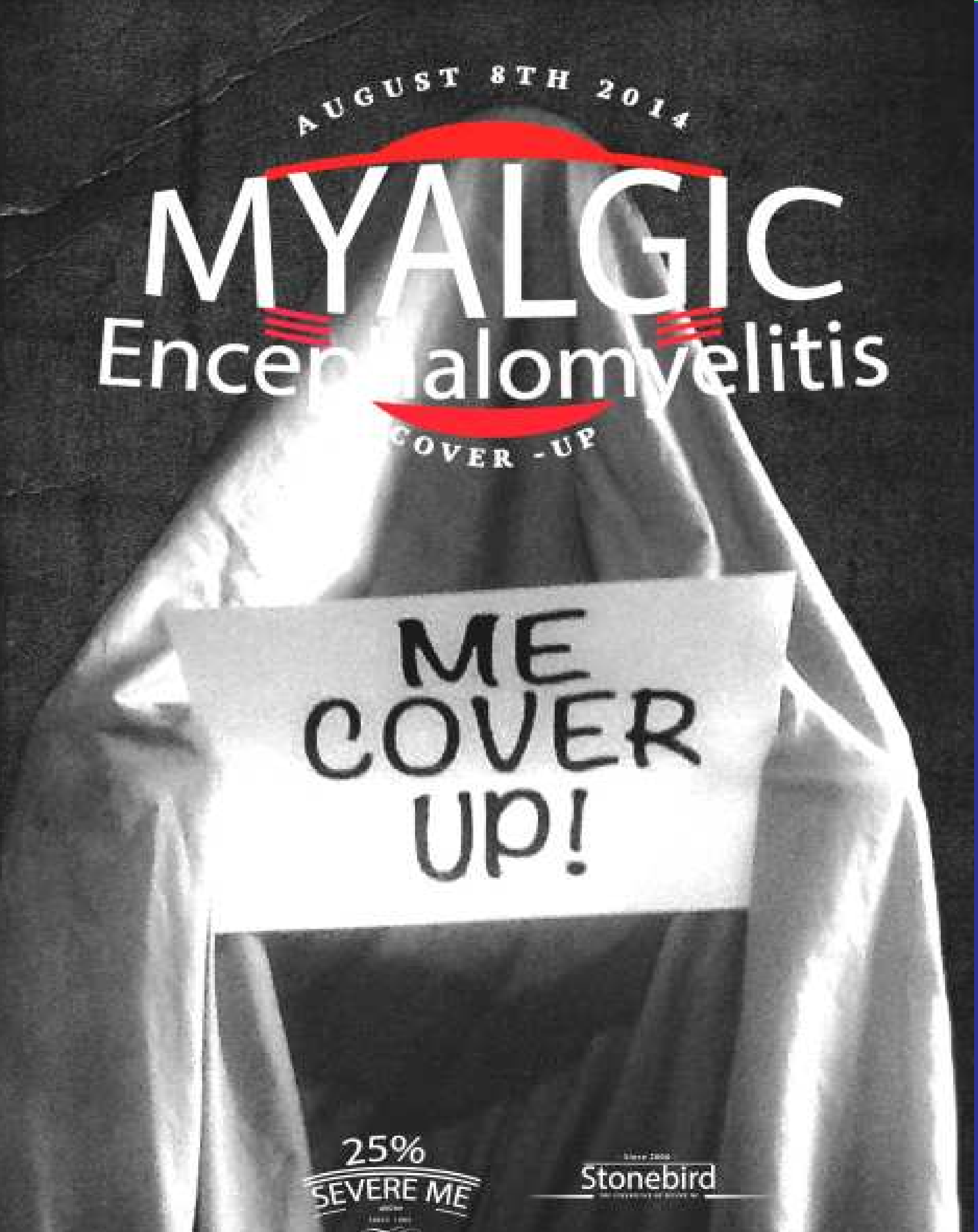


July 2014, no. 8

me voice

The WAMES Magazine

WAMES
Welsh Association of ME and CFS Support

contents

me voice

***me voice* is published 5 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 our website www.wames.org.uk**

Contact tony@wames.org.uk

WAMES Subscriptions
The Coach House Frongôg
Aberystwyth SY23 3HN

the wames information exchange

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

- **newsblog on website**
- **magazine**
- **facebook**
- **twitter**
- **e-group**

We welcome news items, articles, cartoons, jokes, poems, suggestions etc.We will include them whenever it is appropriate. Send them to: admin@wames.org.uk or to the WAMES Subscriptions address in the previous column.

making the web links in *me voice* work in your browser

These should work in Internet Explorer, Google Chrome, Opera, and Torch.

