

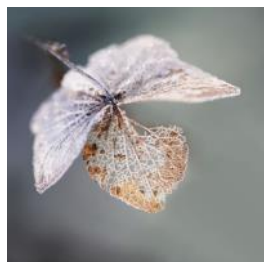
# me voice



the wames magazine dec 2017, no.19



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## HOLIDAY HELPLINE HOURS

WAMES helpline [helpline@wames.org.uk](mailto:helpline@wames.org.uk) 0290 2051 5061  
24-27 December closed 28-31 December 11-3pm  
1-2 January closed 3 January onwards 10-7pm

**We ask that you only use the helpline during  
Christmas and New Year for emergencies.**

For emotional support, the [Samaritans](#) can be contacted 24/7.  
English – 116 123 – free number (24 hours a day, 7 days a week)  
Welsh – 0808 164 0123 – free number (7pm – 11pm 7 days a week)

Children and young people up to age 25 can also contact [Meic](#)  
by phone, email, SMS text and instant messaging.  
8am to midnight, 7 days a week  
FREEPHONE: 0808 80 23456 SMS TEXT: 84001  
IM/Webchat: [www.meic.cymru](http://www.meic.cymru)



## me voice

is published up to 4 times a year. You can subscribe to the paper  
copy for £10 p.a., or receive it free by email, or read and/or  
download it from [www.wames.org.uk](http://www.wames.org.uk)

**Contact:** [tony@wames.org.uk](mailto:tony@wames.org.uk)  
WAMES Subscriptions,  
The Coach House, Frongôg,  
Aberystwyth, SY23 3HN

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](mailto: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**

**Cover Photo by David Craig' "Dark pillars - Scene from Wales during a winter scramble". Cropped to  
fit. [www.connect-photography.co.uk](http://www.connect-photography.co.uk) Creative Commons Attribution-NonCommercial 2.0**

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[www.wames.org.uk](http://www.wames.org.uk)  
twitter: WAMESMECFS  
[www.facebook.com/WAMESMECFS](https://www.facebook.com/WAMESMECFS)

## patron

Lord Barry Jones

**Merry Christmas From  
All at WAMES**



# me 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](mailto:richard.j5@btinternet.com)

## Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months. Check before you go.  
Next Meetings: 11 Feb, 14 April

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.

Contact: Beth 07974 543874  
[www.cwtch-pembrokeshire.co.uk](http://www.cwtch-pembrokeshire.co.uk)  
[cwtch@live.co.uk](mailto:cwtch@live.co.uk)

## ME Support in Glamorgan (MESiG)

Usually meets first Monday of the month, Llanishen, Cardiff 2-3.30 in Bethel Church Centre

Next meetings 8 Jan, 5 Feb, 5 March, 2 April

Contact: [mesigwales@gmail.com](mailto:mesigwales@gmail.com)  
[www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk)

## Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

Contact: Contact: Donna Teague,  
[dateague@hotmail.co.uk](mailto:dateague@hotmail.co.uk), 07413-529994  
Next meeting is on 3rd Jan. Check before you go.

## Neuro-Café Brecon

Meets every 2<sup>nd</sup> Wed 10am-12 noon at Ty Croeso, St Davids House, 48 Free Street, Brecon LD3 7BN

Activities include: drink & chat; games; quizzes, and occasional speakers. More info: Rebecca or Rhian 01745 508524 [Hosted by the Stroke Association]

## 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)  
[headwaysouthpowys@hotmail.com](mailto:headwaysouthpowys@hotmail.com)  
<https://www.facebook.com/HeadwaySouthPowysNeuroCafe/> 01792 529615

## Live near the border?

*An English group may meet closer to you:*

### Shropshire

[www.shropshiremegroup.org.uk](http://www.shropshiremegroup.org.uk)  
Maralyn Hepworth 07516 401097

### Chester

[www.chestermesh.org.uk](http://www.chestermesh.org.uk)  
Joan Crawford 01244 370988

### Ross on Wye

Gill Suttle 01600 890730  
[mesupport@gillsuttle.co.uk](mailto:mesupport@gillsuttle.co.uk)

## For other support groups in the UK:

<http://www.mesupport.co.uk/index.php?page=uk-republic-of-ireland>

## Disclaimer:

**me voice** aims to provide information, not advice. Views expressed within the magazine or on external links may not be shared by WAMES. WAMES articles may be reproduced whole for the benefit of people with ME, provided the source is acknowledged.

## me voice

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**publisher:** Dr Tony Thompson

[admin@wames.org.uk](mailto:admin@wames.org.uk)

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Pixabay



# wames news

## £1 to Keep WAMES campaigning' update!

£1 each donated by the estimated 13,000 people with ME in Wales would enable WAMES to:

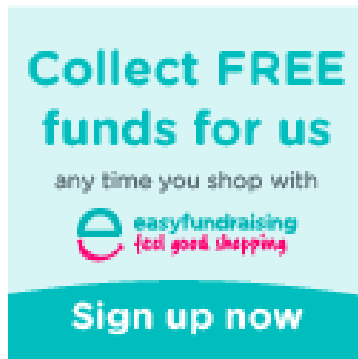
- spend less time completing grant applications
- get us out into the health and social care communities
- and back to campaigning for the next few years.
- **survive!** Without funds, WAMES cannot continue to do its work on your behalf.

**Total donations** so far: £12!

**To keep us on the road Donate online**  
<https://mydonate.bt.com/charities/wames>

**Donate by cheque** to the treasurer at:  
Cornerstones, Clinton Road Lane, Penarth, Vale of Glamorgan, CF64 3JD

**Or raise money free while you shop**



Find out more by watching the video:  
[https://youtu.be/Sn2dsQGAe\\_w](https://youtu.be/Sn2dsQGAe_w)  
<https://www.easyfundraising.org.uk/causes/wames/>

## ME and my world a WAMES photo project



### *The purrs of Pebbles*

Stephanie Burgis says:

*"When I'm stuck in bed, too ill to work or even move, it helps so much to have her purring on my chest.*

*Before, I used to lie there feeling nothing but despair on those bad days.*

*Now I feel her purr resonating through my chest, and the stress and frustration drain out of me, replaced by love."*

## What makes life with ME easier for you?

### How has ME changed your life?

Help WAMES to show the way ME affects your world and those around you.

Take part by observing and recording your life over the next few months.

### Can we photograph you?

If you would be willing to be photographed during January and February, or just want to know more, then please email us at WAMES  
[admin@wames.org.uk](mailto:admin@wames.org.uk)

### Send us your photos

Alternatively aim to send in your own photos that you feel illustrate your struggle with ME.

### Send us a quote

Or tell us about a phrase or quote that describes an aspect of your life and we will look for a suitable image to complement it.

### WAMES photo exhibitions 2018

We will use the photos online and a selection will be exhibited at various venues around Wales.

### Our photographer

Tom Martin, photographer for the Wales News Service (and person with ME) will be overseeing this project.



