



me voice

the wames magazine
december 2016, no.17

WAMES
Welsh Association of ME & CFS Support

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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

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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

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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 Meetings: 4 Feb; 8 Apr; 10 June; 12 Aug; 14 Oct; 2 Dec 2017.

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
cwtch@live.co.uk

ME Support in Glamorgan (MESiG)

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

Contact: Christalla Bailey, 029 2076 2347
mesigwales@gmail.com
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

Contact: Mike or Karen 0796 9665419 (between 2-4pm) karen@kandm46.plus.com

Neuro-Café Brecon

Meets every 2nd 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)

Next meeting 18 Jan 2017

Contact: 01792 529615
headwaysouthpowys@hotmail.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

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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wames news

Dr Nigel Speight—our medical adviser

In April an Interim Orders Tribunal of the Medical Practitioners Tribunal Service placed restrictions on the practice of our Medical Adviser Dr Speight.

These restrictions were that he should withdraw from all ME-related work for a period of 15 months. The stated purpose of these restrictions was "to protect patients and to maintain the confidence of the public"

We are happy to announce that in October a similar panel decided to reverse this decision and so there are currently no restrictions on Dr Speight's practice. However, he is still under investigation by the General Medical Council over his work in the field of ME, and the final decision is not expected before the early summer.

Dr Speight has informed us that he will again be available for giving us advice and support but that in the circumstances he thinks it advisable for him to avoid too close an involvement in potentially controversial cases.

We are delighted and grateful that Dr Speight is still willing to work with us, and other patient groups. We understand that the original complaint against him was related to a single complex case where there was no evidence of patient harm, indeed the evidence was to the contrary, and that the patient had improved considerably since Dr Speight's intervention.

me voice

Back in April we announced we would have to reduce the number of issues to 4 a year due to a manpower shortage.

Unfortunately the WAMES team has been under considerable pressure and as a result, unable to produce another issue since then, so this issue is only the 2nd of the year.

If you have paid to receive a paper copy in 2016, that payment will now also cover 2017.

Holiday helpline hours

24-27 Dec	Closed
28-31 Dec	11am-3pm
1-2 Jan	Closed
3 Jan onwards	10am-7pm

Please use the helpline during the Christmas and New Year for emergencies only.

For emotional support, the **Samaritans** can be contacted 24 hours a day, 7 days a week.

<http://www.samaritans.org/>

English	116 123	(free number 24/7)
Welsh	0808 164 0123	(free 7pm - 11pm 7days)

Young people up to age 25 can also contact **Meic** by phone, email, SMS text and instant messaging.

<https://www.meiccymru.org/>

8am to midnight, 7 days a week

FREephone: 0808 80 23456

SMS TEXT: 84001 M/Webchat: www.meic.cymru

WAMES is 15 years old!

Backed by local support groups in 2001, WAMES set out with big plans to influence service improvement and inform everyone about the serious impact ME and CFS has on our lives in Wales.

At that time UK ME charities had little understanding that their campaigning efforts in England had no impact on us in Wales. Since 1998 decisions about healthcare, education, social care, housing etc. have not been made in London, but in Cardiff, so in 2001 WAMES was set up to challenge the Welsh government and NHS at a national and local level.

Since then local support groups have come and gone, and our role has extended to offering support to individuals and groups, and to provide information on topics that are relevant to the lives of Welsh families affected by ME.

After 15 years we can see we have made an impact. We have influenced many consultations on health, education and social care and are currently part of the Welsh Government group looking into ways to improve healthcare for people with ME and CFS throughout Wales. We also have many links with the media and respond to calls or information from professionals, patients, carers and others.

What next?

What else can go wrong!

Securing Christmas lights to the tree can be a production. One year, when we finally stood back and flicked on the light switch, I noticed that a branch obscured our prized angel ornament. I grabbed the pruning shears, mounted a stool, and snipped once, and the lights went out. My husband quietly said, "You don't have your glasses on, do you?"

—Lynn Kitchen, Parksville, British Columbia

May we wish everybody a Merry Christmas and a Happy, healthy and prosperous New Year

wames news

WAMES' priorities

In April we asked people which activities they would like to see WAMES prioritise.

1. Improving services

The majority agreed that campaigning to improve services for people with ME should be the top priority for WAMES. It was heartening to be told that our efforts are appreciated though it was clear that people would like to know more about that work.

What does campaigning involve?

Often campaigning involves us in identifying key people and talking - stating and restating the views of people with ME and looking for ways to communicate to people how serious this neurological illness is and how great the need is for better, appropriate services.

It can often be hard to tell how much of an impact we make. Without money being made available and professionals joining to champion our cause it can feel as if our influence is like a dripping tap, very slowly educating and changing opinions. But we believe it is important that we continue to do that, reminding everybody we won't be ignored.

It also involves us having a presence, often with a display, at events and meetings where we can meet and influence professionals and decision makers.

In order to do this we need to be prepared to travel, sometimes staying overnight away from home.

2. Awareness raising

This was also considered to be important by many people as there is still a lot of misunderstanding in the general public about the nature of ME.

WAMES has made good contacts with the media but we are unable to make use of all the opportunities. The best way to raise awareness is through real people's stories. That means that many people need to be prepared to join our awareness raising efforts through the media, and also through social media.

3. Communication

We were pleased that many people find our information activities very helpful. A few even thought that we should make our website, social media activities and information leaflets our no. 1 priority! We recognise that they play an important role in our campaigning and awareness raising as well as supporting people with ME. The helpline was also considered to be high priority for a few people. This is currently manned mainly by one person.

4. Volunteer recruitment & fundraising

Only a few people included these in their list of priorities and they thought that they should be low priority activities.

Our dilemma

We are pleased that our efforts to represent and support people in Wales are appreciated, but in order to maintain our current level of campaigning and fundraising, we need people to join us and money to finance it.

Volunteer recruitment and fundraising can no longer be a low priority for WAMES.

People tell us WAMES makes a difference to their lives

WAMES:

- led by people with ME, and their carers
- run by volunteers
- funded by donations

Campaigns

Supports

Informs

All our activities have been led by those whose lives have been turned upside down in some way or another by ME or CFS. Currently WAMES has **11** regular volunteers.

13,000 people in Wales could have ME or CFS

***Together** we can make more of a difference!*

But... many people feel they don't have enough time or good health to volunteer in a big way, although they would like to do something

To make it easier for people to join in we are setting up **Teams** so people can work together in a way that suits them to **Make a difference for ME in Wales.**

The teams will look for ways for a wide range of people to get involved whether you:

- are ill *or* healthy
- mobile *or* bedbound
- knowledgeable about ME *or* know very little
- have lots of free time *or* just a few minutes each week
- can commit regularly *or* prefer one-off activities
- are retired *or* need work experience
- want to work on your own *or* with others

WAMES Teams

We are advertising for **Team coordinators** to help oversee our activities. They will build up an overview of what needs to be done, how we can achieve it and will help individuals to play a part.

Volunteering coordinator
Fundraising coordinator
Communications coordinator

If you are unable to apply for a Team coordinator role please pass on the info to others, these roles don't have to be done by people with ME and more than one person could share a role.

Teams need all sorts of people – there are a wide range of ways to get involved, both big and small. More teams will be set up during 2017.

Register **your** willingness to do something for ME in Wales. Download the volunteer registration from the website or contact Sylvia.

Once you let us know what you are interested in or experienced in, we can discuss how you can get involved.

Be a supporter: Find out how you can support others in small ways if you are currently unable to do much yourself.



Easy fundraising

Raise money effortlessly every time you shop online through easy fundraising.

This will cost you NOTHING except a one off five minutes of your time. PLEASE help us by doing this. If you have any problems please contact Tony at tony@wames.org.uk for help, or to set up the account for you..

www.easyfundraising.org.uk/causes/wames/

Many ways to donate

Donate by cheque or postal order – send to the treasurer.

