



me voice

the wames magazine
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WAMES
Welsh Association of ME & CFS Support

contents

- 3 **support groups**
- 4 **wames news**
health services update
£500 donation
- 7 **news**
MP drop-in
PACE Trial
ME name survey
- 8 **news from wales**
ME and elections
social services changes
measuring patient experience
- 11 **feature**
emotional wellbeing
- 14 **carers**
finding good home care
carers and election
young carers event
- 16 **living with me**
PEM or PAR?
when to reveal disability
- 18 **crossword**
- 19 **u21 pages for under 21s**
tired but wired
crafting for relaxation
revising with the BBC



me voice

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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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www.facebook.com/WAMESMECFS



support



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

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

Brecon Area Contact

Richard Jones 01874 622310
richard.j5@btinternet.com

Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months.

Next Meeting: 11 June 2016
Contact: John James (pm) 01267 233793

Cwtch, Haverfordwest

Young adults aged 18-45 years with long term or chronic physical health conditions meet 1st Friday of the month during school term, 10-11.30 and 3rd Friday 7-8.30pm at Cashfields Community Centre.

Next meetings: 6 May, 3 June 10-11.30am.
15 April, 20 May 7-8.30pm
Contact: Beth 07974 543874
www.cwtch-pembrokeshire.co.uk
cwtch@live.co.uk

FM/ME/CFS Support Group West Wales

This Group which met in Milford Haven, Pembs,

may no longer be running. Please let us know if you have any information about the Group.
<http://fmmeecfswestwales.jimdo.com>

ME Support in Glamorgan (MESiG)

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

Next meetings: 14 May, 6 June
Contact: Christalla Bailey, 029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months. Next meeting: May.

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

Ystradgynlais Neuro Café

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

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

Contact: Caroline Bull 01639 849 192
cbullyvc@gmail.com
<https://www.facebook.com/HeadwaySouthPowysNeuroCafe/>

Live near the border?

An English group may meet closer to you:

Shropshire

www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester

www.chestermesh.org.uk
Joan Crawford 01244 370988

Ross on Wye

Gill Suttle 01600 890730
mesupport@gillsuttle.co.uk

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

editor: Jan Russell

publisher: Dr Tony Thompson

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wames news

me voice update

Thanks to all who have let us know how much you appreciate the magazine.

We hope to be able to continue publishing **me voice** for some time to come, but unfortunately we have to reduce the number of issues to 4 a year.

We have a serious manpower problem.

The WAMES team have been fully stretched with running the charity and working to improve NHS services so we are constantly pressed for time, and energy!

We produce the magazine in-house to keep costs down, so we are always keen to hear from people who wish to join us and help lighten the load.

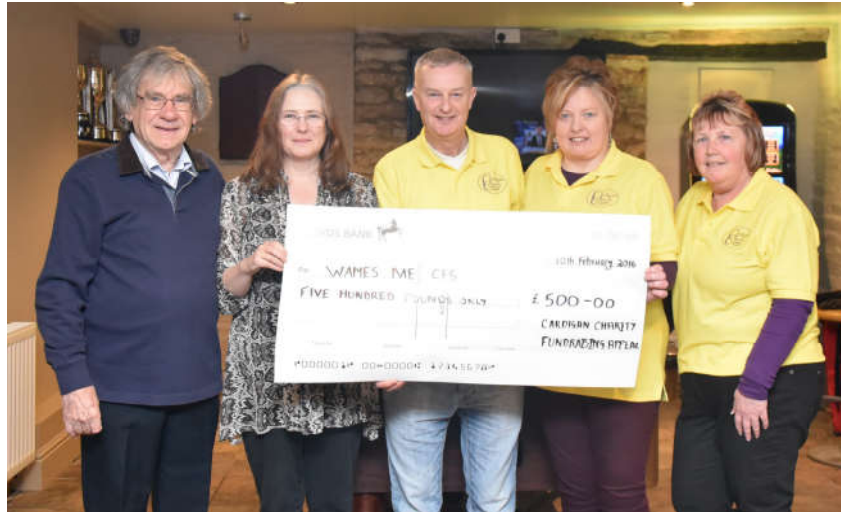
We understand that having ME makes it difficult for people to commit to volunteering, but there are lots of small ways that people can contribute so please get in touch with Jan or Sylvia to talk it over.

We hope to issue **me voice** in March, June, September and December, but please bear with us, if we are sometimes a bit late!

Remember, you can stay up to date with news and events on the website blog, Facebook and twitter.

£500 donation

We were delighted to be named as one of the beneficiaries of *Cardigan Charity Fundraising appeal* in February. <https://www.facebook.com/cardigancharity.fundraisingappeal>



Jan and Tony at the presentation in Cardigan

The group, to whom we are most grateful, raises money for good causes in west Wales, so we will be using the donation to support our work with people with ME and the health services campaign in the Hywel Dda Health Board area (covering Carmarthenshire, Ceredigion and Pembrokeshire).

Is there a fundraising group in your area?
e.g. the Rotary club, Lions club, Student rag group.

Do you know a school, company or professional group that raise funds for a different charity each year?

Why not ask them to raise money for WAMES?

Raise up to £40 for WAMES when you book your family holiday this year



All aboard for
big donations



300 top travel retailers to choose from



Easy fundraising

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

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

wames news

AGM

The 2016 WAMES AGM will be held in south Wales in June. More details to come.

ME Awareness Week

11 – 17 May 2016

This year WAMES will be focusing on:

Sharing info about ME with the NHS

We will do this through the website for GPs www.gpone.wales.nhs.uk and Health Board websites and staff publications.

Sharing effective ways to explain ME

When someone asks you: **‘what is ME?’**
Does your mind go blank?

Do people’s faces go blank when you talk about myalgic encephalomyelitis, neurological conditions and post-exertional malaise?

From the beginning of May we will share some ideas for simple ways to talk about ME on the blog, Facebook and twitter and will invite you to share your favourite explanations.

Tell us about your local awareness raising events and we will advertise them. Contact Sharon if you need information or ideas for awareness or fundraising events. sharon@wames.org.uk

NHS Services for ME & CFS – slow progress

Implementation Group

Prof Jonathan Richards no longer works for Cwm Taf Health Board, so has unfortunately had to resign as chair of the *ME-CFS & FM Implementation Group*. Claire Hurlin from Hywel Dda UHB has agreed to be the interim chair. There have also been other changes in personnel representing Health Boards.