# wames news

## Unrest in Wales

There have been 2 screenings of the Unrest film in Cardiff at the Tramshed cinema during November and December.

Plans for future screenings:

- Welsh Government
- Cardiff MEDSOC (medical students)
- Aberystwyth
- Other parts of Cardiff
- Carmarthen

### WAMES can help you organise a screening by:

- putting you in touch with other people with ME in your area to form a working party
- helping in the search for a suitable venue
- providing guidelines for organising a screening
- offering suggestions for funding it (the licence costs £200)
- helping to advertise the film
- providing publicity materials suitable for Wales
- help with setting up a display or exhibition to support the screening

Keep an eye on our blog and social media for dates and other venues.

Please get in touch with Jan if you would like to know more.

Email in the first instance. [jan@wames.org.uk](mailto:jan@wames.org.uk)

**How to buy the film—see page 7**

## #TimeForUnrest

*is a global campaign to grow and strengthen the global movement for equal recognition, education, research, and funding for ME.*



Watch the trailer: <https://www.unrest.film/trailer/>

Read more about the campaign at <https://www.unrest.film/time-for-unrest/>

Join WAMES in spreading the word about  
**#TimeForUnrest**

## All charities need a treasurer

The treasurer's post will become vacant in 2018. We cannot remain a registered charity or apply for funding without one. Please spread the word.

The role of the treasurer is to:

- Maintain an overview of WAMES' financial affairs and advise the committee on budgets
- Ensure that proper financial records and procedures are maintained

To find out more contact Jan [jan@wames.org.uk](mailto:jan@wames.org.uk)

### Please note:

- Training can be arranged
- Most tasks can be carried out from home
- The post is available as 'role share'
- You don't have to be knowledgeable about ME
- Your work will be critical for continued campaigning and awareness raising in Wales!

## NICE CFS/ME guideline review

WAMES has signed up as a stakeholder. The first meeting is on January 15<sup>th</sup> in London.

It is a 'stakeholder engagement workshop that will help us develop the range of issues that are of most importance for this guideline.'

There are limited spaces, but WAMES plans to attend and will represent Welsh pwme.

## WAMES needs a relational database

If you can use Microsoft Access to create a database for us in the New Year, please get in touch with Kish or Jan.

# news from wales

## NHS Wales & ME

The All Wales Implementation Group (AWIG) reports continued slow progress by the NHS in implementing the recommendations in the 21014 Task & Finish Group Report, which are aimed at improving health services for people with ME, CFS and FM.

### Task & Finish Group Report:

<http://gov.wales/docs/dhss/publications/150407me-cfsreporten.pdf>

Owen Hughes, a clinical psychologist from Powys Health Board takes over as chair of the group in December 2017.

**Aneurin Bevan, Cwm Taf and Betsi Cadwaladr** Health Boards have not begun to plan improvements to services for people with ME.

**Powys** HB is continuing with their plan to refer all pwme to a clinic offering rehab and Activate your Life courses.

### Cardiff & Vale and Abertawe Bro Morgannwg

HBs are planning rehab clinics for multiple conditions – details are unclear. The progress of **Hywel Dda's** pathway group is being slowed down by lack of cooperation from services within the HB.

**WAMES** has continually asked for HBs to make it a priority to raise awareness of ME amongst all staff and to train GPs to recognise and diagnose neurological ME. Health Boards are happy to support this if doctors from within their organisation wish to take the lead. They have so far been unwilling to pay to bring in experts from

elsewhere, and the expertise does not appear to exist within Wales.

The Group continues to meet 2-3 times a year in Cardiff. WAMES' chair Jan Russell is actively involved in the Implementation group, passing on relevant information about patient needs, research, PACE trial etc. Please contact her with information about ME patient experience in the NHS.

## Disability grants in North Wales

The Steve Morgan Foundation provides support for people with physical disabilities in North Wales who are in financial hardship to obtain specialist equipment that cannot be supplied by the NHS, education or social services.



Contact the Foundation on 01829 782808, where you can discuss your needs and request an application form.

More info:

<https://stevemorganfoundation.org.uk/how-to-apply/enable-funding/>

Feelings are much like waves; we can't stop them from coming but we can choose which one we surf

## Welsh government consultation on free bus travel for older & disabled people

Welsh Government consultation: Mandatory concessionary fares scheme in Wales

Consultation End Date: 12 January 2018

Options to improve access to and use of free bus travel in Wales include:

- Welsh Government becoming the Travel Concession Authority
- increasing the age of eligibility for older people to match the UK state retirement age
- the issue of 'companion' passes for disabled people
- extending the scheme to include volunteers

Read the consultation document and find out how to respond





# news from wales

## Community connectors Powys

The Community connectors in Powys aim to provide local information about services to residents.

They were able to help a lady with ME get out and about more by providing information about accessible outdoor spaces near to her home.

She was also told about the local Wildlife Trust, Cruse Bereavement Care, Powys Befrienders and Meeting Point Montgomeryshire who arrange accessible trips.

They also help people find information about health and social care services, support and social activities from the statutory and voluntary sectors.



### How can I access the service?

Powys People Direct on 01597 827666

Community Health and Well-Being Coordination Service 01597 828649

or [community.connectors@pavo.org.uk](mailto:community.connectors@pavo.org.uk)

<https://twitter.com/powysconnectors>

For information about community services and activities in your local community you can also visit the infoengine, a directory of community and voluntary services

<http://powys.info-engine.org.uk>

## Would you benefit from a home visit from Citizens Advice?

Conwy CAB can arrange for an advisor to visit within the county:

(Tuesdays, Wednesdays and Thursdays only)

- to check if you are receiving the right benefits?
- been refused PIP or DLA on review?
- struggling to pay your bills, not able to pay your rent, in arrears with council tax?
- living in housing association accommodation and have a pre-payment meter?
- any other matter?

Telephone 01492 869150 or email

[projects@conwy.cabnet.org.uk](mailto:projects@conwy.cabnet.org.uk)

<http://cabconwy.webs.com>

Not all Bureaux make home visits. Check locally to see if it is possible in your area.

## Petition to develop disability access monitoring

The petition calls for: the Welsh Government to bring in an "Access Certificate" showing numbers from zero to five along the lines of the Food Hygiene Certificate. All buildings used by the public such as shops, food outlets, sports clubs,

pubs and offices as well as public transport services should be assessed on how wheelchair accessible they are, as well as how easy it is for someone with a sensory impairment or learning disability to use.

<https://tinyurl.com/ycwbaw5y>

Closing date: 1 March 2018

## Buy Jennifer Brea's film Unrest

iTunes \$14.99 (£11.32)

<https://tinyurl.com/yb8849qf>

Amazon Prime £12.99

<https://tinyurl.com/yahzqprm>

Vimeo on Demand £10.99

<https://tinyurl.com/ybxl656m>



Google Play £9.99 <https://tinyurl.com/yak9se3j>

It will also be available on DVD in the UK soon.

