



May 2015, no. 12

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

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.

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

Making the web links in me voice work in your Browser

Internet Explorer

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

Google Chrome, Opera, Torch

Hyperlinks and email addresses work correctly.

Mozilla Firefox

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

Read the magazine full screen:

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

In Adobe Acrobat press Control+L

Copy dates for the magazine:

30 June 2015

ME get-togethers around Wales

Carmarthenshire ME Group

Meets on Sat 13 June at 2pm in Coleshill Social Centre, Coleshill Terrace, Llanelli SA15 3BT.

More info: John James
01267233793 [pm only]

FM/ME/CFS Support Group West Wales

All ages, people with FM, ME and CFS and their carers meet 5 May, 2 Jun & 7 Jul 10.30-2pm at Milford Haven Christian Fellowship Hall, Marine House, Nantucket Avenue, Milford Haven, SA73 1BS. Meets 26 May & 23 Jun 4-5.30 pm at Tenby hospital. Carers social 19 May, 16 Jun at 10.30 in Milford Haven.

More info:
0844 887 2385 or 07867 482 929
fibrowestwales@hotmail.com
<http://fmmeccfswestwales.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 1 May, 5 Jun, & 3 Jul 10 -11.30 at Cashfields Community Centre, SA61 1HQ.

Fri 15 May 7-8.30pm
www.cwtch-pembrokeshire.co.uk

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

ME Support in Glamorgan

Next Monday meeting is:
11 May 11-12.30

MESiG AGM & Awareness day is Monday 16th May 2-5pm at Bethel Community Church, Llanishen, CF14 5BL.

Also meets: 1 June & 6 July
11-12.30

More info: Christalla
0292976 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS/FM Group

Meets Montgomery Town Hall, Powys SY15 6PA
Next meeting 6 May
Speaker Dr Claire Bowen.

More info: Mike or Karen
Between 2-4pm on
07969 665 419 or email
Karen@kandm46.plus.com

West Wales ME/FM Group

Meets on:
Monday 25 May & 22 June 11-1 at 65 Tudor Gardens, Merlin's Bridge, Haverfordwest, Pembrokeshire, 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 & group news

WAMES AGM

The WAMES AGM was held on April 27th in Dinas Powys.

2015 Committee

Chair: Jan Russell

Secretary: Vacant

Treasurer: Liz Chandler

Youth & Care Officer:

Sylvia Penny

Young People's Contact:

Michelle Penny

Website & Publicity:

Tony Thompson

2014 Finances

Opening balance:	£2732.60
Income:	£2386.66
Expenditure	£1336.15
End of year balance	£3783.11

The bulk of the income we received last year comprised of money from donations and individual fund raising. We owe thanks to Natasha and Sharon for their amazing fund raising efforts.

Expenditure in 2014 was unexpectedly low, for a number of reasons but is expected to increase significantly in 2015 due to the Health Services campaign. This will be due to increased travel costs and publication production.

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

2014 activities

2014 saw a big increase in calls to the helpline, and many more people used the website.

Facebook and twitter followers have increased at a much more sedate pace. Volunteer numbers went down, restricting our activities.

2015 priorities

- Health services campaign
- Seek grants
- Develop website & publications
- Develop Small steps microvolunteering campaign



WAMES website poll

Tell us why you visit our website:
<http://tinyurl.com/nbn886v>

me awareness week

11-17 May

Join WAMES to raise awareness during ME Awareness Week

Will you be getting dressed & going out?

Why not go blue and add:

- a blue ribbon
- a blue wig (£3.50+ from Amazon or local shop with fancy dress or joke section)
- blue specs, hairband, hat, coat, cardigan, dress etc.
- blue nail varnish, jewellery etc.



Will you be staying at home?

You can still make a difference.
Wear any of the above and take a photo of yourself with a sign saying something like:

I am wearing blue to raise awareness of ME

Or

Yr wyf yn gwisgo glas i godi ymwybyddiaeth o ME

I'm wearing blue for ME

Or

Yr wyf yn gwisgo glas ar gyfer ME

Put on your best PJs and photograph yourself with a sign saying e.g.:

I am raising awareness of ME.... in my PJs

Or

Yr wyf yn codi ymwybyddiaeth o ME ...yn fy PJs

Spread the word

- post your photo:
- on your FB or twitter
- on WAMES' FB & twitter #WAMESMECFS
- on local forums, Health sites, blogs
- or send to us for posting

helpline@wames.org.uk

07763 927971

I change the world in just my pyjamas!



#PyjamaPower

From: <http://helpfromhome.org/campaigns/pyjama-power>



Want to do a bit more?

Contact:

Sharon Price, WAMES
Awareness Week Contact

She can help with ideas,
publicity and planning.

She can provide posters,
leaflets, gift aid forms, sponsor-
ship forms:

sharon@wames.org.uk

07855128647

“WAMES supports pyjama power”

But... ME Awareness week is only the start

Have you often thought you would like to volunteer but have little time or energy?

Join the WAMES **small steps** micro volunteering project.

Why be a **small steps** volunteer?

- you don't need much energy
- you don't need much time
- you can do it wherever you are (even in your PJs)
- you can do something small regularly
- or you can make a one-off contribution
- your contribution will help WAMES
- you could have a big impact on somebody, maybe lots of people.

small steps magazine ideas
In 10 minutes or under you could give us an item for me voice e.g.

- one of your creations: photos, poems etc.
- a joke
- an idea for a low energy activity or place to visit



If you have 30 minutes spare you could:

- tell us which treatments or activities have helped you
- make a simple puzzle (we will lay it out)
- write a short book review
- tell us how ME affects you
- give us tips for carers
- send us ideas and links for a helpful article

small steps online ideas

In 10 minutes or under you could:

- retweet something from our account you think is worth passing on
- like us on Facebook so others see our link on your page
- suggest online sites where we could advertise WAMES
- send us an awareness raising slogan
- suggest volunteering task that would only take 30 minutes

me awareness week

30 minute suggestions:

- check part of our website for errors and broken links (ask us which pages, in which language)
- send us a banner photo for our FB page
- suggest a web page topic with some notes or links
- give us a book or music title or link to something that has helped you and tell us why
- give us your favourite recipe

Do you need more suggestions, or ideas for fund raising?

