me voice

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WAMES
Welsh Association of ME & CFS Support

contents

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 www.wames.org.uk

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Aberystwyth, SY23 3HN

We welcome news items, articles, cartoons, jokes, poems, suggestions etc. We will include them whenever it is appropriate. Please send them to admin@wames.org.uk or to the WAMES Subscriptions address above.

the wames information exchange

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

News blog on website Magazine Facebook Twitter

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wames on the web

www.wames.org.uk
twitter: WAMESMECFS
www.facebook.com/WAMESMECFS

support

WAMES would be pleased to hear from anyone who runs or attends a support group, no matter how informal, whether it caters just for people with ME or multiple conditions.

Contact us if you would like assistance with setting up local meetings.

Brecon Area Contact

Richard Jones 01874 622310
richard.j5@btinternet.com

Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months.

Next Meeting: 6 Feb 2016
Contact: John James (pm)
01267 233793

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 at Cashfields Community Centre.

Next meetings: 5 Feb 10-11.30,
19 Feb 7-8.30
Contact: Beth 07974 543874
www.cwtch-pembrokeshire.co.uk
cwtch@live.co.uk

FM/ME/CFS Support Group West Wales

Meets in Milford Haven, Pembs at Milford Haven Christian Fellowship on the 1st and 3rd Tuesday of every month 10.30-2pm.

Contact: Gary or Cathy
0844 887 2385
Mob: 07867 482 929
Next meetings:
5 & 19 Jan, 2 & 16 Feb
Carers Social: 19 Jan, 16 Feb
fibrowestwales@hotmail.com
http://fmmecfswestwales.jimdo.com

ME Support in Glamorgan (MESiG)

Usually meets first Monday of the month, Llanishen, Cardiff at 11am in Bethel Church Hall.

Next meetings: Jan 4, Feb 1
Contact: Christalla Bailey,
029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

Next meeting: February
Contact: Mike or Karen

0796 9665419 (between 2-4pm)
karen@kandm46.plus.com

Ystradgynlais Neuro Café

Open to all with neurological conditions or symptoms.
Meets at St Cynogs Church Hall, Ystradgynlais, Powys on 1st and 3rd Wed of each month between 1-4pm:

1st Wed (games, informal social time & a cuppa)
3rd Wed (education/info sessions)

Next meetings: 20 Jan , 3 & 17 Feb
Contact:
Caroline Bull 01639 849 192
cbullyvc@gmail.com
https://www.facebook.com/HeadwaySouthPowysNeuroCafe/

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

Ross on Wye
Gill Suttle 01600 890730
mesupport@gillsuttle.co.uk

me voice

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admin@wames.org.uk

WAMES' vision for implementing health services for ME

As talks continue with Health Boards, WAMES has outlined initial key steps we are asking Health Boards to take while developing healthcare pathways for people with ME.

1. Stakeholder engagement / co-production

WAMES welcomes the Welsh Government policy of co-production and the opportunity to do more than just comment on Health Board proposals.

> "In a co-production scenario, service-users and their communities are involved in defining the need or problem, designing the solution, delivering it, and evaluating it, either with professionals or independently, or anything in between. This approach demands longer-term engagement by service-providers but leads to profound and sustainable change. Co-production is also based on the sharing of information and on shared decision making between service users and providers."
>
> [from: http://tinyurl.com/jz55wnv p7]

WAMES has found that Health Boards do not always understand the needs and preferences of people with ME, and there are many gaps in services and examples of mistreatment. As a result we would like the opportunity to present this information to steering groups early on in the development of an action plan.

2. Willingness to recognise and diagnose ME, as well as CFS

The correct diagnosis has implications for management, research and assessment of outcomes. The term CFS tends to be used to cover a wide range of experience. Diagnostic criteria differ greatly. Some criteria require signs of multi-system dysfunction and tend to select a more severely affected patient group than Nseverely affected patient group than NICE would (i.e. Canadian, International).

WAMES supports the Scottish Good Practice Statement's decision to use the Canadian/ International guidelines to diagnose ME, and the NICE guidelines for those who have chronic fatigue, but lack a wider range of ME symptoms. Post exertional malaise (PEM), where physical or mental exertion causes a deterioration in symptoms, is the keycharacteristic of ME, while it is possible to make a diagnosis of CFS without this.

Although some health professionals do not believe that PEM exists, research into PEM has found that physical and mental exertion causes ongoing physiological abnormalities which cannot be explained by deconditioning and are present at all levels of severity. WAMES is asking Health Boards to ensure that this key characteristic of ME is taken into consideration when planning training, choosing diagnostic guidelines, devising care pathways and management guidance.

3. Fully inclusive Pathway with menu of care options

a. As there is no treatment for ME or CFS and everyone is different, WAMES believes that a 'one size fits all' approach to palliative care or management advice does not make sense. In order to avoid patients continuing to miss out on care we recommend that the pathway should aim to be inclusive, referring patients to services appropriate for them e.g.