This Group gives Health Boards a chance to share experiences and encourage each other in implementing the recommendations of the Government’s Task & Finish Group Report.

Patients are represented by Jan Russell from WAMES for ME and Carol Ross for FM. Staff from the Welsh Government departments of Chronic Health and Major Health Conditions represent the Government and report back to the Health Minister.

The Group continues to meet 2-3 times a year. The next meeting will take place after the election and will then report back to the new Health Minister.

It is not the job of the Implementation Group to make decisions about illness names, diagnostic criteria, causes and treatments of ME and FM, etc.

It doesn’t discuss medical issues but strategy and planning issues.

The Government’s Task & Finish Report recommendations “focus on strengthening implementation arrangements and improving patient voice in the system. In making its recommendations, the Task and Finish Group has sought to identify the infrastructure required to support system change.”

More info: Task & Finish Group Report

<http://tinyurl.com/maksqsg>

Health Boards

Progress towards implementing a pathway and improving services continues to be slow. 2 Health Boards haven’t started the process for ME & CFS yet.

3 have begun to plan services but have not met with patients and carers yet to find out what they need and what the problems in their health boards are. Hywel Dda UHB has made the most progress.

Hywel Dda University Health Board

(Ceredigion, Carmarthen, Pembrokeshire)

Executive lead: Kathryn Davies Director of Therapies & Health Sciences

Clinical Lead: To be confirmed

Support: Claire Hurlin, Chronic Conditions lead

Reports to: Musculo Skeletal Population Group

Activities: A Stakeholder (Pathway) group was set up in 2013 consisting of staff, patients and carers, and is meeting monthly during 2016.

The Action plan passed by the Board and covers pathway development, training, awareness etc.

Local care pathways and patients leaflets are currently being developed.

Uneven blood flow to the brain > Brain sends altered signals to the body > Body reacts abnormally to physical & mental stimuli = ME

wames news

Powys teaching Health Board - PtHB

(Montgomeryshire, Radnorshire, Brecknock)

Executive lead: Amanda Smith, Director of Therapies & Health Sciences – has been seconded to WAG

Clinical lead: Owen Hughes, Consultant psychologist & Head of Pain & Fatigue Management Service

Reports to: Neurology Steering Group

Activities: A draft Action plan and pathway has been drawn up focusing on the Pain & Fatigue clinic, but no stakeholder group has been set up and no engagement with patients and carers has taken place.

Powys Focus group

Neuro Voice Powys is inviting people with ME, CFS or FM, and their carers/ families to a Focus Group to discuss service needs in Powys. They will then report back to the NHS.

The meeting will be held in Newtown at 1.30pm 3rd May 2016. Contact Jan for more info.

Abertawe Bro Morgannwg University Health Board - ABMUHB

(Swansea, Bridgend, Neath Port Talbot)

Executive lead: Hamish Laing, Medical Director

Clinical lead ME: Post vacant

Reports to: Long Term Conditions Group

Activities: GP questionnaire; draft pathway and service development; no patient engagement.

Aneurin Bevan University Health Board - ABUHB

(Gwent: Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen)

Executive lead: Alison Shakeshaft, Director of Therapies & Health Sciences

Clinical lead: To be appointed

Reports to: To be confirmed

Activities: Discussions with NHS staff to locate those with interest in ME & CFS. Stakeholder group to be established once clinical lead found.

Cardiff & Vale University Health Board - CVUHB

Executive lead: Fiona Jenkins, Director of Therapies

Clinical lead: Dr Sharmila Khot, Consultant in Anaesthesia & Pain medicine

Support: Dr Jo Hampson, Consultant Clinical Psychologist, Chronic Pain Programme

Reports to: Velindre Chronic Pain Management Service

Activities: Discussions with NHS staff; stakeholder group still to be established.

Cwm Taf University Health Board

(Merthyr Tydfil and Rhondda Cynon Taf)

Executive lead: John Palmer, Director of Primary, Community & Mental Health

Clinical lead: To be appointed

Reports to: To be confirmed

Activities: Initial discussions with NHS staff.

Betsi Cadwaladr University Health Board - BCUHB

(Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire, Wrexham)

Executive lead: To be appointed

Clinical lead: Simon Neal Consultant clinical psychologist & Head of North Wales CFS/ME service

Reports to: Neurology Network

Activities: initial explorations, but serious Health Board problems have pushed ME and FM down their agenda.

WAMES

WAMES' chair Jan Russell is actively involved in both the Implementation group and in discussions with Health Boards.

We are concerned about the slow progress in many Health Boards. After all, a previous Health Minister asked Health Boards to implement pathways and service improvement following the first Task & Finish Group back in 2011 and some Health Boards have still made no progress!

WAMES understands that Health Boards have many obstacles to overcome before they can implement the 2014 recommendations. These include: constant reorganisation; funding crises; the lack of ring fenced funding from government; and the lack of clinical champions keen to improve medical services and understanding of the neuro/immune/endocrine condition we call ME.

In spite of the problems, WAMES is proactively looking for ways to work with Health Boards to:

- identify patient needs in each area
- identify current services and staff that have something to offer people with ME
- devise pathways, training sessions, awareness materials and patient resources.

The first step is always to ensure that the patient voice is heard, but we are also working with Neurological Alliances and Health Board Neurological Delivery Plan steering groups to look for ways that the ME agenda can be integrated into their neurological services delivery plans.

news

PACE trial – data sharing

WAMES has joined professors, clinicians and ME charities from around the world in asking the PACE trial researchers to release data from their study so that other researchers can check their results.

The Information Commissioner and the journal PLOS one (which published a paper from the study) has decided it is possible to share anonymised data so that participants in the trial cannot be identified, but Queen Mary University London continue to refuse.

The researchers have appealed the IO's decision and the final ruling is expected on 22 April.

Read WAMES' letter to the University and other news about the PACE trial on the news blog on the WAMES website.

Invest in ME International ME Conference

The annual CPD-accredited biomedical research conference will take place 3rd June 2016, Westminster, London and now attracts presenters, researchers, physicians, patient groups and journalists from twenty countries around the world.

Download leaflet <http://tinyurl.com/jtlacek>

Discounted rates exist for healthcare staff registering in association with an ME Support Group like WAMES.