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

privacy

If you are concerned about your privacy on the Internet, use either the *DuckDuckGo* or the *Ixquick* search engines, and the *Aviator* Browser. Check them out on the Internet.

internet addresses

Because some of these addresses are so large nowadays, Tiny URL is used where possible to reduce them in size. Should these not work and you need the original address, please contact Jan or Tony.

copy dates for the magazine:

24 Sept. & 15 Nov. 2014

about wames

WAMES secretary

This post is still vacant and is limiting the amount of work we can carry out. Also, in order to remain a registered charity we will have to find a replacement trustee soon.

Interested, but worried the job might be too much for you?

Perhaps you can only offer to help for a limited period of time?

Get in touch and we can discuss ways in which the work can be shared out between more than one volunteer to make it manageable for you.

Please help by telling friends and family about WAMES' need for admin help, which could also be a great opportunity for someone to learn new skills. Contact Jan.

Sharon's sponsored walk

Sharon Price raised an amazing £640 in May for WAMES funds.

She endured blustery conditions to complete the 5.54km walk round Dinas Head in Pembrokeshire. Fortunately she suffered no major after effects

Thanks to her and her boyfriend Gareth for his support.

WAMES poll on Pacing

Have you tried 'Pacing' – has it helped?
Let us know at www.wames.org.uk

Keep up to date

We regularly post news items and research reports on our web blog. Events and local news are posted on Facebook and twitter.

Share your concern and questions on FB with others living in Wales.

WAMES on the Web:
www.wames.org.uk
Twitter: @WAMESsmecfs
Facebook: /WAMESsmecfs

Easy fundraising

In the past 4 months 4 people have been raising money for WAMES simply by adding a couple of extra clicks to their online shop.

One volunteer on a low income has raised £12 by always going shopping through http://www.easyfundraising.org.uk .

2,700+ retailers will give a donation (of varying amounts) if you sign up to easyfundraising before shopping with them. You can even earn donations when you travel, buy insurance or open finance and utilities accounts.

Think how much money we could raise every year if even a small proportion of the 12,000 people with ME in Wales and their families and friends were to shop the easyfundraising way!

Llanfairpwllgwyngyllgogerychwyrndrobwyllllantysiliogogoch

On a beautiful summer's day, two English tourists were driving through Wales.

At Llanfair P.G. they stopped for lunch and one of the tourists asked the waitress, "Before we order, I wonder if you could settle an argument for us. Can you pronounce where we are, very, very, very slowly?"

The girl leaned over and said, "Burrr . gurrr . king."

news from wales

ME Group events round Wales

Carmarthenshire ME Group
Meets on 9 August and 11 October at Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James [pm] for further details.

North Ceredigion Yoga Class tailored for people with ME
Meets on Wednesdays, 2.30-4pm, at Canolfan y Morlan, Aberystwyth. For details contact Cathy Crick on 01570 421144 or 07748 031614 or cathycrick@hotmail.co.uk

ME Support in Glamorgan (MESiG)
Tea in Roath Park 4th Aug: 2pm. Meetings 1st Sep, 6th Oct at Llanishen Community Shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

Contact Christalla 0292976 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

West Wales ME/FM Group
Meetings on 28th Jul, 25th Aug, 22 Sept. 11am to 1pm at 65 Tudor Gardens, Merlin’s Bridge, Haverfordwest, Pembs SA61 1LB. Transport can be arranged from the bus or train stations. Parking is avialble. Contact Tina, tretuil@talktalk.net or 01437 454359.

Haverfordwest Carers meetings
on 30th July, 27th Aug, 24th Sept. Open to all Parent Carers, not just ME, and all ages of ‘child’. 11am - 1pm and again 7-9pm as many carers work. Contact Tina, tretuil@talktalk.net or 01437 454359.

Other support

Wrexham – First get together for people with ME for tea/coffee and a chat. 7th August 2014 at 2.30pm at the Riverside Restaurant at Wrexham Maelor Hospital.

Haverfordwest – Cwtch: a support group for young adults aged 18 - 45 years old who have long term or chronic physical health conditions. (One of the organisers has ME).

They meet the first Friday of the month during school term time for talks and social activities. 10 -11.30 at Furzy Park Community Centre, SA61 1HQ.