- PEM – Any mental or physical activity or travel can make symptoms worse and Graded exercise / activity therapy / exercise prescription are unsuitable for severely and moderately affected patients
- Severely affected – can be house bound or bed bound, requiring domiciliary care and support
- Children and young people, not putting undue pressure to return to school too early
- Severe or fluctuating symptoms – can make reliable attendance at consultations difficult, especially a course of sessions

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A happy Christmas

- Lack of money or time due to family/ job commitments – need cheap flexible options
- Sensitivity to sound, lights, chemicals etc. can make some buildings or phone/ online consultations difficult or even impossible to access
- Cognitive problems - can affect ability to benefit from intensive consultations, courses and printed material
- Ideological differences – patients may fundamentally disagree with the philosophy/approach of some services, basing their understanding on recent research findings.

b. A menu of options drawn from across the Health Board in primary, community and tertiary settings could be part of the planned pathway. ME patients' needs overlap with other neurological and chronic conditions so they could share some general or neurological services. Existing pain and fatigue services are not always the best options for people with ME.
WAMES believes this needs to be specified in the pathway as many health professionals do not know that ME is a serious illness and are reluctant to refer patients for community nursing, OT support, speech and therapy etc.

4. Ongoing training and awareness programmes

Programmes and publicity should be aimed at a wide range of staff, not just those specialising in offering fatigue and pain courses.

Lack of understanding of PEM, the wide range of symptoms or the possible severity of the illness by health professionals during both ME and non-ME consultations can contribute to deterioration of symptoms and cause much distress.

To be really effective training should be given by professionals and patients or carers who are familiar with ME, as well as chronic fatigue.

5. NICE principles of general management

Health Boards undertake to deliver the best 'evidence based' care. Unfortunately, there are considerable controversies and diverging opinions over the nature of ME and what constitutes best practice.

The PACE trial researchers, and NICE, promote GET and CBT as the first line in therapy for all ME patients, but this has been strongly challenged around the world.

Given the controversy and the possibility of GET causing harm to people with PEM, leading to possible legal action, we recommend that Health Boards acknowledge the presence of subgroups under the broad ME-CFS banner, do not recommend a 'one size fits all' approach to care and treatment, and commit to the management principles outlined in the NICE CFS/ME guidelines e.g.:

- help with personal care plan
- shared decision making
- individualised, person-centred options
- mutually agree the pace of progression
- regular reviews
- relapse plan
- the person with CFS/ME is in charge of the aims
- domiciliary care / phone /emails where appropriate
- the right to refuse or withdraw from any component without affecting the rest of care
- supporting info following consultations (due to cognitive problems)

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from all of us at WAMES

news from wales

Help out when you check out this Christmas

We need you to...

1. Join
Head to easyfundraising, search for us to start raising.

2. Shop
There are nearly 3,000 retailers on board, so pick the one you want and start shopping.

3. Raise
After you've made your purchase, the retailer will make a donation to us at no extra cost whatsoever!

Join, shop and raise here:
http://www.easyfundraising.org.uk/causes/wames

NHS Services update

Cardiff & Vale UHB

Leads have now been appointed for ME, CFS and FM.

Executive Board leads:

- Dr Graham Shortland (Clinical Director for Child Health) &
- Fiona Jenkins (Dir of Therapies)

Clinical lead:

- Dr S Khot, consultant in anaesthesia & pain management
- Dr Jo Hampson

Powys Health Board

A stakeholder engagement event for the Pain & fatigue service was held in December, but bad weather meant attendance was low.

WAMES is asking for a wider engagement event to discuss the needs of people with ME and which services other, than the pain & fatigue clinic, could be helpful.

Find services and support

The online database of community services and support organisations ***Infoengine*** is expanding to cover seven counties:

Powys	Ceredigion
Carmarthenshire	Pembrokeshire
Neath Port Talbot	Bridgend
Swansea	

www.infoengine.wales

Dewis Cymru is the new online database of info covering north Wales. Unlike *Infoengine* it only covers services, organisations and online resources related to wellbeing (health, social care, money, housing, safety etc.)

www.dewis.wales

Disability Wales under threat

Following a Welsh Government funding change, as from the 1st of April 2016, campaigning and support charity Disability Wales (DW) will lose 68% of its income. Its recent application to the Third Sector Grant Scheme was turned down. It risks closure in less than four months' time.

Disability Wales has set up a web page for people to be able to show their support to the organisation. Share your message of support and let them know why Disability Wales is important to you.
http://tinyurl.com/zxu3lo5

do you rest?

The lynchpin of ME self-management is Pacing

i.e. balancing activity & rest to avoid increasing symptoms

It is easy to agree that Pacing is good, but not always so easy to stick to it.

Is it time for a reassessment?

What is rest?

It is not:
Watching TV
Listening to the radio
Reading a novel
Writing a shopping list
Catching up on bills or emails
Relaxation exercise of clenching and unclenching your muscles

It is:
Switching off your mind
Relaxing muscles

Aids to winding down so you can rest
Natural sounds
Breathing exercises
Relaxation exercises
Ear plugs and an eye mask
Turn off phone & digital distractions
Focus on a burning candle
Aromatherapy—soothing smells
Soothing music
Set an alarm if you need to

How often & how long for?
Everyone is different. You may need to rest many times during the day. As you get better you might be able to 'switch' between different activities during most of the day and take just one or two rests.

You will need a minimum of 10 minutes proper rest but you may find that as you recover, if you sleep for longer than 20 minutes you get that groggy 'after sleep' feeling. But, there is no right or wrong answer, just one that works for you.

Rest is...
the single most important factor in allowing CFS sufferers (CFSs) to get better, according to ME specialists such as Drs Dowsett & Myhill. In addition many doctors advise busy healthy people to take regular relaxation breaks to avoid burnout.

Going to bed in a darkened room is often the best way to relax and rest. Resting *before* you heed the danger signals is essential.