Donate by bank transfer or standing order
Account name: Welsh Assoc. of ME & CFS
Account Number: 76392081
Sort Code: 09-01-55

Donate online
<https://mydonate.bt.com/charities/wames>
<http://www.charitychoice.co.uk/wames>
Please Gift Aid your donation if you can

Give in celebration

Ask your friends and family to donate to WAMES instead of giving presents at a birthday, anniversary or wedding, you can enjoy your special day knowing you are making a real difference to the lives of people with ME and CFS.

A gift in remembrance –

Celebrate the life of someone special to you by making a gift in their memory.

Many ways to fundraise

Raising funds need not be arduous or cost you any money. It can be a fun activity with friends or family, or a low energy way to work with WAMES from your bed. Ask us for more information about:

Sponsored events

Challenge yourself or a friend to do something active or more low energy like a sponsored silence, pyjama wearing day etc.

Social events

Bring people together at a car boot sale, concert, coffee morning, or treasure hunt.

Use your skills or auction your time

At home make a small change jar from a jam pot.

At school

Hold a non-uniform day, mad hair day or fancy dress day; school fair; Pop idol, play or concert; Teddy bear's picnic; a teacher talent show.

At work

Dress-down Friday, glam day, fancy dress day, loose change jar or swear box, auction of promises, sell packed lunches.

Collect in your area

Ask your local shop or centre to display a collection tin. Contact us for tins.

Local fundraisers

Many areas have organisations that regularly raise funds for charities: student rag days; retired people's groups; associations etc.

wames news

Sponsor Team Shareth

Sharon Price and Gareth Williams, aka Team Shareth, are taking on the challenge of doing a Sponsored Swim of 5 miles between them (not all in one day!) in aid of WAMES



Sharon says:

I have volunteered with this charity for many years and greatly valued the support it gave me during 20 years of chronic ME. Now with my symptoms currently in remission, I want to help those with this unbearable illness. Without much-needed funds, WAMES will struggle to continue all its important work. This is why we ask you to sponsor Team Shareth as we endeavour to swim 5 miles. (Two years ago I could only swim 100m!)

Any amount, large or small, would be greatly appreciated and make a massive difference. Thank you from the bottom of our hearts.

Online fundraising page: <https://mydonate.bt.com/fundraisers/teamshareth>

Donate online or contact Sharon
sharonprice1974@yahoo.co.uk
07855128647

Cheques can be sent to the WAMES
Treasurer, Cornerstones, Clinton Road Lane,
Penarth, Vale of Glamorgan, CF64 3JD

Answer a 100 question ditloid quiz before 1st January 2017 to have a chance of winning one of 10 great prizes including 2 tickets to the play Harry Potter and the Cursed Child, a Lulu Guinness Lips clutch bag, a Kindle Paperwhite and an Amazon Fire TV Stick.



A ditloid is a type of word puzzle, in which a phrase, quotation, date, or fact must be deduced from the numbers and abbreviated letters in the clue e.g. 3 BM = Three Blind Mice!

A quote from A Christmas Carol

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z
							12	3					21		9					23					

I 3 I 5 3 6 6 H 12 7 21 7 23 24 N 15 12 24 3 20 10 26 13 20 I N 3 21
 H 26 2 H 12 14 13 24 10 N 13 21 18 P 10 24 2 I 10 7 P 1 14 14 9 I 3 10
 H 13 6 6 H 10 12 14 I 2 14 13 24 I 3 I 5 3 6 6 I 6 3 8 14
 I N 3 21 H 10 12 14 P 9 13 20 10 H 10 12 14 P 9 24 14 20 14 21 10 N 13 21 18
 H 10 12 14 U 22 23 10 23 24 14 H 10 12 14 P I 20 9 3 24 3 10 20 I 7 22
 H 13 6 6 H 10 12 24 14 14 H 20 12 13 6 6 I 20 10 24 3 8 14 I 5 3 10 12 3 21

Answer on page 14

26 14

Created by [Puzzlemaker](#) at [DiscoveryEducation.com](#)

PACE trial data released

After 5 years of campaigning, finally on September 9, 2016, Queen Mary University of London (QMUL) released some original data from the PACE trial following an Information Commission tribunal ruling on a Freedom of Information Request by ME patient Alem Matthees, from Australia.

The case went to tribunal because the researchers were contesting a decision made in October 2015. QMUL claimed that releasing the data would compromise the anonymity of trial participants. The tribunal disagreed.

PACE trial results of CBT & GET grossly exaggerated

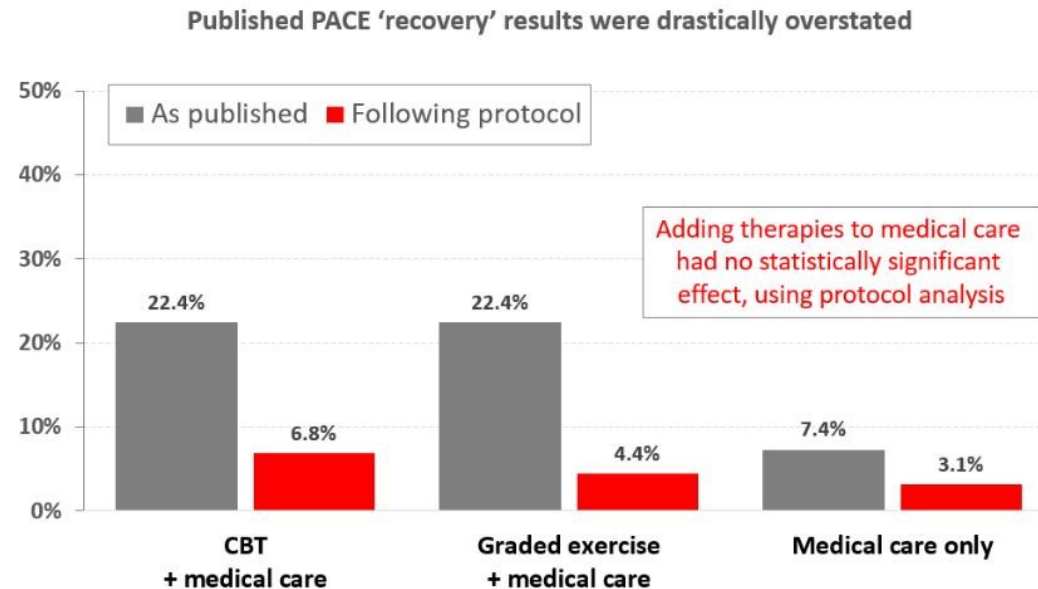
On 21 Sep a group of patients published their analysis of the original data obtained from the PACE trial researchers, with the help of academics from the US.

One of the many criticisms of the trial was that the researchers had changed the definition of recovery after the trial had started, resulting in participants being classed as recovered at much lower levels of functioning. In addition there was no objective measurement of improvement applied. Participants were asked to assess their own level of functioning.

In 2013 the researchers reported the following recovery rates after treatment: CBT 22%, GET 22%, Adaptive Pacing Therapy 7% and Standard Medical Care 7%.

The new analysis based on the researchers original criteria shows that the therapies tested in the £4 million trial are not nearly as effective as the published results claimed them to be:

CBT 7%, GET 4%, APT 2% and SMC 3%.



Source: PACE trial recovery from CFS (White et al 2013): Analysis of FOI data. Virology blog bit.ly/2dgaatn3

13% percent of the study participants although disabled enough to get on the trial, were also scored as recovered before any treatment took place! Details of the reanalysis: <http://tinyurl.com/h8m96ho>

NICE CFS/ME guidelines review

NICE has begun to assess whether their CFS/ME guidelines need to be updated in 2017.