Proceeds from the sale of Unrest will be reinvested into the Time For Unrest campaign, helping to bring the film to medical schools, policymakers, and research centres around the world.

"Moving. Astonishing." - Mark Kermode for BBC Radio 5

"Unrest is ... clever, fascinating, heart-wrenching, and very frustrating. This portrait of a couple coping through extreme adversity ... will chew you up and spit you back out again." - The Upcoming

"Bracingly inventive and moving." - The Observer

"Important for so many reasons." - Cosmopolitan UK

# living with me

## ME is like...

ME is like a burglar who steals from you every minute of every day.

Its booty is your energy, half a sack-full of cognitive functions and whatever else it can find.

Out goes your profession, your social life; your mobility, vision, memory; your ability to look after yourself without help; your idiosyncratic vitality – in short: the way you were in the world.

Focus is on basic needs (food, baths, medical appointments, the occasional visitor...) – a handicap for stirring conversations. Self-confidence is always on the wane.

From <http://inclusionproject.org.uk/guest-post/chronic-illness-and-confidence/>

## Cuddle up with an e-book, audio book or e-magazine this winter!

No more worrying about late returns and library fines due to ME relapses, Welsh library members can download:

- 200+ e-magazines
- 25,000 e-books
- hundreds of audio books

Dig out your library card (for your membership number) and check out 'My digital library' <https://libraries.wales/my-digital-library/>



## Need a noozie in your life?

Noozie makes rechargeable electric hot water bottles and hand warmers, which eliminate the fuss and risks associated with using traditional hot water bottles (no kettles, scalds, lasts 6 hours etc.)

Bottle - sale price £24.95  
Handwarmer – sale price £22.95

<https://www.nooziecomfort.com>  
[contact@nooziecomfort.com](mailto:contact@nooziecomfort.com)

## Book: Yoga, my Bed & M.E.

Donna Owens has developed a gentle yoga for people with CFS/ME. You can do it in your bed and in your PJs.

You can start with just one asana and build up from there. On very bad flare-up days you can just focus on breathing and do a bit more on better days.

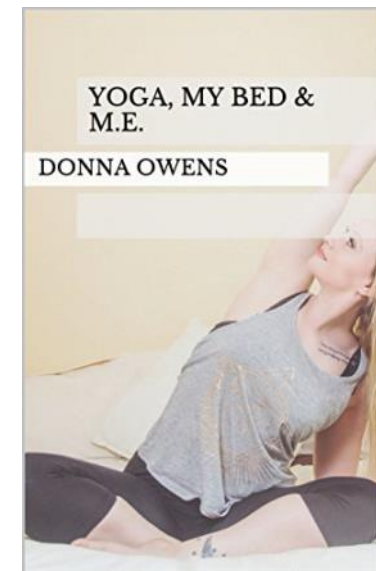
Her book is for anyone interested in very gentle yoga and learning to listen to oneself, and contains:

- Useful information about ME
- Benefits of yoga and meditation
- Six gentle yoga sequences
- Three meditation guides

Amazon prices: £5.50 Kindle    £9.95 Paper

<https://tinyurl.com/yarphruv>

<https://www.yogamybedandme.com>



## Men's sheds in Wales

'Men's Sheds' are social groups or enterprises set up in local communities for the benefit of men - a place to escape the stress and strains of life, a safe haven to gain much needed sanity, a place to think, to make things, to mend things, to invent and be at one with the world...

Each group is different, depending on the interests of the members.



# living with me



Find out if there is one near you, or get help to start one in your area.

<http://www.mensshedsymru.co.uk/shedsinwales/>  
[info@mensshedsymru.co.uk](mailto:info@mensshedsymru.co.uk) 01267 225536

## Winter wellbeing

The short dark days of winter can exacerbate some ME people's mood and symptoms.

Dr Meg Arroll, a psychologist working with Healthspan explains why and advises us to stay positive about winter:

"Research has shown that our brains work differently at different times of the year.

Being able to hold attention is best at the height of summer and worst in the depths of winter.

However, memory is at its best during the autumn equinox when the length of day and night are about the same.

These seasonal variations in brain function are related to the levels of neurotransmitters in the brain, specifically serotonin, which also affects mood.

Therefore, lack of energy, feeling unmotivated and many of the symptoms people struggle with in winter can be linked to how the seasons affect our brain activity."

A Danish study also showed that people who work outdoors are somewhat protected from low mood associated with winter-time, which highlights that even in winter it is important we go outside and engage in some sort of outdoors activity.

We may dread winter, but if you continually tell yourself how horrible winter is, chances are it will feel grim.

Try and change your internal monologue about this time of year by writing a new script – each morning use positive statements."

[From: IL newsletter 22/11/17 <https://www.independentliving.co.uk/how-sad-are-we/> ]

## Top tips...

Break big tasks down into a series of small activities.

It is better to complete one small task before starting another.

On low energy days it is depressing to feel you've not achieved anything, just because you've attempted too big a task.

## Standing Up 4 Sitting Down

Need somewhere to sit down and rest when out shopping?

**#su4sd** is a campaign that was set up by Anchor Trust, calling on retailers and high streets to provide adequate seating in stores and public spaces.

The economic case is unanswerable: shops will be missing out on an estimated £4.5 billion by 2030 if they don't take steps to make the shopping experience easier and more enjoyable for ill and older customers.

More than 1500 retail outlets across the country, including Sainsbury's, Morrisons and Hotten, are supporting the campaign. With more seating and resting areas on offer for those who need them, visiting local shops need not be such a struggle.

You can add your voice to the campaign:

- Write to your local retailer, asking them to provide more facilities for older and disabled shoppers.
- When you go out shopping, tell local shops about the campaign and ask whether they could offer more seating
- Highlight the issue on social media – follow the conversation and post using the hashtag #su4sd

### More info:

<http://www.anchor.org.uk/media-centre/campaigns/standing-up-4-sitting-down>

# cbt and me

Cognitive Behavioural Therapy (CBT), is one of the treatments the NICE guidelines recommends for 'mild or moderate CFS/ME... for those who choose them, because these are the interventions for which there is the clearest research evidence of benefit.' (p 17 Quick Ref Guide)

## What is CBT?

CBT, or Cognitive Behavioural Therapy, is a talking therapy that is used to help treat a wide range of emotional and physical health conditions in people of all ages e.g. anxiety, depression, PTSD, eating disorders, insomnia, IBS, fatigue. It isn't used to cure the physical symptoms of these conditions, but the aim is to help people cope better with their symptoms and in some cases some symptoms can disappear.

## What's the theory behind CBT?

CBT is based on the idea that the way we think about situations can affect the way we feel and behave. For example, if you interpret a situation negatively then you might experience negative emotions as a result, and those feelings might then affect the way you behave.