Scheduled rest
Dr Bruce Campbell recommends resting at the same time every day, regardless of how you feel. This is often called pre-emptive rest.

rest is a skill—do less to achieve more

More info:
Pacing guide by Dr Ellen Goudsmit http://tinyurl.com/ou5kwg6

Rest, pacing & stress, by Dr Sarah Myhill http://tinyurl.com/pv57gd4

Nurture Yourself with Pre-Emptive Rest, by Dr Bruce Campbell http://tinyurl.com/jhz2pxk

Funny signs in Christmas shops

- **At a Music Store in Nottingham, UK : Out to lunch. Bach at 12:30. Offenbach sooner.**
- **In a dry cleaner's shop in Portsea, Portsmouth, UK: Drop your trousers here.**
- **In a department store in Vancouver, Canada: Bargain Basement Upstairs.**
- **In a restaurant in Norfolk, Virginia, USA: Customers who find our waitresses rude ought to see the manager.**
- **In a restaurant window just outside Brixham, Devon, UK: Don't stand there and be hungry, come in and get fed up.**
- **In a health food shop window in Los Angeles, USA: Closed due to illness.**
- **In a pub in West Sussex which is non-smoking: If we see smoke, we will assume you are on fire and take appropriate action.**
- **In a Laundromat, seen in Portland, Oregon, USA: Automatic Washing Machines: Please remove all your clothes when the light goes out.**

news

Close to collapse - report on ME and social care

Action for ME's report published in November reveals that a staggering 97% of people with ME experience two or more difficulties that make them eligible for social care support - but only 16% had received an assessment in the past five years.

Of these, only 6% had been given a care package.

The next step is to hold a formal inquiry to further build the evidence base into social care provision for people with ME.

They aim to explore solutions to address the barriers to access and improve individual outcomes in terms of wellbeing, dignity and autonomy from social care support.

the report: http://tinyurl.com/hjjacox

Scams

Sussex police have produced a short video about the range of scams people experience.

Are you on a suckers list? Find out more at: http://tiny.cc/5bt86x

PACE trial

Opposition to the 2011 PACE trial study took a new turn in October 2015.

Dr David Tuller

A series of articles exposing problems with the PACE trial was written by David Tuller, a lecturer in public health and journalism at the Universtity of California, Berkeley in the US, and published on an American blog on viruses.

Following the first article on Oct 21st he went on to query why the failed FINE trial had been forgotten and why the researchers have links with insurance companies.

The researchers, who had initially refused to talk to Tuller, were given the right of reply, which failed to satisfy the author and many others.

PACE trial follow-up

On the 27th October a follow-up paper was published describing how improvements following CBT and GET were maintained long term, but that other groups had also improved.

A media frenzy followed promoting CBT and GET as the best treatment for people with ME and CFS.

Alternative views & more questions

Many patients, clinicians and researchers responded with their own stories and questions about the trial, including neuropsychologist Keith Laws and psychologist James Coyne.

A number of e-petitions were set up demanding a re-examination of the trial results or retraction. Many individuals and organisations wrote letters of complaint.

6 eminent researchers, including cancer specialist Prof Jonathan Edwards from London and Prof Leonard Jason from the States, wrote to the *Lancet* and the trial researchers asking for an independent re-analysis.

American medical website Medline Plus removed the PACE paper on 5th December.

FOI requests

At least 14 *Freedom of Information* requests for data from the trial have been refused by the researchers, arguing that the requests were vexatious and release of data would undermine their personal credibility and that of the study. At least £750,000 is said to have been spent fighting the requests.

On 27th October however, the government's *Information Commissioner's Office* ordered one request to be met. The researchers appealed and it will take many months before the matter is settled.

What is wrong with the trial?

Criticisms about the trial cover:

- the basic design and lack of objectivity
- changing of the trial's endpoints after the trial began
- the analysis and interpretation of the data
- analyses in published papers lack sufficient detail and transparency to allow independent evaluation of what was done and how the authors interpreted their results.

More info: WAMES website blog http://www.wames.org.uk

E-petition: http://my.meaction.net/petitions/pace-trial-needs-review-now

Matchstick Campaign for ME Awareness

[see page 9]

Janet Smart from South Wales has been given permission to use award winning German Artist, Wolfgang Stiller's work to highlight the situationh in which people with ME have found themselves.

http://tinyurl.com/jl2uv7n

Invitation to take part in a large gene study of ME/CFS

Are you currently diagnosed with ME/CFS (SEID)?

Are you interested in your genetic makeup?

If so, you can help the INIM create a one of a kind genetic database for patients with ME/CFS.

Participation in this study requires you to have a computer with internet access, an email account and your agreement to map your genes through the use of a publicly available genetic testing websites.

If you agree to participate, you will provide them with your raw genetic data for them to compile in the ME/CFS Genetic Database.

Participants will also be completing online surveys at your own pace. As all communication is done via secure email server, NO travel is necessary and participation can be done in the comfort of your home!

More info:
http://tinyurl.com/js3tz22
http://tinyurl.com/zkbfpjp

Christmas Cryptogram by Clement Clarke Moore

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Created by Puzzlemaker at DiscoveryEducation.com

Matchstick Campaign for ME Awareness: Using Art to raise awareness

carers

Do you need help?

Not all carers want an extra hand, even when they really need it.