Next meeting 6th Sep. www.cwtch-pembrokeshire.co.uk Beth 07974 543874 cwtch@live.co.uk

Ode to ME

Anglesey musician Andy Beaumont has written an ode to ME sufferers and their carers, which tells what it feels like to have ME. Andy’s wife, Kate has severe ME and has been ill for 18 years.

The song “Ball with no bounce” can be downloaded following a donation to Andy’s JustGiving page https://www.justgiving.com/ball-with-no-bounce/ All proceeds will go to the ME Association’s research fund.

Take responsibility for your own health says Health Minister

Speaking at the NHS Confederation’s conference in Liverpool, Prof Drakeford called on people in Wales to take more responsibility for their own health, instead of merely handing over ownership of their problems to the health service to deal with.

While it is the role of the Welsh Government to create the right conditions for people to live healthier lives, members of the public must take advantage of this and fulfil their “duty” to look after themselves, becoming “custodians” of their own health.

“The NHS is free from charge but not free from obligation The conversation we have with patients cannot always open with the question ‘What can I do for you?’ as though the encounter is one in which the health service takes onto its own shoulders the whole of the responsibility for that encounter.”

More info: http://tiny.cc/iayjjx
http://tinycc/q63jjx

Mid Wales Health Study

Residents in north and east Montgomeryshire are invited to take an online survey giving your last experience of seeking health care. http://midwaleshealthstudy.org.uk/take-the-survey

The survey will inform the Welsh Institute for Health and Social Care (WIHSC) in their report to the Health Minister of the Welsh Government. Ends 31 July 2014.

Or call in and pick up a questionnaire in Welshpool at either:
The Tourist Information Office
The Market Halls
The Town Council Offices
The Library, Brook Street

More info:
http://midwaleshealthstudy.org.uk

Report cases of hate crime!

A Hate Incident or Hate Crime is a crime or incident committed because of who you are or who someone thinks you are, because of your age, disability, sexuality, religion, ethnicity, gender (including gender identity) or lifestyle choice.

This may include:
- Verbal abuse
- Offensive graffiti
- Threatening behaviour
- Damage to property
- Assault
- Cyber bullying
- Abusive texts, emails or phone calls
- Taking money from you.

Hate incidents and hate crimes are under-reported. The problem needs to be understood so that the right decisions can be made to stop YOU or a member of YOUR family and friends from becoming the next victim.

Victim Support and the Police are working to support victims, protect and prevent further cases.

- If you are in immediate danger call the Police by dialling 999 (non-emergencies 101).
- You can report a hate crime to Victim Support directly. Support can be arranged at the same time if desired. 08456 121 900 Available 24/7
- If it is easier for you, you can complete the form online at www.reporthate.victimsupport.org.uk
- You can report an incident that happened to someone else, whether or not you witnessed it.

Calls are treated confidentially and you have the option to remain anonymous.

Support is tailored to the needs of each victim which may include emotional support, practical support or advocacy. Assistance in reporting a crime to the Police and in attending court is also available, but there is no pressure to do this.

Victim Support is the independent charity for victims and witnesses of crime in England and Wales.

Healthy home grant Swansea

To help support older people have a Healthy Home. Types of work include:
Internal and external handrails and grab rails, steps, ramps, key safes, locks, security lights and much more! This is for one year only.

More info: 01792 798599
enquiries@swanseacareandrepair.co.uk

news from wales

Recycle your old living aids

The Wheelie Good Idea uses old and unwanted independent living aids and mobility equipment which are collected, refurbished and exported to Africa.

This project is run by Clynfyw in Pembrokeshire and is funded by their community apple juicing initiative. If you have any kit that needs a good home and live in SW Wales, please let them know.

If you have trees and would like the apples juiced, or if you like to drink good quality apple juice, get in touch with them.

Clynfyw, Abercych, Boncath
Pembs SA37 0HF
01239 841236 or 07980 290522
info@clynfyw.com

Clynfyw runs holiday accommodation with disabled access, an organic farm and orchard and courses in Pembrokeshire. http://www.clynfyw.co.uk/wheelie.htm

Good health event Dolgellau

17th of October at the Leisure Centre. An event for everybody!

Drop in at any time between 10 am and 2 pm.

