



February 2015, no. 11

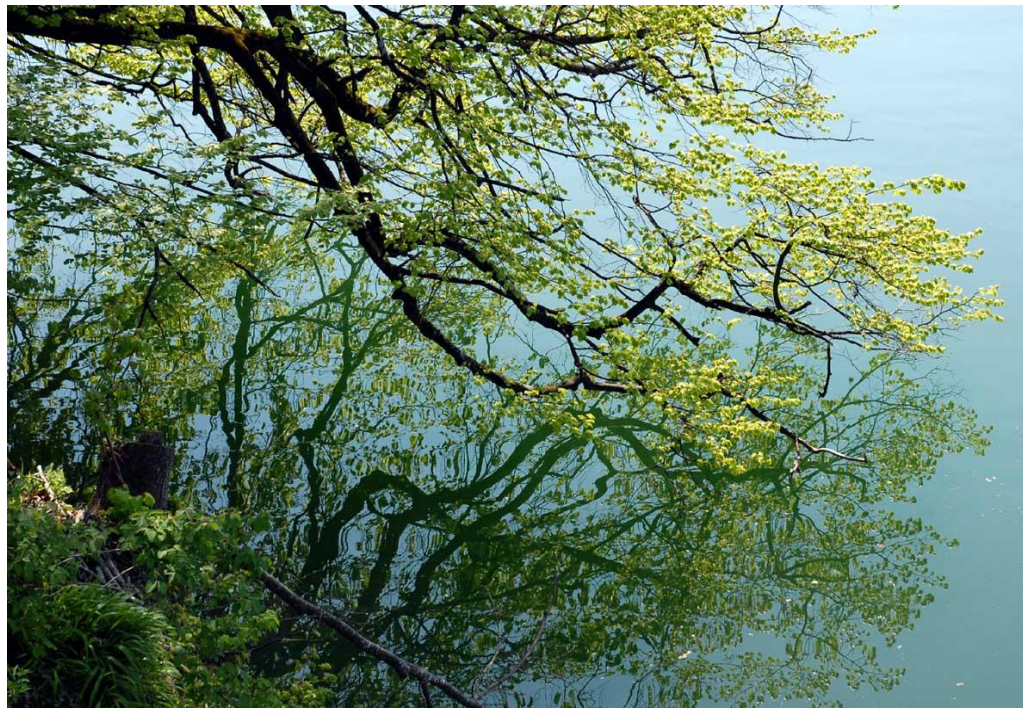
me voice

The WAMES Magazine

WAMES
Welsh Association of ME & CFS Support

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me voice

me voice is published 5 times a year. You can subscribe to the paper copy for £11 p.a., or receive it free by email, or read and/or download it from our Website:

www.wames.org.uk

Contact:

tony@wames.org.uk

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

The WAMES information exchange

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

- News blog 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
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

Read the magazine full screen:

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

In Adobe Acrobat press Control+L

Copy dates for the magazine:

26 April , 30 June 2015

ME get-togethers around Wales

Carmarthenshire ME Group

Meets on Sat 11 April at 2pm in Coleshill Social Centre, Coleshill Terrace, Llanelli SA15 3BT.

More info: John James 01267233793 [pm only]

CHAT (Chronic Health All Together) South Wales

All ages, both sexes, partners and carers are welcome. People with ME, FM and similar conditions meet to catch up, talk about health, have a laugh, general every day chit chat and get to know each other and create a support network.

More info:

Natasha Trew-Burns 07969994643
panoz8228@gmail.com

FM/ME/CFS Support Group West Wales

All ages, people with FM, ME and CFS and their carers meet Tues 3rd Mar & 7th Apr, 10.30-2pm at Milford Haven Christian Fellowship Hall, Marine House, Nantucket Avenue, Milford Haven, SA73 1BS

Meets 24 Mar & 28th Apr 4-5.30 pm at Tenby hospital.

Carers social 21st April at 10.30 in Milford Haven.

More info: 0844 887 2385

Mob: 07867 482 929

fibrowestwales@hotmail.com

<http://fmmeecfswestwales.jimdo.com>

Haverfordwest – Cwtch

a support group for young adults aged 18-45 years old who have long term or chronic physical health conditions. (One of the organisers has ME).

Fri 6 Mar & 1 May, 10 -11.30 at Furzy Park Community Centre, SA61 1HQ.

Fri 20 Mar & 17 April 7-8.30pm
Tues 7 Apr 10.30 Easter family get together:

www.cwtch-pembrokeshire.co.uk

More info: Beth 07974 543874
cwtch@live.co.uk

ME Support in Glamorgan

MESiG meets Mon 2 Mar, & 13 Apr 11-12.30 at the Charity shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

More info: Christalla
0292976 2347

christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS/FM Group

Meets Dragon Hotel, Market Square, Montgomery, Powys SY15 6PA

Next meeting in May.

More info: Mike or Karen between 2-4pm 0796 9665419 or email
Karen@kandm46.plus.com

wames & group news

West Wales ME/FM Group

Meets on Mon 23 Mar & 27 Apr 11am to 1pm at 65 Tudor Gardens, Merlin's Bridge, Haverfordwest, Pembs SA61 1LB.

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

More info:

Tina tretuil@talktalk.net or
01437 454359

WAMES poll about the name for ME

The US has recently published a report recommending a new name for ME. Read more on page ? and vote for the name you prefer in the poll on the WAMES website.

<http://wames.org.uk/cms-english/2015/02/which-name-for-the-illness-do-you-prefer/>

WAMES AGM

This will be held on April 27th in Dinas Powys, the venue to be confirmed. Contact Jan if you wish to attend.

ME Awareness week 11-17 May

Join WAMES in raising awareness and fundraising in May.

Need ideas?