They will look at the 3 US reports produced in 2015 and the reanalysis of the 2011 PACE trial. A decision is expected to be published by summer 2017.

There will be a 2-week consultation with registered stakeholders if information summarised indicates that a 'no update' decision should be considered. There is no consultation if the decision is to update the guideline because it has been based on the availability of new evidence, and is usually supported by stakeholders.

WAMES is a stakeholder and will be monitoring the situation.

news

CBT & GET research

Because of the PACE trial academics, doctors, therapists and statisticians around the world have been voicing concerns during 2015 and 2016 about the validity and safety of using cognitive behavioural therapy and graded exercise therapy for people with ME.

PACE trial researchers continue to claim the trial is good science and stand by their research, although American health organisations are withdrawing their support for the therapies and removing information about it from their websites.

In the UK trials using CBT or GET continue to be supported:

MAGENTA - a study of GET in teenagers conducted by Dr Esther Crawley ended in August 2016 and results are yet to be published.

SMILE - a pilot trial on teenagers with ME/CFS run by Dr Esther Crawley involved comparing the effects of standard medical treatment (SMC) against that of the Lightning Process. The Lightning Process claims to be a combination of neurolinguistic programming (NLP) and osteopathy. The content of the process is copyrighted but according to patient reports involves affirmations and counteracting negative thoughts.

Results were due by the end of 2015 but have not been published yet.

"Don't be a novelist - be a statistician.
Much more scope for the imagination."

Darrell Huff

FITNET-NHS – a study by Dr Esther Crawley comparing CBT and Activity Management delivered by Skype for teenagers. It will begin in 2017.

A media launch in November 2016 caused huge controversy as critics complained that Dr Crawley made a number of inaccurate statements:

- ♦ the purpose of the CBT she will use in FITNET being to alter sleep when the leaflets she produces claims it is to change negative thinking
- ♦ that very little is known about CFS
- ♦ that evidence for CBT and GET is good and PACE was good science
- ♦ that the Dutch FITNET studies showed high recovery rate for online CBT

The Countess of Mar made an official complaint to the BBC about its biased handling of the launch. WAMES recommends caution for young people with ME participating in the 'intensive activities' of the trial.

PRINCE secondary study (The PRINCE Secondary Study: Persistent Physical Symptoms Reduction Intervention) - This is a trial currently run by Kings College London using CBT to reduce medically unexplained symptoms (MUS) in people with a variety of conditions. People with ME are being included in the trial. One person tells how this trial made her symptoms much worse:
<http://tinyurl.com/hb4q3wa>

UK MEGA big data study

A new study has been proposed that will use the most up to date technology to investigate DNA, RNA and other molecules to uncover the distinctive genetics, epigenetics, proteomics and metabolomics of people with ME/CFS, using a very large number of samples.

The ME/CFS Epidemiology and Genomics Alliance (MEGA) hopes that this large scale study will eventually provide enough biological data, known as biomarkers, to be able to distinguish one subtype of ME/CFS from another. They would then use these biomarkers to create diagnostic tests for ME/CFS and to identify, from their biological profile, which new treatments are appropriate for which patients.

There has been a mixed response to this announcement. While the prospect of diagnostic tests and treatments is exciting, many are concerned that the research team includes PACE trial researchers and proponents of the psychological approach to ME.

There are fears that the study will focus on fatigue and not ME, which is characterised by Post Exertional Malaise. Patients have also been asked to support the study before any details have been announced.

In response to this the MEGA team claim to be striving for transparency and have launched a new website and have recruited patients for a Patient Advisory Group. The deadline for the grant application is early January 2017.

WAMES has concerns about this study but hopes that the MEGA team will address those and it will become a key contributor to a major breakthrough in the search for better healthcare for ME people.
Study website: <http://www.megaresearch.me.uk/>

UK Poll results on MEGA study:
<http://tinyurl.com/hnyxae6>



news

Research: demoralisation & depression in ME/ CFS – can you help?

Eminent ME researcher Prof Leonard Jason from Chicago USA would like your help in understanding what external factors may be influencing the development and expression of demoralisation and depression-like symptoms in ME/CFS.

People aged 18 or older with ME and CFS are invited to complete their questionnaire online assessing several factors including access to and quality of healthcare, illness severity, financial impact, and social interactions with both supportive and non-supportive people. This questionnaire will take approximately 90 minutes to complete. There is an opportunity to save pages and return later.

Online survey: An Assessment of Demoralization and Depression-like Symptoms Experienced by Individuals with ME and CFS
<http://tinyurl.com/z8ndsyx>

The difference between chronic fatigue & just being tired

This is a useful comic strip in a short video (2 mins 13 secs) for explaining something about ME and PEM. <https://www.youtube.com/watch?v=fpUsZOQGIVA>

Video lectures about ME and research

Dutch patient group ME/cvs Vereniging posts videos on their You tube channel in their Science To Patients Webinars/ Wetenschap voor Patienten

The most recent are by Canadian doctor and author Dr Byron Hyde <http://tinyurl.com/oetquwv>

The Bateman Horne Centre in Utah USA posts videos of their education meetings. A recent talk by researcher Dr Lucinda Bateman was about the Global Report of Progress in the ME/CFS Field
<http://tinyurl.com/grhrqd9>

Solve ME/CFS
This US research program posts education and research videos online. Lecturers include Drs Nahle, Hanson, Armstrong, Younger, Levine, Nath, Unger, Komaroff.
<https://www.youtube.com/user/SolveCFS>

Action for ME
AfME has posted videos of the UK CMRC Conference and their own conference with speakers including Drs Dunn, Montoya, Newton, Crawley etc. <http://tinyurl.com/havde7b>

RME Sverige
The Swedish National Society for ME posts videos from their conferences including ones in English by speakers such as Drs Daniel Peterson, Oysten Fluge, Leonard Jason, Mady Hornig.
<http://tinyurl.com/jj6q4ta>

WAMES posts select news & research of interest to people with ME and carers in Wales on the website's news blog, Facebook and twitter.
www.wames.org.uk
<https://www.facebook.com/WAMESMECFS>
<https://twitter.com/WAMESMECFS>



online with me

It would be easy to imagine that everybody is connected to the internet these days. Paper publications are becoming less and less common. Public libraries, those historical curators of the printed page, are closing down or reducing opening hours. Every ad, poster, leaflet etc. has a web link. There are even adverts on TV for websites!

But... staring at a screen is not every ME person's idea of fun. In fact reading a screen or watching videos can be difficult for people with ME and can cause relapses, just like other activities. Because of the struggle a fogged brain has to learn new skills, and then remember them later, some people with ME choose not to go online!

Then there's the expense. Computers can cost hundreds of pounds, and a monthly broadband package enabling you to access the internet just adds to the cost.

So, is it worthwhile? Should someone struggling with the cognitive and vision problems of ME, or on benefits or a low income even consider going online?

Why go online?

The internet is a gateway to a whole new world. It allows flexible access to information, people and services 24 hours a day, 7 days a week. In other words you can expand your world at a time that suits you and for the length of time you can cope with, to:

keep in touch with people – send and receive emails, messages, photos etc. or have live conversations with one or more people through

messaging services like Aim or 'face to face' through video telephone services such as Skype.

Facebook and Twitter help keep you in touch with where your friends and family are and what they are doing. Or 'follow' a famous or interesting person's Facebook posts or 'tweets' and get to know more about them.

meet new people in discussion forums (post emails), chat rooms (real time), or dating sites – these can be based around any topic and there are a number just for people with ME, carers, specific hobbies, jobs or special interests. It is also possible to play games with them in real time

learn about ME – you can do this through websites, blogs (where people describe their own experiences or comment on issues that interest them), webinars (seminars online) or video lectures. There are also online self-management courses for ME or chronic illness. e.g. <http://www.cfidsselfhelp.org/online-courses> <http://www.eppwales.org>

keep up to date – news appears 24 hours a day and you can arrange to have it sent to your phone or tablet through Facebook or twitter. You can also choose which type of news you want to see, and when, by visiting news websites or blogs. e.g. <http://www.walesonline.co.uk/> and www.bbc.co.uk/news give general news about Wales.