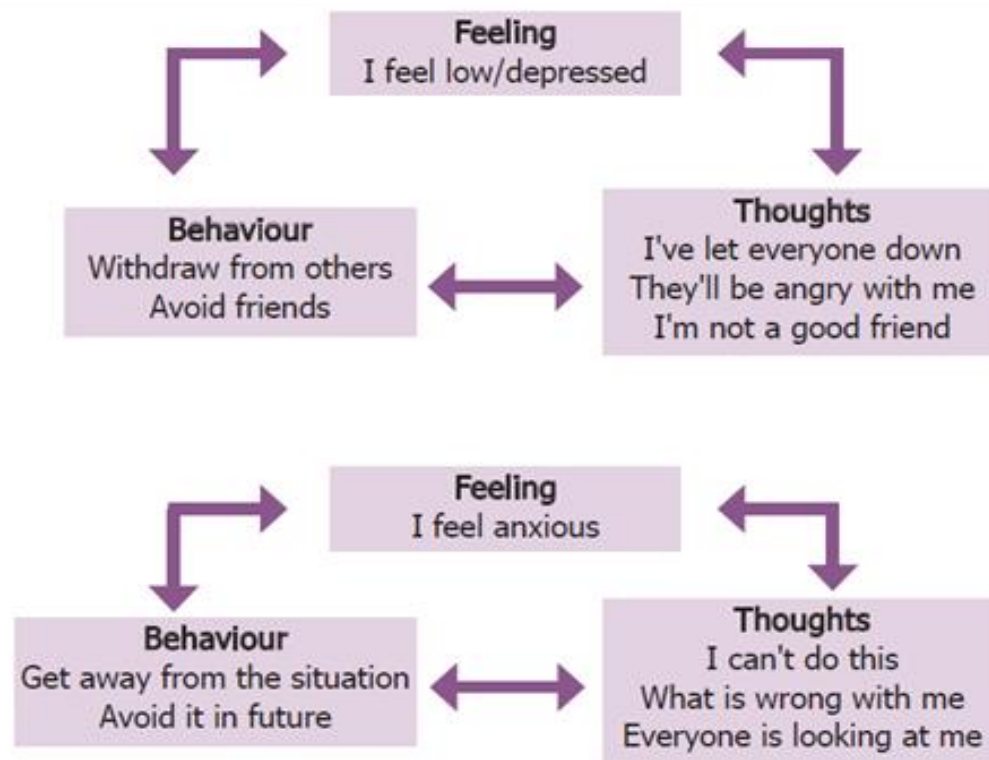
Negative thinking patterns can start at any time, often in childhood. For example, if you didn't receive much attention or praise from your parents or teachers you might have thought *"I'm useless, I can't do anything well enough"*.

Over time you might continue to believe this assumption, even if you experience successes, until as an adult this negative thought becomes automatic and it becomes difficult to believe people when they say positive things about you. This way of thinking might then affect how you feel and behave at work, university or at home.

***"Thoughts can be the bully in your head"***

## How CBT aims to help

The therapist and client work together looking for any thoughts or behaviours that are unhelpful for the client, and explore ways to change them. It focuses on how you think and act now, instead of exploring difficulties in your past.



(Diagram courtesy of MIND)

The goal is to help you challenge your assumptions and break negative thought cycles.

The therapist helps you to identify your specific difficulties and to set goals for you to achieve. You agree to work on these between sessions. The therapist's role is not to tell you what to do, but help you decide your problem areas and advise you on how to continue using CBT techniques in your daily life after your treatment ends.

## How CBT is accessed

- individual sessions with a therapist – NHS or private – 5-20 sessions for 30-60 minutes each
- group sessions

*continued on next page*

**Answer for puzzle page 14**  
"Want to keep Christ in Christmas? Feed the hungry, clothe the naked, forgive the guilty, welcome the unwanted, care for the ill, love your enemies, and do unto others as you would have done unto you."

# cbt and me

- written or computer-based packages, with or without telephone or face-to-face appointments to check progress and help overcome any barriers to putting into practice what you have learned.
- CBT-based self-help books
- websites providing information on CBT techniques (Evidence suggests that support from a therapist makes self-help more effective, especially for low mood)

## Is CBT for ME different?

CBT is considered by some in the medical establishment to be effective for ME because of a number of research trials culminating in:

- the PACE trial which compared a form of CBT with Graded Exercise Therapy in adults
- the FINE trial for housebound adults
- the FITNET trial of online CBT for young people.

## Faulty illness beliefs

The stated aim of all these trials has been to challenge specific beliefs that are believed to be unhelpful. Faulty illness beliefs are said to be perpetuating people's symptoms long after the chronic illness is past.

Those faulty beliefs are outlined as:

- believing the illness has a physical or somatic cause
- believing that exercise is harmful, leading to avoidance of activity and long rest periods