- 40+ organisations to give Advice and Information.
- get your blood pressure taken
- Local Pharmacy on hand to give advice
- Complementary therapies
- Taster sessions
- Memory & Friendship Café
- Light Refreshments
- Entertainment

If you could man a display / stall about ME for WAMES please contact Jan.

ME & CFS Task & Finish Group

WAMES attended the last meeting of this government organised group in May. Work on the report has finished and we are waiting for the Health Minister to announce what steps he expects Health Boards to take to improve services for people with ME and CFS.

Always remember that you are absolutely unique. Just like everyone else.

research

It’s the inside that matters

The DIY Futures storytelling project in Powys recorded people’s stories of mental distress. The hard copy of this moving and beautifully presented book It’s the inside that matters is available in all Powys libraries and is available for purchase in hard copy or can be viewed as an e-book online.

Find out more, read articles and watch videos at http://tinyurl.com/qx9sjny

Alternative diagnoses for ME and CFS

Post-traumatic hypopituitarism (PTHP) http://tiny.cc/obojjx

CFS brain

Brain neuron damage level in CFS is similar to MS http://tiny.cc/wcojjx

Effects of exercise

A review of research found good evidence for altered immune response to exercise in CFS/ME - many of these immune changes relate to post-exertional malaise in CFS, a major characteristic of the illness.
http://tiny.cc/wcojjx

Malformed blood cells

Novel flower shaped blood cells were found in one patient with CFS in the US http://tiny.cc/wcojjx

Bio tissue and blood bank protocol

Following a review of existing tissue banks a protocol for the UK has been compiled. The facility would be most efficient and cost-effective if incorporated into an existing tissue bank. Tissue collection would be rapid and follow robust protocols to ensure preservation sufficient for a wide range of research uses. A central tissue bank would have resources both for wide-scale donor recruitment and rapid response to donor death for prompt harvesting and processing of tissue. http://tiny.cc/0mojjx

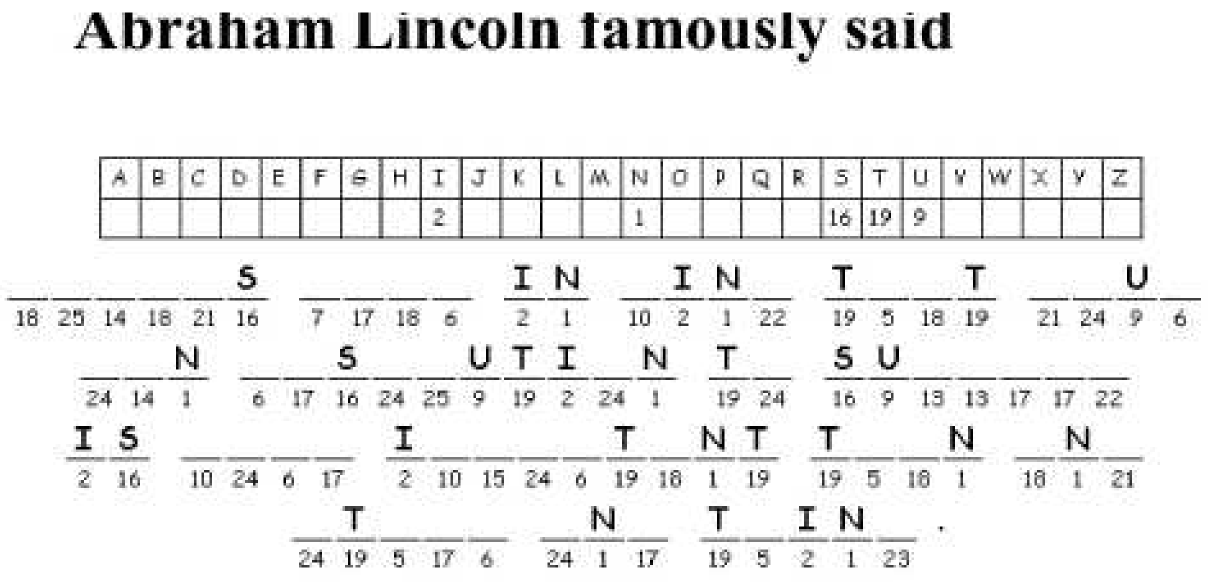
Cognitive impairment

approximately 50% of people showed impairment in attention and motor functioning, and nearly 40% showed impairment in speed information processing and executive functioning. Fatigue predicted attention and executive functioning impairment, and emotional factors predicted verbal memory dysfunction. Cognitive dysfunction in CFS could be explained by pathophysiological processes of the disease http://tiny.cc/xnojjx

Brain inflammation

Magazine Scientific American highlights brain inflammation studies especially Watanabe’s discovery of distinct increases in inflammation in particular regions of CFS patients’ brains. http://tiny.cc/uoojjx

Keep up to date with more research on page 19 and on the WAMES website news blog.



