for help with any computer use. Online banking, setting up email accounts, making appointments, online applications, using search engines, and much, much more.

Every Wednesday, 10-12.30pm at Open Doors, **Rhyl**

Thurs 11th July am – Tai Clwyd. Bus Stop, **Llangollen** estates

Tues 16th July 9.30-2pm at Upper Denbigh Community Project, 9 Pennant Flats, **Denbigh**

Thurs 18th July am – Tai Clwyd Bus Stop around **Denbigh** estates

Thurs 25th July 10-2pm, at King's Hall, **Prestatyn**

Contact: Alex, Digital Denbighshire Digidol – 01824 702441/07885 910953 or [alex@dvsc.co.uk](mailto:alex@dvsc.co.uk)

## MID WALES

### West Wales Neurological Alliance

WWNA's latest project has been to gather information about the psychological support needs and cognitive symptoms experienced by people with neurological conditions. WAMES has contributed information about ME. Publication date is soon and it will be posted on the WAMES website.

For more information about WWNA's activities in Ceredigion, Carmarthenshire and Pembrokeshire contact Jan. [www.wwna.org.uk](http://www.wwna.org.uk)

### Accommodation help for families Carmarthenshire

A new service, for families with children under the age of 18, whose accommodation is at risk as a result of family breakdown is available in Carmarthenshire.

# wales regional news

Priority is awarded to families experiencing a range of issues including those who have children and/or young people who are disabled by medical conditions.

Access to the service is via referral from Carmarthenshire County Council's Children's Services, Housing Services or the Team Around the Family.

To request more information please ring:  
Joyce Thomas (Gwalia 01554 779822) South of the County

Ruth Allen (Hafan Cymru 01267 221194) Covering North of the County:

## MANGO Montgomeryshire

Next meeting of the Montgomeryshire Alliance of Neurological Groups and Organisations:  
Fri 27th September, Newtown 11-1pm

You are welcome to attend the meeting if you would like to find out about the Neurological Voice Project and how it aims to help people with neuro conditions, including ME, speak out and influence services in the county.

Contact Jan for more information.  
[www.mangomontgomeryshire.org.uk](http://www.mangomontgomeryshire.org.uk)

## SW WALES

### Neurological Alliance AGM

SWWNA (the South West Wales Neurological Alliance) AGM:  
Wednesday 18th September  
Port Talbot Resource Centre,  
10am - 1pm.

Contact Jan if you would like to find out more about how working with other organisations in the Swansea, Bridgend and Neath Port Talbot areas can improve all types of services for people with ME.  
[www.swwna.com](http://www.swwna.com)

### Laptop loan project

Age Cymru Sir Gâr has 15 laptops/PCs to loan out for 6 months to housebound older people starting mid-July.

The person borrowing the laptop will also receive 6 months free broadband and a volunteer to teach them how to use it to surf the internet, use e-mail, skype, complete forms and shop online.



client will have the option to purchase the laptop at cost price. If they decide they don't want to use the internet or buy the laptop, then Age Cymru Sir Gâr will simply take back the laptop and pass it to someone else for 6 months.

Contact Peter McIlroy on 01554 784080 or write to him at Age Cymru Sir Gâr, 8 Murray Street, Llanelli, Carmarthenshire SA15 1DZ.

### Stress control courses

Are your feelings of stress, anxiety or low mood getting in the way of your life?

#### Try **Stress Control**:-

- A walk in/self referral course
- Aims to teach people ways to understand and manage their stress, anxiety or low mood
- Taught over 6 x 2 hour sessions
- Courses held in Swansea, Neath, Port Talbot and Bridgend
- You can turn up and register on the day of the course
- Free course materials and relaxation CD available
- You are welcome to bring a friend

#### Course dates:

- Swansea Wednesday 14th August 2013 6pm – 8pm
- Neath CVS Ty Margaret Thorne 17-19 Alfred Street Friday 6th September 2013 1-3pm
- Swansea Chapel Singleton Hospital Thursday 3rd October 2013 10-12
- Bridgend Nolton Hall Merthyr-mawr Road Monday 7th October 2013 5-7
- Neath Monday 4th November 2013 2-4
- Swansea Friday 1st November 2013 1-3

For more information contact the team:

Phone or text: 07967 612246  
Email: [living.lifewell@wales.nhs.uk](mailto:living.lifewell@wales.nhs.uk)

**Stress Control** is run as part of the ABMU Living Life Well Programme.



# severe ME understanding & remembrance day

A day to remember everyone who is suffering or who has ever suffered from Severe and Very Severe Myalgic Encephalomyelitis.