WAMES posts select news & research of interest to people with ME and carers in Wales on the website's news blog, Facebook and twitter.
www.wames.org.uk
<https://www.facebook.com/WAMESMECFS>
<https://twitter.com/WAMESMECFS>



Find out what is happening in your local area on local websites, blogs and Facebook pages.

have your say – on a wide range of services, issues, products and concerns through e-petitions, consultations, review sites and feedback pages.

save time & money – avoid time spent travelling and queuing, and save car park fees by shopping, banking and paying bills online. Look for the best prices in comparison sites and read reviews to ensure you buy the best product for your needs.

Use one of the recycling / upcycling websites like Freecycle to find or offer goods that can be reused. Or buy and sell 2nd hand goods on Ebay, Gumtree or local websites. There are also many sites where you can sell your own creations or set up a business.

expand your knowledge and skills by doing online courses, many of them free. Watch a video or read a guide with detailed instructions.

Message Boards, sometimes called forums, are websites where you can post questions or info.

online with me

They are frequently populated by experts in a particular subject, who give their time for nothing or people who share your experience or interests.

You may have heard about that wonderful online encyclopedia *Wikipedia*, which aims to provide information on any and every subject. Did you know that the online group #MEAction has launched an #MEpedia? So far there are many gaps but as time goes on it should become a useful source.

have fun – you can pursue your hobbies and interests, explore other cultures, explore new music, catch up on TV or radio programmes using playback facilities or play games with friends. Whether you enjoy painting, jigsaws or Scrabble you will be amazed at what you can do at the press of a key, swipe of the finger or touch on a joystick!

Can't go on holiday? Or visit friends and family? Explore the pyramids, art galleries, castles etc., take train rides, or explore from the air, 'walk' the streets of a distant town and much more in a virtual tour.

How can I go online?

The cheapest way

1. Attend free classes locally to learn the basics.
2. Use the free computers at the public library or community centre.
3. Sign up for a free email address e.g. google.com, mail.com or yahoo.com
4. Search the free online database of public places in Wales where there is free access to computers,

the internet and other forms of digital technology. (Of course you have to be online in the first place to search it! You may need to ask a friend or phone the public library to help you find the info you need).

<http://getonline.digitalcommunities.gov.wales/>

The low energy way

1. Buy a smart phone that makes phone calls, takes photos and goes online (only one device to master and lightweight to hold)
PC Advisor <http://tinyurl.com/z6cn8fl> recommends Vodafone Smart Prime 6 (£49.24 from Amazon) and others at prices up to £150, though they can cost a lot more.

2. Buy a mobile phone package that includes online access (aka data download). They start at £5 a month, and vary depending on how many free minutes and how much 'data' you wish to use.



3. Learn how to make the most of your phone (aka device) by reading the support websites for your mobile and by watching instructional videos on *Youtube* (a collection of videos online).

Already have a computer & telephone line?

1. Choose a landline phone package that gives you unlimited internet access & an email account (and maybe even free calls) from £20 a month e.g. EE, Post Office, Phonecoop (Some providers also offer mobile access in the package.)

2. If you need to upgrade your equipment (aka hardware) ask friends or family if they have something useful gathering dust in their cupboards OR check ads online (e.g. freecycle, preloved) or in a local free paper for free or cheap 2nd hand monitors, keyboards etc.

Other options

If you need a smaller or bigger screen to see more clearly, or something easily portable, consider a laptop or tablet. Make sure it does everything you need it to do before purchase as they are not all the same.

Laptops – screens vary in size from 12" to 17",



although 15.6" is the most common. PC Advisor <http://tinyurl.com/jt4m4yo> recommends laptops from £180.

Tablets – screens vary in size from 6" to 10" (there are larger but they are heavier) and use a variety of operating systems i.e. they work differently. PC Advisor <http://tinyurl.com/jt4m4yo> recommends Amazon Fire £49.95 - £135. Other tablets vary from £80 to over £1,000.

Some tablets come with a keyboard as well.

Just a thought - When choosing new equipment it is usually a good idea to read comparison reviews, but if you are a beginner these reviews will make little sense to you. Solutions to this are to opt for a cheap device, learn the basics and expect to upgrade later when you know more about what you want to do online.

online with me

How do I learn more?

Public library – borrow books, videos, read magazines

Community – ask around for classes

Online – the BBC have a great collection of articles and videos to introduce you to going online, social media, staying safe, webcams etc.
<http://www.bbc.co.uk/webwise/0/>

Friends & family – ask around until you can find someone who will be able to answer your questions in 'no-geek speak', or who might be prepared to help you to get going.

The internet is a global network of computers that works much like the postal system, only at sub-second speeds. Just as the postal service enables people to send one another envelopes containing messages, the internet enables computers to send one another small packets of digital data.



Can I avoid online searching making me more ill?

As with everything people with ME do, Pacing is the order of the day, but there are many other ways to reduce the impact of computing and being online. Some might help you:

Light – keep the screen in good indirect lighting, without glare, to avoid eye strain. An anti-glare screen or tinted specs might be helpful for some.

Monitor / screen height & angle – standard advice is to place the monitor, tablet or phone 20 to 28 inches from your eyes and 4 to 5 inches below eye level. Experiment to see what works best for you.

If you're looking back and forth between a screen and papers, keep those materials where you can see them with minimal head movement. If you are lying down you may need a stand or holder to keep the device in the best position.

Eyesight – don't let your eyes get too dry. Blink often and consider changing your contact lenses to those which provide you with increased moisture all day. Book an annual eye test to check if you need specs or tints to help specifically with computing.

Adjust your computer display – you can alter the brightness of your screen. Try different colours for text and background and increase the size of text if necessary.

Take breaks – as many as are best for you. Practice typing with your eyes closed. Install software to remind you to rest your eyes and

other muscles. [General advice for healthy people is to follow the 20/20/20 rule: Take a 20-second break every 20 minutes. Focus your eyes on points at least 20 feet from your computer. Keep your eyes moving while looking at objects at various distances.]

Mouse & keyboard? - reduce hand & wrist pain by changing your posture, supporting your arm, altering the way you use the keyboard such as with a trackball, changing the type of mouse, use voice recognition software, use a pen on a touch screen or 'swype' instead of type.

<http://tinyurl.com/huez6pt>

<https://www.abilitynet.org.uk/homepage>

Electro sensitivity - reduce symptoms by using an earthing product

Reduce screen time – if screens are a problem print out and read on paper, or transfer some files to an e-reader to lessen the impact. Many computers and tablets have programs that will read the text on your screen aloud to you.

Don't skim read – read slowly, out loud if necessary, to make processing the information easier.

Effect on sleep - you can switch your device to night mode when using it in the evening (might have to load an app) to make it easier to get to sleep after using the device. It will help to turn all devices off at least one hour before trying to sleep.

More info: Ways to stop the internet from aggravating symptoms. <http://tinyurl.com/zawfsq6>

Whether you decide to go online or explore the internet more will be your decision and will depend on what is best for you at this moment in time.

Whether you decide to go online now or later –
ENJOY!

Jan Russell

glub, gloop:

a light hearted look at therapies, *by Alan Dearing*

Everyone, these days, is getting therapy and the need has become a little bit of an expensive habit. In order to counter this, market provision of self service therapies must be set up. We will sit in a comfortable and tastefully furnished waiting room for an hour, and then depart refreshed, having received therapy in a homeopathic way. (I really think this could work!).

