



February 2013

me voice

The Wames Magazine

WAMES
Welsh Association of ME & CFS Support

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Spring flowers at Frongôg

me voice

me voice is published 5 times a year. You can subscribe to the paper copy in black and white for £10 p.a., or receive it in colour either free by email, or read and/or download it from our website www.wames.org.uk

email tony@wames.org.uk
or write to
WAMES Subscriptions
The Coach House Frongôg
Aberystwyth SY23 3HN

contribute

Topics for future issues:

- what has helped or hindered your recovery or the management of your ME?
- how has poetry helped you? (for the April issue)
- running a social enterprise
- coping with travel and holidays

Could you supply information on or edit these pages?

- benefits and money
- carers and caring
- young people with ME
- living with ME tips

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 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.

email them to:
admin@wames.org.uk

or send them to:

The Coach House Frongôg
Aberystwyth SY23 3HN

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and 1 Dec.

WAMES

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about wames

Welcome to the first issue of **me voice: the WAMES magazine**. We're excited about this new venture, and hope it will provide a distinctly Welsh context for sharing news and views surrounding ME and CFS.

First, a big thankyou to Vicky Smith for the design of the magazine. Second, we plan to expand its scope to include tips for living with ME, personal experiences and local news. Please let us know what you think of the magazine and your ideas for further improvements in layout and content for future issues.

The Welsh Association of ME & CFS Support (WAMES) is a voluntary organisation which gives a national voice to people with ME & CFS in Wales, their carers and families, in order to improve services, access to services, awareness and support.

Our Vision is for a Wales where adults and children with ME and CFS and their carers are taken seriously and treated with respect, where diagnosis, treatment and services are accessible without a battle.

Our campaigns

WAMES has been campaigning at a national level since 2001 for service improvements. Eventually in 2011 the Health Minister told the Local Health Boards to develop services for ME & CFS in line with the Welsh care pathways and NICE guidelines.

Since then WAMES has been talking to the Health Boards about ways that services can be improved using the helpful recommendations from the care pathways but we are also highlighting the unhelpful recommendations about management and treatments which are not suitable for people with neurological ME.

We also seek to bring about change by contributing to consultations and surveys, and by working with other groups: Wales Neurological Alliance; Long Term Conditions Alliance Cymru, local alliances and the Hardest Hit Campaign (welfare reform).

AGM

Our short AGM will be held on March 23rd in Dinas Powys and is open to all members. If you wish to become a member, and/or attend please contact Jan.

wames volunteering opportunities

- Secretary
- Awareness raising
- Welsh language
- Publicity
- Online
- Young people
- Communication
- Awareness raising
- Volunteer coordinator

me awareness week: 6-12th May

Tell us about your event and we'll advertise it in the April issue of **me voice**, FB, twitter etc. Need awareness ideas? Contact Jan enquiries@wames.org.uk

fundraise or donate:

WAMES depends on donations and grants. Increase your donation - Gift aid it!

wames on the web

Follow us on twitter and facebook
<https://twitter.com/WAMESMECFS>
www.facebook.com/WAMESMECFS
e-group
<http://health.groups.yahoo.com/group/WAMES/>

get involved

help us campaign

Complete our survey and / or tell us your story so we can provide health boards and social services with 'evidence' that improvements are desperately needed – the deadline has been extended.

Complete online or request it in paper or electronic file.

contact us

helpline@wames.org.uk
0292 051 5061

Secretary and campaigns

Jan Russell 01970 636515
enquiries@wames.org.uk

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sylvia@wames.org.uk

Young People's contact

Michelle Penny
michelle@wames.org.uk

Publications Officer

Tony Thompson
tony@wames.org.uk

www.wames.org.uk

news from wales

Get-togethers

MWWMEG AGM

The final AGM of **Mid and West Wales ME Group** will be on Fri, 8 March at The Coach House, Frongôg at 11.00 am. Ring Tony on 01970 636515 for directions. Ring Derryan on 01970 828896 for a lift. NB Meeting Room at Frongôg is upstairs. Please bring slippers.

Clwyd ME Support Group is

holding a lunch meeting for people in North East Wales at 12pm on Saturday 9th March at the Beaufort Park Hotel, New Brighton, Near Mold. This is an opportunity for people with ME, CFS and Fibromyalgia, their families and other carers or friends to enjoy a reasonably priced lunch and meet with other people who understand the difficulties their illness brings, and support each other. For more info email clwydme@googlemail.com or ring 01745 822953

Swansea valley meeting

Contact Jan if you are interested in meeting others with ME and their families in the Swansea valley (Ystradgynlais, Ystalyfera, Pontardawe, Clydach) during March. enquiries@wames.org.uk Or ring Kayleigh 07429617002

Carmarthenshire ME Group

Meets Cae Maen Day Centre, Coleshill Terrace, Llanelli SA15 3BT at 2pm Sat 13 April. Please ring John James pm 01267 233793 for further details. If you have not been to a get-together before, please ring as it is sometimes necessary to cancel a meeting or change the venue.