Check our **small steps** web page – we'll be adding new suggestions all the time.

So, what's stopping you?

**Become a
small steps volunteer**

...and change the world.



**Add a Twibbon to your
Twitter or Facebook page
for ME Awareness week**

[http://twibbon.com/Support/
spread-the-me-word-3](http://twibbon.com/Support/spread-the-me-word-3)



news from wales

Health Boards & ME

The Government's Task & Finish Report, published last September, gave Health Boards a deadline for appointing leads for ME and FM.

All Health Boards except Cardiff & Vale have appointed an Executive lead. Many have also appointed a Clinical lead.

It is expected that the clinical leads will meet in Cardiff for the first All-Wales Implementation Group meeting on 13th May 2015. Jan will be there as the ME patient rep and Carol Ross as the FM patient rep.

Health Boards are also required to find a 'home' for ME which is not in mental health. Hopefully we will find out at the meeting how Health Boards have decided to classify ME.

Hywel Dda HB

There is still only one Health Board to have begun the process of developing a pathway and identifying services for people with ME - Hywel Dda., covering Ceredigion, Carmarthenshire and Pembrokeshire.

Although progress is much slower than expected, the aim is to complete a draft report and pathway by the end of August. Patients and carers are fully involved in this process.

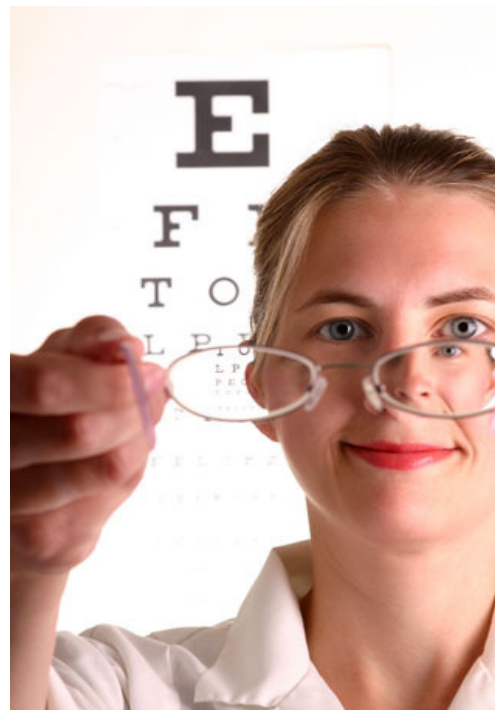
Over the counter medicines

Health Boards have announced that, in an attempt to save money, they are encouraging patients to 'self care' and to purchase some of the simple and inexpensive products over the counter for the treatment of minor ailments. Often these are cheaper than the Health Boards can source and include simple painkillers, laxatives, vitamins, hay fever treatments and head lice treatments.

They advise that Community Pharmacists are highly trained health care professionals and are in an ideal position to assist with 'self care' and to advise on the most appropriate product for each individual patient.

NB Savers chemist chain are one of the cheapest sources of many products.

My personal trainer told me to bend down and touch my toes. I told him,
"I don't have that kind of relationship with my feet. May I just wave?"



Choose wise if you hurt your eyes

"Your local optician is often the best place for you to go if you have problems with your eyes, not A&E", Deputy Health Minister Vaughan Gething said as he launched a new campaign.

The Welsh Government has begun a drive to encourage people to visit an optician to access acute eye care, rather than going to their GP or an Accident and Emergency unit.

Optometrists can provide free expert advice for urgent problems and those seeking help do not have to be registered with them.

An optometrist will see you free of charge within 24 hours or refer you to someone who can. Many opticians are open on Saturdays. Our campaign is about getting people to choose well and access the most appropriate healthcare for their problems."

Home from hospital fund

A new, £20m-a-year Welsh Government fund will support people in their own homes and local communities, reducing pressure on hospitals, Health and Social Services Minister Mark Drakeford recently announced.

The Welsh Government will invest a further £17.5m in the Intermediate Care Fund this year to continue projects which have proven to be successful in helping older and vulnerable people remain in their own homes.

The fund will support schemes which improve out-of-hospital care and help people to return home from hospital.

Hate crime survey

Have you experienced discrimination and harassment because you are ill?

The police and government want to learn more so they know how to tackle the problem.C

Complete the online survey at
<https://www.surveymonkey.com/s/XPBDLBF>

Mental health services users survey

If you have used any of the following inpatient services in the past year. Mental health charity MIND would like you to complete their survey on Independent Mental Health Advocacy (IMHA):

- Child and Adolescent Mental Health Services
- Older Persons Mental Health Services
- Forensic Mental Health Services

To take the survey online, please visit:

<https://www.surveymonkey.com/s/IMHA2015> ...before the 31st May 2015

Welsh Water Help U

Welsh Water are reducing their tariffs for customers whose income is less than £12,500 from April 2015

More info:

<http://tinyurl.com/oo3hr5a>

Telephone: 0800 052 0145



About GPs

- GP numbers in Wales have declined by 1% in the past year
- the number of GPs per 100,000 patients declined from 67.8 to 66.5
- There are fewer practices in Wales than a decade ago
- Nine out of ten UK GPs think the 10 minute consultation is inadequate for patient care
- 35% of GPs in Wales are considering leaving the profession within the next 5 years
- Wales needs to recruit an extra 95 GPs this year to reach the UK average

More info:

News blog on the WAMES website

news from wales

Digital Communities Wales

is a Welsh Government project.

- Find out about
- computer courses near you
- computer equipment to hire
- accessibility hardware or software

0845 474 828

<http://tinyurl.com/q55e0oc>

Speak-easy Energy Advice Project

Speakeasy Advice Centre specialises in providing free debt and welfare benefits advice, as well as running an Energy Advice Project.

The Project can provide advice and assistance over the telephone, by post and by email to people living across Wales and hold face-to-face appointments in the Speakeasy office in Roath, Cardiff. All of their advice and assistance is free of charge. The Project team advise on a number of domestic energy-related issues, such as fuel debt, payment options and budgeting, and saving energy at home; and can support clients to access services and liaise with suppliers.