Severe ME Understanding & Remembrance Day : This day aims to bring public attention to the illness for the sake of all those presently suffering from Severe Myalgic Encephalomyelitis and to remember all those who have died from ME. A day to honour the strength of spirit of all those who have endured and continue to endure decades of suffering and profound physical dysfunction and yet receive little, or no recognition or help, but rather continue to experience gross misrepresentation and misinterpretation of their illness and profound disability.

People with Severe ME are far too hidden away...at last a day on which we can make our physical reality, our physical neglect and our needs known .

*Remember us, remember them.* Let that be our motto for the day. We are severely ill and we are here.

ME is a World Health Organisation classified Neurological Disease, with serious multi-system dysfunction. People who suffer from it severely are house and bed-bound. They experience paralysis, pain, muscle dysfunction, dysautonomia, acute noise and light sensitivity, gastric issues; profoundly affected by the environment, they need to live lives of almost total isolation in order to cope.

The rainbow has been chosen as the emblem for this day in order to symbolise a bridge from ignorance to knowledge. The many colours of the rainbow represent the fact that ME does not discriminate and also it is an illness of many layers. The rainbow bridge also helps us to remember those who have lost their lives to this disease and to honour their memory.

**We need this special day - this is a new day especially for the ones most neglected and unseen - a day for to speak out and raise funds**

*..for those of us who are shut away from ordinary living, in darkened rooms, too noise sensitive to have direct contact with others, too ill to sit up or move, paralysed, shaking with massive physical spasms, in agony on every level, experiencing burning, throbbing, screaming, tortuous levels of pain, unable to eat, unable to swallow, unable to fundamentally live in the normal ways of the world.*



## A day for focus

The 25% Group are launching an 'official' day solely connected to Severe ME, on Sophia Mirza's birthday : 8th August. Sophia who had true severe Myalgic Encephalomyelitis, was treated outrageously by the medical profession and by others in healthcare. What happened to Sophia should never be forgotten and so it would mean a great deal to use her birth date to honour her memory and to help others.

Find out more from the WAMES helpline or [http://25megroup.org/campaigning\\_Severe\\_ME\\_Day.html](http://25megroup.org/campaigning_Severe_ME_Day.html)

# living with me

## Coping with heat

After the bad weather we have experienced over the last 18 months it is a relief to have some dry sunny weather. The last thing we want to hear is that it might be bad for us! However some people with ME struggle when the temperature rises and all of us can experience problems with prolonged high temperatures.

A few simple precautions can help us to make the most of the warm weather and avoid unnecessary discomfort:

### Keep out of the heat

- avoid going out in the hottest part of the day (11am – 3pm)
- reorganise your day so you are more active when it is cooler
- wear a hat when out, use high factor sunscreen
- wear light, loose-fitting clothes, preferably cotton or linen.
- cover yourself up - this may actually keep you cooler, especially if the heat is low in humidity

### Indoors

- use the coolest rooms in your home, as much as possible
- lying on the floor might be cooler as heat rises

- close the curtains in rooms that get a lot of sun
- keep windows closed while the room is cooler than it is outside. Open them when the temperature inside rises, and at night for ventilation.
- water external and internal plants, and spray the ground outside windows with water (avoid creating slip hazards) to help cool the air.
- turn off lights and electronic equipment that emit heat even in standby mode

### Stay cool

- take cool showers or baths, and splash yourself several times a day with cold water, particularly your face and the back of your neck
- tie up long hair in a pony tail
- run cold water over your wrists for 10 seconds on each hand. This will reduce your temperature for roughly an hour.
- soak your feet in a bucket of cold water. The body radiates heat from the hands, feet, face and ears, so cooling any of these will efficiently cool the body. Kids' paddling pools are great for adults feet too.
- try storing lotions or cosmetic toners in the refrigerator to use on body, including feet.