North Ceredigion Group

meets Tuesday, March 12th 2-4pm at 11 Nant Seilo, Penrhyncoch. Please contact Dr Derryan Paul 01970 828896 edpaul@phonecoop.coop for a lift or directions.

North Ceredigion Yoga Class

11 Nant Seilo, Penrhyncoch on Thursdays 2-30-4.00pm. Contact Derryan 01970 828896 edpaul@phonecoop.coop for more information

ME Support in Glamorgan (MESiG)

meets March 4th, 11am -12.30pm at The Community Shop, Llangrannog Road, Llanishen, Cardiff CF14 5BL Contact: Christalla Bailey, 029 2076 2347 christallaconstantinou@talktalk.net



Influence health & social care training

Would you like to influence the next generation of health and social care professionals training in Swansea?

The College of Human and Health Sciences invites patients and carers to be involved in their training programmes so that students hear about local people's experiences and learn how to be the best health and social care staff. This is a great opportunity to raise awareness of ME and other conditions!

You could be involved in:

- interviewing students
- planning programmes
- teaching in the classroom
- making a digital story
- programme meetings

To find out more contact: Julia Terry, 01792 513801

j.terry@swansea.ac.uk

www.swansea.ac.uk/humanandhealthsciences

Consultations

Cross border healthcare and patient mobility

This consultation sets out the Welsh Government's approach to implement a newly adopted directive of the European Union. It clarifies people's rights to access healthcare in another member State of the European economic area. Closing date 15 March 2013 <http://tiny.cc/o42wsww>

Swansea services

The overall purpose of this new plan is to simplify the delivery of services and to ensure that everyone is working towards the same agreed priorities.

The Single Integrated Plan will replace the current Community Strategy and the plans for Community Safety; Health, Social Care and Wellbeing; and Children and Young People.

Survey for individuals: <http://tiny.cc/u2vpsww>

There are also a number of background documents that you might like to look at before completing the survey:

<http://tiny.cc/q4vpsww>
Tel: 01792 544009

Closing date 4 March 2013

CFS/ME NICE guidelines review

At the beginning of January, The ME Association wrote to NICE (National Institute for Clinical Excellence) to ask for clarification on what was happening regarding the expected 2013 review of the NICE guideline on CFS/ME.

They replied saying the review process is being overhauled and more information would be announced during 2013/14.

ME Association news item:
<http://tiny.cc/x33wsw>

ME & the menopause

Gina Bailey thanks all those who contributed their experiences of the menopause to her book which is now available from Amazon.

The Menopause and M.E. (C.F.S)
by Gina Bailey - Paperback (£9.99 + p&p) and e-book (£4.58).

ME support groups can order 5 or more copies (signed if wished) from Gina for £8 each, P&P free. Payment by cheque payable to Gina Bailey or Paypal
11 Savage Road, Bridlington, East Riding of Yorkshire YO15 3HW
ginahardstaff_8@hotmail.com
[Let Jan know if you would be willing to review this book for **me voice**]



Wheelmate

There is now a website (and smartphone app) for wheelchair users to help find wheelchair accessible toilets and parking spaces.
www.wheelmate.com

New journal about fatigue

The first two issues of a new journal from the International Association of CFS/ME are available free online.

Fatigue: Biomedicine, Health & Behavior is an international, interdisciplinary journal that addresses the symptom of fatigue in medical illnesses, behavioural disorders, and specific environmental conditions.

Access it and download articles from <http://tinyurl.com/b3nyd2m>.
www.iacfsme.org

BT – 195 card

This is a free Directory Enquiry free service for people who have difficulty in reading or handling the phone book.

Call FREEPHONE 195 and talk to an operator: Monday to Friday 9am to 4.30pm.

The Pin Registration Team will ask you some questions, then send you a form with a reply paid envelope. You then need to sign the form, get your GP or other health professional to sign it too, and send it back in the envelope provided. You will then be sent a PIN number.

When you need to know a phone number, dial 195 (this is free), say your PIN number and you will be told the number you want.

More info: www.bt.com
195registration@bt.com
Trefone users need to contact TYPETALK on 0800 7311 888 or go to www.typetalk.org

House of Commons written Q&A on ME

On 17th Jan 2013 Mr Anderson asked the Secretary of State for Health:

other news

1. what recent steps he has taken to ensure that every child and adult with myalgic encephalomyelitis receive suitable and appropriate treatment for their condition; [137185]

2. what recent assessment he has made of the 2007 National Institute for Health and Clinical Excellence guidelines on chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) and the Medical Research Council sponsored trial into CFS/ME conducted in February 2011. [137186]

Mr Lamb answered that no assessments of (1) or (2) have been made but they understood that CBT and GET were “moderately good treatments” and, in effect, they were leaving the consideration of this to NICE and of the PACE trial to the MRC to decide. There is a paragraph on doctors’ responsibility to provide the necessary care to patients, mindful of the recommendations.

The answer finishes with an assurance that the Government has prioritised improved care for people with long-term conditions and the Government’s actions that prove this. <http://tinyurl.com/a4mjnfe>

can't work? why not volunteer!