Need for large genetic studies

Prof George Davey Smith, a clinical epidemiologist at the University of Bristol, says there is a need for large scale genetic studies of ME/CFS as it is not possible to draw accurate conclusions from small scale studies.

At the UK CFS/ME Research Collaborative (CMRC) conference in Nov 2015 he announced his intention to play a role in the largest set of studies ever proposed for ME/CFS: Prof Stephen Holgate's Grand Challenge, which is progressing.

More info: <http://tinyurl.com/zt6qlho>

US National Institute of Health study (NIH)

The NIH has announced a major in-depth study of ME/CFS to be led by Dr Avindra Nath, who said: "Our hypothesis is that post-infectious ME/CFS is triggered by a viral illness that results in immune-mediated brain dysfunction".

The plans have led to much discussion and requests for changes so the NIH has called for research proposals and comments from patients and researchers. It looks as if the plans will continue to evolve.

More info: <http://tinyurl.com/h9sc5bb>
<http://tinyurl.com/h5jfabx>

Take part in survey on name & criteria

Prof Leonard Jason invites those with ME and CFS & family to take this 15-20 min online survey on their opinions of the name and criteria for ME and CFS, March 1, 2016
<http://tinyurl.com/hpf2gms>

Burrswood hospital changes

Burrswood hospital is a private Christian hospital in Kent, which has accepted a number of patients from Wales over the years. Due to the difficulty of recruiting the full range of specialist care they need, they will no longer take the most severe patients i.e. those with ME who fulfil all of the following criteria:

- History of being entirely bed bound
- Entirely dependent on others for all care including feeding
- Severe sensory hypersensitivity

The in-patient service will continue during 2016 & a statement about the future will be made later.

More info: 01892 863637

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

Awareness-raising drop-in London: invite your MP

A drop-in, hosted by the All-Party Parliamentary Group on ME will take place on Wednesday 11 May from 12.30pm to 2pm at Portcullis House, Westminster, London.

This event offers MPs the opportunity to better understand the key issues facing people with ME. MPs attending can pick up a new ME information pack with key information to help them support their constituents with ME.

You can use a template letter to invite your MP to this event but it is a good idea to personalise your letter to your MP if possible, perhaps adding a sentence or two about your own experience of ME.

Find the details of your local MP on the Parliament website <http://www.parliament.uk/mps-lords-and-offices/>

More info: <http://tinyurl.com/go66kz3>

Neurological research conference: co-production

The Wales Neurological Alliance held a conference on Co-production in research into neurological conditions in Cardiff on 14th April.

WAMES was there with a display about ME and research needs and exploring ways to encourage research in Wales.

More info: <http://tinyurl.com/zwsq5h9>

What is co-production?

Co-production is an approach to public services which involves citizens, communities, and the professionals who support them, pooling their expertise to deliver more effective and sustainable outcomes and an improved experience for all involved.

In co-production, citizens and patients have rights and responsibilities as equal partners. This can be at an individual or community level and can involve the public sector, the third sector and other agencies.

The co-production process begins with the question ‘how do you want to live your life?’ rather than ‘what services are you eligible for?’ This starting point recognizes that citizens and service-recipients are experts by experience and can identify what is important to them, and they also have rights and responsibilities as equal partners in the process.

In a co-production scenario, service-users and their communities are involved in defining the

need or problem, designing the solution, delivering it, and evaluating it, either with professionals or independently, or anything in between. This approach demands longer-term engagement by service-providers but leads to profound and sustainable change.

The Welsh government and statutory organisations are committed to co-production in principle, but making it work in practice is an ongoing process!

Measuring neurological patient experience and services

People with ME took part in 4 focus groups designed to gather experiences from people with neurological conditions during February and March.

The goal was to help Public Health Wales to develop appropriate PROMs and PREMs.

What are PROMS & PREMS?

PREMs - Patient reported experience measures aim to:

- Enable the NHS to understand what it feels like to be a patient with a neurological condition in Wales
- Enable the NHS to use the information to improve services.

PROMs - Patient reported outcome measures aim to:

- Support diagnosis and monitor progress in clinical practice
- Provide information for patients and clinicians regarding choice of treatment
- Support healthcare providers to improve service effectiveness and quality

- Support healthcare providers to ensure that services are clinically and cost effective

The experiences people shared will be written up and used as the basis for a survey which will be undertaken annually. Participants will continue to be involved by reviewing the draft questionnaire.

Health wise Wales study

HealthWise Wales is a Welsh Government initiative to involve everyone in Wales in improving the health and wellbeing of the population, by taking part in research. If you join the study you have to agree to give your contact details and to allow them to access and use your NHS records in confidence, now and in the future.

They are hoping to gain real insights into health because they study large numbers of people over a long period of time e.g. the Caerphilly cohort study looked at the impact of a healthy lifestyle on men in Caerphilly over 35 years.

Find out more:

<https://www.healthwisewales.gov.wales/about/healthwisewales@cardiff.ac.uk> 0800 9 172 172

Sudoku

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

welsh news

ME & the Welsh Government elections

The Welsh Government elections on May 5th could have a major impact on the lives of people with ME.

Welfare/ benefits and employment are still the responsibility of the UK government. But the Welsh Government has powers in 20 areas including:

- Education and training
- Health and health services
- Highways and transport
- Housing
- Local government
- Social welfare

Voting

Register to vote by 18th April. Anyone can also request a postal vote. This is especially helpful for those with mobility problems as not all venues are fully 'accessible'. Contact your local council registration office by ringing the council or online here: <http://www.aboutmyvote.co.uk/register-to-vote>

Find out more about the election:

<http://tinyurl.com/jhh877z>

Who are candidates?

Local authorities publish names of candidates who are standing in an election at the latest three weeks before polling day.

More info about policies at local party offices, libraries and:

<http://www.welshconservatives.com>
<https://wales.greenparty.org.uk>

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

<http://www.plaid2016.wales>

<http://ukip.wales>

WAMES

WAMES is contacting all candidates, looking for their support in improving health, social care and education services for people with ME. In particular we will be informing them of the Task & Finish Group recommendations and the need for greater patient and carer involvement in the process.

We are also looking for a commitment to stable and well-funded NHS and Social Services in Wales – it is time to stop constantly reorganising and provide support to make past changes work effectively.