In particular, they are funded to help individuals and families in financial hardship apply to The British Gas Energy Trust (BGET) for grants to help clear arrears and give them a fresh start to deal with future energy bills.

More info: 02920 453111

energy@speakeasyadvice.co.uk

166 Richmond Road, Cardiff,
CF24 3BX.

www.speakeasyadvice.co.uk

British Gas Energy Trust

This is a charitable trust covering England, Scotland and Wales that provides free grants to clear gas and electric debts, pay outstanding funeral expenses and to purchase white goods for people facing hardship.

It is free to apply and recipients do not have to repay it. The trust is open to everyone, regardless of who their energy supplier is, so people do not need to be with British Gas to apply:

<http://tinyurl.com/9rucjxk>

regional news

NORTH WALES

A chance to be creative

Artefact will be delivering creative activities in Gwynedd, Anglesey, Conwy and Denbighshire between June and the end of October 2015.

Artefact is an initiative which offers creative experiences in museums, galleries and archives for people with mild to moderate depression, stress and anxiety.

Participants attend a series of creative sessions led by community artists in order to build confidence and to learn new skills with people with shared experiences.

More info: <http://www.artefact.uk>
Maria Hayes me@mariahayes
01766 830049 / 07817 297922

SGLTCA

The South Gwynedd Long Term Conditions Alliance will take place on Mon June 22 at 10am at Dolgellau Hospital. If you'd like to represent WAMES and ME in Meirionnydd, please contact Jan for more info.

Doctor, Doctor I feel like a needle.
I see your point!



Blaenau Men's Shed

Get out, share your skills and experience, make new friends and contribute to your community. Men of any age or background are invited to meet on a regular basis to do activities, share a cuppa and get support, if needed.

First meeting at Y Maen Wellbeing Centre, Church Street, Blaenau Ffestiniog on Friday 15 May 2015 at 1 pm.

Befriending Service

For the over 50s in Gwynedd and Anglesey.

Enabling older people to live independently through emotional support in the home, regular telephone calls and group support to encourage social interaction.

More info: Swyn Angharad
SAngharad@redcross.org.uk
(01248) 672 632 / (07725) 201 507

MID WALES

Lets talk health

Hywel Dda University Health Board and Hywel Dda Community Health Council are holding a series of events in communities across Carmarthenshire, Ceredigion and Pembrokeshire to provide information and to listen so they can improve services.

Find out more about local health services and to share your views.

Cardigan 2.00 - 4.00 pm, 21 May
The Great Hall, Guildhall, Cardigan, SA43 1JL

Aberystwyth 6.30 - 8.30 pm,
27 May, St Paul's Methodist Centre, SY23 2NN

Burryport 6.30 - 8.30 pm, 2 June
Memorial Hall, SA16 0BN

Brynamman 10 - 12, 9 June
Aelwyd yr Urdd, SA18 1SG

Llandovery 2 - 4 pm, 15 June
Rhys Pritchard Memorial Hall, SA20 0DD



Tenby 2 - 4 pm, 23 June
De Valence Pavilion, SA70 7JD

Haverfordwest 6.30 - 8.30, 29 Jun
Pembrokeshire Archives SA61 2PE
Online Q&A 6 - 8 pm 24 June
www.hywelddahb.wales.nhs.uk/letstalkhealth

SW WALES

SWWNA

The South West Wales Neurological Alliance will meet 27 May.

WAMES is one of many organisations that join together to try to improve services in the Abertawe Bro Morgannwg (ABM) Health Board area.

SWWNA is currently trialling Health Alert bracelets and Health Passports and taking part in the Neuro Delivery Plan meetings. If you would like to represent WAMES and ME at the Alliance please contact Jan for more information.

Mindfulness & Stress Courses Rhondda Cynon Taf

- The courses help people to better understand and manage their feelings and thereby improve their well-being.
- Courses are 'walk in' / self-referral
- All adults are welcome, no one is expected to speak during the

sessions and anyone attending is welcome to bring a friend

The Courses available are:

Stress Control

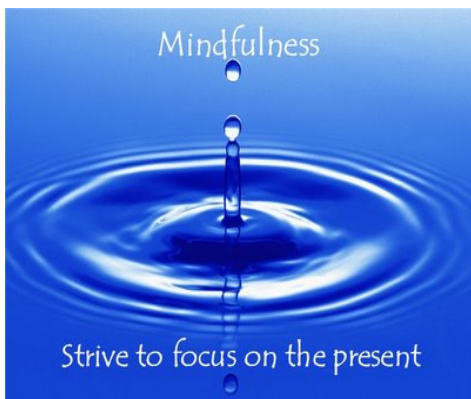
- This course is based on Cognitive Behavioural Therapy (CBT) techniques
- The Course aims to help people understand the causes of stress and how to manage its symptoms

Mindfulness

- This course is based on Acceptance and Commitment Therapy (ACT) with some meditation
- Mindfulness is a technique that once learnt can be useful throughout your life.

Courses begin 2-4 June in Llantrisant, Tylorstown, Abercwmboi and Dowlais

More info: 01443 744800
CTT_stresscontrol&mindfulness@wales.nhs.uk



SE WALES

Debt and benefits advice, Barry

The Citizens Advice Bureau in partnership with Barry Communities First are offering drop in advice sessions in Barry for those who need assistance with debt, benefits or other issues.

These sessions take place at the Community Enterprise Centre, Skomer Road on Mondays 9:30–12:30pm or at Coastlands Family Church, Tennyson Road, Colcot on Thursdays, 4:30– 6pm.

A drop in service is also available at the CAB office on 119 Broad Street, Monday to Friday, 9.30– 4.30pm
 Telephone advice: 03444 77 20 20

Free 'Road to Wellbeing' Classes

Activate your life and **Stress control** classes will teach attendees how to manage stress and their reactions to everyday situations, using a combination of tested techniques, such as mindfulness.

There will be no register of attendance taken and no need to register in advance. Classes are free and open to anyone.