If you feel ready to do something new, but you know you are not well enough yet to look for employment...

Or if you hope you will be looking for 'a job' in the not too distant future... **Consider becoming a volunteer.**

What volunteering can offer you:

- help you learn new skills;
- help you brush up on old skills
- help give you confidence
- widen your horizons
- make a difference to people and causes
- improve your employability – add to your CV
- help you learn more about yourself
- can give training and references
- be fun and rewarding!

What could it involve?

- work from home or at a local office or in the community
- work at your own pace or to a timetable
- be creative or practical
- use skills or do the boring jobs nobody else wants to do

- take on a challenge or use existing knowledge
- be part of a team or work on your own
- work on short term project or get involved long term
- receive expenses and if appropriate, training and equipment

What you can offer – compile your volunteering CV:

- how much time, and when and for how long?
- at home or elsewhere?
- any limitations due to health?
- can you travel? do you have your own transport?
- what skills or experience do you have?
- would you be willing to learn new skills?



What's available?

There are many different types of volunteering opportunities available

WAMES and local support groups always need help.

If you do not want to focus on ME but still want to be involved with helping people with health and disability issues in your area, there are many opportunities and your involvement will also give you opportunities to raise awareness of ME if you wish e.g.

- Community Health Councils reps
- Community health champions
- Befriending / sitting
- Mental Health first aid
- Patient Transport

• Advice: CAB, disability rights etc.
Or maybe you would like to do something completely different?
e.g.

- gardening
- maintain a churchyard
- mentoring (using your skill to train or support)
- cutting toe nails
- leading a singing group

the list is endless!

Contact your local Volunteer Bureau – they are all over the country (contact numbers on back page) or look for opportunities at www.volunteering-wales.net/ www.gwirvol.org for young people.

See list of volunteer centres on back page.

Volunteering is not for me – what are my options?

Consider setting up a Social enterprise project or a small business or doing a short term internship.

We'll feature those in future issues. If you have experience of any of them, please get in touch and share your insights.

Sick and disabled people all over the country are being assessed as fit to work and have their disability benefits withdrawn.

Did you know?

- More than 40% of these decisions are appealed
- Nearly 40% of the appeals are successful.
- The assessments cost £110 million
- The appeals cost £60 million a year
- 1300 people have died after being put into the work-related activity group
- 2200 people have died before their assessment is complete
- 7100 people die after being put into the support group
- there are 2.5 million unemployed, and an average of eight people chasing every vacancy.

[source: IL newsletter]

Why We're Not Benefit Scroungers

Graduate Stef Bensted developed ME while studying for a Phd at Cambridge University. She began to blog about disability, chronic illness and the welfare system and then wrote a book aiming to provide a bomb-proof argument

against the idea of benefit fraud and a wilful sickness culture, a damning indictment of the processes used by governments to identify those who should be receiving help, and sobering tales of ordinary people's struggles against a range of illnesses, that could strike any one.

More information, including extracts from the book, can be found on her website www.aidaaleksia.com £4.50 for print copy, £1 for pdf.

A fair society?

Dr Simon Duffy of the Centre for Welfare Reform has published a report showing in detail how the most vulnerable in our society are being targeted for the most cuts in benefits as they fall into the categories that are liable for cuts on several counts. He believes the cuts will not solve the current economic crisis, but will lead to greater injustice, social damage and increasing costs in other parts of the welfare system.

A fair society? How the cuts target disabled people
<http://tinyurl.com/a4vsxnb>

A Vimeo illustrating the unfairness of the cuts (3 mins)
<http://vimeo.com/57552944#>
[NB a vimeo is a silent film or programme of slides]

April 2013 Benefits & social care changes

- Local council tax support replaces council tax benefit.
 - Mandatory reconsideration and direct lodgement of appeals with HM Courts and Tribunals Service (HMCTS) for universal credit and personal independence payment.
 - Community care grants and crisis loans for general living expenses (including rent in advance) will be abolished and replaced by new local provision i.e. Welsh government.
 - Crisis loan alignment payments and other crisis loans paid due to issues with benefit will be replaced by a new national scheme of Short Term Advances. This will be administered by the Department for Work and Pensions.
 - Total weekly benefits (jobseekers allowance, income support, employment support allowance, housing benefit, child benefit, carers allowance and later the new universal credit) will be limited to £500 a week for lone-parents/couples or £350 per week for single claimants. This benefits cap does not apply to households where someone is claiming working tax credits or getting disability living allowance.
 - Launch of universal credit pathfinder to demonstrate how the new scheme will work.
 - From 8 April working age disability living allowance (DLA) will be replaced by a new personal independence payment (PIP) in pilot areas in England.
 - The level of in-year rises of income that will be disregarded from calculations of tax credit entitlement will decrease from £10,000 to £5,000.
 - Local housing allowance rates will be uprated in line with consumer price index (CPI).
 - Housing entitlements for working age people in the social sector will reflect family size aka 'Bedroom tax' i.e. benefit reduced if you have more bedrooms than you need.
 - From 5 April the Simplified PAYE Deduction Scheme (SPDS) will close. The SPDS provides an alternative to standard PAYE for non – business employers. It was intended to offer a simpler system particularly for domestic employers or elderly/disabled individuals employing carers.
- More info
<http://tiny.cc/brypsw>

welfare

welfare

ESA changes

The Wearespartacus website has posted a 10-page report on changes to the Employment Support Allowance procedures at <http://tinyurl.com/bx58j4s>

They claim that the regulations are presented as minor clarifications, but in fact represent fundamental changes in how capability for work is to be assessed.