EU referendum 23 June 2016

How would leaving the EU affect the lives of people with ME?

The media debate about the EU referendum has largely been about trade, sovereignty and security. There has been relatively little discussion about what leaving the EU would mean for ordinary voters, especially people with ME and the other 11m people with a limiting long term illness, impairment or disability who live in the UK.

Staying in Europe

Pro Europe proponents cite laws and directives from the EU that have been particularly beneficial to ill and disabled people e.g.

- non-discrimination measures on goods and services
- accessibility – requiring lifts, cars, public transport, telecommunications and buildings to be accessible to all

- medicines – braille on packets
- agreement to accept Blue badge across Europe
- promotion of independent living
- measures against institutionalisation, combatting of poverty
- challenging injustice and aiding employment, independent living, community services etc. in the UK through the European Social Fund

Campaigners say that EU directives do not guarantee success on the ground but the European Commission is, nonetheless, an important accountability mechanism. The requirements also act as a moral and legal compass for the ways in which disabled people should be included in society.

More info: <http://tinyurl.com/guf63e9>

Leaving Europe (Brexit)

Campaigners argue that in addition to the economic and sovereignty reasons to leave the EU, additional considerations include:

- leaving the EU does not mean leaving the European Convention on Human Rights – that is a separate issue
- EU economic policy has enforced austerity measures that have led to severe cuts in health, social care & disability services across Europe
- advances in disability equality and inclusion are not the result of EU policy, they are the product of struggle by disabled people in both EU and non EU countries. There is no automatic link between EU membership and higher standards of support and inclusion for disabled people

More info: <http://tinyurl.com/hwoz3la>

welsh news

NHS digital strategy

The Welsh Government has a 5 year plan to increase the use of digital technology in the NHS. This will involve:

- **Connect online with health services** – to book appointments, order repeat prescriptions, talk to clinicians for virtual appointments and consultations.
- **Access health records online** – to view hospital appointments or details of GP visits, prescription and test results, and feed in details gathered from other sources such as apps and wearable devices.
- **Use digital tools and smartphone** apps to manage their own health – allowing people to monitor conditions like diabetes and asthma. Smart technologies such as sensors in patients' homes will be used to help people live independently for longer.
- **Receive digital reminders and alerts** – including medication or exercise reminders, appointment alerts and updates about agreed care plans.
- **Free Wi-Fi** will also be made available at all NHS Wales hospital sites for patients, visitors and staff to use.

Press release: <http://tinyurl.com/hvxmt6k>

Disability Wales

At the last minute the Welsh Government announced a £600,000 funding package over the next three years to save Disability Wales from closure. Their income is much reduced but they are now recruiting staff to enable them to

continue campaigning for disability equality and providing information to all.

<http://www.disabilitywales.org>

District nursing survey N Wales

Give your views, good or bad, on the district nursing service in north Wales. For further information about the survey or to let the health watchdog know your views, please contact the North Wales Community Health Council on tel 01248 679 284 or e-mail admin@waleschc.org.uk or visit the website www.bcchc.org.uk

Changes to Social Services

The Social Services and Well-being (Wales) Act 2014 became law on April 6th 2016 and aims to give people a stronger voice and greater control over the support they need, as well as ensure services are sustainable for the future.

It also promises to:

- strengthen powers to safeguard vulnerable people and give carers greater rights
- ensure easy access to information and advice is available to all
- introduces new eligibility criteria focused on individual need, replacing the threshold system
- introduces portable assessments, so people who move from one part of Wales to another will receive the services they need in their new area without undergoing a new assessment.

Training has been available to Social Services departments for some months, but it is likely to take some time for all staff to become familiar with all aspects of the new law.

More info: <http://tinyurl.com/hkk6ppc>
Assessments guide <http://tinyurl.com/hwkhmhw>
Care and support <http://tinyurl.com/hkk6ppc>

£4m for Independent Living

From 1 April 2016 the enhanced system of delivering essential housing adaptations such as ramps, handrails, walk-in showers and stair-lifts, will be rolled out across Wales.

Enable – Support for Independent Living aims to make it quicker and easier for people to get help when they need it.

Political Word Search

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

Twenty answers on page 13

A dwarf goes to a very good but very busy doctor and asks "I know you are busy but do you treat dwarves?"

The doctor replies "Yes, but you will have to be a little patient".

emotional well-being

Stress affects thousands of people within Wales. Research suggests 1 in 4 adults will have a mental health issue at some point in their life, and stress plays a big part in this.

The MEA survey of 2010 (p. 8) found that a significant proportion of people with ME/CFS experienced some emotional distress:

Any mental health diagnosis as part of your illness?

	Major problem	Minor problem	Rating Average
Depression	46%	40%	0.66
Anxiety and/or panic attacks	38%	38%	0.57
Mood swings or emotional lability	37%	35%	0.55

Answered Question: 2477

The NHS has traditionally encouraged people to protect their physical health by exercising, not smoking or drinking to excess, avoiding spreading viruses etc.

Now they want to help us protect and improve our mental and emotional health.

People who are emotionally healthy are in control of their emotions and their behaviour. They are able to handle life's challenges, build strong relationships, and recover from setbacks.

NHS Wales is promoting a number of initiatives and courses in the hope that eventually there is something for everyone regardless of location or level of fitness.



1. Five ways to wellbeing

The Five Ways to Wellbeing are an emotional wellbeing equivalent of 'five fruit and vegetables a day'.

You can use each point to help you identify what is important to your own wellbeing and discover concrete ways of building positive actions into your daily life.

1. Connect: With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

2. Be Active: Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and one that suits your level of mobility and fitness.

3. Take Notice: Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

4. Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

5. Give: Do something nice for a friend, or a stranger. Thanks someone. Smile. Volunteer your time. Join a community group. Look out as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

emotional well-being

More info:

resources to download to help you work out how *you* can improve your well-being in each of the 5 categories. These may need to be modified for people with moderate to severe ME.

<http://www.wales.nhs.uk/sitesplus/888/page/61014>

Background: <http://tinyurl.com/zhd6zsp>

Group workshops:

South West: Neath, Swansea, Port Talbot, Bridgend

Dates: <http://tinyurl.com/hjgvtb2>

Contact: living.lifewell@wales.nhs.uk

Phone/ text 07967 612246

South Gwynedd: soon to be offered by Tan y Maen

<http://tinyurl.com/z4rgec2>

tanymaen@btinternet.com

01766 830 203

2. ACTivate your life course

ACTivate Your Life is a four session taught course (not a group therapy) which aims to help you to have a better life, a life with less suffering and greater freedom to do the things that matter to you.