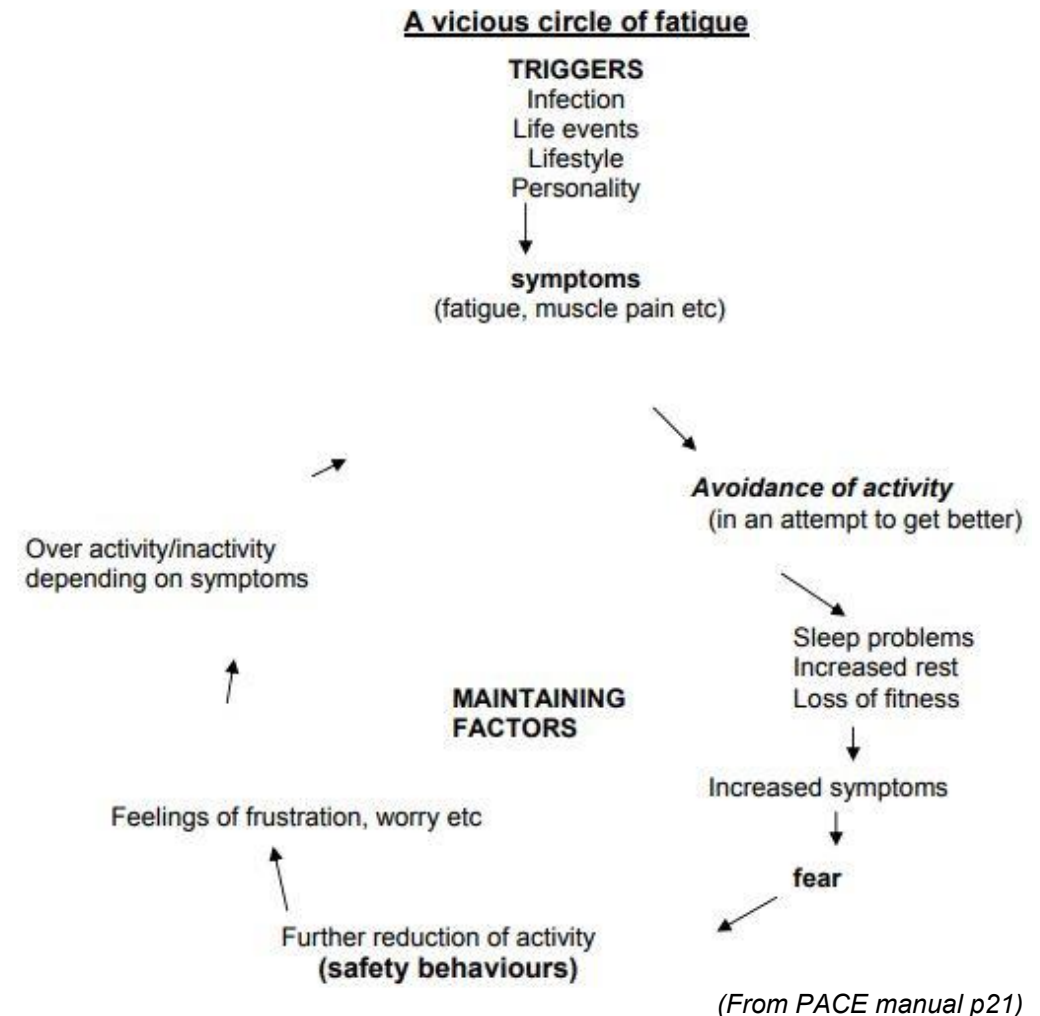
## Complex Incremental Pacing /CBT

The manual for the PACE trial calls their version of CBT *Complex incremental pacing/ cognitive behavioural therapy* which combines CBT with graded activity, and states (p13):

'The manual has the following components: Initial stabilisation of activity and rest, establishing a regular sleep pattern and then graded increases or changes in activity to work towards planned goals. CBT also actively addresses the participant's understanding of their illness which may involve challenging unhelpful beliefs, e.g., about symptoms or activity that may be preventing recovery.'

'Just as there are many factors involved in triggering CFS/ME, there are also many factors that are involved in sustaining it. According to this model, the symptoms and disability of CFS/ME are perpetuated predominantly by unhelpful illness beliefs (fears) and coping behaviours (avoidance).

These beliefs and behaviours interact with the participant's emotional and physiological state and interpersonal situation to form self-perpetuating vicious circles of fatigue and disability. (PACE p18)'





# cbt and me

The factors perpetuating CFS/ME according to the PACE manual are (p18):

1. Fear about activity making the illness worse, leading to reduction in activity tolerance and fitness.
2. Avoidance of activities for fear of making their symptoms worse, thus leading to loss of confidence
3. Over-vigorous activity alternating with resting for long periods, leading to 'boom and bust' and overall deterioration
4. A disturbed sleep pattern – irregular hours is likely to increase feelings of fatigue and other symptoms.
5. Symptom focussing may result in an exacerbation of symptoms and lead to further avoidance.
6. Life stress and low mood caused by the symptoms interrupting daily life
7. Perfectionism - thoughts/beliefs such as "I must finish this decorating/ piece of work/tidying up before I sit down", may lead to a boom and bust cycle of activity and rest.

'The essence of CBT is helping the participant to change their interpretation of symptoms and associated fear, symptom focussing and avoidance. Participants are encouraged to see symptoms as temporary and reversible and not as signs of harm or evidence of fixed disease pathology. In this way it is anticipated that they will gain more control of their lives, as they, and not their symptoms, dictate what they do. (PACEp14)'

'Treatment is focused on addressing the cognitive and behavioural factors that maintain the vicious circle of CFS/ME. This involves the participant becoming aware of and changing unhelpful thoughts and beliefs about their situation and altering their patterns of behaviour (PACE p21)'

The behavioural strategies the manual recommends (PACE p23):

- Establishing a baseline of activity and rest
- Establishing a consistent pattern of activity and rest
- Graded activity in order to work towards specified goals
- Establish a sleep routine
- Graded exposure to situations that may cause anxiety, e.g. socializing.

## Critics of the CIP/CBT approach say:

Proponents of this approach need to challenge their own faulty assumptions because:

- there is research evidence of ongoing biological dysfunction
- there is research evidence of biological dysfunction following exercise
- there is no research evidence that believing in a biological cause for the illness (somatic attribution) leads to a worse outcome for patients
- lack of diagnostic tests and definitive research findings does not make the illness a psychological creation
- patient experience and ME physician observations should not be ignored
- the design of the PACE trial has many failings (according to statisticians and researchers), included patients with broadly defined chronic fatigue (not all had ME), and did not show CIP/CBT to be sufficiently effective.
- there is research evidence of subgroups of patients, which is likely to affect which treatments are effective – one approach will not suit everybody
- this version of CBT is prescriptive, unlike standard CBT
- although it is possible that some patients might benefit from challenging their negative thinking and changing their approach to their life and illness at some point, they should not be made to feel liars, failures and responsible for their condition in the process.

## Can CBT help people with ME and CFS?

We'll look at this subject in the next issue of **me voice**

### More information:

NICE guidelines <https://www.nice.org.uk/guidance/cg53>

NICE Quick ref guide <https://tinyurl.com/y7cl79js>

PACE manual: CBT for CFS/ME <https://tinyurl.com/y8rp79z9>

MIND web pages on CBT <https://tinyurl.com/ybbxm98a>

NHS Wales Direct on CBT <https://tinyurl.com/ycl6wgb5>

**Jan Russell**

# research

## ME blood cells are drained of energy

New research from Newcastle has been looking at PBMCs, which are blood cells that help make up the immune system, which protects the body against disease and foreign invaders.

This research used a technique known as 'extracellular flux analysis' carried out by new technology – a machine called a Seahorse XF Analyzer. This assesses mitochondrial function. The technique involves using probes to detect oxygen levels around the cells.

The study found that the energy production was consistently lower in cells taken from ME/CFS patients compared to healthy cells.

**More info:**

<https://tinyurl.com/ya3pg5d7>



## Hyperactive brain in CFS?

An Oxford researcher found that the increased putamen glutamate, decreased ACC GABA and elevated resting state functional connectivity of the default mode network suggest a hyperactive brain status in CFS.

The global decrease of GSH and total creatine also suggest CFS patients may have an abnormal bioenergetic status with higher oxidative stress.

**More info:** <https://tinyurl.com/ya2sf99u>

## The Norwegian Rituximab trial reports negative results

Full results are expected in 2018 but participants have been told about the failure of the trial. The next step for researchers Fluge and Mella will be to determine the best way forward in understanding what has been learned and how to find out which sub-group of patients may still benefit from the drug.

**Read more:** <https://tinyurl.com/yb97ha6b>

## CFS & Gulf War Illness are unique disorders

US Researchers have found distinct molecular signatures in two brain disorders long thought to be psychological in origin — chronic fatigue syndrome (CFS) and Gulf War Illness (GWI).

More info: <https://tinyurl.com/y8tgmzgg>

## Science for ME: new forum

Science for ME is an independent, patient-led, international forum for people with ME/CFS and the carers, clinicians, scientists and advocates.