There are positive changes to allow more cases to be placed in the Support Group without full assessment. However, these are overshadowed by changes that will clearly reduce entitlement overall.

The problems fall into two areas, likely to lead to claimants' capability being overestimated:

- The assumptions that can be made by an assessor about ability to function if aids or medication were used.
- Which symptoms can be considered in which parts of the assessment.

Dr Charles Shepherd commented: "The new regulations are going to make it almost impossible for people with ME/CFS (physical disease) to score points in the



mental health descriptors in relation to cognitive dysfunction. The only way they will now be able to do this is through having a separate mental health diagnosis (i.e. depression) as well".

"This is the complete opposite to what the Fluctuating Conditions Group set up by the Government's independent adviser on the Work Capability Assessment (Professor Malcolm Harrington), of which the Countess of Mar's Forward ME Group is part, have recommended and is now being tested by the an Evidence-Based Review set up by the Department for Work and Pensions."

EDM To Annul Changes to ESA

<http://tiny.cc/h0ypsw>
Caroline Lucas (Green Party MP for Brighton Pavilion) has tabled an

Early Day Motion (EDM) 947, (<http://www.parliament.uk/edm/2012-13/947>) to ask that the Employment and Support Allowance (ESA) amendments be annulled. So far, 28 MPs have signed, only 3 from Wales.

The amendments made to the ESA mean that claimants can only score on either the physical descriptor for a physical illness or the mental descriptor for a mental illness

The Government has produced a document at <http://tinyurl.com/bjgfkyp> explaining the amendments to the regulations.

Please contact your local MP at their office or at www.theyworkforyou.com if you would like them to sign the EDM.

Pat's petition

On February 7th some of the team at Pat's Petition (the group campaigning for a Cumulative Impact Assessment of the way in which welfare reform is having a disproportionate impact on disabled people and carers), went to meet Liam Byrne the Shadow Work and Pensions Secretary, and Anne McGuire. The meeting was very successful. Liam is determined that he will give them an Opposition Day Debate as soon as he can, calling for a Cumulative Impact Assessment – if possible before the budget.

The petition closed in November with 62,706 signatures, failing to gain the required number of 100,000 signatures for a Commons debate. Keep up to date at <http://carerwatch.com/>

Wow petition

The Disabled People Against Cuts website calls for a Cumulative Impact Assessment of Welfare Reform, and a New Deal for sick & disabled people based on their needs, abilities and ambitions. Sign at <http://tinyurl.com/aunec7b>

MPs Criticise Atos in Debate

On 17th January a Commons debate united politicians from all parties. It was introduced by Labour back-bencher Michael Meacher who said that over 30 MPs wanted to speak out against Atos, the private contractor which administers the government's work capability assessments.

In his speech he gave just a few examples from hundreds of dreadful outcomes suffered by his constituents and a synopsis of the history and 13 shortcomings of Atos, calling for action from the government. Many MPs gave emotional accounts of how very sick individuals had been incorrectly assessed and told to return

to work. Some of them later died, they said, and MPs told of others who had killed themselves or become suicidal following such decisions.

The transcript of this debate can be found here -

<http://tiny.cc/n4ypsw>

or watch the recording of the debate here - <http://tiny.cc/l5ypsw>

Guardian article by Amelia Gentleman <http://tinyurl.com/a3jf37q>

See also www.guardian.co.uk/society/atos the Guardian list of 74 articles critical of Atos and 2093 articles on the deleterious effects of cutting benefits at www.guardian.co.uk/society/benefits

ESA descriptors

This might be useful to anyone currently undergoing a benefits review: a list of the ESA descriptors and how many points are awarded for each.

<http://tiny.cc/wlypsw>

House of Commons written Q&A: CFS, ESA & DLA

19th Dec 2012

Kate Hoey: To ask the Secretary of State for Work and Pensions how many people with chronic fatigue syndrome as their primary condition received:

(a) employment and support allowance and

(b) disability living allowance in

(i) Vauxhall constituency and

(ii) England and Wales since May 2010. [131482]

Mr Hoban: Information on how many people with chronic fatigue syndrome as their primary health condition received employment and support allowance (ESA) is not readily available and to provide this would incur disproportionate cost.