Suffering is often made worse when we struggle and try to escape from our distress- but it doesn't need to be this way.

The course will help you understand why your struggles to overcome your problems may have been making things worse; it will help you to do things differently and to make life better for yourself. You will learn a lot about how your mind works and you'll discover that your mind often works against you, but you can stop your mind spoiling things for you by learning how to take more control.

The course is based on *Acceptance and Commitment Therapy* which is a new psychological approach that teaches people how to reduce their suffering and how to lead a richer, more fulfilling life by accepting the things they cannot control and making a commitment to do the things that they really care about.

The four sessions of the course run weekly for approximately 2 hours with a break half way through the session. The classes are supported by a Power-

Point presentation, course notes and activity sheets- all free of charge. Often you just turn up without registering or handing over personal details.

Location of courses:

South west: Swansea; Neath; Bridgend; Port Talbot

Dates: <http://tinyurl.com/hjgvtb2>

Contact: living.lifewell@wales.nhs.uk

Phone/ text 07967 612246

Gwent: Ebbw Vale; Hengoed; Newport; Chepstow; Monmouth; Abergavenny; Caldicot; Cwmbran

Powys: Bronllys hospital

Contact: 01874 712499

office@painandfatigue.co.uk

for dates and details

Cardiff & Vale: The Hayes, Barry, Whitchurch, Caerau, Canton

Dates: <http://www.stepiau.org/action-for-living/dates>

3. Stress & anxiety control courses

The Stress Control course is designed to help people:

- Understand the causes behind stress, anxiety and worry
- Learn about vicious circles in these areas and how to break them
- Learn techniques to control stress for example stressful thoughts and stressful feelings
- Practice stress reducing techniques
- Learn how to gain control over other problems that often accompany stress, such as low mood, panic attacks and poor sleep

The course is run weekly over 4-7 sessions for approximately 90 minutes with a break halfway through the session. You can turn up and register on the day of the course. Free course materials and relaxation CD are provided. Some areas also do courses specifically on anxiety and coping with life.

Locations:

South west: Swansea; Neath; Bridgend; Port Talbot

Dates: <http://tinyurl.com/hjgvtb2>

Contact: living.lifewell@wales.nhs.uk

Phone/ text 07967 612246

North Wales: many centres
For more info contact 0300 777 2257

ask@parabl.org

<http://www.parabl.org.uk/english/groups/>

Cardiff & Vale: Canton, The Hayes, Barry, Whitchurch

Dates: <http://tinyurl.com/jmtuky4>

emotional well-being

4. Mindfulness

The practice of Mindfulness can help you manage stress, handle thoughts better and live your life more fully.

It means paying attention in the present moment to yourself, others and the world around you. Mindfulness meditation develops calm and focus, letting you stay with whatever's happening even if it's difficult.

With guidance, we can let go of troubling thoughts and unhelpful states of mind and access a sense of calm and acceptance. Learning to focus the mind and settle attention allows us to let go of being compulsively busy, preoccupied and anxious, and access our capacity to be more aware of our experience in the present moment.

Becoming aware in that way, without judging our experience as being right or wrong, is a key to managing difficulties more effectively and living more fully. Courses last 6-8 weeks and require a commitment. Many businesses and charities also offer courses costing £30-£500.

Locations:

North Wales: many centres
For more info contact 0300 777 2257

ask@parabl.org
<http://www.parabl.org.uk/english/groups/>

More info: NHS choices
<http://tinyurl.com/kq5o3ua>

Free MP3 downloads
(courses cost a lot)
<http://www.sfwales.org>

Online course:
<http://www.bemindfulonline.com/>



FreeDigitalPhotos.net/Stuart Miles

5. Other resources

Actif Woods Wales

Runs outdoor woodland activities which promote health and well-being, for people with health conditions www.coedlleol.org.uk 01654 700061

Computerised CBT programme <http://tinyurl.com/jkk77f5>
<http://www.mywellbeinghub.co.uk>

Wellbeing self assessment <http://tinyurl.com/jvc8kq9>

NHS choices Moodzone <http://tinyurl.com/bu5els2>

Hywel Dda Mental health & wellbeing <http://tinyurl.com/jnuxgqb>

Powys mental health & wellbeing <http://tinyurl.com/jkch9d3>

Aneurin Bevan Road to Wellbeing <http://tinyurl.com/j2pv5gr>

Cwm Taf mental Health support <http://tinyurl.com/pbegpud>

Cardiff & Vale Stepiau <http://www.stepiau.org>

Arts in health and wellbeing <http://tinyurl.com/z6h6a4w>
01248 682567 elizabeth.aylett@wales.nhs.uk

The downside of mindfulness <http://tinyurl.com/z2qfxdj>
<http://wames.org.uk/cms-english/2016/01/the-downside-of-mindfulness/>

The key to creating the mental space before responding is mindfulness.

Elizabeth Thornton



carers

2016 elections

Are you one of the 370,000+ people in Wales (12% of the population) caring, unpaid, for a friend or family member?

Find out what the election issues are for carers in the:

Carers Trust Manifesto

<http://tinyurl.com/hrztcq4>

Carers Wales manifesto

<http://tinyurl.com/zxwqhwhz>

(or ask Sylvia or Jan for a copy)

The Carers Trust invites you to email candidates via their online tool <http://tinyurl.com/j75eqwm>

Also don't forget to vote at the EU referendum on Jun 23rd.

More info about the elections on p. 9. Let Jan or Sylvia know which issues you want WAMES to bring to the candidates' attention.

A percussionist, tired of being ridiculed by other musicians, decides to change instruments. He walks into a music shop and says,

"I'll take that red trumpet over there and that accordion."

After a second, the shop assistant says, "OK, you can have the fire extinguisher but the radiator stays."

Finding good home care

The online *Good care guide* lists care agencies in the UK and includes vetted reviews, where available.

<https://www.goodcareguide.co.uk>
support@goodcareguide.co.uk

The guide is split into childcare and eldercare providers, but many of the eldercare providers will also provide care for younger adults.