The goal is to provide a platform to discuss all aspects of this disease, with a special focus on science, support, and advocacy valuing:

- high quality scientific research, which will be necessary to produce effective treatments;
- open, critical discussion of claims and ideas; mutual support and respect;
- equality.

<https://www.s4me.info/> See also:

Facebook: <https://www.facebook.com/sci4me>

Twitter [https://twitter.com/s4me\\_info](https://twitter.com/s4me_info)



## Errant Vicar

One Sunday, a vicar felt he couldn't face conducting the morning service. He phoned his churchwardens and said he was ill. Then he drove 50 miles to a course where no-one would know him and played golf. Peter brought this to the Lord's attention.

"He will be punished," said the Lord. The errant vicar then proceeded to get a hole in one, not once but twice.

"I thought you said he will be punished," Peter said to the Lord.

He replied, "Oh, he will suffer - who is he going to be able to tell?"

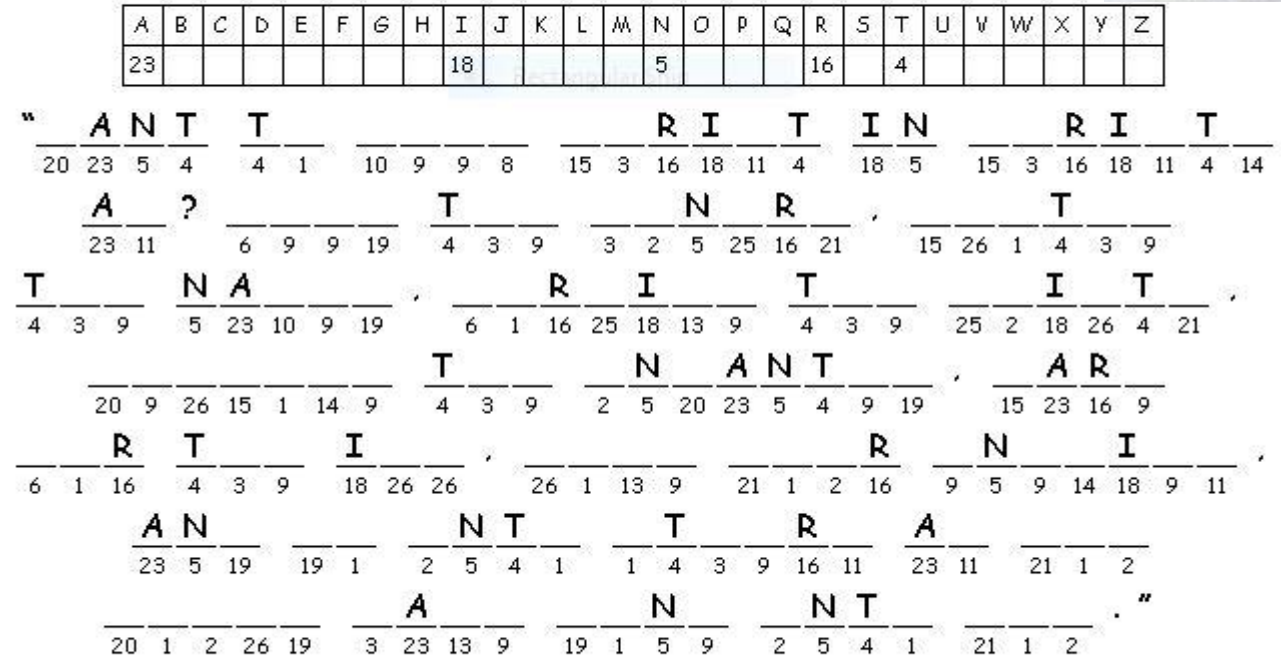
**Santa on the brain**  
 Christmas: The time when everyone gets  
 Santamental.

**Waiting**  
 My wife took our three-year-old to  
 church for the first time. Getting  
 impatient while waiting for the ser-  
 vice to start, he turned to her and  
 asked, "What time does Jesus get  
 here?"

**Meet and greet**  
 Spotted outside a church in Michigan:  
 "Honk if you love Jesus. Keep on texting  
 while you drive if you want to meet him."



## A thought for Christmas



Created by [Puzzlemaker](http://Puzzlemaker.at/DiscoveryEducation.com) at [DiscoveryEducation.com](http://DiscoveryEducation.com)

Answer on page 10

from  
 Steve Maraboli, *Unapologetically You: Reflections on Life and the Human Experience*

### Limited knowledge

As we were putting out cookies for Santa on Christmas Eve, I accidentally dropped one.  
 "No problem," I said, picking it up and dusting it off before placing it back on the plate.

"You can't do that," argued my four-year-old.

"Don't worry. Santa will never know."

He shot me a look. "So he knows if I've been bad or good, but he doesn't know the cookie  
 fell on the floor?"



# xmas puzzle

## Old and New Ways to Communicate

### Across

2. Denser in quality than paper
3. Another term for printed work
5. Prehistoric man carved these on walls
8. Plane flying high with a string of words following
10. Formerly used to announce winner of the Olympic Games
11. These used to be delivered on bicycles at times of trouble
12. Modern application used on a mobile phone
13. The Indians used to send these
14. It rings and you have to pick it up to speak