Information on the number of recipients of disability living allowance (DLA) with main disabling condition of chronic fatigue syndrome by area from May 2012 to February 2012 is:

Month	England	Wales	Vauxhall
May 2010	28,200	1,800	
May 2011	32,110	2,000	50
Feb 2012	34,910	2,130	60

<http://tinyurl.com/aonpcb2>

House of Commons Written Q&A: ME, DLA & disability premium

20th Dec 2012

Stephen Gilbert: To ask the Secretary of State for Work and Pensions how many people have been refused (a) disability living allowance and (b) disability premium for housing benefit on the grounds that

myalgic encephalomyelitis (ME) is an ineligible criterion in each of the last five years; and if he will make it his policy to extend those allowances to people with ME. [134621]

Esther McVey: Entitlement to disability living allowance (DLA) is not based on having a specific health condition, but depends on what help the person needs with personal care as a result of their disability, and/or the extent of their mobility difficulties. No one, therefore, has been refused DLA on the grounds that myalgic encephalomyelitis is an ineligible criterion. Anyone who meets the eligibility criteria will be awarded DLA.

Disability premium is payable in housing benefit and council tax if the claimant is receiving a qualifying benefit or is registered blind or satisfies the incapacity for work condition. A person cannot qualify for a disability premium for housing benefit or council tax benefit on any grounds if the claimant has, or is treated as having, limited capability for work or has reached the qualifying age for pension credit and neither the claimant nor partner is getting income support, income-based JSA or income-related ESA. <http://tinyurl.com/aynynhx>

welfare

APPG & Welfare

Following the recent meeting of the All Party Parliamentary Group (APPG) on ME held on Tues 15 Jan 2013, which focused on Welfare, Chair Annette Brooke MP has invited officers of the APPG to meet with Mr Jerry Ashworth (Atos) and Dr James Bolton (DWP) on 26th February at 3pm. The discussion will focus on issues with the Work Capability Assessment for people with ME.

The minutes: <http://tiny.cc/ndzpsw>
The postponed meeting on the severely affected, has been rescheduled for Wed 13 March, 2.30pm, Room O, Portcullis House, Westminster. See the agenda: <http://tiny.cc/uezpsw>

Whilst these meetings will not be open to members of the public, if you have any particular points you would like to raise, please notify your constituency MP and /or ask them to attend the APPG. For general queries, contact the secretariat: Tristana@ActionforME.org.uk

young people

ME makes us miss out on so many fun and important things in life. Here are some ways to find out what is happening in Wales.

CLIC Online

CLIC is an online channel and printed zone offering information, news and advice for all young people aged 11 to 25 in Wales on a wide range of subjects and issues, including where to get support.

The focal point of CLIC is interactive websites which allow you to upload articles, pictures, videos and themes, and to publicise events and activities.

In addition each county is getting its own site which brings you the news, organisations and information for your area. Follow CLIC on twitter, FB, you tube and tumblr. www.cliconline.co.uk

Have your say!

Funky Dragon is the children and young people's assembly for Wales.

Its mission is to enable children and young people in Wales to get their voices heard by Government and others who make decisions about policies and services that affect their lives.

Sign up for their newsletter (only email) and keep up to date with what's happening and give your opinion e.g.

- Do we need a Public Health Bill?
- Why should Wales keep the current system of GCSEs and A-Levels?

- Do you think that young people in Wales will be disadvantaged by not being in the same system as England?
- Is it better to have modular examinations and continuous assessment or end of course exams?
- What do you think should be done to raise awareness of the issues linked to too much screen time for children and young people?

www.funkydragon.org
enquiries@funkydragon.org

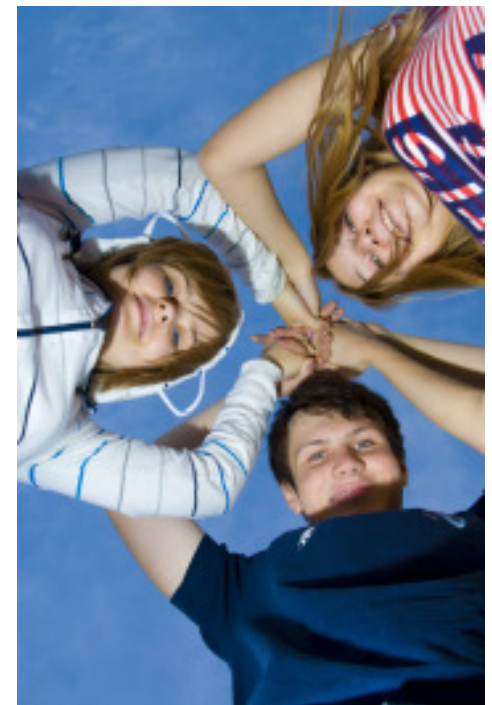
Swansea office 01792 450000
Wrexham 01978 358987

Youth volunteering

Volunteering is a good way to help yourself at the same time as helping others. You can try something new, have fun and even get some qualifications or experience for your CV. And there are opportunities for different levels of health.

GwirVol supports young people aged 14-25 to get involved in volunteering. There are special youth advisers in the 22 volunteer centres who can give info about volunteering opportunities, training and what employers are looking for.

www.gwirvol.org



Zoom film festival

Wales' largest film festival for young people will take place from Monday 11th – Friday 15th March 2013.

Films from around the world will be shown, plus workshops and masterclasses in all aspects of filmmaking.