Sometimes 24 hour care or live-in care is required, but not all local agencies can provide this service. Private national agencies may be able to help.

The Care Agency

The Care Agency operates throughout the UK and can help provide a professional alternative to residential or nursing homes, with an affordable live in carer or companion for short or long periods.

Registration Fee

There is a non-refundable lifetime registration fee of £75.00 (including VAT).

Agency Fees

The Care Agency fee for any carer is £16.07 per day + VAT.

Carers' Salaries

Salaries are set by The Care Agency but are paid directly to the carer by the client or their representative. Current salary rates range from £62 per day and depend on the level of care required.

The client provides full board and lodging for the carer.

For further details, terms of business and a brochure, please contact The Care Agency office on 01455 559 988 or 0845 604 4152. Alternatively you can email info@thecareagency.co.uk

Beech Nursing and Care is their sister agency and provides a premium service to self-funding clients. They provide fully trained and carefully vetted carers to help clients with visiting home care, helping clients to feel in control. A carer can visit for an hour or for the day. Beech Nursing and Care can also provide night care.

More info: <http://www.thecareagency.co.uk>



Pixabay

carers

Carers Rights Guide 2016

This guide covers:

- Benefits
- Other financial help
- Practical help
- Technology
- Your workplace
- Other help

The Carers Wales edition also includes information about the new Social Services and Well-being (Wales) Act which came into force in April 2016. Download from: <http://tinyurl.com/hyht58g>

Or contact for a free copy:

Carers Wales
Unit 5, Ynys Bridge Court
Cardiff CF15 9SS
029 2081 1370

info@carerswales.org

Carers Allowance recipients to be exempt from benefit cap

In January 2016 the UK government announced its intention in Amendment 24 to remove carer's allowance from the list of benefits that are included within the benefit cap.

Recipients of carer's allowance with a benefit income above cap levels would still be included in the cap but their carer's allowance payment would be disregarded from the cap.

<http://tinyurl.com/jnscng4>



FreeDigitalPhotos.net/Stockimages

Young carers support in Gwent

On Tuesday 8th March 2016 the Aneurin Bevan University Health Board launched its Young Carers policy for all schools in Gwent.

To find out more about support available for young carers in your area:

Torfaen Young Carers 01495 762200

Newport Young Carers (Barnardos)

01633 251192

Caerphilly Young Carers (Barnardos)

01633 612712

Monmouthshire Young Carers (Crossroads)

01495 769996

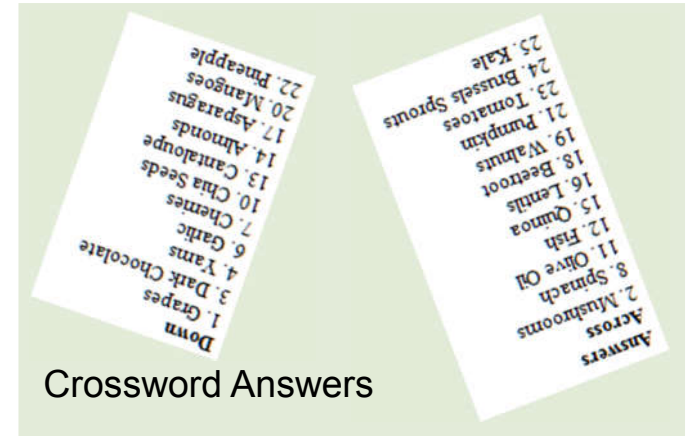
Blaenau Gwent Young Carers 08000 323339

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

Carer's Week

6-12 June 2016. The theme this year is:
Building Carer Friendly communities

More info: <http://www.carersweek.org>



Crossword Answers

Have you tried the EPP course for carers?

Would you recommend it to other carers of people with ME?

Let Jan know, so we share your experience with carers who contact us.

Looking after me is free and aims to help carers to learn ways in which they can look after their own health needs whilst they are caring for another person, and to cope with that caring situation.

More info: <http://tinyurl.com/m4oxu7b>

Changes to social care assessments

The new Social Care and Wellbeing Act (2014) came in on 6 April.

Carers Wales has produced an updated guide for carers and those they care for. *Assessments: a guide to getting an assessment in Wales from April 2016* <http://tinyurl.com/hwkhmhw>

living with me

Making the hard choices

In a recent podcast artist and blogger and pwme (person with me) Michael Nobbs talked about his need to make some hard choices and slow down - the difficult subject of saying "no" to things we may dearly love to do in order to give ourselves some of the things that we truly need.

"... if we are prepared accept our limits and pursue only what's truly important the reward is a much easier, happier and more creative life".

Giving up what's impossible and choosing carefully between the things that are possible will mean we can make progress even when moving at a snail's pace.

Are you focusing on what's truly important to you? Michael's blog *Sustainably Creative* helps you stay on creative track one small step at a time.

<http://www.sustainablycreative.com>

FOMO (fear of missing out)

With everything that is going on in this big, beautiful world, you are going to miss out on something. If you are worried about what you are missing, you aren't finding the most meaningful parts of what's happening right now.

Letting go of FOMO means abandoning the need to catch up, keep up, and measure up to connect with what's right in front of you.

More info: *When to say no: do a couple things well instead of everything poorly* <http://tinyurl.com/ndwzwem>

How to end the endless game of catching up <http://bemorewithless.com/catch/>

PEM or PAR?

Kasper Ezelius of the Swedish patient group ME-föreningen suggests replacing PEM (Post exertional malaise) with:

- PAR – Post activity relapse or
- DPAR - delayed post activity relapse

More info: <http://tinyurl.com/jbq5e3f>

Falls or trips?

Statistics tell us that one third of people over 65 years old falls each year

"younger people trip downstairs, older people have...a...FALL".

However, far from falling more, older adults actually have a lower incidence of falls. A 4 month study of university students found that more than half of them fell during normal daily activities...

As we get older we probably get a bit more cautious, because we become more aware of the risks of injury. Whether young or old, healthy or ill therefore, it pays to be aware of how to prevent and cope with falls.

More info: <http://tinyurl.com/hm3p3nx>

Virtual Men's Sheds

Men's sheds have become more and more popular across Wales where men have been setting up local meetings where they can get together, learn new skills, practice existing ones in a useful way, and generally socialise with other chaps.

The UK Association has a new proposal, to set up a "virtual shed", which could be used by all those people who can't get to a real-world Men's Shed, because of disability, geographical remoteness or lack of interest in the mainly woodworking/ metalworking activities available.