Recognise the red flags:

- there isn't enough time in the day for all the chores or for yourself
- you feel more negative than positive about your situation
- family members or friends express concern about how you are coping
- you start yelling at the person you're caring for, or worse, become neglectful or abusive
- you start resenting your caring duties

No need to feel guilty, just recognise it as a sign that you are becoming overwhelmed and may need help.

Carers in Ceredigion combined their thoughts and experiences on how to tackle such a problem in a booklet. Here is an excerpt:

"Asking for help

One thing that can really help you with these difficult feelings is to get some support – practical or emotional. You are not on your own, though it may feel like it. There are professionals and others who can − and want to − help. It might not always be easy to find the right key to unlock the door, but it pays to be persistent.

Remember, if you can no longer cope, they will have to pick up the pieces. It's not always easy to ask though. You may not know where to go or feel you don't have the time to find out.

Some carers fear losing control or being judged, or feel that they have failed in some way.

Try considering it a strength to be able to ask for help. You may feel that you don't need help at present. If so, just tuck this away for future reference. At different times you may feel desperate for information and at others totally overwhelmed by it. Again, keep this for when you need it.

The professionals

It may be helpful to remember that professionals – those working in the paid caring professions – are often confronted with an ever-increasing workload and responsibilities, and many are not well paid. It can be frustrating, you may have to be persistent, but don't give up. The professionals are doing their best, they are there to help you as well as the person you care for and they want to be supportive.

All professional organisations have a way for you to comment on your experience – use it. If you reach the point at which you feel you are not being heard an advocacy organisation may be able to help. You have the right to have your views taken into account when an authority is considering how best to provide support for a disabled person.

Most importantly of all for your situation, carers who provide a 'substantial' amount of care on a regular basis are entitled to request a separate Carer's Needs Assessment. Someone from Social Services will come and talk to you about the help you need as a carer.

> "Involving the person with ME in both their care and also the care of the carer provided my wife and I with an invaluable partnership. Yes, I am her carer – but actually we're in this together.
>
> "Looking after yourself as a carer also gives the person with M.E. an opportunity to care for you."
>
> *Duncan from AfME booklet*

Carers say that the assessment has been an opportunity to get information and to talk through the problems they are dealing with.

The person you care for

Good caring is not always doing everything for the person you care for. One of the most challenging aspects of caring is to allow the person to try to do as much as they can or want to for themselves. We all need some control over our lives. Continuing to make choices and decisions is important, even if it is the small things like what clothes to wear or what to eat.

Friends and family

If you have written off friends or family members because they haven't been involved so far, here's the time to have a rethink.

They may feel unable to offer help because they don't want to suggest you can't cope. Or they may want to help but feel worried that their offer will become unlimited and they wouldn't want to let you down. But you don't want them to take over, just to help out now and again. So be specific about what it is you want them to do and how often.

It could be cooking an extra couple of portions of an evening meal once a week so you don't have to. Or sit with the person you care for a few hours every week so you can go to a class or take some exercise.

Making a rota for tasks that can be shared can be helpful. If you can get lots of people to each do something small, it can add up to a big difference to you. You get time to yourself, a precious commodity, and those around you, who care about you, feel they are contributing in some small but significant way.

Other carers
Obviously each carer and each situation is unique, but your shared experience puts you in an excellent position to help each other.

A support group offers a space where you can share knowledge, practical information and how you feel about your experience. The best ones value and understand you beyond your caring role. You can meet other carers through local carer support groups or online through carer forums and chat rooms.

Looking after yourself
Looking after someone usually takes place over a substantial period of time so you need to pace yourself. If you collapse under the strain it provokes a crisis and others will have to step in.

To avoid this you need to pay attention to your own needs. It may seem some times that your needs are in conflict with those of the person you care for, but remember that the impact of the disability or illness on your lives is one that you both share.

It could be that you need to make time to spend with the person you care for which is pleasurable and fun. And then there may be some things that you need. Take some time to write down what those needs are.

Do you need time for yourself, someone else to talk to, to get out in the fresh air, get more sleep…?

Time for you
One of the main stresses of caring is not knowing when, and perhaps how, it will end.

We can usually find the extra resources within ourselves to keep it all together to deal with some emergency or crisis, but when the situation continues, stress builds up and can lead to burnout. To continue long-term caring you need breaks to take a step back and to gather your energies.

Respite or replacement care
This is a chunk of time away from your caring role. Impossible, you say. There *are* obstacles to getting respite care, but ask yourself first if they really are obstacles or whether you are putting them there.

The objections carers raise are real − that the person they're caring for won't allow anyone else to be involved, that they won't want to go away from home, that they don't want social services involved, and so on. But these can and should be overcome.

Some carers think that only they can do it. If it means you can carry on caring then surely the compromise is worth it?

Having a serious break is the only way to really recharge your batteries. And it's much better to do it before you break down or face a crisis.

When you take this time out have a good think about what you do with it. Do something for yourself rather than fill it with chores. Rest, invest the time wisely.

Talk to others
Start talking to anyone who will listen − other carers, friends, family, professionals and neighbours. Putting into words what is happening helps you deal with the difficult feelings and gain some perspective.

To save your sanity you have to break down the isolation and connect with others. If you have access to the internet there are many new ways of keeping in touch such as Facebook, MSN and chat forums.

If you are not coping, and feel your emotional health is suffering, your first port of call should be your GP. They may be able to refer you for help or prescribe a self-help book or medication. If you really feel as if you are going under you may want to talk to a counsellor about your feelings."