Festival events are happening in Rhondda Cynon Taff, Merthyr Tydfil, Blaenau Gwent, Torfaen, Caerphilly, Caernarfon and Pembrokeshire.

More info: www.zoomcymru.com
and Zoom HQ at The Factory, Porth on 01443 888337





young people

Low energy activities

Tell us what you do for fun, without breaking the energy bank.

In the next issue...

...we'll be asking if poetry is cool?

If you write or read poetry of any kind (ballads, rap, sonnets, haiku etc), whether to describe what its like to have ME or watch someone close with it, or to escape from the limitations of the illness, get in touch. Send us your poems and tell us what you like, why you like it and what inspires you.

me
awareness
week
6 - 12 may 2013

Exam Howlers from 16 year olds

Q. Name the four seasons.

A. Salt, pepper, mustard and vinegar.

Q. Explain one of the processes by which water can be made safe to drink

A. Flirtation makes water safe to drink because it removes large pollutants like grit, sand, dead sheep and canoeists.

Q. How is dew formed?

A. The sun shines down on the leaves and makes them perspire.

Q. What causes the tides in the oceans?

A. The tides are a fight between the earth and the moon. All water tends to flow towards the moon, because there is no water on the moon and nature abhors a vacuum. I've forgotten where the sun joins the fight.

Q. What are steroids ?

A. Things for keeping carpets still on the stairs.

Q. What happens to a boy when he reaches puberty?

A. He says goodbye to his boyhood and looks forward to his adultery.

Q. Name a major disease associated with cigarettes.

A. Premature death.

Q. How can you delay milk turning sour?

A. Keep it in the cow.

Q. How are the main 20 parts of the body categorised (e.g. the abdomen)?

A. The body is consisted into 3 parts - the brainium, the borax and the abdominal cavity. The brainium contains the brain, the borax contains the heart and lungs and the abdominal cavity contains the five bowels: A, E, I, O and U.

Q. Give the meaning of the term 'Caesarean section.'

A. The caesarean section is a district in Rome.

Q. What is a seizure?

A. A Roman Emperor. (. . . Julius Seizure ; I came, I saw, I had a fit?)

Q. What is a terminal illness?

A. When you are sick at the airport.

Q. What is a turbine?

A. Something an Arab or Shreik wears on his head.



me q&a

What makes ME different?

Normal activities make you feel worse for a while, although you may not notice this until the following day, or later. This is called the post-exertional response or relapse.

What is pacing?

A way of balancing physical and mental activities with rest every day and learning not to overdo it in order to avoid making symptoms worse.

WAMES Pacing leaflet

<http://tiny.cc/p2xpsw>

carers

Carers count – count me in!

Are you a registered carer?

If you provide support to someone who cannot manage without your help, and you don't get paid for it then you're a CARER.

Only a small proportion of carers are registered. Many have never heard about the Carers Register or their local Carers Forums. In these tough times it is especially important for carers to know their rights and access all the support they are entitled to.

The more carers that register the stronger the voice of local 'Carers Forums' will be to help all carers.

Be Recognised! Be Valued! Get Better Services!

Contact your local carers service for more information.

WAMES survey

Can you help someone complete a WAMES survey? And answer a few questions about yourself? More info on p3.

Anglesey Carers Outreach Service
01248 722 828
www.carers.org/local-service/anglesey

Blaenau Gwent
01495 315700
www.blaenau-gwent.gov.uk/220.asp

Bridgend Carers Centre
01656 658479
www.carers.org/local-service/bridgend

Caerphilly carers
01443 864604
<http://tiny.cc/tlwpsw>

Cardiff
<http://tiny.cc/obwpsw>

Carmarthenshire Carers Service
0300 0200 002
www.cavs.org.uk/carers-service/

Ceredigion
<http://tiny.cc/38vpsw>

Conwy Carers Outreach Service
01492 533 714
www.carers.org/local-service/colwyn-bay

Denbighshire NEWCIS
01745 331 181
www.carers.org/local-service/denbighshire

Flintshire NEWCIS
01352 752525

www.carers.org/local-service/flintshire

Gwynedd Carers Outreach Service
01248 370 797
www.carers.org/local-service/gwynedd

Monmouthshire carers project
<http://tiny.cc/vkwpsw>

Neath Port Talbot
01639 642277
<http://tiny.cc/zowpsw>

Newport carers contact
01633 258376
<http://tiny.cc/6mwpsw>

Pembs
01437 771196
<http://tiny.cc/obwpsw>

Powys Carers
01597 823 800
www.powyscarers.org.uk

Swansea Carers Centre
01792 653344
www.carers.org/local-service/swansea

Vale of Glamorgan
01446 704604
<http://tiny.cc/ziwpsw>

Wrexham Carers service
01978 318812
www.carers.org/local-service/wrexham

Did you know?

The 2011 census reveals Wales still has the highest percentage of residents who are providing care compared with regions in England.

The number of carers increased from 5.2 million to 5.8 million in England and Wales between 2001 and 2011.

The care provided by friends and family to ill, frail or disabled relatives saves the state £119 billion a per year.