More info:

Aneurin Bevan Health Board website
<http://tinyurl.com/pxicneh>

Blaenau Gwent 01495 363250
 Caerphilly 01633 618033
 Monmouthshire 01873 735549
 Newport 01633 261867
 Torfaen 01495 768 613

Cardiff and Vale Long Term Conditions Alliance

A meeting is due to be held on Tues 30 June, 2-4pm . If you would like to represent WAMES and ME, and join with other groups to improve services in the area, please contact Jan.

regional news

Answers to Cross-word on page 16:

20 Big Dipper
 18 Tea Cups
 17 Pirate Ship
 16 Orbiter
 14 Calypso
 12 Ghost Train
 10 Enterprise
 9 Roller Coaster
 8 Mega Phobia
 6 The Walzer
 1 Log Flume
 21 Dodgems
 19 Dive Bomber
 15 Skid
 14 Carousel
 13 The Twist
 11 Zipper
 7 Ferris Wheel
 5 Helter Skelter
 4 The Whip
 3 Oblivion
 2 Mont Blanc

Down

Across

Sudoku

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

carers

Carers week 8-14 June

Too many carers across all age groups are struggling to look after older, disabled or seriously ill loved ones alone.

This year Carers Week 2015 will focus on **Building Carer Friendly Communities** urging individuals, organisations and service providers in every community, including schools, hospitals, GPs and local authorities to take action to improve the lives of carers.

This could mean running or attending a local event, or by pledging to support carers in some way e.g. an employer could design and implement a carer-friendly policy, a GP could be more flexible about appointment times or an individual could visit a neighbour in a caring role.

More info:

<http://www.carersweek.org>

Check with your local Carers service for local events.



Carers Week info events Cardiff

Cardiff & Vale Councils with Cardiff & Vale University Health Board are holding two Information Days during Carers Week 2015 at Cardiff City Stadium, Leckwith.

Staying Safe – Tuesday 9 June
Staying Well – Thursday 11 June

New Social Care Code of Practice

It will replace the Welsh Code of Practice for Social Care Workers from 1 July 2015.

In particular, it will emphasise the importance of working in partnership with individuals and their carers, giving them a voice to express the kind of care they would like, and control over how they receive it.

Carer's Allowance earnings limit increased

The government has increased the Carer's Allowance earnings limit from £102 to £110 a week

The earnings limit is the amount that a carer can earn before their Carer's Allowance has to stop. This amount will now be £110 a week. Derek Sinclair, welfare rights worker at Contact a Family, said: "We are very pleased that the earnings limit has increased to £110 per week as this will mean that parents who are working 16 hours on the national minimum wage will be able to get Carer's Allowance."

More info:

<http://tinyurl.com/khu7x22>

Carers UK gives information about claiming for the Allowance:

<http://tinyurl.com/q8zip86>

Ways to wellbeing in Barmouth

Want to get more out of life?

New free course starting on 19th May 1-3.30pm at The Dragon Theatre, Jubilee Road, Barmouth

More info: Phil 07964 858095

Run by Tan y Maen

www.tanymaen.btck.co.uk

Help for carers who want to work

There is a 'Work Coach' based within each JobCentre Plus.

Carers who are of working age and are in receipt of Carers Allowance will automatically be contacted every three years to go in and meet the Work Coach for a chat (otherwise known as a work focused interview).

You don't have to wait to be called in, you can phone your local JobCentre Plus and request this support.

Carers may also be entitled to help with the cost of replacement care for their dependant whilst they attend training or interviews and money towards the cost of clothing for interviews.

The Work Coach can provide calculations to enable you to see how much better off you might be if you take on paid employment.

More info about JobCentre Plus

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

Rights for Carers Workshop

Cardiff 27 May

Are you interested in finding out about your rights as a carer?

Come along to Carers Wales, River House, Ynysbridge Court, Cardiff CF15 9SS between 10-2.30

on Wednesday 27th May 2015.
A light lunch will be provided.

More info: Pat McCarthy
029 2081 1370 / 0786 653 9075.

Supporting carers in their communities

Carers Wales has launched an initiative to create a network of Local Carer Ambassadors across Wales who will use their knowledge and expertise to help other carers.

The aim of the Local Ambassador role is to complement other services available, identifying hidden carers, connecting carers in their local community with services and with each other.

They will signpost to available support and may attend meetings where a carer's voice is needed, to support the ethos of joint working and co-production.

Keep up to date with research papers, news and events on the *news blog* on the WAMES website, Facebook or Twitter.

ME/CFS a multi-system disorder

The symptoms and illness severity of people from 5 different places were analysed and categorised.

The American researchers concluded that ME/CFS is not simply a state of chronic fatigue. The data indicates that fatigue severity is matched by cognitive, autonomic, pain, inflammatory and neuro-inflammatory symptoms as the predominant clinical features.

Choice of name

87 patients with CFS completed a self-report survey. Terms containing the word "physical" were consistently more likely to be chosen. Three main themes emerged from the thematic analysis:

1. Physical nature of the illness
2. Stigma,
3. Evaluation of the terms, giving a more in-depth understanding of the findings.

According to CFS patients, an umbrella term has to reflect the physical experience of their illness.

Vitamin B12 and folic acid

People with ME and FM who used frequent injections and higher doses of B12 for a longer time and higher

daily amounts of oral folic acid felt a greater benefit.

A Thyroid condition or use of opioid analgesics could interfere with the efficacy.

Mindfulness & depression

Mindfulness was found to be as effective in relieving depression as anti-depressants.

Computer simulation & PEM

2 German researchers used a computer simulation to explore the mechanism for post-exertional malaise.

Simulations exhibited critically low levels of ATP and a prolonged recovery time. Additionally an increased acidosis and lactate accumulation was observed in CFS.

Electrical pulse stimulation

Skeletal muscle cell cultures from people with CFS and controls were subjected to electrical pulse stimulation (EPS) for up to 24h and examined for changes associated with exercise.

research

Four main differences were found in the muscle cells from subjects with CFS: increased myogenin expression in the basal state; impaired activation of AMPK; impaired stimulation of glucose uptake; and diminished release of IL6.

These differences point to a genetic /epigenetic mechanism.

Cytokine induced inflammation in CFS

A sub-group of patients with CFS were found to have raised levels of serum TNF- α and may have low level inflammation.

Analyses are underway to further characterise other inflammatory markers and to determine whether such changes could affect muscle function or central fatigue.