### Eat & drink

- drink regularly even if you do not feel thirsty – water or fruit juice are best.
- try to avoid alcohol, tea and coffee - they make dehydration worse.
- don't be tempted not to eat - try to eat more cold food, particularly salads and fruit, which contain water.
- carry a bottle of water with you. Freeze it first and it will stay cold longer and can also be used to roll on your skin.
- eat spicy foods - they make you sweat without actually raising body temperature. Once your skin is damp, you'll feel cooled by its evaporation

### Cooling aids:

- chillow pillow – a pillow filled with water that stays cool [www.chillow.co.uk](http://www.chillow.co.uk) or [www.amazon.co.uk](http://www.amazon.co.uk)
- migraine relief strips, such as *Kool n soothe*
- cooling sprays and gels
- keep cool scarf – made with a synthetic microporous material that is activated by water [www.keepcool.org.uk/keep\\_cool\\_relief\\_belt.htm](http://www.keepcool.org.uk/keep_cool_relief_belt.htm)
- fill a spray bottle with water and mist your face or the air around you – commercial ones vary in effectiveness
- put a metal bowl of salted ice in front of a fan, and adjust the fan so that the air is blowing over

the ice. Or, use one or more 2 litre bottles and fill them mostly full of water (70%) & rock salt (10%).

Leave 20% free for expansion. Freeze them, then place them in a large bowl (to catch the drips). Position a fan to blow on them. As the salty ice in the bottles melts, the air cools around them. The fan will blow that air at you. The water & salt in the bottles can be refrozen every night and used again repeatedly.

### Some people are at higher risk:

- Older age: women over 75 years old appear to be more vulnerable to the effects of heat than older men, possibly due to having fewer sweat glands and being more likely to live on their own.
- Chronic and severe illness: some conditions affect the way the body copes with heat. Medications that potentially affect renal function, sweating, thermoregulation or electrolyte balance can make people more vulnerable to the effects of heat.
- Unable to adapt behaviour: due to mental confusion, being bed bound or very young.

More info: <http://tiny.cc/e0f9zw>

## Holidays in the UK

### Free breaks at Kerry Farm

The Papworth Trust offer free short breaks at their cottages at Kerry farm near Newtown, Powys for people who need accessible accommodation and facilities. The next round of applications, for a break in 2014, will open in October 2013. You can ask to be added to the e-mail list.

Phone 0800 952 5000 Text 07860 021210 Email [info@papworth.org.uk](mailto:info@papworth.org.uk)

Write to: Papworth Trust, Bernard Sunley Centre, Papworth Everard, Cambridgeshire, CB23 3RG [www.papworth.org.uk](http://www.papworth.org.uk)

Another organisation that fund holidays for people with disabilities or on low incomes: [www.familyholidayassociation.org.uk](http://www.familyholidayassociation.org.uk)  
Family Holiday Association  
3 Gainsford Street London SE1 2NE 020 3117 0650

### There are many websites for holiday ideas e.g.

[www.openbritain.net](http://www.openbritain.net) accessible holiday ideas in Wales and England  
[www.livability.org.uk/services/accessible-holidays-for-disabled-people/](http://www.livability.org.uk/services/accessible-holidays-for-disabled-people/) includes a hotel in north Wales  
[www.goodaccessguide.co.uk](http://www.goodaccessguide.co.uk)



## Am I disabled?

**Yes, if you have....**  
*a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities.*

Equality Act 2010  
<http://tiny.cc/jjj7zw>

## Holidays Abroad

### Where to go?

[www.disabledaccesssholidays.com](http://www.disabledaccesssholidays.com) accessible locations and accommodation around the world  
[www.disabledholidaydirectory.co.uk](http://www.disabledholidaydirectory.co.uk) UK & overseas

# tips for the summer

## Travel insurance

Anyone with a medical condition should take out insurance before travelling abroad. Not all companies offer insurance for people with a pre-existing medical condition and quotes can vary immensely so shop around or use a comparison site, more than one if you can. E.g <http://medicaltravelcompared.co.uk> [www.moneysupermarket.com](http://www.moneysupermarket.com)

You will be asked to select your condition and answer a number of questions e.g:

### Myalgic encephalopathy

- In the last two years has this condition interfered with your activities of daily living?
- How many unplanned hospital admissions have you had for this condition in the last twelve months?

Be sure to name all your conditions e.g. Irritable Bowel, Depression, High Blood pressure. Each condition will attract a supplement. Conditions that are controlled by medication e.g. high blood pressure, will cost less than more unpredictable ones. Any problems that arise from a condition that is not listed will NOT be covered by the policy.

## EHIC

The European Health Insurance Card (EHIC) will entitle all UK citizens to treatment in the EU on the same terms as citizens of the country you are in. It is free, and you can get an application form from the Post Office or from the Department of Health website.