The main carers' benefit, Carer's Allowance, is £58.45 for a minimum of 35 hours – equivalent to £1.67 an hour, and is currently received by 600,000 people.

[Source: *Carers Wales*
<http://tiny.cc/drwpsw>]

Your experiences needed

Carers UK needs your help to make the case for a better deal for carers. They are conducting a major new research survey to examine the State of Caring in the UK.

They need evidence on the impact of caring for ill, frail or disabled loved ones on carers' health, well-being, careers and finances.

Fill in their online survey about your experiences of caring at:
www.surveymonkey.com/stateofcaring

Carers Workshop

Carers Wales is holding a free workshop for carers who would like to learn more about their legal rights on Tuesday 5th March 2013 at River House, Ynysbridge Court, Cardiff CF15 9SS from 10.30am until 2.00pm. A light lunch will be provided.

For further information contact: Pat McCarthy, Carer Participation Officer on 0786 653 9075

Carerwatch

Carerwatch is a campaign group for carers across the UK run by independent, unpaid carers. They have experience of the care system as it operates in the UK today and they consider it to be desperately under funded and not fit for purpose. They aim to provide a non-party-political campaign platform to change the way that opinion-formers, politicians and journalists think about carers. But first and foremost they intend to get the system changed

They are currently supporting Pat's petition (the group campaigning for a Cumulative Impact Assessment of the way in which welfare reform



is having a disproportionate impact on disabled people and carers). They invite carers and ill and disabled people to share their story on their blog. <http://carerwatch.com/>

Guide to benefits changes

From Carers UK
<http://tiny.cc/kvwpsw>

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around."

Dr. Leo Buscaglia (1924-1998)

carers

Look after yourself - viruses

As a carer you need to be as healthy as possible – don't forget your own health needs! Flu and noroviruses (vomiting bug) have been more common this winter so protect yourself and the person you care for by limiting the spread of viruses

There are around 200 viruses that cause colds and three that cause flu. According to the Common Cold Centre in Cardiff, a cold is most contagious during the early stages when the person has a runny nose and sore throat. A sudden fever of 38-40°C (100-104°F) is one indication that symptoms are caused by a flu virus.

Close personal contact is necessary for the virus to spread and the home and school are the places where spread most often occurs. The common cold viruses are not spread by contact such as kissing but by droplets that are sneezed or coughed out by an infected person. Other people can breathe in these droplets or transfer the droplets to their eyes or nose on their fingers.

Protect yourself and others against colds and flu by:

- Using a tissue when you sneeze or cough
- Washing your hands regularly and thoroughly
- Putting used tissue in the bin as soon as possible
- Regularly cleaning surfaces such as keyboards, telephones and door handles (the virus can survive on household surfaces for up to 2 days, much longer for norovirus)
- Avoiding contact with people whilst you are infectious

More information:

Common Cold Centre Cardiff
www.cardiff.ac.uk/biosi/subsites/cold/

NHS Direct Wales 0845 4647 symptom checker

<http://tiny.cc/40wpsw>

flu: <http://tiny.cc/a2wpsw>

Hand washing video

<http://tiny.cc/b3wpsw>

BBC programme on winter viruses: clips <http://tiny.cc/b4wpsw>

Effective hand washing should take 10 seconds

carers

Care to Work Project

The STARS project supports carers and former carers across Ceredigion and Pembrokeshire to access training, education, and voluntary/work placements.

STARS stands for 'Support, Training And Recognition of Skills'.

They run a popular 'Moving forward with Confidence' day to support carers and former carers in planning their next moves and their personal and professional futures. It is run by the Mid & West Wales Chamber of Commerce in partnership with Crossroads Care so they are able to offer replacement care for any carer attending their training days/courses and events.

They also offer one to one support. If you are a carer or former carer not in full time paid work and interested in becoming involved with the project or if you wish to talk to the Project Officer please call Marie on 07792 566799 or email wright@mwwc.org.uk

Carer interview on social care reform

WAMES' volunteer Sylvia Penny who cares for her adult daughter with ME, her adult son with Asperger's and her 90 year old mother, was one of the people interviewed on BBC Wales about the proposed changes to social care in Wales.

In the draft bill more people who look after disabled, sick and frail relatives could be entitled to help at home under proposals to change the law in Wales. Carers will have their needs assessed and could get a payment that puts them in control of their own care budget. But the Welsh government has said extra funding will not be required to deliver the Social Services and Wellbeing Bill.

WAMES joins other charities asking who will benefit, what support will be offered and when – the proposed date for changes of 2016 is a long time away!

BBC news item: Helping hand for carers proposed in Wales
<http://tinyurl.com/b63hlmb>



Proposed social services bill

The Deputy Minister for Children and Social Services, Gwenda Thomas introduces the bill in a video on the Welsh Government website. (She speaks in Welsh first, then English)

According to the government the legislation will:

- Strengthen powers for safeguarding of children and adults, so that vulnerable people at risk in our society can be protected more effectively;
- Allow Welsh Ministers to consider extending the range of services available by direct payments, meaning people will have more control over the services they use;
- Introduce national eligibility criteria and ensure people are assessed on what they need, rather than just on what services are available locally;

- Introduce portable assessments, which means if people move from one part of Wales to another they will not require their needs to be re-assessed if these haven't changed;
- Introduce a National Outcomes Framework to set out very clearly what children and adults can expect from social services, to measure achievements and see where improvements are needed;
- Introduce equivalent rights for carers so that people who care for someone such as an elderly or disabled relative or friend would get similar rights to the people they care for; and
- Establish a National Adoption Service to improve the outcomes of children in need of a permanent family.