The most popular form of much needed balm comes to us disguised as the soap opera, the programmes that regularly top the ratings. We love to watch ordinary lives in process because we can then empathise, identify with our own situations which, of course, are even more muddly and, hopefully, get some clue to sorting it all out.

What we need are remedies that are more readily available and calorie free. So I have developed a new therapy, based on ancient Sanskrit texts that I discovered in a cave near Port Talbot. A clinic will open at the site of the old pop works, down the Lido in Merthyr.

Clients will be asked to sit at a specially designed kitchen sink, with their legs comfortably under the basin. This innovation has been introduced to prolong the experience in conformity with the slow movement philosophy. Instructions are then to be followed closely.

Liquid cleaning fluid should be added to the plugged sink. A lemon scented variety is splendid, as it introduces the idea of sharpness and of cutting through. Water of an agreeable warmth is then allowed to fill the sink, and the client will be encouraged to enjoy the soap bubble forms and



the spectrum of colours therein, whilst swishing about reflectively. An unhurried cleansing of dishes then proceeds, until the client is relaxed enough to part with cash.

Therapies abound, if you look for them, and they don't all involve chocolate. Cats eat grass and dogs pee on lamp posts. The life therapy movement is then left with the paradoxical problem of finding out what the problem is.

I used to visit an alternative clinic, and kept going just because talking to the therapist was so interesting. If it feels good and it doesn't cause too much pain in the wallet, it's a therapy.

Of course it is necessary for me to adopt a troubled expression when confronted by washing up, or the wife might start charging me by the session!!

Answer to "Quote from a Christmas Carol" on page 7

"I will honour Christmas in my heart, and try to keep it all the year. I will live in the Past, the Present, and the Future. The Spirits of all Three shall strive within me."



living with me

Don't get 'cut off' in a power cut

If you rely on your devices to keep you safe and in touch with the outside world it pays to protect them from blackouts and power surges.

1. Electricity supply - if you have a power cut, first check your own fuse box to see if any fuses have blown or any of the switches have been tripped. If not, check with a neighbour to see if they also have no power. If so, call the electrical distribution company for your area—the number may be on your electricity bill or you may be able to find it on <https://www.ecotricity.co.uk/customer-service/power-cuts-or-gas-leaks/electricity-power-cuts> Keep the number handy just in case as your computer won't work when the power is off!

2. Lightning - Unplug sensitive equipment (TV, computers) from the mains during a lightning strike or other power interruption.

3. A surge protector will protect your computer and other equipment with intricate microprocessors from unexpected surges in electric current. Costs from £20.



4. An uninterruptible power supply (UPS) for your desktop computer. A UPS is a device that allows your computer to keep running for 5-10 minutes when power is lost, long enough to save data and close down safely.

Another use for a UPS is one that you keep turned on permanently for devices like cordless phone base stations and your broadband router, keeping them working during short power cuts (DSL based broadband will keep working during a power cut, cable broadband often doesn't work as the cable system often lacks battery backup). You could also have a lamp with a low energy bulb connected for tasks where more light than a torch is useful. Prices start at £46.

5. Don't overload circuits - too many desktop computers, and network devices connected to a single circuit can easily overpower the electrical supply.

6. Avoid overheating - keep all vents and fan outlets free of debris, boxes, files, folders, and furniture. When performing routine system maintenance, verify that PC and server exhaust fans are working properly and are unobstructed.

7. Use a certified installer - installations, appliances, fuse boards and wiring should comply with BSC 7671 'Requirements for Electrical Installation Contracting'. Any alterations should be made by an electrical contractor who is a member of a recognised regulatory body.

8. A landline phone will work in a power cut while a cordless one needs power and a mobile needs recharging.

9. Charge laptops, tablets and mobiles regularly so you don't get caught out.

10. A wind up mobile phone charger will charge your mobile and even touchpad and kindle.

11. Keep a list handy of phone numbers of emergency and friends who can help. They are no good if they are only in the memory of a cordless or powerless mobile phone!

Glasses plus mouse = glassouse

Do you find a computer mouse hard to use? GlassOuse is designed like a pair of glasses, and only slight head movements are required in order to move the cursor around on a phone, tablet, laptop, computer or Smart TV.

A small mouth-controlled blue device which is connected to the GlassOuse enables the user to click the left hand mouse button, using their teeth or lips, so that they can type, surf the web, etc.

Other assistive devices on the market which use eye control (which is very tiring) or head movement with 3-D cameras (£800-£2,800).

GlassOuse costs £275 free P&P <http://www.glassouse.uk>



living with me

Live-in care – the third option

Long-term care tends to be split into two types:

- domiciliary care, where somebody (or more likely many people) comes to your home to provide care; and
- residential, where the person who can no longer manage unaided, moves into a care home with others in a similar situation.

The third option is becoming more popular, as care home fees continue to rise, and the quality of service provided by many care agencies comes under fire. Live-in care has a number of advantages:

- eases the loneliness experienced by many older and disabled or ill people living alone;
- avoids the significant upheaval of relocating into residential care at a time of life when familiar surroundings are much valued.
- enables couples to stay together when one needs more care than the other
- a cheaper option for 2 people

Average all-inclusive fees for live-in care start from £695 per week, and you are not always tied into a long term contract, so if you want to test the water with care for a long weekend, that is fine.

The following companies operate in Wales:

<https://coriniumcare.com/live-in-carer-wales/> 01453 839290

<http://www.helpinghandshomecare.co.uk> 0843 775 8388

Check out the media, Google or this online directory for local companies:

<http://www.homecare.co.uk/homecare/listings.cfm/searchcountry/Wales>

Keep warm this winter

We've already had one cold snap this winter so prepare for more by checking out this good advice for everyone who is old or frail from Age Cymru:

Winter wrapped: a guide to keeping well and staying warm in winter

<http://www.ageuk.org.uk/cymru/get-involved/spread-the-warmth/what-is-spread-the-warmth/>

Nest

– keeping Wales warm

Nest is a Welsh Government scheme working to make Welsh homes warmer and more energy-efficient places to live. If you're worried about the cost of heating your home, you can call Free-phone 0808 808 2244

Mon-Fri 9-7 and speak to an advisor.

They can offer advice on:

- Saving energy and water
- Money management
- Making sure you're on the best energy and water tariff
- Whether you are entitled to any benefits to boost your income

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

advicewales@est.org.uk



Access to work grant

An Access to Work grant can pay for practical support if you have a disability, health or mental health condition to help you:

- start working
- stay in work
- move into self-employment or start a business

[The grant is not for business start-up costs.]

How much you get depends on your circumstances.

The money doesn't have to be paid back and will not affect your other benefits.

More info: <https://www.gov.uk/access-to-work/overview>

atwosu.london@dwg.gsi.gov.uk

Telephone: 0345 268 8489

Textphone: 0345 608 8753

Monday to Friday, 8am to 6pm

<https://www.gov.uk/access-to-work>

carers

The story of an unwilling carer *...continued*

It must be 20 years ago that I wrote the following article for the Mid Wales ME Group newsletter. I felt then that my responses to being a carer might well help others embarking on that unexpected and unwanted task.

Perhaps now is a good time to review those responses and see what changes, if any, have taken place.

The story of an unwilling carer

I knew from the beginning of my wife's illness nine years ago that there was something seriously wrong with her. She moved rapidly from being a person with a sharp and agile brain, and body to match, who was capable of doing well anything she turned her mind to; to a person whose brain, still as good as ever but often clouded with pain and weariness, was no longer supported by her body's ability to carry out the things she wanted to do.

Watching the one you love change so dramatically is an awful experience and I knew she would never willingly inflict it upon herself - it is so totally alien to her nature. But coming to terms with the implications of this knowledge is a very, very different matter indeed.