The card won't help with continuing medical treatment, such as blood tests or injections when abroad. For this, you need an E112, which needs to be authorised in advance by the Department of Health. <http://tiny.cc/psf7zw>

## Medication

Make sure you take enough supplies to last the holiday plus extra in case of delays. Consider dividing them into more than one package in case a bag gets lost (put them in your flight bag if flying, except for liquids). Check your medication isn't banned in the country you'll be visiting e.g. codeine (in Dubai, for example). It might be a good idea to get a letter from the doctor listing the prescriptions, or take your prescription form, just in case emergency supplies are required. Over the counter products can be very expensive in some countries.

Breakfast in the hotel was served from 7 till 10..... But by half 8 I couldn't eat another thing!

# research

## Norwegian Rituximab trial to go ahead

Following the results of the phase 2 clinical trial, which indicates that Rituximab appears to be a safe and effective treatment for at least a sub-group of people with ME/CFS, the Norwegian researchers now have funding from the Norwegian government to proceed with a phase 3 clinical trial.

This is a longer term study that involves larger numbers of patients and aims to confirm it is effective and monitor any adverse effects from longer term use.

### In the UK:

**The ME Association** - The MEA Ramsay Research Fund has funding ring-fenced for a Rituximab trial at the request of the donor. In addition they have set aside up to £50,000 from the Research Fund to help co-fund a well designed trial. They are also happy to join with other charities or funding bodies, to help co-fund a trial.

### Donate:

- by cheque made out to The MEA Ramsay Research Fund and send to The ME Association

- 7 Apollo Office Court, Radclive Road, Gawcott, Buckingham MK18 4DF
- Or by credit/debit card by calling MEA Head Office on 01280 818964 or 818968 and speaking to Gill or Helen. The donation will then be 'ring fenced' for two years.

**Invest in ME** have now decided to embark on a fund-raising exercise to raise funds specifically for a UK Rituximab trial. The target is £150,000 and over £10,000 has been raised so far. Donations can now be made to the separate Rituximab Trial Fund.

More info: <http://tiny.cc/ovn5zw>

### Donate:

- [online http://ldifme.org/donate](http://ldifme.org/donate)
- via bank transfer/cheque/salary payment as long as the Rituximab Trial Fund is specified – code BRF03RITUX.
- Bank Transfer  
Bank: Lloyds TSB Eastleigh  
Sorting code: 30-92-94  
Account number: 02252685

- \* Send cheques payable to 'Invest in ME' to:  
Invest in ME, PO Box 561,  
Eastleigh, Hants, SO50 0GQ

More info about Rituximab from the MEA: [www.meassociation.org.uk/?p=8459](http://www.meassociation.org.uk/?p=8459)

## Physical Rehabilitation survey

The peer-reviewed journal Disability and Rehabilitation has published the results of Action for M.E.'s survey into the experiences of people with ME/CFS who had undertaken physical rehabilitation therapies i.e. Graded Exercise Therapy (GET), Graded Activity Therapy (GAT) and Exercise on Prescription (EoP). Both positive and negative experiences were recorded

They found **positive experiences** of rehabilitation included:

- supportive communication
- the benefits of a routine linked with baseline setting and pacing
- the value of goal setting
- increasing confidence associated with activity.

**Negative experiences** included:

- poor communication,
- feeling pushed to exercise beyond a sustainable level,
- having no setback plan,
- and patients feeling blamed for rehabilitation not working.

More info: <http://tiny.cc/hnm5zw>

## Biobank gets £1m funding boost

The UK ME/CFS Biobank project has been awarded a grant totalling £1,029,411 (\$1,588,225) over three years by the US National Institutes of Health (NIH).

A biobank is a large collection of biological samples including tissues such as blood, which provides a valuable database for scientific research. Patients with an illness, as well as healthy people (controls), volunteer their tissues for inclusion, and each sample can be linked with detailed clinical information about the donor.

The grant will enable important research on the immunology and genetics of ME/CFS, which may lead to the discovery of much needed disease biomarkers. It will also help to expand the Biobank to store samples from over 500 participants, including almost 300 patients and over 200 controls (comprising healthy controls and people with multiple sclerosis), which will be made available to medical researchers internationally.