See more about their plans and how you can get involved here

In Australia, "The Shed Online" publishes the articles that members write on a wide range of topics, and promotes further activities, many of which could also be of interest to existing Sheddors.

If you have views, ideas or can offer support for setting up a UK online shed, please mail Patrick Abrahams at admin@menssheds.org.uk who will initially link up interested people.

Info: <http://menssheds.org.uk> contact@menssheds.org.uk
07933 954061 (Anne Oxley, Director of Services)

living with me

Independent living aids at Argos

Argos now stock 250+ gadgets to help with your health, leisure, mobility, communications and home needs. You can buy online or in your local store.

<http://www.argos.co.uk/independent-living>

Problem-Solving Toolkit

This guidebook from Cerebra aims to support disabled people and carers, as well as their families and advisers, who are encountering difficulties with the statutory agencies in relation to the provision of health, social care and education support services.

This toolkit aims to unpick these problems and to develop effective strategies for resolving issues such as:

- Inter-agency disputes
- No such word as “can’t”
- The budget is spent
- The panel/manager says “no”
- Too difficult to think about
- Delay
- “I don’t have authority to”
- Personalities
- Highly contested fact dispute

Download the Toolkit: <http://tinyurl.com/gkpmkdp>

Cerebra, 2nd Floor Offices, The Lyric Buildings, King Street
Carmarthen, SA31 1BD enquiries@cerebra.org.uk 01267 244200



Disabled access day

was on 12th March, sponsored by by Euan's Guide, the listing and review site that helps disabled people and their friends and families know which venues are truly accessible. Sign up for news of future events.

<http://www.disabledaccessday.com/home/>

Plan a trip with the help of the reviews of accessible venues across the UK.

<https://www.euansguide.com>

Applying for a job – when to reveal your illness / disability

According to the UK government website an employer isn't normally allowed to ask you questions about your health or disability before they offer you a job.

They can only ask you about this for very limited reasons, for example to:

- make 'reasonable adjustments' – e.g. if you need a large print version of a test or application form
- decide if you can do something that is an essential part of the job

Things to consider:

- Not declaring a disability in an application can lead to problems in the future if there is an employment tribunal. An employer cannot be expected to make reasonable adjustments if they do not know that you have a disability.
- The revelation of a disability at the interview can lead to the interview being all about your disability and not about your abilities.
- If you don't declare, how do you explain gaps in your CV? (You also miss the opportunity to explain how amazing you are to have achieved so much in spite of your 'challenges'.
- Disclosing after an offer has been made could avoid discrimination and it would be too late for the employer to withdraw.

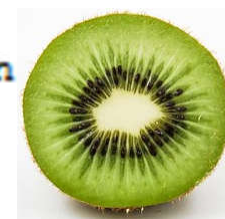
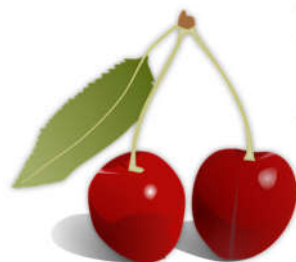
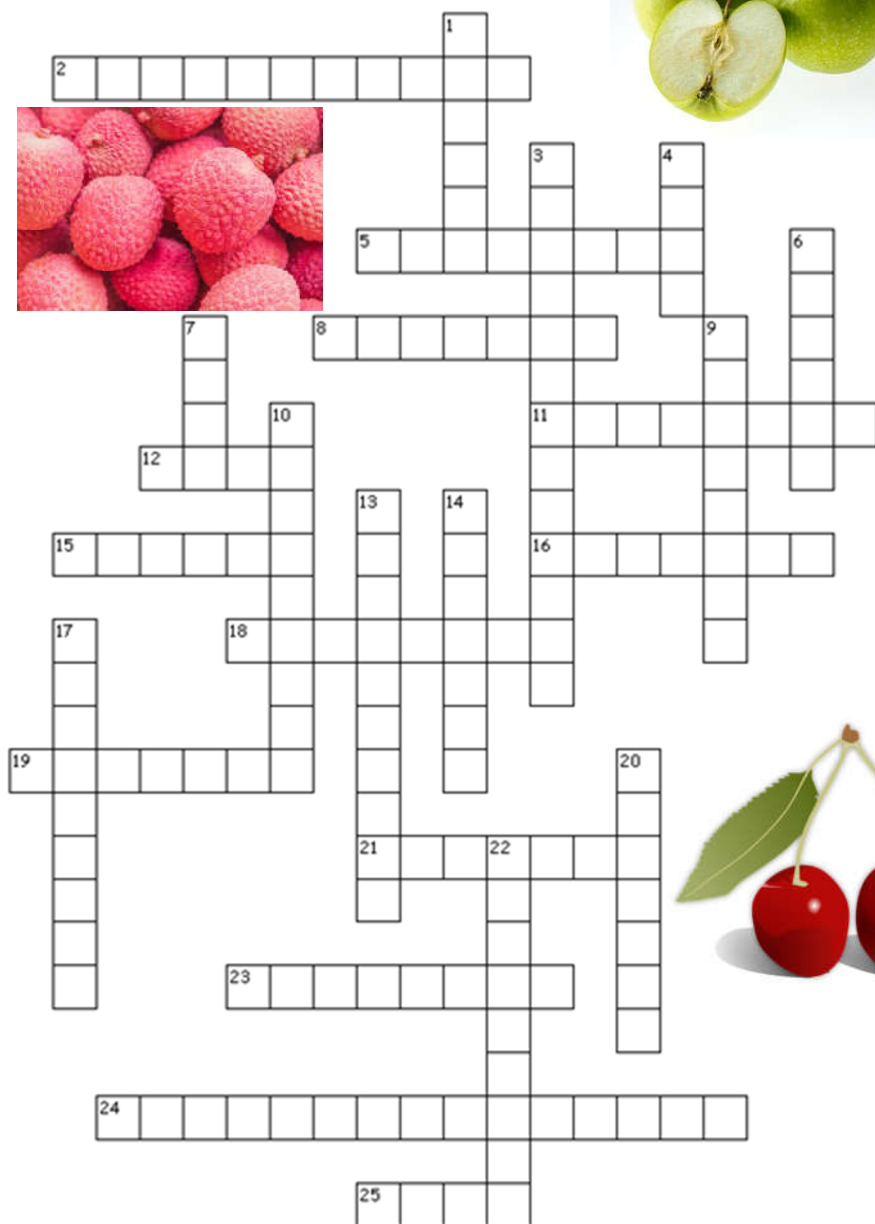