- tell us your story – we'll help you distribute it in the media etc
 - wear blue ribbon and/or blue clothes
 - wear pyjamas or dressing gowns when out
 - add a twibbon to your FB site
 - collecting tins in local shops etc.
 - display posters in libraries, community centres etc.
 - sponsored event at school work etc.
- Raise money for WAMES online through:
- <https://mydonate.bt.com/charities/wames>
- shop online through <http://www.easyfundraising.org.uk/causes/wames/>
 - sell unwanted goods on Ebay in aid of WAMES at:
<https://www.paypalgivingfund.org.uk>

More information:

Contact Sharon Price, our Awareness Week Contact. She can help with ideas, publicity and planning. She can provide posters, leaflets, gift aid forms, sponsorship forms.

sharon@wames.org.uk

07855128647

Subscriptions for paper copies now due - ONLY £11

welsh news

Tell your story

During 2015 there will be many opportunities for WAMES to share the stories of people with ME when talking with Health Boards and health professionals.

We will be inviting some people to do this in person at meetings, but we can also use your story, even if you wish to remain anonymous.

We will also be able to include your experiences in our publications and can use a variety of formats:

- **written description** of how ME makes you feel, or your struggle to get help
- **poem or artwork** that describes your experience
- **an audio recording**
- **video** – if you wish to make your own, check out AfME's digital story telling toolkit for ideas. <http://tinyurl.com/p9rhedd> Otherwise let us know you are interested so we can hook you up with a local digital mentor.

My Health online

Many patients can now take a greater involvement in their own healthcare via the internet, in a similar way to shopping or banking online.

My Health Online gives patients the opportunity:

- to book GP appointments
- order repeat prescriptions
- update their general details such as change of address all from the convenience of their home computer.

Advantages of online services include:

- No hanging on the phone, waiting to get through to the GP surgery
- Convenient access to GP services from home or work — or anywhere with internet access
- Reduced administration for the GP practice

Nearly 400 practices across Wales have the service. If your GP practice is one of them you will need to call in and sign up. Your GP will issue you with a registration letter. You will need to have proof of identity on you to enable them to do this.

More info MHOL@wales.nhs.uk
<http://tinyurl.com/k57er76>

easyfundraising
.org.uk



Please help

WAMES

get off to a flying start!

✔ Holidays ✔ Insurance ✔ Clothes ✔ Hotels ✔ Flights ✔ Electricals

ME & isolation

James Martin's TV show *Operation Meet the street* looked at loneliness.

An episode screened on Dec 18th features young couple Paul and Kate in Ammanford. Kate has ME and Paul is her full time carer. Their story begins at 4mins 50sec. Simon's story of the effect of FM on his life begins at 18 min. It was suggested that the Men's sheds movement [begins at 25 mins] might be helpful. Simon finds out more at 35 mins.

James Martin introduces Simon to Paul who share an interest in writing and Kate to an Animal Sanctuary for animal therapy [35 mins 30].

Available on YouTube:
<http://tinyurl.com/kpo629x>

How your holiday can raise funds for WAMES

Your holiday could raise well over...
£100 in **FREE** donations!

easyfundraising.org.uk collect **FREE** donations as you shop online.

These donations are paid by the retailers at no extra cost to you. To raise a free donation, you simply need to visit your favourite online retailers from easyfundraising.org.uk first ...it's that simple!

Please support us for free at:
<http://www.easyfundraising.org.uk/wames/>

Services for independent living survey

The Wales Audit Office is seeking the views of people aged 55 and over on the Council services that support people to remain independent, such as information and advice, social activities and leisure services.

Part of their work is to look at the impact of austerity on key services so wish to hear from anyone who has used a service, either provided directly by their local council or indirectly paid for through council funds.

The information gathered will form part of a key report that will be published in summer 2015.

Take part in the survey online: <http://alittlehelp.wao.gov.uk> or ring 029 2032 0500 for more info.

Annual Welsh Poetry Competition

Budding writers and published authors are invited to submit a poem, in English, of less than 50 lines in length. The organisers wish to inspire entrants to capture life in the present day.

The Welsh writer and poet Sally Spedding will be the judge

- First prize: £400
- Second prize: £200
- Third prize: £100



Sally Spedding

Deadline for entries: 31 May 2015.
Further details are available from: <http://www.welshpoetry.co.uk/>

The Welsh Poetry Competition
 9 The Avenue, Pontypridd, CF37 4DF info@welshpoetry.co.uk

news from wales

More info about the judge: www.sallyspedding.com

Get online campaign

Do you think you can help someone in your life to do more online? Communities 2.0 are asking people to commit to doing something as simple as setting up an e-mail address or helping show a friend or family member how they can save money on the web.

The Welsh Government's Digital Inclusion training programme ends soon but has been helping the most disadvantaged people in society, to participate with digital technologies.

A new programme will be announced to keep the momentum going.

CRYPTOGRAM: Saying from the 'Tree of Life', 2011

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regional news

NORTH WALES

Disability Arts Cymru Poetry Competition

Disabled people aged 16+ are invited to submit work in English or Welsh that is in response to any piece of work on display in the current visual art exhibition showing at the Ucheldre Centre in Holyhead until March 8th. You can also view the work at www.disabilityartscymru.co.uk/gallery/dac-annual-exhibition-2014

Deadline : 31 March 2015.

Judge is poet Menna Elfyn
<http://www.mennaelfyn.co.uk>

Prizes: First prize: **£100**
Second prize: **£50**
Third prize: **£25**

Selected poems will be part of an e-publication.

Eligibility: you must be a DAC member to enter this competition, but membership is free for artists in Wales in all creative fields who identify as disabled people or those with long-term physical and/or mental health conditions.

If you are not already a member, you can join at the same time as entering the competition or beforehand online,

by post, or by email
kate@dacymru.com or
post@dacymru.com

Up to 4 original poems may be submitted and must be typed/clearly written on separate A4 sheets, and not be longer than 40 lines. They may also be submitted by email.

Fee: £3 for each entry but £10 for 4.

For more info about the rules:
www.disabilityartscymru.co.uk
02920 551 040 kate@dacymru.com

Disability Arts Cymru, Sbectrwm,
Bwlch Rd, Fairwater, Cardiff CF5 3E

Back to work and money advice

Work it out - a fun, free drop in event to find out all there is to know about finding work and sorting out your money.