The Biobank was launched in 2011 and has been funded by Action for M.E., the ME Association, ME Research UK and a private donor. It is managed by the London School of Hygiene & Tropical Medicine (LSHTM)'s ME/CFS

research group called CURE-ME (*Creating clinical and biomedical Understanding through Research Evidence – For the ethical study of ME/CFS*)

<http://tiny.cc/upm5zw>

## WAMES view of collaborative research

3 major research collaborations have been announced over the last few months:

- On the 23rd of April 2013 the **UK CFS/ME Research Collaborative** (UK CMRC) was launched. Key ME charities and biomedical researchers have joined together with researchers who have previously conducted research with a more psychosocial approach to the illness, believing that this is a great opportunity to change the direction of ME research in the UK and attract more scientists
- Invest in ME (IiME) have chosen to join with the Alison Hunter Memorial Foundation (AHMF) of Australia believing that an international collaboration concentrating on biomedical research into strictly defined ME is the way forward. **IiME/AHMF BRMEC (Biomedical Research into ME Collaborative)** held a first meeting on 30th May in London.

- In the US the **OMI-MERIT (ME Roundtable on Immunology and Treatment)** is a strategic initiative of the Open Medicine Institute (OMI) and its collaborators to bring together leading clinicians and researchers to tackle the under researched disease of ME/CFS

- The MERIT group is focused on developing and applying a multi-factorial approach to the discovery of new diagnostic and treatment solutions for ME/CFS, particularly increasing the use of new technologies. Some UK charities are also supporting this.

WAMES wishes to see more biomedical research into ME as a matter of priority in the hope it will lead to a greater understanding of ME and the subgroups of CFS and uncover accurate diagnostic tests and appropriate treatment options.

We understand the desire of many people with ME and their carers to shun all research and researchers that take time and money away from biomedical research. ME has been sidelined and mocked by scientists and clinicians for too long. But we acknowledge the value of discussion and collaboration as a way for all to arrive at a common understanding.

Whether the UK CMRC will pro-

duce research that is well designed and implemented and that will benefit both people with ME and CFS, only time will tell. We will be watching all of these research collaborations with interest and wish them well on their journeys.

More info:

**OMNI Merit** <http://tiny.cc/ctm5zw>

**Phoenix Rising:** [http://](http://phoenixrising.me/archives/16786)

[phoenixrising.me/archives/16786](http://phoenixrising.me/archives/16786)

**IiME / AHMF meeting**

<http://tiny.cc/iuam5zw>

**A tale of 2 collaboratives**

<http://tiny.cc/dvm5zw>

## Mitochondrial dysfunction differs in CFS and FM

Spanish researchers found that differences in the mitochondria in people with CFS and Fibromyalgia (FM) could help diagnose the conditions and may be a potential target for research into treatments. <http://tiny.cc/2zm5zw>

## Cognitive problems & pain not related in CFS

Using questionnaires and objective tests on women with CFS, Belgian

# research

researchers found that cognitive impairment was significant in CFS but not related to the level of pain they experienced, leading to the theory that pain in CFS might be unique.

<http://tiny.cc/ilo5zw>

## Impaired information processing speed found in CFS

A slowing in information processing speed appears to be the main cognitive deficit seen in persons with CFS. Importantly, this slowing does not appear to be the consequence of other CFS-related variables, such as depression and fatigue, or motor speed.

<http://tiny.cc/u2m5zw>

## More research results

are posted on the WAMES news-blog at [www.wames.org.uk](http://www.wames.org.uk)

### Research: (Irregular noun)

That which I do for the benefit of humanity, you do for the money, he does to hog all the glory.

# young people

## Research evidence is poor

3 Australian researchers wanted to know just how much research had been done into treatments for young people with ME or CFS. The results of their survey are shocking!

- Only 24 articles based on 21 studies were considered significant enough to be reviewed.
- The quality of the studies is variable.
- Most assessed behavioural treatments which aim to change the way you think and act.
- They found 1 exercise programme and 1 immunological treatment.
- Not easy to compare studies because they used different ways of choosing participants and there were differences in the treatments.
- There is 'some' evidence that treatments using Cognitive Behavioural Therapy (CBT) might help, less evidence for multidisciplinary rehabilitation i.e. using a mixture of approaches.
- Little is known about the effects of treatments over time.

<http://tiny.cc/38q7zw>

## Wanted: Young people with big ideas

Are you 13-25? Need money, support or training to help improve your community?

**02thinkbig** helps young people launch ideas and programmes that benefit the places where they live. You provide the big idea we provide £300 and the support to make it happen.