To write this honestly is extremely difficult for me, but I'm trying to do so because it might help other carers to know that they are 'not alone' and that



others do experience the same or similar negative emotions (even if they are kept under the surface). Being a carer is desperately lonely job, as there are so few people that you know well enough and who really understand, that you can talk to about your emotions and problems - and carers, like sufferers, need to talk!

First let me say that I understand that the sufferer's lot is far worse than that of the carer, and I would never pretend that it is otherwise. But carers do have their problems too! I am constantly amazed at how well and uncomplainingly my wife has coped with her ME over the years and ashamed at how badly I have coped with 'caring'.

Negative emotions

I have experienced a range of negative emotions - here are a few of them! The worst I have had is that of resentment. It has taken several forms.

Resentment at what ME has done to our lives together; how it has ruined our active social life; how if I am to have time with friends away from (and sometimes in) the house, I have to do it alone, something I still find it very difficult and never wanted to do in our lives together.

Resentment at having to do many of her chores as well as my own, for we used to try to share the domestic work between us. Resentment at having to make breakfast almost every morning.

Resentment at having to do these things as well as my professional work, which can involve meeting deadlines and some degree of stress.

Yes, written down, it does look pathetic and selfish, but the resentment has been real, nonetheless. And trying to convince my partner that the expression of this resentment is not aimed at her but at the illness itself, has been very difficult, and for her, very hurtful.

And it gets even sillier - for I even felt envious! Envious of the fact that while I am rushing around doing things I do not want to do, she is sitting in the sun, or lying in bed or watching sport on TV. And I don't even like sport! And *she* is in pain!

Perhaps for me, the most difficult emotion is shame. On the odd occasions during the last nine years when I have been ill, she has looked after me wonderfully and at great cost to herself. Yet I have never been able to come close to her caring ability - however hard I tried, it did not last and I found the old resentments creeping back. As an incurable optimist, I kept thinking it is going to get better, but it doesn't. I am learning to adjust but it is a slow, shaming process.

I also find it increasingly difficult to maintain such religious faith as I had. I cannot understand how God, who we are told is supposed to care for each individual, could allow such a waste of a person's undoubted talents. I feel totally helpless in the face of her distress at the waste of her life - platitudes have little meaning after nine years of pain.

carers

Our friends tell me that I am a good carer, but I know that I am not - only I (and she!) know just how inadequate I really am. If I were marking myself, I would give myself about 1/10 of the beginning and about 3/10 now. Being a carer is a hard and lonely ongoing learning experience which I'm slowly getting better at, but doubt that I will ever fully come to terms with - for it is a role that nobody would ever willingly assume, except perhaps for a real 'Saint!'

20 years later...

20 years on, her ME is still with us, and I am still NOT a Saint! There have been years when my wife has been slightly better, but on occasions, as now, other problems associated with ME have negated any slight improvement she may have felt. But that hasn't stopped her, and for 20 years she has played a part in raising awareness of the neurological illness of ME and played a key role in family life.

I am immensely proud and full of respect for the way she has ploughed on and achieved so much, despite the real physical cost to herself in the process.

My resentments have gone, although occasionally I still have minor attacks! I still find it hard that we cannot do things together much of the time, but I'm deeply grateful that our relationship has remained as strong as ever.

Sadly both of us are 20 years older, and whereas I used to be the strong one, able to do all the physical chores, this is no longer the case and I suppose we are more similar now in what we can cope with.

Increasingly we need to care for each other and this is hard for me to accept. I am resigned to, and indeed used to doing things on my own, but it is

always better when she is with me – I then feel whole and not a half.

I do not feel ashamed of my caring abilities any more – I do a better job now and I fully accept the need to help, when she requires it. I suppose I would mark myself at about 6/7 out of 10 nowadays (although I am not sure what marks my wife would give me!)

Since retiring I have tried to spend time supporting my wife to do the things she couldn't do without help. It is great to see her make good use of her abilities after feeling useless for so long, but it is a struggle to persuade her to rest when she is frustrated by not being able to do even more!

We both accept that ME rules *both* our lives, and that it will probably always do so. It has caused many negatives – we have little social life together, few friends who really understand, we rarely 'get out' although we do manage a holiday each year, and we increasingly need paid help in and around the home.

We have found ways of coping with, or alleviating some of the problems it brings, and hope we will continue to adapt to the new ones that will inevitably arise as we continue to get older. However, the fact remains that this illness imprisons those who have it, and to a large extent those who care for them.

Anonymous

Young Carers Awareness Day

is on 26 Jan 2017. This year's theme is 'When I grow up' and it's all about helping young carers to achieve their dream jobs or career.

See how you can get involved - <https://carers.org/young-carers-awareness-day>

Supporting Carers - Credu

Powys Carers and North Wales (WCD Young Carers) are now called Credu (it means 'believe' in Welsh)



Check out the new website <http://credu.cymru>
Credu supports carers and their families in Powys (Credu Powys) They help carers to both look after their loved ones and take care of themselves as individuals. They provide:

- information and resources online
- confidential advice and support in person through a team of outreach workers
- opportunities to meet other carers in the area through groups, activities and trips
- carer wellbeing assessments
- advocacy for dealing with other service providers and supporting carers to represent themselves
- counselling sessions
- training opportunities
- 'drop in' shop and hwb in Machynlleth on the main street opposite the Job Centre
www.facebook.com/credushops/
- main office Llandrindod Wells (Marlow, South Crescent, LD1 5DH)
- facebook <http://tinyurl.com/hmcjvzg>

Adult Carers – chris@powyscarers.org.uk
Young Carers – jan@powyscarers.org.uk
Siop a Hwb – Teresa@powyscarers.org.uk
Operations/General – marie@powyscarers.org.uk
Tel: 01597 823800, 9am – 5pm, Mon - Fri

carers

Help someone manage their benefits

When a person is unable to manage their welfare benefits, someone else can do it on their behalf in a number of different ways.

The most common is when a family member or a friend acts as an **appointee**.

If the person also has substantial finances or property that needs looking after, the Court of Protection can appoint a **deputy** to make decisions on their behalf.

When a person has capacity to manage their own benefits, but would nevertheless like someone else to do it on their behalf, they can authorise this by giving a **power of attorney**.

Who is an appointee?

An Appointee is a person who has been appointed by the Department of Work & Pensions (DWP) or a local authority to receive welfare benefits on behalf of someone who is unable to manage their affairs, generally because of reduced mental capacity or severe physical disability.

In some circumstances this can be arranged for people with severe ME. An appointee cannot be appointed simply because it is more convenient to have one, or because it is hard for a person to get to the bank.

It is important to note that an Appointee has no role beyond welfare benefits.

An appointee's responsibilities

- sign the benefit claim form
- tell the benefit office about any changes which affect how much the claimant gets
- spend the benefit (which is paid directly to you) in the claimant's best interests
- tell the benefit office if you stop being the appointee e.g. the claimant can now manage their own affairs
- If the benefit is overpaid, depending on the circumstances, you could be held responsible.

How to become an appointee

To become an appointee you should make a request to the Department of Work and Pensions (DWP). You, and the person you will be representing, will then be interviewed to ensure you are suitable, and if so, you will be formally appointed to act on their behalf.

The phone number to ring will vary depending on which benefits the customer is receiving. e.g. if it is Attendance Allowance, you need to ring the Attendance Allowance helpline.

Who is an attorney?

An **Attorney** is someone whom an individual has authorised in a legally-binding document to make decisions on their behalf when they are unable to do so.

It is now possible to make a Lasting Power of Attorney (LPA), authorising the attorney to make specific decisions e.g. after the person has lost capacity to make them himself or herself.

Different LPAs cover property/finance and health/welfare; and some people make both.

An LPA is a formal document which has to be signed and witnessed, but only becomes binding when it is registered with the Office of the Public Guardian.

It is important that anyone with ME is sure that the person they choose to act for them not only understands what they want, but also keeps up to date with the issues surrounding ME and healthcare controversies.