From:
Say 'I'm Fine'...and Mean It! If you look after someone, who is looking after you? http://tinyurl.com/hjz36t9 Ceredigion residents can get a free copy by ringing 01545 574000]

More info:
Caring for someone with ME
available from 0117 927 9551
Action for M.E., 42 Temple Street
Keynsham BS31 1EH

carers

Unpaid care in Wales worth over £8 billion a year

People in Wales who provide unpaid care for a disabled, seriously-ill or older loved one in Wales saves the state £8.1 billion a year – this has almost doubled in 15 years, vastly outstripping the rate of the general population growth in Wales during this same period (7%).

Valuing Carers 2015 – the rising value of carers' support, is the third in a series of reports from Carers UK and the University of Sheffield looking at the value of carers' support to the UK economy.

Researchers attribute this rise to a dramatic increase in the number of hours people are caring for, combined with an increase in the cost of replacement care.

Since 2001, the number of people providing 20-49 hours of care a week has increased by almost a third (31%) and those providing 50 hours of care or more a week has increased by nearly a quarter (23%).

However, as the Welsh population continues to age, local authority funding is in decline, leaving families to increasingly step in to fill the gap.

Carers Wales Director Keith Bowen has warned: "If even a small percentage of people were unable to continue caring in Wales, this would be catastrophic for the economy."

A breakdown of the figures for Wales by local authority area are in the Appendix on Page 17 http://tinyurl.com/q2knrjg

Get Christmassy for Carers!

Carers Trust Wales wants everyone to know that whilst the majority of people are looking forward to winding down over Christmas, taking a break from work and enjoying some relaxing family time, the story is quite different for the 370,000 unpaid carers across Wales.

Work doesn't stop for carers at Christmas time. In fact, it can be a particularly stressful time of year. Carers Trust research earlier this year found that 30% of carers don't get a break of any kind during a typical week, and 65% of carers spend any breaks they do get doing chores around the house.

That doesn't provide much opportunity for Christmas parties, shopping for presents for loved ones or watching a classic Christmas film with the family – activities that most people would consider standard for this time of year.

That's why Carers Trust Wales are encouraging the nation to Get Christmassy for Carers to show their support and appreciation for unpaid carers.

People are being encouraged to get Christmassy, either by decorating their workplace or themselves (santa hats, reindeer antlers etc.), take a selfie, and share it on Instagram, Twitter or Facebook using #ChristmassyforCarers.

Also, to help Carers Trust Wales continue to support unpaid carers across Wales, people are being invited to text 'CARW15 £3' to 70070 to donate £3.

Know a carer under 18?

Show them Babble, a safe online community where young carers in the UK can chat http://babble.carers.org

Flu has arrived in Wales

but FEWER people have taken up their free flu vaccination

The flu virus spreads easily via droplets which are sprayed into the air when an infected person coughs or sneezes. Direct contact with contaminated hands or surfaces can also spread infection.

The majority of cases confirmed in Wales so far this season, have been caused by the Flu A(H1N1) virus, which was responsible for the 'swine flu' pandemic in 2009 and 2010.

The annual flu vaccination is available for carers who should get the vaccine to protect themselves and the person they care for.

More info: http://ww.beatflu.org http://www.curwchffliw.org or Beat Flu or Curwch Ffliw on twitter and FB.

New Year's Day

Now is the accepted time to make your regular annual good resolutions. Next week you can begin paving hell with them as usual.

Mark Twain

carers

Carers Trust Wales election manifesto

The Carers Trust Wales has launched its manifesto of priorities and asks for political parties in the run-up to the National Assembly for Wales election in May 2016.

They want Wales to be a country that protects, promotes and recognises the valuable contribution that all carers make.

The key practical and achievable things goals:

1. Living, working, and learning - better access to education and employment, and better support when they are in education and employment. a better financial settlement for carers.
2. Investing in Carers - introduction of a Carer Well-being Fund to provide additional breaks for carers.
3. Support for carers of people with dementia
4. A better deal for young and young adult carers - support mechanisms to help them to stay and succeed in education

Caring Wales: A manifesto to promote, protect and recognise all carers http://tinyurl.com/hrztcq4

Carers Wales election manifesto

Health & care
Carers are reporting cuts to care packages, rising care charges and direct payments failing to keep pace with the costs of care services.

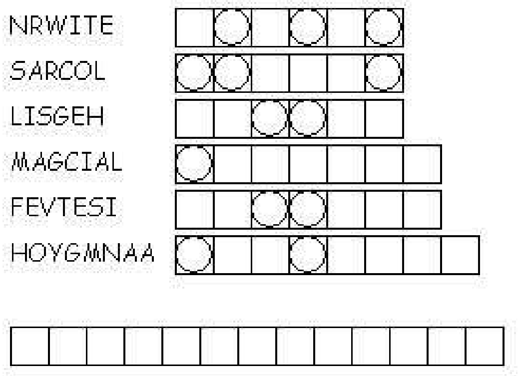
Families are being forced to fill the growing gap between the demand for care and the support available. This is having a serious consequence to their mental and physical health and pushing them into social isolation.

Employment & training
Many carers want to combine work and caring but cannot access the support to do so.

Recognition, information & advice
A lack of recognition of who carers are and the impact of caring results not just in carers missing out on advice and support, but also prejudice, discrimination and social exclusion.