Find out more  
<http://www.o2thinkbig.co.uk/>



### O2 Think Big Project Categories

Think Big funds all sorts of things. The only limit is your imagination.

**Think Campaigning** – make a stand and push for change

**Think Neighbourhood** – improve the local area

**Think Planet** – work for a better environment



**Think Learning** – share knowledge and ideas

**Think Expression** – help people discover their artistic talents



**Think Well-being** – inspire people to lead a healthier life

You can view examples of projects on the website but don't feel your project needs to be 'all singing all dancing'. Choose a project idea that suits your energy levels.

### Want to apply?

When you are ready to make an application just go to [www.o2thinkbig.co.uk/](http://www.o2thinkbig.co.uk/), read the entry criteria, register and complete the online application form. When you are asked for the Youth

Partner Promo Code please enter YOCY. Youth Cymru will provide info and advice to any young people in Wales who wish to make a project bid.

[www.youthcymru.org.uk](http://www.youthcymru.org.uk)  
[mailbox@youthcymru.org.uk](mailto:mailbox@youthcymru.org.uk)  
01443 827840 Monday to Thursday, 08:50 until 16:20 Friday, 08:50 until 15:20

Cymraeg: 01443 827844 Monday, Wednesday and Thursday, 09:30 - 15:00

## Help to study?

a useful page for anybody with a disability who wishes to go to university.

<http://tiny.cc/mbr7zw>

## Cardiff re:store project

Are you aged 16-25? Are you looking for an exciting volunteer opportunity for summer?

Are you a young entrepreneur who'd like to experience managing your own shop? Are you creative? Making music, art, dance etc?

Be a part of **somewhereto\_re:store!** A massive campaign coming up this summer that's all about young creative entrepreneurs taking over the Cardiff high street for 6 weeks kicking off on the

weekend of July 20th and 21st. Some money is available to support selected projects and volunteers.

Don't Miss the Chance to showcase all the things you love, boost your CV with real life experience, gain first hand experience and meet new people this summer! For more information about how to get involved contact [cat@somewhereto.org](mailto:cat@somewhereto.org)

More about the scheme: <http://somewhereto.com/>  
Cardiff Young People's site: <http://thesprout.co.uk/>

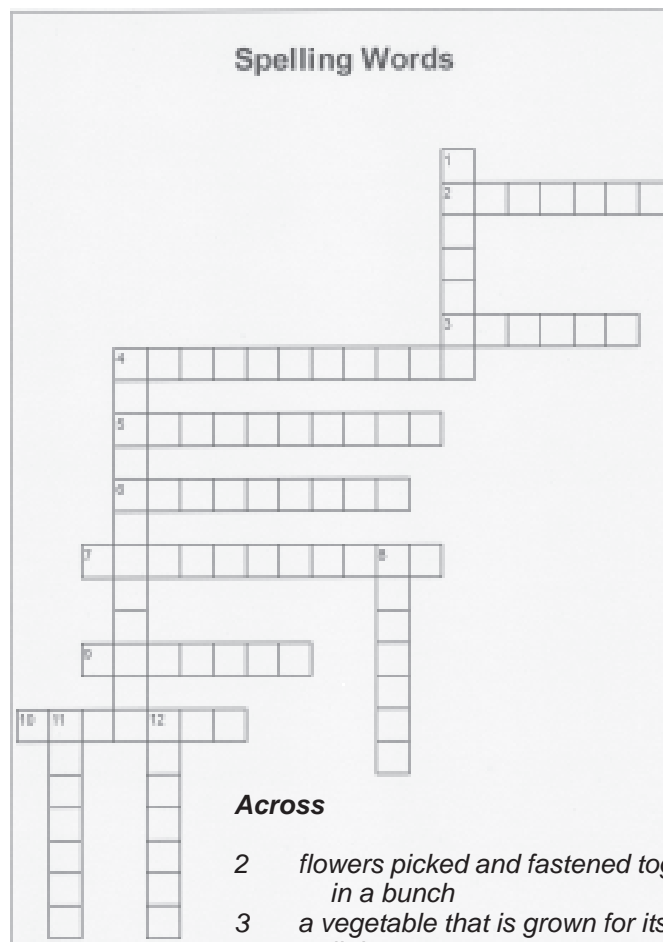
## Did you know?