Canolfan Dewi Sant, South Parade,
Pensarn, (Abergele) Conwy LL22 7RG

Thursday 12th March 12 – 3pm
Free lunch & goodies. First come, first served!

Run by Communities First. More info: 01492 338914
<http://tinyurl.com/pobmsua>



Help for aged 50+

Age Connects North Wales Central can now offer the following services from their offices at 15 Bridge Street, Denbigh, LL16 3LF

Paper Pals Service

A service to help you sort your mail, make appointments, arrange transport and query bills. Sessions are £15 per hour with the second hour at a reduced cost of £10. You can book weekly or monthly sessions.

Foot Care

The Foot Health Technician can help keep your feet in good shape. Cost £15

Massage

A very gentle 15 minute shoulder and neck or hand massage by a trained practitioner. Cost £5.

More info or to make an appointment: 01745 816947
<http://ageconnectsnwc.org/page/about-us>

New Mens Sheds

Colwyn Bay: 07887 602733
brian@colwynbaymensshed.org.uk

Denbigh: Thursdays 10-2
Trefeirian, Love Lane, Denbigh
01745 828360
MensSheds@redcross.org.uk

Llanrwst: 01745 335536

Prestatyn:
sheds@artisans-collective.org.uk

Rhyl: rhylmensshed@gmail.com
01745 334976

More info:
<http://www.menssheds.org.uk>

Art Therapy workshop

This training event is for those who want to learn more about the therapeutic application of visual art.

Tutor: professional art therapist Siân Hutchinson

When? 10-4pm, 30 April & 1 May

Where? Ystafell Glyder Fawr, Penrallt, Gwynedd Council, Caernarfon, LL55 1BN

Course fee: £20 which includes lunch
Registration closing date: 12pm Wed 23 April

More info: 01286 679721
gwawrwynroberts@gwynedd.gov.uk

MID WALES

Neuro drop-in event



Neurological Conditions - Information & Advice Drop-In

Friday March 13th 2015 from 11am - 4pm

The Monty Club, 11 Broad Street, Newtown, SY16 2LU



Do you, or someone you care for, have a neurological condition, or have symptoms like these?

Fatigue, pain, weakness, tremor, muscle stiffness, poor co-ordination, stumbling, foggy brain, headaches, poor memory, impaired taste, smell & touch, sensitivity to sound & light...

Come along and chat with those who can help:

- Therapists from Powys teaching Health Board
- Advice & Advocacy Services
- Charities & Support Groups

Free Refreshments

Close to bus station & Back Lane Car Park

Do you need more help:

- Coping with your symptoms
- Managing in your home
- Claiming benefits
- Supporting your carer
- Making a complaint

To find out more about the event, get help with transport or carer respite so that you can come along, or if you can't make it but want more help, please contact:

www.neurovoicepowys.org.uk Email: nvp@neurovoicepowys.org.uk Mobile: 07918 077 721

Men's shed

Abergavenny

If you are interested in joining 'a place of leisure where men come together to work' contact: 0777554 7775 or 07971 160455

More info:
<http://www.menssheds.org.uk>

Powys People Direct

From March 31, there will be a single telephone number for Powys County Council children and adults information and support services.
01597 827 666

Digital stories

Pembs

Moving Stories is an exciting project that is developing and showcasing a portfolio of creative media projects.

During 2015 they are inviting people with neurological conditions in Pembrokeshire to tell them their stories and help plan and / or feature in videos, sound recordings, animations or photographs.

More info: <http://tinyurl.com/otjrok7>

Tell Jan if you are interested.

regional news

Enabling Wales training

Disability Wales' unique Project will provide an innovative development and training programme consisting of six training modules.

Young Enabling Wales will be providing the confidence and peer support that young people (16+) need to stand up for their rights, equality and shape their generations future. It will help young disabled people gain a range of skills and knowledge that will support them to take active roles as leaders, champions and role models, both nationally and in their community

Where? Hafan Cymru, Stephens Way, Pensarn, Carmarthen, Carmarthenshire, SA31 2BG

When? 23/24 Mar, 8, 16, 21, 29, 30 Apr, 28 May.

More info: <http://tinyurl.com/nfm42b9>
02920 20887325
Julie.Bilton@disabilitywales.org

NB 'disabled people' have an injury, illness, or condition that is likely to have a long-term effect on physical appearance and / or limitation of function.

SW WALES

Free Stress Control Courses

Stress Control is a 6 session taught course (not a group therapy) which helps people to understand how stress and associated problems such as low mood, anxiety, panic and sleep affect them. The aim is to help turn you into your own therapist.

The course is based on Cognitive Behavioural Therapy which looks at the connection between thoughts, feelings, bodily sensations and behaviours to help people discover what may be maintaining their stress and learn ways to manage it more effectively.

The six sessions of the course run weekly for approximately 90 minutes with a break half way through the session. The classes are supported by a PowerPoint presentation, a booklet and a relaxation CD - all free.

The six sessions:

1. What is stress? The first steps
2. Controlling your body
3. Controlling your thoughts
4. Controlling your actions
5. Controlling panic feelings and medication
6. Controlling your sleep, wellbeing and controlling your future.

news

There will be a rolling programme of Stress Control courses throughout 2015 in Bridgend, Neath, Port Talbot and Swansea in the morning, afternoon or evening. Anyone and everyone is welcome to attend.

More info: The ABMU Living Life Well Programme

living.lifewell@wales.nhs.uk or
phone / text: 07967612246.

<http://tinyurl.com/7seln43>

SE WALES

MESiG petition

In September 2014 Cardiff based support group *ME Support in Glamorgan* (MESiG) handed in a petition to the Welsh Assembly for a ME/FM clinic in SE Wales. In November the Health Minister replied informing them of the Action Plan to improve services devised by the Task & Finish Group. MESiG wrote back with more questions.

All the documents can be downloaded from the National Assembly website
<http://tinyurl.com/pjzpb5f>

Hello Brain

Hello Brain is a website that provides easy-to-understand scientific information about brain health.