FreeDigitalPhotos.net/Ambro

Contact the Equality Advisory Support Service if you think you've been treated unfairly. <https://www.gov.uk/equality-advisory-support-service>
0808 800 0082

FREEPOST Equality Advisory Support Service FPN4431

Super Foods



Across

2. You ring these, seasoning for food
5. What a fun guy
8. Popeye's favourite food
11. Popeye's girlfriend
12. Piscivores eat these
15. A seed like a grain and used in place of rice
16. Legumes normally soaked before cooking
18. In the UK we eat this vegetable pickled
19. Bolts partner and what keeps your roof up
21. Make these into Jack o Lanterns
23. Fruits mistakenly called a vegetable
24. Hated Christmas vegetable
25. Green leafy vegetable like a cabbage

Down

1. Fruits used to make wine with
3. Cocoabeen, opposite of light
4. A starchy tuber famous in Caribbean cooking
6. Keep the vampires at bay with this
7. Nickname for our antipodean neighbours
9. Fruits used to make brandy
10. Superfood from the mint family
13. Small round fruit with ribbed skin
14. One of the healthiest nuts known
17. Green woody and with a tip
20. Yellowish red tropical fruits
22. Ham and ? make up an Hawaiin pizza

Crossword answers on page 15

U21

u21@wames.org.uk

'Tired but wired' – how do *you* cope?

One of the sensations people with ME experience is that feeling of being physically tired but mentally wired. Our minds seem restless and over active and we can't turn them off.

This can happen after we have done too much or have been exposed to bright lights, sounds, smells etc. (often called sensory overload).

There is no guaranteed way of dealing with this, though some find antihistamines (for allergies), aspirin or ibuprofen can help.

Can't relax? Get repetitive!

A drug free way suggested by many is to take up a repetitive activity which helps them to switch off and fits in with their pacing plan.

Crafting

Research studies have found that complex crafting is good for mental health and relaxation

Knit one. *Purl one*. Knit one. *Purl one*. Knit one. *Purl one*. The rhythmic and repetitive nature of knitting is calming, comforting and contemplative. It's not a stretch for you to imagine knitting as a mindfulness practice, or perhaps a form of meditation.

Neuroscientists are studying other forms of creativity and finding that activities like cooking, drawing, cake decorating, photography, art, music and even doing crossword puzzles are beneficial, according to *Time magazine*.

The studies being done are all in the early stages, and remember that crafts are also activities, so have to be paced, just like everything else, but, the good news is that if you're looking for a way to reduce 'post-exertional' symptoms and improve your mental health, trying a creative activity might help.

Choose your craft

Card making

Impress your friends and relatives by making your own greetings cards.

<http://tinyurl.com/hdkgs4r>

Painting & colouring

If you don't feel like drawing pictures from scratch you can buy or download pages to colour-in on a wide range of themes. e.g.

<http://www.activityvillage.co.uk/colouring-pages>

<http://www.coloringpagesforadult.com>



No paper and paint handy? Paint virtual pictures.

<https://kids.tate.org.uk/games/paint/>



Modelling

Air clay, plasticine and playdough are all fairly easy to make or purchase and can be relaxing to roll and mould.

<http://handsonaswegrow.com/pretend-create-learn-with-play-dough/>

Picture beads

Create 'pictures' in any shape you wish with a peg board and beads

<http://www.hobbycraft.co.uk/kids/kids-craft-activities/picture-beads>

Friendship bracelets

Bracelets can be made from all sorts of materials e.g. wool; embroidery thread; tubing; zippers; plastic bottles; loom or rubber bands; nylon cord.



You Tube videos: <http://tinyurl.com/ze4sycq>

<http://tinyurl.com/zjr9qsu>

U21

And don't forget the old favourites:
Knitting crocheting embroidery
cross stitch

The Craft Club website has
worksheets on:
finger knitting origami knitted chain
paper lace twining etc.
<http://www.craftscouncil.org.uk/what-we-do/craft-club>

Blogs
Crafting with ME <http://tinyurl.com/h7h4h9m>

Make ME crafts <http://ldifme.org/teams/make-me-crafts/>

Some people with ME join with others and sell their crafts to make money for ME research. <http://www.makemecrafts.com/sellers.php>

BBC Bite Size

is a fantastic online resource designed to help students in & out of school. You can also download an App for Android and iOS.

Articles, video clips, flash cards and quizzes give easy-to-manage, bite-sized chunks of information to help you study what you want, when you want, from Key Stage 1 through to TGAU.

<http://www.bbc.co.uk/education>



Picture beads

Chronic fatigue is common in teenagers

Researchers in south west England looked at the experiences of 5,756 teenagers. They found that chronic disabling fatigue, lasting more than 6 months, affected 1.9% of 16-year-olds.

Almost 3% had fatigue lasting 3 months.

Girls are almost twice as likely to suffer as boys. This was not the case for younger teenagers. Fatigue was equally common in 13 year old boys and girls, though fewer kids were affected - 1.3%.

These results are based on responses to questionnaires sent to both the teenagers and their parents. No doctor checked to see if they had ME or CFS, and people with depression were included.

Does this mean that ME or CFS is common? The researchers and the media think so, but until they study only people with a confirmed diagnosis of ME, perhaps we should take these findings with a pinch of salt!

More info on the *wames blog*: <http://tinyurl.com/hl5qdba>

Confucius says Cryptogram

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
16			8			9												17		23					

S

U S

A

11 26 2 10

21 19

21 17

22 3 24 21 22 23 17

19 26 16 19

19 26 2

G

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A

A

D

D

9 22 16 1 17

15 16 10 10 22 19

3 2

20 2 16 15 26 2 8

8 22 10

19

A D

U S

G

A

S

A D

U S

16 8 7 23 17 19

19 26 2

9 22 16 1 17

16 8 7 23 17 19

19 26 2

A

S

S

16 15 19 21 22 10

17 19 2 4 17

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

The saying is
"When it is obvious that the goals cannot be reached, don't adjust the goals, adjust the action steps."