A survey of 500 young people with ME found they experienced a wide range of symptoms. The most common were:

- Fatigue 14%
- Headache 10%
- Neurological disturbance\* 7%
- Sleep disturbance 5%
- Eye pain 4%
- Muscle pain 4%
- Abdominal Pain 3%
- Depression 2%
- Joint pain 2%
- Painful glands 1%

\* neurological disturbance (dizziness, disturbed balance, difficulty with concentration, poor temperature control)

[AyME / OU survey]



### Across

- 2 *flowers picked and fastened together in a bunch*  
3 *a vegetable that is grown for its long, light green stems*  
4 *to make room for*  
5 *the quality or state of being brilliant*  
6 *to make someone to feel confused and foolish in front of other people*

### Down

- 1 *The period of time that one is gone*  
4 *A shortened form of a written word*  
8 *having or showing general ability*  
11 *Suitcases, trunks and personal belongings of travelers*  
12 *to make someone believe something that is not true*

## All fall down for ME video

A video of the All Fall Down For ME event outside the Houses of Parliament in London on ME Awareness day in May is on YouTube.

The event saw protesters join together in a two minute 'collapse' to represent the pain and fatigue experienced by people with ME. <http://tiny.cc/a7j7zw>

## Let's Do It For ME success

Let's do it for ME! the patient-driven campaign to raise awareness and funds for a UK centre of excellence for translational biomedical ME research has reached its fund- raising target of £100,000.

The aim is to also provide clinical assessment, diagnosis and treatment for patients, training and information for healthcare staff, based around the Norwich Research Park in the east of England. It also aims to work collaboratively with international biomedical researchers.

<http://ldifme.org/a-uk-centre/>



## Invest in ME DVD

The 2013 Conference DVD can be ordered online or by sending a cheque for £14 to: Invest in ME, PO BOX 561, Eastleigh SO50 0GQ, Hampshire

Cheques should be made payable to Invest in ME. <http://tiny.cc/pdk7zw>

# carers

## First aid is for everyone

A blocked airway can kill someone in three to four minutes, but it can take more than eight minutes for an ambulance to arrive. So a simple procedure such as opening someone's airway can save their life whilst waiting for emergency help to arrive.

You're more likely to give first aid to someone you know than to a stranger. Knowing what to do will allow you to react rapidly to help relatives, friends or colleagues if an accident does happen.

### Top 8 first aid misconceptions

#### **1. You should put butter or cream on a burn.**

The only thing you should put on a burn is cold water - keep the butter for cooking. Put the affected area under cold running water for at least ten minutes.

#### **2. If you can't move a limb, it must be broken (or if you can move a limb, it can't be broken).**

The only accurate way to diagnose a broken limb is to x-ray it. If you suspect a broken bone try to support the injury with a cushion or

items of clothing to prevent unnecessary movement. As soon as possible call 999.

#### **3. The best way to treat bleeding is to put the wound under a tap.**

If you put a bleeding wound under a tap you wash away the body's clotting agents and make it bleed more. Instead put pressure on the wound with whatever is available to stop or slow down the flow of blood. As soon as possible call 999. Keep pressure on the wound until help arrives.

#### **4. Nosebleeds are best treated by putting the head back.**

If you put the head back during a nosebleed, all the blood goes down the back of the airway. Instead advise them to tilt their head forwards and ask the person to pinch the end of their nose and breathe through their mouth.

#### **5. If someone has swallowed a poison you should make them be sick.**

This won't help and with some poisons if it burnt on the way down, it will burn on the way up. The best thing to do is get medical advice and find out what poison was taken, at what time and how much.



#### **6. If you perform chest compressions on someone whose heart is beating you can damage their heart.**

It's difficult in emergency situations for non-medics to assess whether a person's heart is beating. Although not ideal the evidence is that it isn't dangerous to do chest compressions on a casualty whose heart is beating.

#### **7. You need lots of training to do first aid.**

You don't - what you mostly need is common sense. You can learn enough first aid in a few minutes to save someone's life – whether it's from a book, attending a course or

watching videos online.  
([www.redcross.org.uk/firstaid](http://www.redcross.org.uk/firstaid))

#### **8. You need lots of expensive equipment to do first aid.**

You don't need any equipment to do first aid, there are lots of ways to improvise anything you need.

#### **Remember: anyone can save a life!**

[From the BBC website]

#### **Fast first aid tips**

<http://tiny.cc/zrq5zw>

Not online? Look for local classes run by the Red Cross or St John's ambulance

## House of Commons debate on carers

<http://tiny.cc/r0q5zw>

## The Carers Strategy for Wales was updated in June.

<http://tiny.cc/11q5zw>

## Carers count – count me in!

Don't forget to register as a carer. It will make it easier to access information or support when you need it and it gives a stronger 'voice' to your local carers forum. Contact your local council and register with your GP.