Rituximab and Cyclophosphamide trials in Norway

Links to video interviews and articles by researchers Fluge and Mella about the 2nd phase of the Rituximab trial and a new drug trial with those who hadn't responded well to Rituximab, can be found on the WAMES news blog.

me and fm...

Getting an accurate diagnosis is an ongoing problem for people with ME.

There is a long list of medical conditions with overlapping symptoms that create difficulties for doctors when attempting to diagnose.

A major concern has been when ME has been mistaken for depression, but a number of people with ME have found that due to the lack of ME specialists they have initially been referred to a rheumatologist and mistakenly diagnosed with Fibromyalgia (FM).

Does the diagnosis matter?

Some doctors believe there is little difference between ME and FM. A wide range of symptoms can be experienced by both conditions and so they say that the diagnosis depends on whether fatigue or pain is the major symptom. Some also believe that the diagnosis doesn't really matter as the treatments are the same!

It would appear however that the type of pain and fatigue experienced are not exactly the same in each condition. Similar symptoms are also

not all caused by the same dysfunction in the body.

Researchers are beginning to discover significant differences in the bodies of people with ME and FM that could require quite different treatments and suggest that pain is, at least in part, being produced in different ways.

Differences in symptoms

Triggers

Many people with ME develop symptoms following a virus. The onset of FM is frequently traced to a physical or emotional trauma

Epidemics

ME has occurred in epidemics, but none have been reported for FM

Flu-like symptoms

ME diagnostic criteria includes low-grade fever and sore throat, FM criteria does not.

Pain

In FM pain states such as hyperalgesia (pain amplification) and allodynia (pain from a typically non-painful source) are common.

...what's the difference?

FM usually features tender points (painful areas in the muscle that occur in certain places). ME is associated more with the type of muscle aches you get with flu. Not everyone with ME experiences pain.

Fatigue

Fluctuating muscle fatigue, cognitive fatigue and loss of energy following exercise is found in ME. Wired fatigue, brain fog and flu-like fatigue are also common. Persistent general fatigue and tiredness is not experienced by everyone with ME or FM, though brain fatigue or 'fibro fog' is common in FM.

Sleep

The types of unrefreshing sleep are vastly different. People with ME may sleep most of the time, yet never feel rested and experience abnormal sleep patterns. FM, on the other hand, is generally characterised by one or more recognized sleep disorder such as alpha-EEG



anomaly, as well as abnormal sleep rhythms. In many, the sleep disorders pre-date FM. Generally, those with FM get very little sleep.

Post – exertional

exercise can cause relapse (symptoms to become worse) in ME while it can improve symptoms in FM.

Severe symptoms

There have been deaths from ME from organ failure (most commonly pancreatic or heart failure) but this level of dysfunction has not been reported with FM.

Physiological similarities

- Reduced heart rate variability – sympathetic nervous system activation in FM & ME
- Reduced aerobic capacity in FM & ME
- Increased lactate in muscles & problems with lactate metabolism in FM, & increased lactate in brain in ME
- Homocysteine increased in spinal fluid in both FM & ME
- Reduced brain blood flow in FM & ME
- Neuropeptide Y increased in FM & ME

me and fm...

- COMT Polymorphism
Implicated in both
- Reduced salivary awakening response cortisol & IL-6 increased in FM & ME
- Decreased grey matter in the brainstem in both

Physiological differences

- Neurotransmitter responsible for the transmission of pain - Substance P is increased in FM, but reduced in ME
- Nerve repair agent BDNF is increased in FM but reduced in ME
- Pro-inflammatory IL-8 is increased in FM but decreased in ME
- Hormone that controls hunger and feelings of satiety – Leptin is reduced in FM, but increased in ME
- Cellular antiviral enzyme – RNaseL is frequently elevated in CFS, not in FM
- Greater immune dysfunction in CFS/ME
- Abnormal nerve response in FM
- Stress-system (HPA axis) abnormalities are predominantly from the adrenal glands in ME and from the hypothalamus in FM

Mitochondrial dysfunction

Mitochondrial citrate synthase activity and Mitochondrial DNA content (mtDNA/gDNA ratio) is significantly lower in FM. Expression levels of peroxisome proliferator-activated receptor gamma-coactivator 1-alpha and transcription factor A, mitochondrial by immunoblotting were significantly lower in FM and normal in ME.

Gene expression

no post-exercise alterations in gene expression in FM, but 1 CFS subgroup showed an increase (those with POTS) and 1 a decrease.

- Sleep disruption
- Cardiac and perceptual responses to steady-state, submaximal exercise differs
- Mechanisms of autonomic function
- Muscle biochemistry

Can I have both FM and ME?

Is it possible to have both FM type pain and the PEM (Post exertional response) of ME?

Some say yes, others say no. Recent research found that a significant proportion of people with Multiple Sclerosis (MS) also have FM.

As exercise is the key treatment for FM but a major cause of relapse in

...what's the difference?

ME, a dual diagnosis poses a serious challenge!

Unfortunately until researchers pin down the precise nature of the different subgroups in ME and CFS, we will have to live with many unanswered questions.

Fibromyalgia...

means pain in the fibrous tissues in the body.

Most patients with fibromyalgia say that they ache all over. Their muscles may feel like they have been pulled or overworked.

Sometimes the muscles twitch and at other times they burn.

A fibromyalgia diagnosis would require:

- 7 areas of pain and a severity score of 5 points,
- or pain in 3-6 areas and a score of 9 or more.

The symptoms must still remain for at least 3 months and not be part of another disorder.

[From: UKFibromyalgia website
<http://www.ukfibromyalgia.com/what-is-fm.html>]

The cardinal feature of ME...

is post-exertional malaise i.e. prolonged restoration of muscle power following either mental or physical exertion which includes:

- a dead, heavy feeling that occurs quickly after starting to exercise;
- next day soreness or fatigue after non-strenuous, everyday activities;
- feeling mentally tired after the slightest effort;
- being physically drained or sick after mild activity; and,
- minimum exercise making you physically tired.