More info:
http://tinyurl.com/zxwghwz

Christmas Cryptogram by Clement Clarke Moore



Created by Puzzlemaker at DiscoveryEducation.com

Unscramble each of the clue words.

Take the letters that appear in ○ boxes and unscramble them for the final message.

PEM, PENE or DOPE?

Dr John L Whiting's acronym for the strange post exertional phenomenon which is the cardinal feature of ME, is the term DOPE. His DOPE stands for: Delayed Onset Post Exertional fatigue.

In DOPE there is a time gap of 1-3 days (occasionally longer) between the exertion (which includes things like having an enjoyable night out and not recognising it as exertion) and the symptoms that follow later.

This unusual GAP IN TIME
... is the diagnostic giveaway in terms of saying ah-ha, this is ME.
... is not part of normal physiology

What is strange is that the exertion in question may be FULLY tolerated symptomatically AT THE TIME of activity, with no clues or forewarning as to what is to follow later.

More info: http://tinyurl.com/pjqtdnu

living with me

Make the most of winter

Don't let the cold damp weather and short days get you down:

- Put up a feeder and enjoy the birds through the window
- Light candles and sip cocoa in front of a fire
- Enjoy the crackle when walking on frosty grass
- Plant bulbs in a pot and watch the plants grow towards Spring
- Enjoy the spectacle of large flocks of birds, especially early morning or as the sun sets at piers, estuaries, town parks
- Follow the lights: private houses with outside Christmas decorations; public buildings lit up; town Christmas lights; dams, rivers & canals
- Phone an old friend or family member you haven't spoken to in ages
- Sort your photos and remember good times
- Clear out cupboards, donate to charity
- Sign some e-petitions about causes that matter to you
- 'Take stock' – can you improve your self-management strategy?
- Watch old videos that make you laugh!

Remap – unsung heroes of independent living

If you have a particular problem associated with a disability or long-term condition, and you can't find the right product to help, Remap's brilliant volunteer engineers can often come up with a one-off solution for you.

The charity has been providing its services free of charge to disabled people from more than 50 years. It has a network of over 70 groups across Wales and England, so there is probably help near you. For more information: www.remap.org.uk or 01732 760209.

Winter store cupboard

Many meals and snacks can be made from a well-stocked store cupboard. Check yours in case a relapse or bad weather keeps you indoors.

Consider keeping the following:

Milk – long life, evaporated or dried,
Breakfast cereals and porridge – a healthy snack any time of the day
Pasta, rice and couscous, crackers or crispbread
Tinned meat and fish especially oily fish such as sardines or mackerel
Pulses –lentils, beans, baked beans
Canned veg, tomatoes and tinned fruit

With a few items from each food group in stock you have the makings of some balanced meals if you aren't able to shop.

More info:
About healthy eating in general: http://www.nhs.uk/livewell/goodfood http://www.carewelluk.org

Advice for carers: http://wales.gov.uk/topics/health/publications/socialcare/guidance1/nutrition/?lang=en

Meal ideas for young people: www.cwt.org.uk/publications

living with me

Optikey

This free software designed to help people with impaired speech and motor function to control their computer and type and click with only your eyes. It was developed by Julius Sweetland, whose aunt had MND.

Read more: http://tinyurl.com/jtp3p4s

Apps & software for the disabled?

interesting video that looks at whether there is enough accessible technology for disabled people.
https://youtu.be/D70TR0gN5MI

Heat pad

Helen from Llanelli recommends an electric heat pad to ease pain and stay warm.

The Dreamland Intelliheat pad measures 40x35 cms / 16x14 inches and can be used all over the body; back, neck, shoulder and abdomen. It has 5 heat settings and can be machine washed and tumble dried. It even shuts off after 3 hours and costs less than 1p per session.

No more boiling kettles for hot water bottles!

Purchase from major stockists for around £30: Argos, Amazon, John Lewis etc. Please order it via Easyfundraising and make WAMES your charity of choice.

CallerAlert

CallerAlert ensures you don't miss callers to your front door.

1 Visitor presses doorbell
"PLEASE WAIT" illuminates and user remote vibrates

2. Door chime & notification
The doorbell chimes inside and then illuminates

3. Send a confirmation
The home owner presses the remote

4. Visitor notified
The doorbell lets the caller know they are on their way

The CallerAlert remote uses unique radio-frequency to notify the caller that you are on your way, and it has a range of up to 420ft, leaving you free to move around your home. Lightweight and comfortable to wear, you can carry it on a belt clip, wrist strap or lanyard – or simply put it in your pocket. It vibrates when the doorbell is pressed.

The indoor chime unit can be plugged in wherever you like in the house, and there is a choice of three different alert modes: melody alone; melody and flashing light; or melody and solid light. You can choose from a selection of melodies at different volumes.

More info: www.yousafe.co.uk
Concept Solutions (UK) Ltd
The Beeches, Brighton Road
Lower Kingswood, Surrey KT20 6SY
01737 831 226 info@yousafe.co.uk

Low tech ways to keep your house warm

As the weather turns colder, it's especially important for people with M.E./CFS to make sure they keep their homes toasty.

With increasing energy prices, we know this can be a challenge – which is why we like the BBC's 14 low-tech ways to keep your house warm over the winter. http://www.bbc.co.uk/news/magazine-24757144

And remember, you may be eligible for a cold weather payment if you're receiving certain benefits.