## Prepared to care?

This year the theme for Carers Week (10th to 16th June) was Prepared to Care?

Every day at least 6,000 people in the UK start caring. Becoming a carer can impact significantly on a person's life – it takes time, energy, can leave you isolated and can be costly. The results of a survey of carers has been published in the report: A state of caring. It found:

- Almost a third (31%) of those caring for 35 hours or more per week receive no practical support with caring.
- Over half (56%) of carers who gave up work to care spent or have spent over 5 years out of work as a result.
- More than 4 in 10 (44%) of carers surveyed have been in debt as a result of caring.
- 84% of carers surveyed said that caring has a negative impact on health, up from 74% in 2011-12.
- Almost half (46%) of carers surveyed have raised concerns about poor quality care services.
- Over half (54%) of those caring for someone discharged from hospital in the last year had either not been consulted about their discharge or had only been consulted at the last minute.

Read the report:  
<http://tiny.cc/5nq5zwarers>

## Young carers see education and job prospects damaged

The BBC reports that about 250,000 carers in Wales and England are young people and that their education and future job prospects are at serious risk.

In its report, called Hidden from View, the Children's Society says that it found young carers had "significantly lower" educational attainment at GCSE level - the equivalent to nine grades lower overall - than their peers.

Young carers were more likely than the national average to be "not in education, employment or training" (Neet) between the ages of 16 and 19.

Children's Society chief executive Matthew Reed said: "Our new analysis shows that caring can cost children dearly. They are missing out on their childhoods and school, gaining fewer qualifications and therefore are less likely to earn a decent living. "All children must be allowed to thrive and enjoy their childhoods."

Children's Society report:  
<http://tiny.cc/g31c0w>

BBC Report  
<http://tinyurl.com/c9uzkt9>

## The life no-one sees

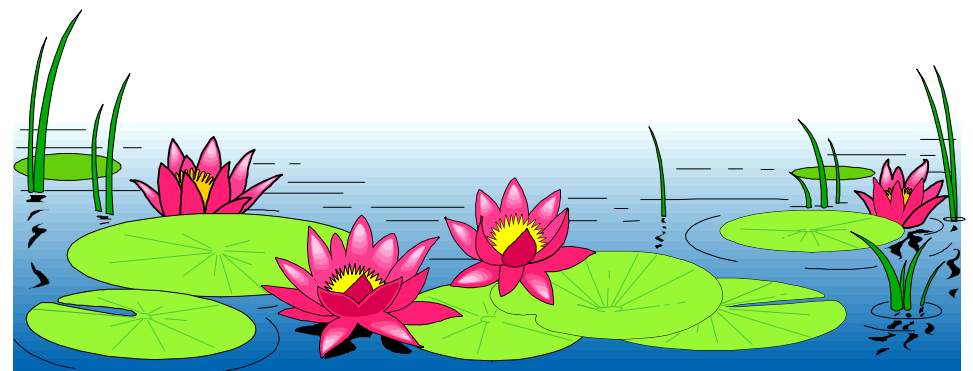
Each morning I wake and do what I must,  
And I fight the feeling that I might combust,  
I hide behind a warm smile and I work for free,  
This is the life that no-one sees.

Each noon I cook, I clean and I care,  
Sometimes I sit there just brushing her hair,  
I hide behind bright eyes and I work for free,  
This is the life that no-one sees.

Each night I lay awake, wonder how it would be,  
If our lives were normal, but I can only dream,  
I hide behind joyous laughter, and I work for free,  
This is the life that no-one sees.

Yet I still love life, I strive to make her better,  
I am the glue holding this all together,  
I am no longer hiding, and my words are free,  
This is the life that I want you to see.

*Written by young carer Kayleigh Jones*



# 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 assistance in setting up local meetings

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

**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** meets in Penrhyncoch, Aberystwyth. Contact Dr Derryan Paul on 01970 828896 [edpaul@phoncoop.coop](mailto:edpaul@phoncoop.coop)

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

**Pembrokeshire** Get togethers 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

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## wames on the web

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facebook [#WAMESMECFS](https://www.facebook.com/WAMESMECFS)

e-group  
<http://health.groups.yahoo.com/group/WAMES/>

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