Did you know?

The route a piece of information takes through neurons around your brain is called a pathway, and the more you use a pathway the more defined it gets. A bit like a well-trodden track through a field or forest – the more people walk on it, the easier it is for others to walk there too.

Our brains contain billions and billions of neurons (small cells) which provide the communication paths for information to travel between the body and the brain and around the brain itself."

<http://www.hellobrain.eu/en>

liME conference 29 May London

Speakers will include Prof Ian Charles, Dr John Chia, Professor Sonya Marshall-Gradisnik and Dr Don Staines



WAMES will be happy to sponsor professionals for a reduced rate.

Contact Jan

More info:

<http://www.investinme.eu>

US suggests new name for ME

The committee formed by the Institute of Medicine in the USA to examine diagnostic criteria in ME/CFS released its 280-page report on Tuesday 10th February.

Its primary message is that the disease is serious, chronic, complex and multisystem, and that it frequently and dramatically limits the activities of affected patients. Accordingly, the committee has recommended:

- **New diagnostic criteria**, which it says are more focused on the core symptoms than many other definitions.

- **A new name** for the disorder – ‘**Systemic Exertion Intolerance Disease**’ (SEID). The committee points out that the name ‘CFS’ perpetuates misunderstanding of the illness and dismissive attitudes from health care providers and the public, and it believes that “SEID captures the central characteristic of the disease – that exertion of any sort can adversely affect several organ systems and many aspects of patients’ lives, often seriously and for long periods”.
- **A new code** for the disorder in the International Classification of Diseases (ICD-10), not linked with ‘chronic fatigue’ or ‘neurasthenia’ as at present.
- **An official toolkit** appropriate for screening and diagnosing patients, that could be developed centrally by the US Department of Health and Human Services.

As president of the Institute of Medicine Victor Dzau says, “The diagnostic criteria offered in this report are intended to promote prompt diagnosis for patients and enhance treatment, as well as improve public understanding of the disease.” The committee recognises, however, that new criteria will only improve diagnosis and care if healthcare providers actually USE them. This will be the big challenge for the future.

[[Summary supplied by ME Research UK](#)]

<http://tinyurl.com/nd29ne2>

Safer internet day

was on 10 Feb. Parents and carers can find information to help them support children in staying safe online.

<http://tinyurl.com/qzodahm>

Anglesey carers health fair

Do you look after someone?

Visit the Health fair for:

- Free health checks
- Fun exercise and dance classes
- Relaxation therapies
- Advice on carers' issues
- Information about local support and services

All carers are invited to drop in between 10am – 3pm to the free event on 7th March 2014, Town Hall, Bulkeley Square, Llangefni LL77 7LR

More info:

Ann Perkins - 01248 724944

ann@medrwnmon.org

State of caring survey

Carers Wales invites you to take part in this annual survey to find out how caring affects finances, health and a person's ability to live their own life.

This year the information will shape the Carers' Manifesto in preparation for the General Election in May.

Take part online

<http://tinyurl.com/p8gegrc>



More info: 029 2081 1370

beth.evans@carerswales.org

50 years celebration

Carers UK & Carers Wales are celebrating 50 years of working to make life better for carers.

More info:

<http://www.carersuk50.org>

Powys Carers Counselling Service

What Is Counselling?

- A way of helping you during times of difficulty, crisis and change
- A confidential setting for you to explore your feelings and thoughts
- An opportunity to consider your options and decide what is best for you
- It may be about the past, the present or looking into the future

What can I expect?

- Confidentiality and support
- To be listened to and not judged
- Help to sort out your problems and find your own solutions
- To go at your own pace
- The chance to seek other help if you want to

After the first session you can decide whether counselling is for you. The trainee counsellor will offer you a further 5 sessions initially. Further sessions can be agreed between you and your counsellor. Available free of charge to all carers aged over 18 and registered with Powys Carers Service.

More info: 01597 823800

<http://www.powyscarers.org.uk/index.php/General/carer-support.html>

Traffic Trauma

A man in a hurry, taking his young son to school, turned against a red light.

"Oh dear, I just made an illegal turn!" the man said.

"That's all right, Dad," the son said. "The police car right behind us did the same thing."

carers

Carers Community Connectors Gwent

Being a carer can be very rewarding, but it can also lead to feelings of stress and isolation.

The Community Connectors for carers can:

- encourage you to take time out for yourself, thereby improving your emotional and physical well-being
- help you to find out what is going on locally and provide names, places and contact numbers
- help you to overcome obstacles that might stop you engaging in activities, whilst being sensitive to your caring commitments.

Blaenau Gwent:

(C2BG) 01495 315700

info@blaenau-gwent.gov.uk

Newport: 01633 656656

community.connectors@newport.gov.uk

Torfaen: Amy 01495 742468 Leanne

01495 742447 CC@tvawales.org.uk

Caerphilly: asdit@caerphilly.gov.uk

01495 233 209 0808 100 2500

Monmouthshire:

enquiry@communityconnections.me.uk

01600 710895 01291 630524

Student carer campaign

Carers Trust has launched a new campaign, Going Higher, calling on universities to ensure that young adult carers receive the support they need for the duration of their education.

Young adult carers face a challenging time at university, on the one hand they want to do well in their studies and become independent, and on the other they continue to feel the need to care for their families.

Young adult carers are also four times more likely to drop out of college or university than their peers, and 42% have paid employment alongside time spent in education and caring in order to support them in their studies.

Carers Trust is asking universities to take three steps:

- Identify the number of young adult carers attending the university.
- Support all young adult carers throughout their education to ensure they maintain good mental health, complete their course and achieve the best grades possible.
- Report on young adult carer progress to showcase universities' achievements.

Find out more about the campaign and how you can get involved if you are a student, support worker or Student Union Welfare Officer.