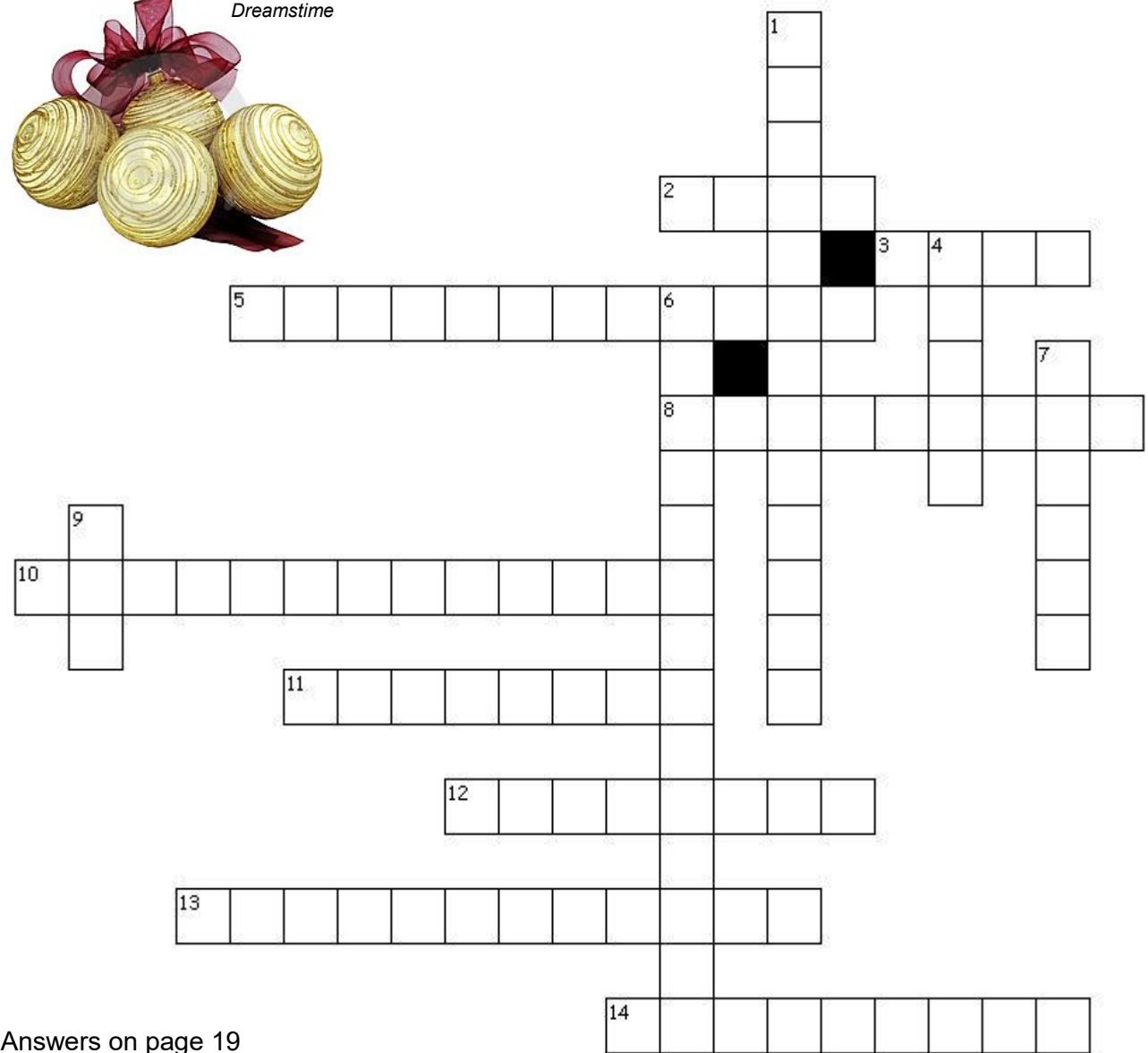
### Down

1. The ancient Egyptians wrote with these
4. Electronic letter
6. Immediate communication
7. There are 26 of these in the alphabet
9. Used to send documents via telephone

Created by [Puzzlemaker](http://Puzzlemaker.com) at [DiscoveryEducation.com](http://DiscoveryEducation.com)



Dreamstime



Answers on page 19

## Misplaced

A pastor I know of uses a standard liturgy for funerals. To personalize each service, he enters a "find and replace" command into his word processor. The computer then finds the name of the deceased from the previous funeral and replaces it with the name of the deceased for

the upcoming one.

Not long ago, the pastor told the computer to find the name "Mary" and replace it with "Edna." The next morning, the funeral was going smoothly until the congregation intoned the Apostles' Creed.

"Jesus Christ," they read from the preprinted program, "born of the Virgin Edna."

# carers

## Working Carers Survey

As the working population ages and our loved ones are living longer, supporting carers who work is becoming increasingly important. More and more of us will be juggling caring responsibilities at home alongside work.

Carers Wales would like your views if:

- you are a working carer
- you have been a working carer
- you think you may be a working carer in the future
- you have views you would like to share

They will use the findings for a report which will be shared across Wales to inform employers and the Welsh Government about how working carers can be supported.

Find the survey at <https://tinyurl.com/yaarfnms>



## Would 'flexible working' help you?

Since 30 June 2014 all employees who have worked for their employer for 26 weeks can request flexible working.

This could include changing working hours or working from home.

Only one request is allowed in a year and any request granted will mean a permanent change to terms and conditions unless a trial period is agreed.

Employers can refuse a request, but must give good business reasons from a specific list which is set out in the law. Employees can appeal against this decision.

A CBI Employment Trends Survey revealed that 96% of requests from carers have been accepted and that the overall impact on employers has been a positive one:

- 69% report a positive impact on employee relations
- 63% report a positive impact on recruitment and retention
- 35% report a positive impact on absence rates
- 28% report a positive impact on productivity.

More info:

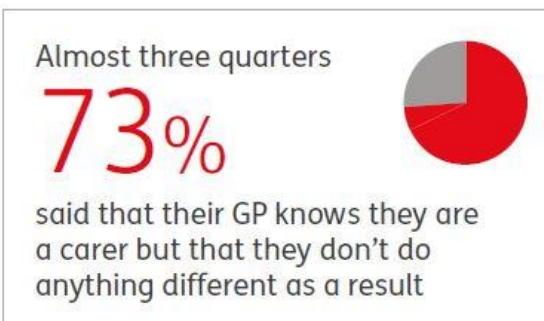
<https://tinyurl.com/ybvcdley>

## State of caring Wales report 2017

This readable summary of a survey of 400 unpaid carers found that much still needs to be done to support carers.



The report also makes recommendations on what can be done to improve the situation.



Recommendation: To create a more 'carer friendly' NHS

- A new duty for the NHS to put in policies to identify carers and to promote carers' health and well-being.
- New measures to monitor how GPs are identifying and supporting carers to ensure that carers can look after their own health.

<https://tinyurl.com/y8tuenw>



# carers

## Welsh unpaid carers are missing out on vital support

Carers Wales polled the general public for Carers Rights Day, 24 Nov, and found:

- half (50%) believe they don't know a 'single family member or friend' who cares,
- almost 1 in 4 (22%) know a work colleague looking after a loved one.

In reality, 1 in 10 (12%) Welsh residents are carers and 1 in 9 people in the UK workforce juggle a paid job with unpaid caring.



The findings come one year after Carers UK's Missing Out report showed the impact of carers were not being identified quickly enough.

Amongst carers who 'struggled' to recognise their roles:

- half saw their finances affected (50%)
- and the mental health of 76% was negatively affected as a result

Amongst all of those polled, including those that had not recognised carers in their social circles or at work, 7 in 10 (70%) said they would feel confident providing 'emotional support' to a new carer.

Yet, less than half (45%) would feel confident pointing people in the direction of information about caring.

Carers Wales is asking the public to equip themselves with more knowledge and understanding of how to support carers, to improve confidence in reaching out to carers.

More information: <https://tinyurl.com/yd3nkg3f>

## Top tips for carers at Christmas

**1. Emergency contact details - make sure you get the emergency contact details for services you use e.g. Social Services, GP, hospitals, pharmacy. Also find out opening closing times so you know when they are available.**

**2. Colds & flu** – make sure you have had your flu jab and take special care to avoid getting or passing on bugs - Christmas + virus = extra hard work!

**3. Check medications** – make sure you have enough to last the season for yourself and those you care for. Some GPs/pharmacies will provide a double prescription.

**4. Spread out activities** to make the season more manageable for all e.g. dinner on Christmas eve; presents on Christmas day; friends or family on Boxing day.