[From: the DePaul Symptom Questionnaire (DSQ)]

<http://tinyurl.com/lavpueb>]

By Jan Russell, with a lot of help from:
Cort Johnson

<http://tinyurl.com/kbvyh7v>

FM/ME/CFS Resources http://fmcfsmc.com/fm-cfs_difference.php

young people

ME Awareness week 11-17 May

Pyjama power rules!

Get involved - more information on p4

Are you preparing for exams?

Check out our tips in issue no. 6 of **me voice** (Feb 2014)

Don't forget to take time to rest and relax and do something that's fun.

Pacing is the name of the game!
We wish you all the best!!

BBC Learning zone

For a change, why not check out the BBC learning zone for a range of short films and animations designed 'to provide inspiration for the classroom and beyond'. Films cover a wide range of topics for ages 4-16.

<http://tinyurl.com/pkrhpza>



Sally Holland, New Child's Commissioner

New Children's Commissioner

Sally Holland began her new job at the end of April. She was a Professor at the School of Social Sciences at Cardiff University, and is the Director and founder of CASCADE Children's Social Care Research Centre.

The role of the Children's Commissioner is to act as an independent champion for children and young people, advocating their interests and making sure their voices are heard at a local, national and international level.

More info:

<https://www.childcomwales.org.uk>

Music with The Prince's Trust, Rhyl

If you are 16-25 and into music but out of work, then *Get Started* with the Prince's Trust and achieve your goals.

- Improve your confidence and teamwork skills
- Improve your music skills
- Compose, record and perform a piece of music as part of a group challenge
- Gain an Agored Cymru Arts Award
- Receive up to three months support

See if this programme is for you on the Taster Day Wed 13 May
Programme runs 18 - 22 May

More info and to book:

Sian Jones 07970876717

sian.jones@princestrust.org.uk

This programme is entirely free, and your travel costs and lunch will be provided.

Your say, your way - Wales needs you

'Your Assembly – your say, your way' is a website to support young people's understanding of the National Assembly for Wales and democracy.

Everyone in Wales should have a say in how their country is run. One

way of doing this is by voting in Assembly and UK elections. But what if you're not old enough to vote yet?

There are still lots of ways you can make a difference. They want to know what matters to you and make sure your voice is heard.

Give your contributions through Twitter, Facebook or by emailing: yourassembly@assembly.wales
<http://www.yourassembly.org>

Whizz-Kidz

is a charity that gives disabled children and young people the independence to enjoy an active childhood – at home, at school and at play.

By providing them with customised mobility equipment, training, advice and life skills, they are given the independence to be themselves:

- Customised Mobility Equipment Provision
- Life Skills Training
- Wheelchair Skills Training
- Information and Advice to Beneficiaries and their Families
- Campaigns on Disability Issues
- Raising Funds to enable all the above to happen

More info:

www.whizz-kidz.org.uk

020 7233 6600

Summer Flowers & Shrubs Wordsearch

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

Amaryllis
Aster
Begonia
Bluebell
Buddleia
Carnation

Chrysanthemum
Crocus
Dahlia
Fuchsia
Foxglove
Geranium

Gladioli
Holly
Hydrangea
Ivy
Marigold
Peony

Poinsettia
Poppy
Red Robin
Roses
Snowdrop
Sunflower

Research

Antiviral therapy

92% of teenagers with CFS/ME improved with the anti-viral drug valacyclovir over 3-5 months at a centre in the States.
[Not all results for adults in other studies have been as good]

Sleep disturbance

A review of 6 studies of sleep in children with ME/CFS found sleep was more disturbed than in healthy children. More research is needed to find out more about the different types of sleep problems.

Cognitive function

Norwegian researchers tested 120 teenagers and 59 who were healthy. Those with chronic fatigue had reduced information processing speed, working memory, cognitive inhibition response time and verbal learning.

What are cognitive skills?

They are the underlying brain skills that make it possible for us to think, remember and learn.

They are the skills that allow us to process the huge influx of

information we receive each and every day at work, at school and in life.

If your cognitive skills aren't up to speed, no matter what kind of information you try to grasp—or how many times you try to grasp it—the process can feel sluggish and slow.

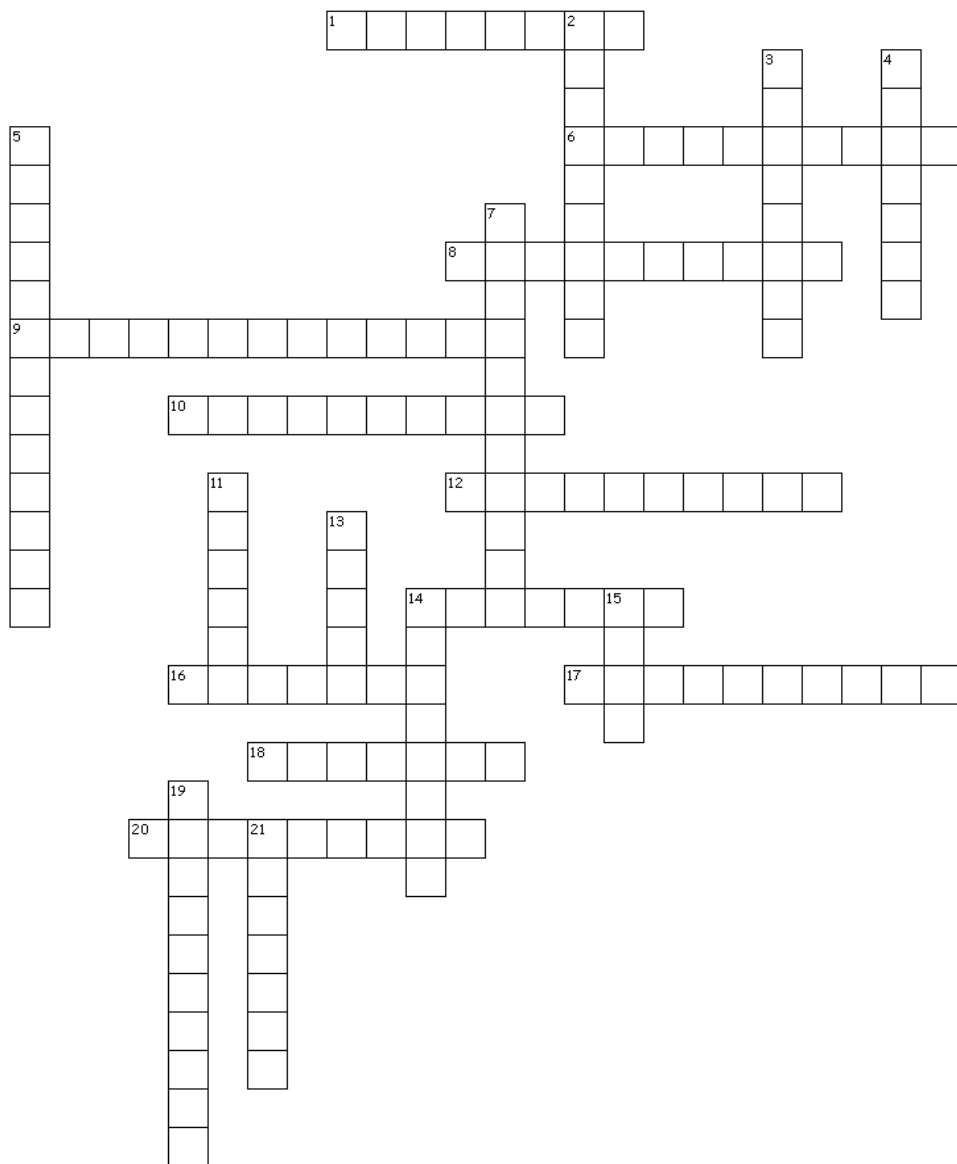
An ME person's ability to think and remember is one of the things that is affected by the illness and you will find your abilities fluctuate like many ME symptoms. It has nothing to do with being stupid!