1. Use tin foil between the radiator and the wall to prevent unnecessary heat loss.
2. Thick curtains, with a thermal lining
3. let the sunlight in during the day.
4. Fake double glazing - a special film, for example:
   http://tinyurl.com/qhrbttq
5. Stop heat being lost up the chimney. e.g chimney balloon or woolen insulators.
6. Reduce mini-draughts. letterboxes, keyholes, Cat or dog flaps
7. DIY draught excluders
8. Don't block your radiators
9. Put a shelf above the radiator to channel the warmth
10. Keep doors closed to unused rooms.
11. Cover bare floorboards to avoid heat loss
12. DIY loft insulation - check for grants - & replace damaged tiles
13. Insulate loft hatch
14. Set timers on heating

welfare

DWP cuts specialist disability employment advisors in Jobcentres by over 60%

There has been a steep fall in full-time specialist employment support for disabled people in jobcentres.

(*Independent* article: DWP cuts specialist disability employment advisors in Jobcentres by over 60 per cent, by Jon Stone, 10 Nov 2015)

There have been deep cuts to the numbers of full-time specialist disability employment advisors posted in Jobcentres, new figures show.

Between 2011 and 2015 the number of Jobcentres employing a full-time advisor to help disabled people navigate the support system and find employment fell by over 60 per cent from 226 to just 90, with reductions in every recorded year.
http://tinyurl.com/nck7u2r

New Year: Time to Diet?

Doctor: Well, well. It seems that your weight is perfect. It just happens that you are eleven feet too short.

590 suicides in England linked to 'fitness for work test' (WCA)

Public health experts from the Universities of Liverpool and Oxford have shown in a study that, for every 10,000 Invalidity Benefit (IB) claimants who were reassessed in England between 2010 and 2013, there were an additional six suicides, 2,700 cases of self-reported mental health problems, and an increase of more than 7,000 in the number of anti-depressants prescribed.

The most significant increases took place in the most deprived local authority areas of England.
http://tinyurl.com/z9f4rxs

Government cuts will make it harder for disabled people to find work

Government plans to cut unemployment benefits for disabled people will make it harder, not easier, for them to get back into work, according to a House of Lords report.

The Employment and Support Allowance (ESA) is set to be cut by £30 a week for new claimants from April 2017 to bring it in line with Job Seekers Allowance. Lord Low, one of the peers who led the review, said: “The review finds no evidence that the £30 a week disabled people receive as part of ESA-WRAG [Work Related Activity Group] is acting as a disincentive to work and thus there appears no justification for this reduction in payment.

“In fact our review found that the current ESA rate is already not enough to work as an income replacement considering that claimants are often, through no fault of their own, out of work for a considerable time.

“The Government should halt this cut and instead introduce better and more personalised and tailored support to help disabled people who can work take steps to do so.”
It also claims some health conditions, such as anxiety and stress, could be worsened, and social isolation could increase.
http://tinyurl.com/z92aj38

In the run-up to the general election, civil servants sketched out plans to charge claimants a fee if they tried to appeal to a tribunal after being found ineligible for benefits, Disability News Service (DNS) can reveal.

The policy proposal was drawn up earlier this year, in case it could be used by the new government.

An extract from a Department for Work and Pensions (DWP) document, which emerged through a DNS freedom of information request, suggests Tory ministers have not abandoned the idea of charging for benefit appeals, despite the proposal causing controversy when a DWP document was leaked to the *Guardian* in February 2014, with benefits experts and campaigners labelling the idea a “disgrace”.
http://tinyurl.com/pjtn7bn

Government U Turn on Tax Credit cuts

The government has abandoned some of the planned cuts to Tax Credits announced in the Summer Budget 2015. Other cuts to tax credits will go ahead, for example limiting the Tax Credits payable to two children for new births from April 2017 and not applying the family element for new claims also from this date.

Revised at a glance Guide to the Benefit Changes in the Summer Budget 2015
http://tinyurl.com/z87j3om

U21

Wishing you all a very merry Christmas!

We'd love to hear from you in the New Year. Let us know how you cope with your ME or what you'd like to see in the magazine.

u21@wames.org.uk

Managing ME/CFS: A guide for young people

by Rosamund Vallings

Dr Vallings is a doctor in New Zealand who has spent much of her career helping people with ME/CFS.

In her new book she explains the illness in a way that is easy to understand and relevant to young people. The book includes:

- suggestions for managing everyday tasks.
- tips for working through the ups and downs of the illness.
- ways to create the best chance of recovery.
- stories from young people who are managing this illness.

Dr Vallings' message to young people is to learn as much as you can about ME/CFS and to actively take charge of your health. As she says,
'Only you know how you really feel.'
Anyone caring for a young person with ME/CFS will also find this book useful.

Calico Publishing.
Kindle Edition from Amazon = £9.60
ISBN 978-1-87742-914-9 ePub
ISBN 978-1-877429-15-6

Friendship is born the minute one person says to another. What! You too, I thought I was the only one.

C.S.Lewis

In 1996 it was estimated that there were 25,000 children in the UK with Myalgic Encephalomyelitis.

graphic by Janet Smart

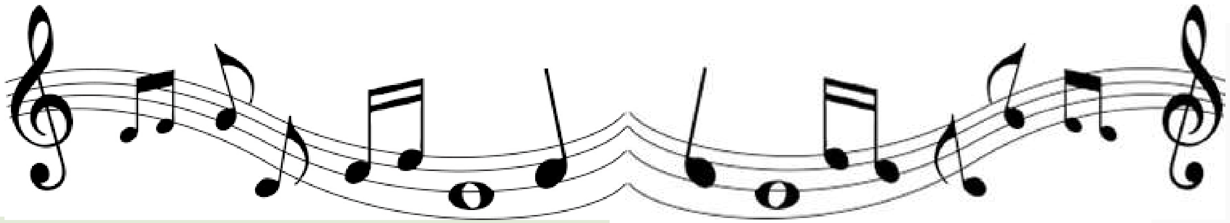
What is ME? A guide for children

Hayley Green's short illustrated book for younger children explains how ME hurts.