<http://www.carers.org/goinghigher>

Student carer resource

Get info and advice about looking after your health, benefits, your rights, budgeting etc at <https://matter.carers.org>

New discount club for carers

CarerSmart is the first club of its kind and is launched by Carers Trust, giving the UK's seven million carers a chance to save money on a range of products and services whilst they continue to provide care.

Carers will be able to save money on a range of products by getting cash back in numerous high street stores as well as discounted rates on energy bills, insurance renewals and lifestyle activities, such as the gym, the cinema, days out and travel.

They will also have access to free legal advice. As part of Carers Trust, carers can also find out more about



both local and online services to support them in their caring role.

They will be able to use an online calculator to work out how much they could potentially save and it is estimated this could be as much as £600 per year.

The CarerSmart club is free to join at <http://www.carersmart.org>

In Case of Emergency (ICE)

Do you have an ICE – In Case of Emergency number listed in your mobile phone? e.g. *ICE wife*

This is a very useful number to log....just in case something happens to you and the person helping you wants to let someone know about the incident.

However you may want to think about what happens if you have locked your phone, would the ICE number still be accessible?

Unless the ICE information is accessible from the lockscreen itself:

- Android users can download an app called ICE which does exactly this.
- Apple iPhone users have this built in, it is just a case of activating it.
- Please check with your mobile provider.

<http://incaseofemergency.org>

Why register as a carer?

If you look after someone who can't get by on their own due to old age, frailty, illness, disability, mental ill health or addiction, your GP practice will want to make a note on your medical records that you're a carer.

That's because:

- Being a carer can affect your health. You may injure yourself when lifting someone or sometimes feel anxious or depressed.
- As a carer, you can request a free flu vaccination. This could help prevent you from becoming too ill to look after the person you care for. Ask your GP practice for details.
- Your GP practice can also refer you to your local carers' centre. They will send you an information pack with details of benefits and services you may be entitled to because you look after someone.

Research news

Canadian guidelines & teenagers

Recent Norwegian research found that the majority of teenagers with CFS they examined met the strict requirements of the Canadian guidelines for ME.

They found few people with a less severe form of the illness, that might be called CFS.

Recovery rates after glandular fever

Glandular fever is a common cause of weakness, fatigue etc in young people and can lead to long term ME.

Recent research shows that outcomes for younger people who develop ME/ CFS after glandular fever are not great, but are probably better than expected. Around half were in work 11 years after onset, though fatigue remained high for most.

No inflammation found

Low-grade systemic inflammation in the body, caused by cytokines has been suggested as an important part of CFS.

Norwegian researchers measured cytokines in teenagers and found the levels were the same in healthy and ME young people.

POTS

Postural orthostatic tachycardia syndrome (POTS) is characterized by

chronic fatigue, nausea and dizziness, especially when standing. There is considerable overlap of symptoms in patients with POTS and ME.

US researchers found that teenagers with POTS have excessive heart rate during exercise and slower heart rate recovery after exercise. They also have increased blood flow from the heart during exercise. Not all people with ME experience this.

Pain in teenagers with CFS

A Norwegian study found that teenagers with CFS experienced more severe pain and had lower pain thresholds than healthy people. The reason was unclear.

More information about all these research results on the blog on the WAMES website.

Free leadership training in the arts

Free training for young people (18-30) is available for those interested in creative arts - e.g. music, performance, visual arts, digital arts, crafts or something else altogether.

The aim of this relaxed training day is to help you to share your skills with others and to become part of the next generation of leaders of creative activities!

This might be through delivering regular sessions and/ or behind the

scenes helping to manage and organise workshops - whatever you prefer!

Among other things, you will learn:

- How to cut through the jargon and find out what running a group is really all about
- How to make a group work ... and not fall at the first hurdle
- How to assign roles based on what's needed
- How to keep communication flowing
- How to find a space and keep it
- How to get yourselves known
- How to know the rules so you can work out how to do things differently
- How to get the confidence you need to make it happen!

There is no charge for these workshops and lunch will be provided.

The trainers for the workshops are from Dynamix (<http://www.dynamix.ltd.uk/en/>) and plan to make the day fun, interactive and accessible to all.

30th March – Swansea
1st April – Cwmbran
9th April – Wrexham

All workshops will run from 10.30 to 3.30pm

young people

More info:

<http://tiny.cc/sgexux>

BBC Get creative campaign

Join the celebration and debate about the creative arts in the UK . Share your work with others and be inspired to try new things. All ages and abilities are welcome.

More info: <http://tinyurl.com/qcuxll8>

BBC Little Painting challenge

BBC Learning is launching a UK-wide competition to get the nation painting and drawing on pre-printed postcards. 1000 amateur artists will have the opportunity to have their work displayed at the prestigious Whitworth, Manchester's gallery during a special exhibition in May.

3 age categories:

- 16+ beginners, (prize worth £500)
- 16+ experienced (prize £500)
- 7 -15 (prize worth £250)

Closing Date: 5pm on Thurs 2 April

Postcards: available free from libraries or download from the website.

More info:

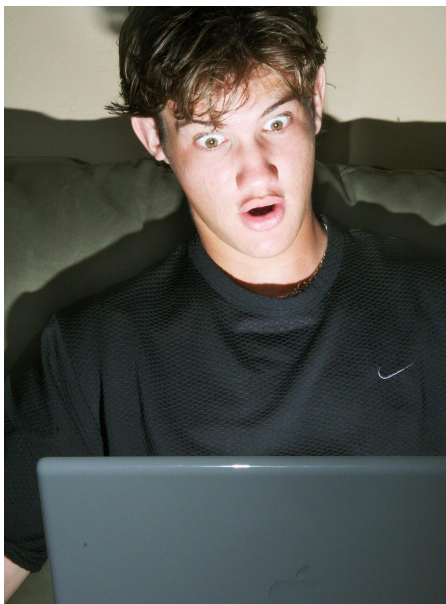
<http://tinyurl.com/pkcwduz>

young people

Safer internet day

Safer internet day was on 10 Feb. The internet provides lots of opportunities for chatting with friends, playing games and creating your own content. To help you get the most out of the internet, the latest information on staying safe online can be found at:

<http://www.saferinternet.org.uk/advice-and-resources/young-people>



<http://skoolbo.co.uk>

Skoolbo is a new website which uses games to help young people with reading and maths. Ask an adult to create a free account and then play along with you.