More info: <https://www.gov.uk/power-of-attorney/make-lasting-power>

Office of the Public Guardian

customerservices@publicguardian.gsi.gov.uk

Telephone: 0300 456 0300

Textphone: 0115 934 2778

Monday, Tuesday, Thursday, Friday, 9am to 5pm, Wednesday, 10am to 5pm

How to increase a carer's State Pension

Your State Pension is based on your National Insurance record.

Carer's Credit is a National Insurance credit that helps with gaps in your National Insurance record.

You could get Carer's Credit if you're caring for someone who receives a disability benefit for at least 20 hours a week. If you receive Carer's Allowance or get Child Benefit for a child under the age of 12 you automatically get credits.

Find out more:

<https://www.gov.uk/carers-credit>

Carer's Allowance Unit

Telephone: 0345 608 4321

Textphone: 0345 604 5312

Monday to Thursday, 8:30am to 5pm
Friday, 8:30am to 4:30pm

carers

Online help for carers

Relationship support for carers

The Carer's Trust has produced an online relationship guide for carers

<http://relationships.carers.org>

What's in the online relationship guide?

If you are looking after your partner you can face unique pressures. The guide includes support about:

- the challenges of caring for your lover
- the art of healthy arguing
- dealing with resentment & frustration
- dealing with hidden issues
- coping with the stresses of caring



If you care for a family member, friend or neighbour you are likely face a different set of challenges. The guide includes support about:

- role reversal if you care for a parent
- caring for a sibling and how things might change between you
- spotting vicious cycles & how to break them
- New help and advice pages
- A map to help carers find their local support service

Carers Trust <https://carers.org>

Carers Wales <https://www.carersuk.org/wales>

Carers online forums

give carers the chance to take a break and focus on themselves, rather than the medical condition or the person they care for.

Carers space - <https://space.carers.org>

a new version of the Carers' Trust online community for adults works on tablets, mobiles and on your desktop. Aims to create a friendly space to chat or ask for advice from other carers or the online support team.

Carers UK Forum <http://www.carersuk.org/help-and-advice/get-support/carersuk-forum>

- a community where you can talk to other carers over the age of 18 who understand what you are going through and who can support you through everything caring has to throw at you.

Babble <https://babble.carers.org> — an online community for young carers, where those aged under 18 who are caring for a family member or friend can chat, share their experiences and access information and advice.

Local information online

Anglesey Carers Outreach Service

<http://tinyurl.com/jp8yzlb> 01248 370 797

Anglesey Council

<http://tinyurl.com/jlmtf2r> 01248 752752

Blaenau Gwent Council

<http://tinyurl.com/zgv2dj4> 01495 315700

Bridgend Carers Centre

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

01656 658479

Caerphilly carers

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

029 2088 2663

Caerphilly Council services

<http://tinyurl.com/gvb488p> 01495 233218

Caerphilly Young carers

<http://tinyurl.com/zrrcmr2> 01633 6125859

Cardiff & Vale carers centre

<http://tinyurl.com/zpukybu> 029 2056 6171

Cardiff & Vale Young Carers

<http://tinyurl.com/gpgea84> 02920 465250

Cardiff & Vale UHB carers

<http://tinyurl.com/zafsr6v> 029 2074 5307

Carmarthenshire Crossroads care

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

0300 0200 002

Carmarthenshire carers forum

<http://www.ccf.wales>

Carmarthenshire Council carers info

<http://tinyurl.com/jxekh3u> 0300 333 2222

Ceredigion Council

<http://tinyurl.com/j9ukjhl>

Ceredigion carers support service

<http://tinyurl.com/gq6u95b> 01239 615 945

Conwy Carers Outreach Service

<http://tinyurl.com/jp8yzlb> 01248 370 797

Conwy Council carers help for carers

<http://tinyurl.com/hzaowq8> 0300 456 1111

Conwy Young carers

<http://credu.cymru/for-you/meet-wcd/>

01597 823 800

Denbighshire NEWCIS

www.carers.org/local-service/Denbighshire

01745 331 181

Denbighshire Young carers

<http://credu.cymru/for-you/meet-wcd/>

01597 823 800

Denbighshire Council

<https://tinyurl.com/zkwytt6> 0300 456 1000

Flintshire NEWCIS

<https://carers.org/partner/newcis-flintshire>

01352 752525

Flintshire Council

<http://tinyurl.com/gr6ed8j> 01352 803444

Flintshire Young carers

<http://tinyurl.com/hwqr67u> 01352 755422

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Gwent - Carers Trust South East Wales

<http://tinyurl.com/j9rpjem> 01495 769996

Gwent young carers

<http://tinyurl.com/hemzcax>

Gwynedd Carers Outreach Service

<http://tinyurl.com/jp8yzlb> 01248 370 797

Gwynedd Council

<http://tinyurl.com/z4eo8r8> 01286 682888

Monmouthshire carers project

<http://tinyurl.com/hd3etk7> 01633 241553

Monmouthshire Council

<http://www.monmouthshire.gov.uk/carers-assessment>

01633 644644

Neath Port Talbot Carers Service

<http://www.nptcarers.org.uk> 01639 642277

Neath Port Talbot Council

<http://tinyurl.com/zfsrpxm> 01639 686802

Newport carers service

<http://www.carersuk.org/search/newport-carers-service>

01633 264763

Newport Council carers

<http://tinyurl.com/zq3jr28> 01633 656656

Pembrokeshire Council carers

<http://tinyurl.com/zj23aro> 01437 764551

Pembrokeshire Investors in carers

<http://www.pavs.org.uk/carers/> 01437 769422

Powys Carers

<http://credu.cymru> 01597 823 800

Powys Council

<http://tinyurl.com/jrqludv> 01597 826000

Swansea Carers Centre

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

01792 653344

Swansea Council

<http://www.swansea.gov.uk/carers>

01792 636519

Vale of Glamorgan Council carers

<http://tinyurl.com/gnl3c3p> 01446 700111

Wrexham Carers service

<http://avow.org/en/wrexham-carers-service/>

0800 276 1070 / 01978

318812

Wrexham Council

<http://tinyurl.com/hyg6hdy>

01978 292066

Flu jabs

A flu jab for carers protects the person with ME. Viruses change regularly and vaccine protection fades over time, so if you are a carer and had the vaccine last year you should get vaccinated again this year to protect you, and the person you care for, from flu this winter.

Festive Crossword Answers

11 - Nativity
9 - Stocking
8 - Tree
5 - Snowman
4 - Wise Men
3 - Holly
Across:

8 - Turkey
7 - Pantomime
6 - Carols
2 - Reindeer
1 - Chimney
Down:

Young Adult Carers – A Special Invitation for You!

Save the dates: 11, 12 April 2017

A Taste of Bangor University Life



Are you a young adult carer aged 16-25 and looking after a family member?

Would you like support with your study or work? A chance for you to tell us what would make these easier for you.

Would you like a taste of University life?

During your time at Bangor University you will:

- Meet other young adult carers
- Meet other young adult carers who are already studying at the University
- Have lots of opportunities to share information and have your voice heard
- Learn about the financial support available to you
- Stay in University accommodation
- Have a go at all sorts of activities
- HAVE LOADS OF FUN!

If you're interested in coming along to this event, please contact us by emailing

Elizabeth: etaylor@carers.org or phoning 07703 840054



The FITNET research study on young people with CFS/ME

A big research study was announced at the beginning of November by Dr Esther Crawley who runs the Bath Paediatric CFS/ME Service.

She is inviting young people aged 11 to 17 to get involved:

“We want to test whether a treatment called “FITNET-NHS”, which delivers cognitive behavioural therapy (CBT) for CFS/ME at home via the internet, is effective and value for money.