More info about cognitive skills:
<http://tinyurl.com/pgu5nxb>



young people

Fairground Rides Crossword



Clues

Across

1. Ride in a hollow wood tube or boat on water
6. Third person famous Austrian dance
8. Very large and extreme irrational fear of something
9. ----- skates, protector for hot drinks
10. Starship -----
12. Spooky railway ride
14. Style of Afro-Caribbean music from the mid 20th century
16. 3D real time space flight simulator
17. One eyed person and ocean going vehicle
18. You drink hot beverages from these
20. Asterism of seven stars

Down

2. White mountain in French
3. The state of being completely forgotten or unknown
4. Strip of leather or cord fastened to handle and used to flog or beat someone with
5. Originally meant confused or disorderly haste
7. Ride consisting of giant vertical revolving circle with cars suspended on its outer edge
11. Metal fastener for trousers or skirt etc.
13. Famous 60's dance
14. 1945's musical by Rodgers and Hammerstein
15. Uncontrolled slip usually on a wet surface
19. Jump from high board and plane that drops objects in war
21. Electric bumper cars

Tros Gynnal advocacy service

Tros Gynnal Plant offers help to young people to speak out and access services and help in many parts of Wales.

On 1st April Tros Gynnal Plant took over the advocacy service for children and young people in Conwy, Gwynedd, Anglesey, Wrexham, Flintshire & Denbighshire. The service was previously provided by NYAS.

The service will operate from Tros Gynnal Plant's Caernarfon office. Full contact details are:
Unit 2 Victoria Dock, Balaclava Road, Caernarfon LL55 1TH

More info: 01286 238007
northwalesadvocacy@trosgynnalplant.org.uk

<http://www.trosgynnal.org.uk>

"Memorisation is what we resort to when what we are learning makes no sense." Anonymous

Doctor, Doctor I keep painting myself gold

Don't worry it's just a guilt complex!

Answers on page 9



From <http://www.mypetonline.co.uk>

UK CFS/ME Conference Oct 2015

UK CFS/ME Research
Collaborative Annual Science
Conference

- Tues 13 - Wed 14 October
- Newcastle-upon-Tyne

Prof José Montoya will be the
keynote speaker.

Open to researchers and
associate members. Become an
associate member free of charge
by contacting AfME

<http://tinyurl.com/kng82cj>

0117 927 9551

More info:

<http://tinyurl.com/n2shw44>

The Campaign to end loneliness

is raising awareness about
loneliness and the impact of
loneliness and isolation on Mental
Health and Emotional Well Being
and its impact on older people and
others

www.campaigntoendloneliness.org

[https://www.youtube.com/watch?
v=s1NflrOE1Q](https://www.youtube.com/watch?v=s1NflrOE1Q)

Loneliness can be twice as
unhealthy as obesity, according to
researchers who found that

feelings of isolation can have a
devastating impact, particularly on
older people.

The scientists tracked more than
2,000 people aged 50 and over and
found that the loneliest were nearly
twice as likely to die during the six-
year study than the least lonely.
Poverty increased the risk of an
early death by 19%.

More info: <http://tinyurl.com/kl879zp>

To counteract loneliness a range of
befriending schemes have been set
up around Wales. Some for older
people, some for anyone.

More info: Ask at your local library

<http://www.ageconnectswales.org.uk>

Are you a dog owner?

A new campaign has been launched
to uncover Lyme disease hotspots
by examining ticks found on dogs.
Infected ticks can spread a bacterial
infection to humans and Lyme
disease is one of the conditions that
doctors need to exclude before
diagnosing ME.

It is estimated there are up to 3,000
new cases of Lyme disease in
England and Wales each year. Lyme

disease can often be managed
effectively if it is detected early on but
can cause chronic pain and severe
fatigue if left untreated.
BBC wildlife presenter Chris
Packham is backing the Big Tick
project.

*“Lyme disease can often be
managed if detected early”*

Lyme disease is caused by a bite
from an infected tick. Dogs can be
bitten while being taken for walks
through wooded areas or parkland in
both urban and rural areas. Signs
including lameness, lethargy and
fever can be seen and, left untreated,
these can lead to more serious
conditions such as kidney disease
and heart failure. Many cases of tick
infestation are likely to go unnoticed
by owners as they are only detected
by a thorough examination.

Throughout spring and early summer
when ticks are most active, vets
taking part in the Big Tick Project will
be giving dogs visiting their practice a
tick check. The ticks collected by vet
practices will be sent for testing to the
team of scientists at the University of
Bristol leading the Big Tick Project.
For advice on how to remove a tick
correctly from your pet speak to your
vet.