O2 – Think big grants

O2 Think Big looks for young people with great ideas and helps them turn those ideas into reality by awarding funding and delivering training and support.

Grants up to £300 are available under the 'Think Big' scheme, and up to £2,500 can be awarded for projects progressing to 'Think Bigger'.

All projects have to help the community or tackle a problem with society, the bolder and more creative the ideas, the better!

Funding could pay for: Materials and equipment integral to the project, Cost of renting space, Transportation, Advertising, Professional fees for people to teach skills needed for the project.

Who? Ages 13-25

Deadline: 11 March 2015.

More info: 0800 902 0250

<http://www.o2thinkbig.co.uk>

Did you know?

Your brain weighs 3lbs or 1.36kg of ever-changing tissue.

Find out more at

www.hellobrain.eu/en/

Word Search

Historic and Preserved Counties of Wales

Anglesey	Pembrokeshire	Carmarthenshire
Merionethshire	Powys Radnorshire	Clwyd
Mid Glamorgan	Brecknockshire	Denbighshire
Monmouthshire	Caernarfonshire	Dyfed
Montgomeryshire	Cardiganshire	Flintshire

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

Do you have mild ME?

What does that mean for you?

We'd like to know what symptoms you experience and how badly they make you feel.

How much do symptoms fluctuate and how serious are relapses?

What problems do you face in everyday life?

What services would help? What type of information would help?

Use the contact form on the website, send us an email or contact Jan directly, so we can raise awareness and campaign for appropriate services.

Need a simple mobile phone?

OwnFone is a mini, light, customisable mobile phone that allows you to call only the people you need, no extras to struggle to understand.

You can have up to twelve UK names on your OwnFone and it receives calls too. The company will set it up for you, so no tiny print instruction leaflet to decipher! It's about the size of a credit card so you can keep it on you at all times. You can even hang it round your neck to avoid losing it.



Use your OwnFone day to day or as an emergency phone. It is rechargeable and in Shutdown mode your OwnFone will last up to a year without a charge.

It comes in a wide range of colourful designs so there's an OwnFone to suit everyone.

Prices begin at £40 and you can pay for calls monthly or buy 6 or 12 months of airtime up front at a discounted price.

You can design your phone and order online or ring 0800 669 6699 9am to 5pm Mon to Fri.
<http://www.ownfone.com>

BBC care cost calculator

The BBC has launched an online guide to the care system for the over-65s.

The "care calculator" covers both residential care and the support provided in people's own homes, for tasks such as washing and dressing.

Submit your postcode and find out how much each service costs wherever you live in the UK. In Wales, help at home is capped at £55 a week. £513 is the average weekly fee in Wales for care homes.

More info: <http://m.bbc.co.uk/news/health-30990913>

Healthy eating blog

After being diagnosed with Postural Tachycardia Syndrome (POTS), a condition that some people with ME also have, Ella Woodward began her search for ways to improve her debilitating symptoms.

This led her to share her healthy eating ideas and recipes online in a blog. She now runs cooking classes in London, has launched an app and a cookbook.
<http://deliciouslyella.com>

living with me

Halogen ovens

Helen from Llanelli tells us that buying a table-top halogen oven is the best decision she has made in a long time because:

- it is very easy to use
- it is small so saves space
- it will roast, grill, bake, fry, steam, defrost and reheat
- you can use less fat, so is healthier
- a full meal can be cooked in one go (e.g. roast dinner) —no danger of forgetting to cook part of the meal!
- it switches off automatically
- there are a few automatic settings
- cooks evenly due to the fan

Models do vary so check out the reviews. One with a hinged lid is easier to use. Price: £30-60.

Reviews:

<http://tinyurl.com/q5q8mzd>



occupational therapy & me

During 2015 Health Boards will be assessing how they can implement the Task & Finish Group Report in order to improve services for people with ME and FM. Part of this will be finding out which health professionals already provide care for patients and which could, with training.

There may be a shortage of medical consultants and GPs with an interest in, or experience of ME, but many therapists have been quietly working with people with ME.

About Occupational Therapy

Occupational therapists (OTs) are employed by both the NHS and council social services. They provide practical support to help people recover and overcome any barriers that prevent them from doing the activities (occupations) that matter to them. This helps to increase people's independence and satisfaction in all aspects of life. It does not necessarily mean helping people back into employment.

They aim to help people find solutions to everyday problems. e.g. advising you on approaching a task differently, using equipment or assistive technology, adapting your living or working environment, and finding strategies to reach your chosen goals.

You and Occupational Therapy

Your first contact with OT services may well come about when a social worker, GP or hospital doctor suggests a needs assessment, so that you can access equipment, services, or housing adaptations, to make life easier or safe.

Right from the outset, one of the major challenges with OT services is fragmentation. Not only are they divided geographically, but also between needs that are perceived to be "health", and those which are designated as "social care".

This division inevitably comes about because traditionally, the NHS has picked up the tab for health needs, which are provided free at the point of use, whereas local authorities are responsible for social care, and charge for these according to the scale of need and ability to pay. Moves are being made to integrate health and social care, but change often comes slowly.

In some areas independent occupational therapists are providing

services that would once have been the province of the NHS or local authority, as people find the wait too long, or want their own independent needs assessment to support their

claim for equipment or adaptations.

Multi disciplinary teams

Increasingly Health Boards in Wales are setting up multi-disciplinary teams or MDTs. They contain a range of professionals such as GPs, occupational therapists, physiotherapists, nurses, dieticians, psychologists etc. These teams may work with

anyone needing support (general) or with a specific group of people (specialist) with cancer, neurological conditions, cardiac disease, pain and fatigue etc.

Some cater only for children or the elderly. General teams are often called can be called Reablement Services. Sometimes they will provide individual help starting with a needs assessment. Sometimes they offer courses over a fixed time period.