CBT focuses on cognitive behavioural strategies to identify, challenge and change cognitive (thinking) processes.

We want to compare this with another treatment for CFS/ME called Activity Management which will use video call (e.g. Skype).

In the first part of the study, we want to know whether young people, like you, will want take part in the study and whether young people think FITNET-NHS and Activity Management are acceptable treatments.

In the second part of the study, we want to see how effective FITNET-NHS and Activity Management are at treating young people with CFS/ME and measure the costs of each treatment.”

If you want to get involved with this please take time to look into all the pluses and negatives.

There has been a lot of discussion about this trial on social media and WAMES has the following concerns:

- We do not believe it is a good use of public money. Patient surveys and poor results from the PACE trial raise questions about the effectiveness (and safety) of CBT and GET in adults.
- This study is based on the Dutch FITNET trial in children with fatigue, which did not produce better long term results than usual care and it is unclear whether all participants had strictly defined ME. We believe that Dr Crawley is wrong to say CBT has been proven to be effective in young people.
- Because everybody with ME is different and improves at a different rate, some people have found that CBT is being making them feel bad that they are not recovering quickly enough. Changing their thinking doesn't make everybody feel better.
- Activity management at the Bath Centre includes gradually increasing activity. This trial expects young people with ME to participate in 'intensive activities' which we believe could cause a post-exertional exacerbation of symptoms for some people.

More info:

Dutch FITNET trial <http://tinyurl.com/zq43yo5>
FITNET study <http://tinyurl.com/jee5npn>

FITNET controversy <http://tinyurl.com/phv5m8f>
Bath Paediatric CFS/ME service
<http://tinyurl.com/gprs9ux>

U21

u21@wames.org.uk



**Christmas greetings
from all of us at
WAMES**

Pace your way to a
happy and healthier
new year!



U21

What is your favourite app?

Color therapy is one of the most popular apps for teenagers in the US. It is a stress-relieving, digital colouring book for adults.

<http://www.colorthrapy.me>

Neko Atsume: Kitty Collector is a cat collecting game developed by Hit-Point for iOS and Android,

Color Switch." In this game, you must follow each color pattern you're shown on each obstacle to progress.

Christmas gift money ideas?

Tweezy £6.99 from Amazon



Smartphone Projectors from £15.99 at Amazon



Underwater lights for bath or pool
Prices start at £8.49 at Amazon



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

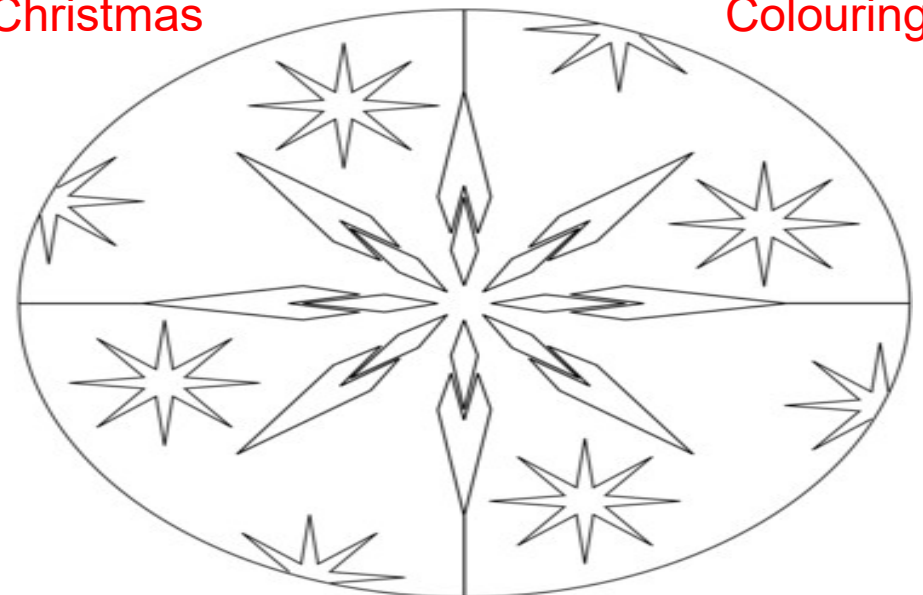
Christmas Wordsearch

Advent
Candle
Chestnuts
Decorations
Elves
Gingerbread
Jingle Bells
Mince Pies
Partridge
Tinsel
Toboggan
Wreath

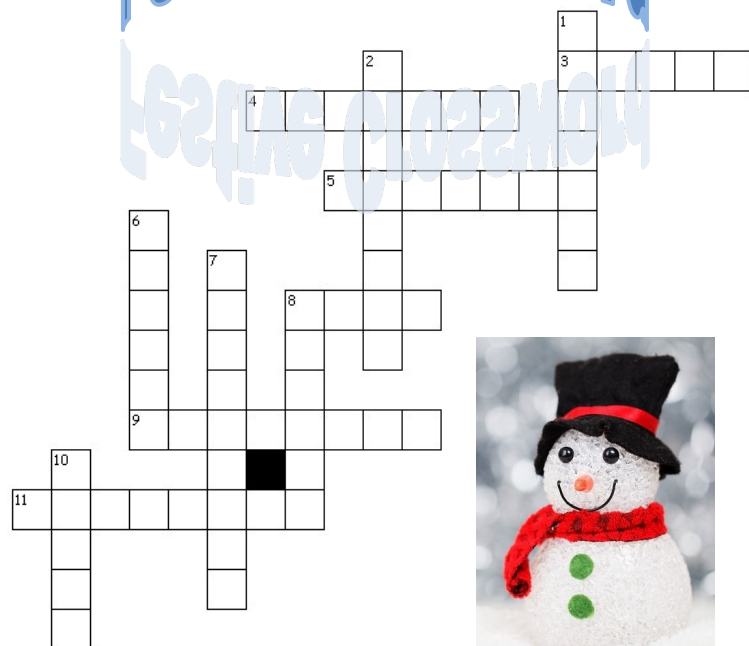
Created by Puzzlemaker at DiscoveryEducation.com

Christmas

Colouring



Festive Crossword



Across

3. Green, prickly plant with red berries
4. The 3 men who brought gifts to Jesus at his birth
5. Make this from white flakes falling from the sky
8. You put your presents below this
9. Hang this at the foot of your bed or mantelpiece

Down

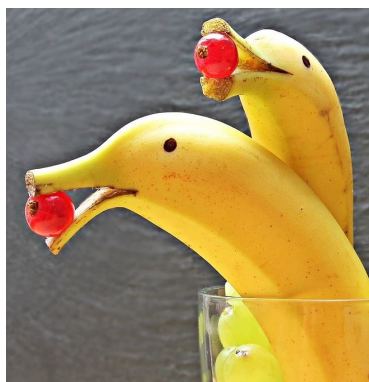
1. Santa climbs down this to make his delivery
2. They pull Santa's sleigh
6. Pluralised Christian name of former Countdown numbers wizard
7. Festive family entertainment
8. Gobble, gobble
10. Paper greetings sent to friends and family

Created by [Puzzlemaker](#) at [DiscoveryEducation.com](#)

Answers on page 21



Ed Gregory, stokpic.com



A Sign of the Times

As a little girl climbed onto Santa's lap, Santa asked the usual, "And what would you like for Christmas?" The child stared at him open mouthed and horrified for a minute, then gasped: "Didn't you get my E-mail?"

The Terry Hetherington Young Writers Award 2017



£1000 First Prize
Applications by January 31st 2017



Competitors should be aged between 18 and 30 yrs on the 31st of January for the application year. They must also:

1. Be resident or studying and/or on contract in Wales, or
2. Have their main home in Wales, but are studying or on contract outside Wales.

For the full terms & conditions, and to apply, please go to the Young Writers Award on the website:

www.chevalwriters.org.uk