<http://tiny.cc/gr4ysw>

Online forum

An email support group for those caring for people with CFS, ME and associated illnesses. All caregivers need support, and this list enables them to share their unique problems with others in the same boat.

CFS-Care Internet Forum
<http://tiny.cc/p9wpsw>

WAMES

does not have a medical research programme but we encourage people to support other organisations and researchers who are searching for answers, especially those engaged in biomedical research.

We regularly post significant research results on our website's newsblog, faceblog and twitter.

CFSRF pain study

The CFS Research Foundation research programme continues with a new three year study into why around three quarters of people with ME suffer pain.

The study will be conducted by scientists at three London institutions and will use a special method of imaging the brain to examine the brain's pain matrix.

They will also examine whether pain in ME is primarily due to problems in the muscles and joints themselves or more due to the way the brain and spinal cord process pain.

Through this research they will better understand how certain brain chemicals are involved and will give doctors, scientists and researchers reasons to test certain currently available medicines as treatments for ME.

To support this research send a cheque or donate:

CFS Research Foundation
2 The Briars, Sarratt
Rickmansworth, Hertfordshire
WD3 6AU <http://cfsrf.org.uk>
01923 268641 info@cfsrf.org.uk

Over the years the CFS Research Foundation has funded some very exciting research on enteroviruses & muscles, mitochondrial function, parvovirus B19, altered gene expression etc.

Their hope is that bio-medical discoveries will pave the way towards both a diagnostic test and, from there, possible therapies which may lead to a cure.

Open Medicine Institute



Following a meeting of established scientists and clinicians from around the world (including Dr Charles Shepherd of the ME Association) in June 2012, the top 10 research proposals were agreed:

- Clinical Trials: Rituximab and Valgancyclovir
- Neuro Registry & Biobank
- Protein Panels
- Other Mono & Combo Therapy
- Biomarker Exploration Studies
- DNA Genetics

- Mass Spec/ Environmental
- Viral Testing
- Advanced Biomarker Study
- Natural & OTC Substances

£8.5 million (\$13.5 m) is needed to fund this. They believe that if each person with ME donated £1 (\$1.60), their goal would be achieved.

The Open Medicine Institute was founded in 2009 in California by Dr Andreas Kogelnik to merge recognised clinical expertise with sophisticated bio and computer technologies in order to understand 'difficult' neuroimmune diseases such as ME/CFS, MS etc. See their website for more details and how to donate: www.openmedicinefoundation.org

Ampligen not approved

On 4 Feb the US Food and Drug Administration turned down the application from Hemispherx Biopharma for the approval of Ampligen, an immunomodulatory drug for the treatment of CFS.

The reasons given were the lack of consistency within the clinical trial results, as well as the limited size of the database available to evaluate Ampligen. This was due to

research

concerns about how the studies had been conducted, including multiple discrepancies and gaps in the safety data i.e. there was insufficient safety and efficacy data. They emphasised however that they still supported the development of drug pathways for CFS. <http://tinyurl.com/8cvzr4>

Mainstreaming ME Research

The invest in ME 8th annual biomedical research conference will be held in London on 31 May.

The focus will be on infection, immunity and ME, showing some of the major initiatives being taken to set up a collaborative strategy for biomedical research into ME to further this complex but exciting area of research.

Book by 12 March for a discount. A further discount is available for medical professionals who are sponsored by ME Groups.

Contact WAMES if you wish to be sponsored by us.

More information
<http://tinyurl.vom/bdmd7hw>

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

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

Clwyd ME group
clwydme@googlemail.com
01745 822953
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
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 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@phonecoop.coop

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

Find your nearest Volunteer Bureau

www.volunteering-wales.net/
www.gwirvol.org for young people

Anglesey 01248 724944
Blaenau Gwent 01495 306602
Bridgend 01656 810400
Caerphilly 01443 863540
Cardiff 029 2022 7625
Carmarthenshire 01554 778601
Ceredigion 01570 423232
Conwy 01492 871110
Denbighshire 01824 702441
Flintshire 01352 755990
Gwynedd 01286 672626
Merthyr Tydfil 01685 353900
Monmouthshire 01291 672352
Neath Port Talbot 01639 631387
Newport 01633 241550
Pemb 01437 769422
Powys 01597 822191
Rhondda Cynon Taf 01443 846200
Swansea 01792 544000
Torfaen 01495 742420/766231
Vale of Glamorgan 01446 421782
Wrexham 01978 312556

Live near the border? An English group may meet closer to you:

Shropshire
www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester
www.chestermesh.org.uk
Joan Crawford 01244 370988

me voice

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