Accessing services

Traditionally GPs have been called the 'gatekeepers' to care and support as a referral from them was needed to access other professionals. Health Boards and Councils are now developing ways that patients can request consultations directly with therapists through 'single access' phone numbers.



However you access their services, a well-informed OT should be up-to-date with the latest developments in assistive technology which may be of benefit to you, and should also be able to help with access to different sources of funding.

The CFS/ME NICE guideline recommends referral to an OT. Some people have benefitted from energy management advice, aids and adaptations, relaxation strategies etc.

Your experience of OTs? Has an OT therapist in Wales helped you?

Let Sylvia or Jan know. Health Boards like to duplicate examples of local 'good practice'.

There is a You Tube video showing a consultation with an OT at <http://tinyurl.com/px546zs>

Fullfact.org

Can we believe what politicians, the NHS, researchers etc. tell us?

Full Fact is the UK's independent factchecking organisation. They monitor newspapers and broadcast programmes, parties' websites, social media and Parliamentary debates. They also get tip offs from readers.

During the election they're running an 18 hour/day election centre doing rapid analysis of the campaigns' claims.

They publish all their findings on their website <https://fullfact.org>

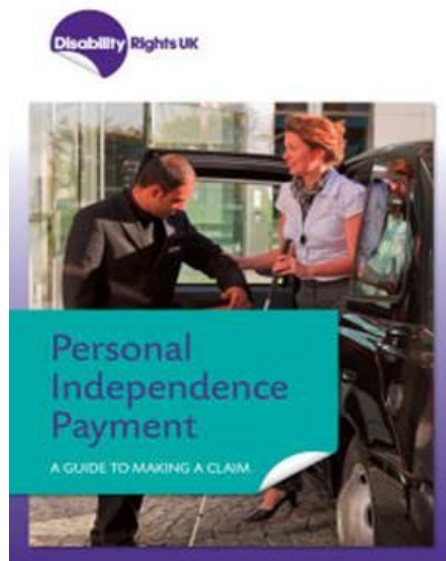
UK general election and Wales

While health, education, transport and housing are largely the responsibility of the Welsh Government, there are a number of issues that we can be asking political parties questions about, in the run up to the election.

- Welfare and disability
- Further devolution
- Austerity measures
- Environment / climate change
- Immigration
- Europe

The Institute for Financial Studies (IFS) has calculated that working age benefits will have to be cut by a horrifying 25% in order for the Tories to meet their spending plans.

Benefits and work say that if we are hoping that, in the run up to the



election, national charities are going to make their members aware of just what is at stake for sick and disabled claimants, we will be disappointed.

A report by the Commission on Civil Society and Democratic Engagement has found that the Coalition's Lobbying act has largely succeeded in scaring charities into not speaking out on behalf of vulnerable people before the election.

The Lobbying act obliges charities and other non-governmental organisations to register if they are planning to spend more than £20,000 – including staff time – on campaigning activities during the run up to the election which could possibly influence the way people vote.

There is then a strict limit on how much money may be spent. The rules apply even if the campaigning

is entirely non-party political. Where two or more organisations mount a joint campaign they must jointly remain within the cost limits, further limiting how much they can spend. <http://www.benefitsandwork.co.uk>

Benefits sanctions

More reports in the media have produced horrifying claims about sanctions.

- More than 466,000 people have their benefits suspended including 2,000 who are barred from claiming for three years.
- Work Programme staff were told to increase sanctions against clients in order to hit financial targets, says former employee
- A FOI request revealed that the DWP has investigated decisions, about the welfare payments of 60 claimants following their deaths. This is the first time the DWP has tacitly admitted that there could be a link between sanctions and suicides. Campaigners against welfare sanctions believe that the numbers who have died are a lot higher and that the changes to the benefits rules have amounted to "passive euthanasia."

welfare

PIP in Wales

As more people in Wales are being moved from DLA to PIP (Personal Independence Payment) our helpline is increasingly hearing horror stories from claimants with ME.

One issue is that Capita are refusing to release to clients the medical reports that they submit to the DWP. **Please contact our helpline** if you have experienced problems of any kind while claiming, so we can assess the extent of the problem and campaign accordingly.

A recent account of being transferred to PIP makes it clear that you can score more points under the new system, and yet receive less support.

The government claim for PIP has been that it would save money – £1.2 billion per annum – while also targeting support to those in most need. The Institute for Fiscal Studies says that the benefit is costing an extra £1.6 billion a year, as delays and mismanagement take their toll.

Short-cuts that were recently introduced to reduce the backlog of applications have made it easier to reject claims, according to the main union representing the Department for Work and Pensions (DWP) staff.

More info: <http://tinyurl.com/phnijyyw>
<https://www.gov.uk/pip/overview>

research

Exercise

Exercise has been in the news again with a study based on the PACE trial in the Lancet online journal.

Researchers claim that fear avoidance of exercise plays a strong role in perpetuating fatigue and disability in CFS, and that the best treatment for this is CBT and GET.

There was a flurry of media reports, many of which promoted the findings as good news.

Other articles countered the claims saying:

- people with ME are highly motivated to recover and be active
- the paper ignores evidence of muscle, brain and immune system abnormalities in ME/CFS, which are more likely to cause the debilitating central (brain) and peripheral (muscle) fatigue
- energy management programmes, not graded exercise, are more appropriate aids to recovery
- CFS/ME is not one condition, but consists of subgroups, so patients need approaches that are tailored to the individual
- the PACE trial produced evidence of only modest recovery

- the PACE trial was accused of serious failings and inaccuracies in the way it conducted the trial,
- presented information and measured recovery
- trial participants were told they would recover using CBT and GET so the study could have measured the placebo effect, not fear avoidance
- contradicts earlier research by one of the researchers who found that CFS patients do not have an exercise phobia

WAMES joins other ME charities and organisations in rejecting the unscientific conclusions of the PACE trial and uncritical reporting of the study, and calls for research treatments that takes account of the research showing multi-system dysfunction.