More info:

<http://tinyurl.com/m24olen>

living with me

MGD RX eye bag

This patented, re-usable warm compress has been recommended by a member of the Stockport ME group for eye problems. It has flax inside, and you need to heat it in the microwave, and then rest to allow the warm silky surface to sooth your eyes.

In the box, there is a comprehensive information booklet, which suggests twice daily use at first. There are also safety instructions, as you must not over heat the eye bag.

Depending on your type of dry eye condition, you may experience relief for a couple of hours, or even much longer.

This may become an additional technique to soothe or treat your existing eye problems, or even prevent further complications.

- Examples of conditions or symptoms that this can treat: Melbomian Gland Dysfunction
- Blepharitis
- Dry Eye Syndromes
- Chalazion
- Styes and Cysts
- Eyelid inflammation
- Grittiness
- Burning



- Irritation
- Foreign body sensation
- Transient blariness
- Stinging and sore when reading

More info:

<http://www.eyebagcompany.com/products/The-EyeBag>

£14.25 from Amazon

<http://tinyurl.com/mfyrzi8>

[From: *Hermes* Mar 2015]

New support for circulation problems

Lots of people suffer from poor circulation in their legs, particularly in older age or with poor mobility. This can cause problems from cold feet and swollen ankles to potentially life-threatening deep vein thrombosis (DVT), which often starts in the legs.

There are a number of simple steps you can take to try and alleviate the situation, without resorting to prescription drugs. In no particular order, these are:

- Move more. If you can, get up and walk around every hour during the day. If you can't, try and do regular ankle rolls and toe pointing/flexing, rather than remaining completely static.
- Make sure you keep hydrated. Plenty of water; caffeinated drinks and alcohol only in moderation.
- Keep it loose! Tight clothing – belts, skinny trousers, tight socks, can all impede circulation. As can the habit of twisting your legs into a pretzel when you're sitting down.
- Put your feet up. Lying down or sitting with your feet elevated can help the circulation in your legs.
- Quit smoking, if you haven't already. It increases the risk of blood clots

If you have had an operation in hospital, you may well have found your legs encased in inflatable, massaging "boots", designed to keep your blood circulating and avoid clots during a time when you aren't able to move very much.

There is an interesting, if expensive alternative (£222) from Win Health, which is worn strapped to the calf, and concealed under trousers.

The Venowave is a peristaltic pump which is lightweight and comfortable to wear, either short-term, following hospital discharge for example, or long-term, for people with chronic circulation problems.

More info: <http://tinyurl.com/n8awrdt>

Access to loos on the move

The National Key Scheme (NKS) offers people with disabilities independent access to locked public toilets around the country.

Toilets fitted with National Key Scheme (NKS) locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

Keys can be bought through your local council or library. Guides and keys (£5.40 each) can be ordered from tinyurl.com/lxrx77g

0207 250 3222

More info: tinyurl.com/lqtwfb8



Direct payments Co-operatives

People in Wales who receive direct payments for their care needs will be able to form co-operatives to take control, own and manage the services they need to support them under a new project.

The new citizen-led direct payment co-operatives project will provide more than 4,000 Direct Payment recipients in Wales with a new way to manage their payments.

All members will have a say on how the co-operative is run. It will support people to support themselves, allowing them to share resources and pool their direct payments to design services that meet their needs, by employing their own carers (the admin responsibility that comes with being an employer can be



dealt with by the co-operative, instead of the individual). Find out more about different ways to manage Direct Payments or Community Care Packages:

- Llandudno Junction - Conwy Business Park, 3 June
- Llanelli - Selwyn Samuel Centre, 10 June
- Cardiff - Future Inns, 16 June
- Llandrindod Wells - Media Resource Centre, 23 June

To attend any of the events:

Kelly Stuart: 029 20887325

kelly.stuart@disabilitywales.org

For information about the project:

Becky Newsome:

rebecca.newsome@disabilitywales.org

Successful ESA claims on the rise

Years of misery for claimants, and millions of pounds spent on rushed assessments, reduced the number of claimants receiving employment and support allowance (ESA) or incapacity benefit (IB) by just 3%.

The latest DWP statistics, show that the claimant count for ESA/IB has fallen by just 83,000 since the Coalition took control in May 2010,

from 2,613,000 to 2,530,000, and is currently on the increase again. [From: Benefits & Works n/l]

New ESA form

The government has said in its March stakeholder bulletin that it has improved the ESA50 which is used as part of the work capability assessment for ESA.

'Following the fourth independent review of the Work Capability Assessment, we have improved the ESA50 questionnaire. It now is clearer that evidence from care professionals such as community psychiatric nurses, support workers and carers can prove extremely useful when deciding whether someone is entitled to Employment and Support Allowance (ESA).'

Welsh successor to ILF

Health Minister Mark Drakeford has announced that he will be implementing a grant scheme, administered by local authorities to pay existing Independent Living Fund recipients their current level of funding.

The grant scheme will run from July 2015 until the end of March 2017.

welfare

Funding of £20.4m has already been confirmed for the period July 2015 to end of March 2016 and funding beyond this date is subject to the next Spending Round.

Help from 'One change' campaign

Turn2us has launched their annual campaign under the banner 'One Change'.

This year they are looking at how all it takes is one change in circumstances such as redundancy or illness for households to be pushed onto the breadline.



Recent research has found that eight out of ten low income households have seen no improvement in their financial situation in the past year.

In addition, households that have experienced just one change in their circumstances are now twice as likely to be struggling financially.

The campaign will run until 15 May. To see how Turn2us can help: www.benefitsawareness.org.uk

on Twitter at #OneChange
on Facebook #turn2us

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.

Cwtch, Haverfordwest

Young adults aged 18-45 years with long term or chronic physical health conditions meet 1st Friday of the month during school term.
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://fmmeccfswestwales.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 FM Group

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?

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

contacts

WAMES

helpline@wames.org.uk
029 20 51 5061

Chair & Campaigns

Jan Russell 01970 636515

Youth & Care Officer / Media Contact

Sylvia Penny 029 2051 5061

Young People's Contact

Michelle Penny
Michelle@wames.org.uk

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