Max Pixel



© Candybox ImagesID 11372551 | Dreamstime Stock Photos

**5. Get everyone on board** - ask the person you care for what they want guests to know about having ME and explain to the guests in advance how this will affect the celebrations.

**6. Reduce sensory load** - look for imaginative ways to reduce the lights and noise e.g. tell stories and jokes with pictures and/or mime; silent crackers; ban party poppers; no loud music or blaring television when people are also chatting.

**7. Share dinner preparations** - ask one person to do the starter, you can do the turkey, one person does the vegetables and finally someone else does the pudding, brings the drinks or the Christmas crackers.

**8. Plan some 'me time'** and prepare ways to reduce stress e.g. breathing exercises; favourite relaxing CD; foot bath.

**9. If you have a present wish list** why not add something to lighten the caring load e.g. time saving gadgets; tech to keep you in touch with people so you feel less isolated; voucher for cinema or theatre; respite visit from an understanding friend to enable you to go out.





**Welcome to the pages for young people U21 (under 21).**

**Got something you want to share? [U21@wames.org.uk](mailto:U21@wames.org.uk)**

**Want to get connected with others your age in Wales? Contact [michelle@wames.org.uk](mailto:michelle@wames.org.uk)**



## Are you a good friend?

Once ME strikes everything in our world is different, but for our friends nothing has changed in their world, and this can create an invisible barrier between us.

They can feel abandoned and bewildered – unsure what to do or say. They might know nothing about our new world, so for both them and us it is a steep learning curve!

What can we do to be a good friend when we are struggling to cope with how awful we feel and how little we can do?

### 1. Forgive them!

All of us mess up at times, including our healthy friends.

They might say or do something which is insensitive, thoughtless, or downright rude. e.g.

“But you don’t look sick”

“At least it’s not...”

“Make an effort... it’s not much to ask.”

They might be very supportive in the beginning, but when our illness drags on ‘compassion fatigue’ can

*continued on next page*

# U21

[u21@wames.org.uk](mailto:u21@wames.org.uk)

**Christmas  
Greetings  
from  
All of us at  
WAMES**

**And best  
wishes for  
a  
Healthier  
New Year**



# U21

set in and they don't get in touch so often. They are not trying to be hurtful, they simply don't understand

Being able to forgive our friends will give our friendships the space they need to move forward and change. It will also prevent us from wasting precious energy on feeling perpetually hurt, bitter and resentful.

Forgiveness takes practice and patience, especially when living with pain and fatigue, which can wear down our tolerance levels, but it is crucial if we aren't going to be 'the angry friend' for the rest of our lives. Being 'the compassionate friend' is a much happier place to be.

## 2. Let friendships change

Some of our closest friends might disappear as they struggle to come to terms with what has happened to us. Some may be afraid of upsetting us or even fear that what we have is catching, in spite of being told otherwise!

This can hurt, but if we can let them go without 'taking the hump' or 'making a scene', then maybe things will change and they will drift back into our lives later.

Be glad if a friend sticks with us, and wants to learn about our illness and support us. It might take time, but it will be worth cultivating a different kind of friendship with them.

We need to use our energy on the people who care and can cope with us.

## 3. Explain your new situation to them

Even the most dedicated and thoughtful of friends are not psychic. If we don't spell it out to them, they will not know what it's like living with ME, how little energy we have, how sick or how much pain we feel, how crowds, noise and lights affect us, how we need to limit activities and how our ability to do things can fluctuate.

It may not be possible to have a big conversation and explain it all in one go, but most importantly they need to know we are not ditching them. We need to find a way to explain we still want to keep in touch, but for the foreseeable future it will have to be in a different way.

## 4. Show an interest in their lives

It is hard to watch life go on without us and much easier to retreat into ourselves and feel we are the only ones that need lots of care. It may be a struggle for us, but it will mean a lot to the people who want to be our friends if we show an interest in their lives.

This can include texting people to ask them about their day, sending "good luck" or "thinking of you" cards for big events we are likely to miss. Small actions like this can have a big impact. It might help to think of all our friends as 'long distance' friends. (We may even need to keep family relationships alive this way!)

For the moment we cannot expect to be a big part of their lives, but one day that might change and it will be good not to have to learn all about them from scratch again. When we show we are interested in their lives, even though our own is imploding, it is a big deal that won't be forgotten.

## 5. Don't lose sight of yourself

Sometimes it feels as if ME robs us of everything that makes us 'us'. It can be difficult to believe that we are the same person that our friends once liked.



At times we will feel depressed and worthless. Our activities may shrink and change, but it is important to remember that we are still 'us' and each of us has a unique approach to life. Our friends can remind us of who we are and we can share with them our changing interests and the way we live in our smaller world. Even if it is only sharing a pic of our wacky new duvet cover or the cool noise reduction headphones we wear a lot!

We deserve to have supportive and long lasting friendships with people who know all about us and still love us.

It will be a bumpy ride, and we will need to forgive our own mistakes, but being ill doesn't mean we can't still be an amazing friend!

## Crossword Answers from page 15

- | Answers            |                   |
|--------------------|-------------------|
| Across             | Down              |
| 1. Hieroglyphics   | 1. Card           |
| 2. Email           | 2. Text           |
| 3. Instant Message | 3. Cave drawings  |
| 4. Letter          | 4. Sky writer     |
| 5. Fax             | 5. Carrier Pigeon |
|                    | 6. Telegram       |
|                    | 7. Whatsapp       |
|                    | 8. Smoke signals  |
|                    | 9. Telephone      |





Merry Christmas

Artzy Creation

Download Christmas colouring pages from  
<http://createu.life/printable-christmas-ornament-coloring-pages/>

## Christmas fun, games & activities

<https://www.whychristmas.com/fun/>

## Christmas gift ideas

**To keep you warm on the sofa:**

Killer whale tail blanket

Mermaid tail blankets also available

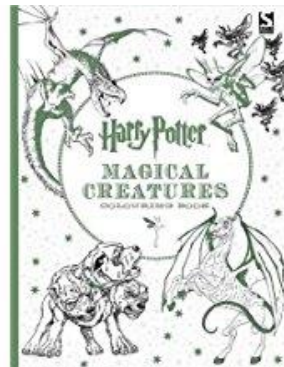
Prices vary from £17-20



**To destress:**

A Harry Potter colouring book:

£5 from many shops



**To keep the grey cells working:**

Gear ball brain teaser puzzle £15-18



# U21

**To record your ME world:**

Attachable wide angle and zoom camera lenses for your mobile phone.

Some come with a mini tripod. Make sure to buy the correct one for your phone. Prices start at £8

## Christmas in different Languages Wordsearch

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

Bozic  
 Jol  
 Kaledos  
 Knishtlindje  
 Nadal  
 Natale  
 Noel  
 Vianoce

Gabonak  
 Jul  
 Kerstmis  
 Milied  
 Nadolig  
 Navidad  
 Nollag  
 Weihnachten



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