"People with ME have a battery that doesn't charge properly."

Book £4.70
Kindle: £4.70 (on offer for £1.99)
ISBN: 1508510369

U21

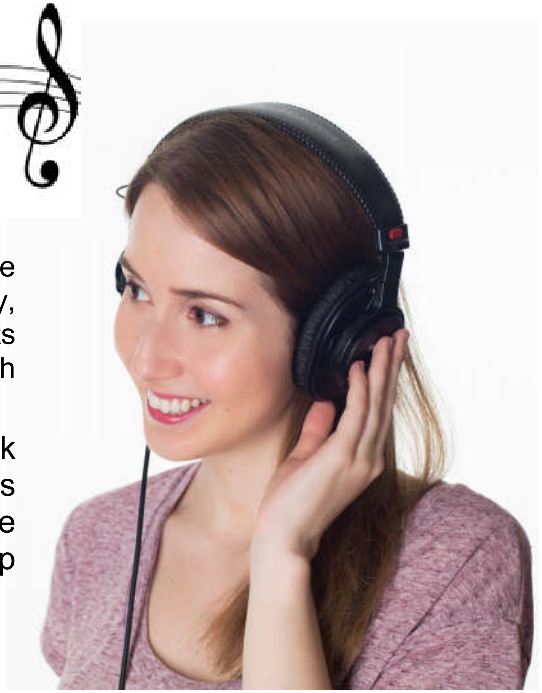


Learning to live with ME means learning to live without many things we loved or had come to rely on.

Has ME made it hard for you to enjoy music?
Many of us find that the music we used to love now sounds too loud, too fast and too discordant. Our brains seem to get overloaded and we hear noise that tires and hurts us, rather than music that excites and gets our feet tapping.

Never fear, music can be part of your life again at some point. When you feel up to it, try these tips from other people with ME:

- to begin with stick to the music you know, but avoid anything that causes an adrenalin rush, choose the slower calmer tracks
- turn down the volume
- Explore different styles of music. Rock and reggae may leave you feeling battered but maybe some kinds of jazz, pop, folk or classical will be easier to tolerate. They may not be trending with your peers, but might just be the 'medicine' *you* need.
- Look for compilations described as soothing, relaxing or meditative. Love songs or ballads (rock or folk) might fit the bill.
- ask friends, family or the local library to recommend some of their slow soothing favourites (but be prepared to pin a smile on your face and say thank you if they produce your least favourite artists!)
- you might feel as if you are only person of your age listening to Mantovani, Enya or Sian James, but you would be surprised and anyway, nobody needs to know!
- instrumental can be easier than vocal— less for the brain to process.
- look for new music free on online streaming services like Spotify, Napster etc., You can make playlists free, but you have to pay if you wish to download.
- pace yourself—listen to one track at a time. As your health improves (or on better days) you may be able to listen to more. Always stop *before* you start to feel really bad.

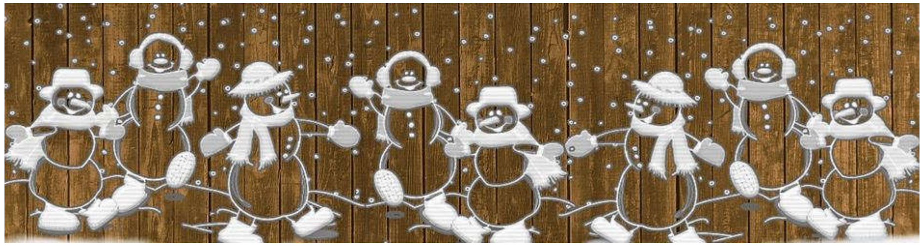


If all music is still too much, try recordings of natural sounds e.g. trickling brook, the wind in the trees, waves lapping on the shore. Pan pipes or Native American flute can also be very peaceful e.g. http://tinyurl.com/pwvswuj

Go on, be a trendsetter. Start soft and slow and eventually you could be listening to those old favourites again, but don't be surprised if your taste in music has changed and continues to change!

Thanks to WAMES FB members for suggestions)

Above all—enjoy!
Music streaming http://tinyurl.com/qc9ga7l http://tinyurl.com/gmlcxyt



U21

Welsh Music Awards Nominees

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

Calan
Geraint Jarman
H Hawkline
Houdine Dax
Keys
Richard James
Trwbador
Zefur Wolves

Catfish and the Bottlemen
Gwenno
Hippies vs Ghosts
Joanna Gruesome
Paper Aeroplanes
Tenderprey
Zarelli

Created by Puzzlemaker at DiscoveryEducation.com

Please Note:
CHRISTMAS IS CANCELLED

Apparently, YOU told Santa that you have been GOOD this year ...

He died laughing

Stop Press:

Welsh Music Prize Winner
Gwenno Saunders for sci-fi inspired album
http://tinyurl.com/pke62fj

U21

Choose an inspiring quote and relax while you colour