MEA: <http://tinyurl.com/oygf9g5>
MERUK: <http://tinyurl.com/nln8ne6>

Other comments are available on the WAMES news blog.

POTS

Postural tachycardia syndrome (PoTS), a form of dysautonomia, is characterized by orthostatic intolerance (the development of symptoms when standing upright), and is frequently accompanied by a



range of symptoms including palpitations, lightheadedness, clouding of thought, blurred vision, fatigue, anxiety and depression.

There is an overlap in symptoms between POTS and CFS and a subgroup of people with ME have been found to also orthostatic intolerance.

Recent research findings:

Brain abnormalities found in POTS - diminished grey matter volume
<http://tinyurl.com/qxo4k2q>

Reduced blood flow to the brain could be causing POTS.
<http://tinyurl.com/pmxychp>

Increasing blood pressure with phenylephrine (a decongestant) reduces orthostatic intolerance symptoms.
<http://tinyurl.com/l7efnmk>

Sleep

Belgian researchers found both similarities and differences between insomnia and CFS. There was an increase in the duration of slow wave sleep in CFS.

<http://tinyurl.com/l4jvkgn>

Not everyone with CFS has insomnia but those who do can experience less fatigue if the insomnia is treated.

<http://tinyurl.com/mzl5879>

Possible treatments

Roburins—french oak wood extract
<http://tinyurl.com/p8bccmw>

Oral CoQ10 (200 mg/day) plus NADH (20 mg/day) for fatigue
<http://tinyurl.com/o5vntjn>

High isoflavone diet (soy protein)
<http://tinyurl.com/ouop63a>

Guided imagery can decrease pain
<http://tinyurl.com/px286tk>

Warm needling acupuncture can improve fatigue
<http://tinyurl.com/nomah9d>

NB No treatment has been found to help all people with ME or CFS. Many trials are small pilot trials and more research needs to be carried out to confirm the results.

Keep up to date with research papers, news and events on the newsblog on the WAMES website, Facebook or twitter.

Distinct stages found in ME/CFS

New research from Columbia University in the States has found that patients who have been ill under 3 years have increased levels of certain cytokines, in their blood, unlike those who have been ill for longer.

They believe these differing immune signatures prove that ME/CFS is a biological illness, that the disease has distinct stages and could help suggest treatments.

ME/CFS may reflect an infectious “hit-and-run” event.

There are already human monoclonal antibodies on the market that can dampen levels of a cytokine called interleukin-17A that is among those the study shows were elevated in early-stage patients.

Before any drugs can be tested in a clinical trial, Dr Hornig and colleagues hope to replicate the current, cross-sectional results in a longitudinal study that follows patients for a year to see how cytokine levels, including interleukin-17A, differ within individual patients over time, depending on how long they have had the disease.

More info: <http://tinyurl.com/ppo6vfo>

Cryptogram Solution:

There are two ways through life; the way of nature, and the way of Grace. You have to choose which one you'll follow.

Doctor, Doctor

The following quotes were allegedly taken from actual medical records as dictated by physicians:

The patient has been depressed ever since she began seeing me in 1983.

Patient was released to outpatient department without dressing.

Discharge status: Alive but without permission.

The patient refused an autopsy.

The patient expired on the floor uneventfully.

The patient's medical history has been remarkably insignificant with only a 40 pound weight gain in the past three days.

On the second day, the knee was better and on the third day it had completely disappeared.

The patient had waffles for breakfast and anorexia for lunch.

She is numb from the toes down. The skin was moist and dry.

When she fainted, her eyes rolled around the room.

Research talks on video

Alan Light's gene expression research

<http://tiny.cc/xe7wux>

Elizabeth Unger's multi-site study

<http://tiny.cc/zh7wux>

Jarred Younger's leptin research

<http://tiny.cc/bk7wux>

Nancy Klimas on the work of the Institute for Neuroimmune Research Institute

<http://tiny.cc/qm7wux>

Sudoku

		4			3	1		
2	5			8				7
1					6		8	3
				3			1	
5	4		8			3		9
		8	9		7	5		
	1				5			
	3			2			4	
6				4	9	7		5

me groups

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

Anglesey & Gwynedd Fibromyalgia / ME Group

Contact: Rhian Medi (secretary)
01248 722184
fmsmemonagwy@yahoo.com

Brecon Area Contact

Richard Jones 01874 622310
richard.j5@btinternet.com

Carmarthenshire ME Group

Meets Llanelli every 2 months. Please ring John James (pm)
01267 233793 for further details.

CHAT (Chronic Health All Together) South Wales

People with ME, FM and similar conditions meet monthly in Cwmbran, Newport or Cardiff. More info:
Natasha Trew-Burns 07969994643
panoz8228@gmail.com

Cwtch

Young adults aged 18 45 years with long term or chronic physical health



conditions meet 1st Friday of the month during school term in Haverfordwest.
10-11.30 and 3rd Friday 7-8.30pm
www.cwtch-pembrokeshire.co.uk
Beth 07974 543874
cwtch@live.co.uk

FM/ME/CFS Support Group West Wales

Meets in Milford Haven, Pembs on the 1st and 3rd Tuesday of every month 10am-1pm. Contact Gary or Cathy 0844 887 2385
Mob: 07867 482 929
fibrowestwales@hotmail.com
<http://fmmeecfswestwales.jimdo.com>

ME Support in Glamorgan (MESiG)

Usually meets first Monday of the month, Llanishen, Cardiff
Contact: Christalla Bailey,
029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FMGroup

Meets Montgomery. Please phone

Mike or Karen on
0796 9665419 (between 2-4pm only please) or email
karen@kandm46.plus.com for more information.

West Wales FM/ME/CFS Support Group

Meets Haverfordwest, Pembs 4th Monday of month. Contact Tina
01437 454359, tretiul@talktalk.net
See page 2 for dates & more info about get togethers

Live near the border?

Shropshire

www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester

www.chestermesh.org.uk
Joan Crawford 01244 370988

contacts

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