Abraham Lincoln famously said

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Answer on page 15.
Created by *Puzzlemaker* at DiscoveryEducation.com

Em's blog & WCA

Em has ME and talks about her experience of the WCA (Work Capability Assessment). http://emwithme.blogspot.co.uk/2014/04/wca-debacle.html

http://emwithme.blogspot.co.uk/2014/06/wcatake-2.html

Info for Tribunal chairs

ME is listed in the Equal Treatment Bench Book which contains guidance on Equality & Diversity issues for the judiciary, this includes Tribunal Chairs. It may be useful for people with ME to highlight this information with the members of a tribunal in case they are unfamiliar with it.

The ME entry can be found on Page 28 of the disability glossary – the *Equal Treatment Bench Book - Physical disability,* November 2013 It talks about the symptoms, the toll of travel and the possible need for rests during the tribunal. http://tinyurl.com/pnv62de

More about the Book can be found on the UK government Courts and tribunals website.

http://www.judiciary.gov.uk/publications/equal-treatment-bench-book/

5th review of WCA

The Department for Work and Pensions (DWP) has appointed Dr Paul Litchfield to carry out the fifth and final Independent Review of the Work Capability Assessment (WCA).

The completed report will go to Parliament before the end of 2014.

On the .Gov website, it is clearly pointed out that: "..the Secretary of State is not required to accept any or all of the recommendations, and any recommendations may be subject to further assessment by DWP."

Many may feel that the consultation exercise will have little impact on any changes to the WCA, as previous recommendations have made little difference to the personal experiences of claimants.

The call for evidence begins on 10 June 2014 and runs until 15 August 2014.
More info https://www.gov.uk/government/consultations/work-capability-assessment-year-5-call-for-evidence

Give your comments online http://survey.dwp.gov.uk/index.php?sid=73893&lang=en

Review of PIP

Paul Gray CB has been appointed to conduct the first review of PIP (Personal Independence Payment)

The Independent Reviewer is interested in hearing from both organisations and individuals who have information about how the PIP assessment is operating. Paul Gray is keen to take a broad look at the overall PIP process, so he is seeking input about all stages of the claimant journey. Evidence is particularly invited from those with first hand experience of PIP. Closing date 5 Sep.

The report to will go to Parliament before the end of 2014.

More info:
http://tinyurl.com/qdlgww6
pip.independentreview@dwp.gsi.gov.uk
PIP Independent Review Team,
Room 3S25, Zone South H, Quarry House, Leeds, LS2 7UA
020 7449 7536

Half GPs charge for medical evidence

Half of GP surgeries are charging sick and disabled benefit claimants who request medical evidence to support a benefit appeal, a survey by the Citizens Advice Bureau (CAB) has found.

The CAB say that this demonstrates the 'obstacles' people face when appealing against Employment and Support Allowance (ESA) 'fit for work' decisions, as well as the financial difficulties experienced by sick and disabled benefit claimants in accessing their medical records.

According to the results of the survey, 50% of GP surgeries said that they charged benefit claimants for medical evidence and 61% of those said they asked their patients to pay between £10 and £50.

Shockingly, 5% said that they asked patients to pay between £50 and £100, while 2% charged even more.

26% of GP surgeries who asked benefit claimants to pay for medical evidence admitted that they only asked 'some patients'.

14% of GP surgeries surveyed by the CAB said that they only provide medical evidence to 'some' groups of patients, while 15% admitted that they turn down ALL requests from sick and disabled benefit claimants for medical evidence.

Among the reasons given for refusing to provide medical evidence for ESA appeals were ‘a lack of time and that they did not feel it was their job to do so’.

More info http://www.citizensadvice.org.uk/results_of_gp_survey_14_may.pdf

Mandatory reconsideration

Mandatory reconsideration (MR) is when people’s employment and support allowance (ESA) benefits are cut while DWP give a second opinion on their claim.

When this new stage called was introduced DWP said it should take on average two weeks, but Citizens Advice regularly see people waiting 6 weeks without a decision, and without payment of ESA. Some CAB advisors have reported not seeing a single client getting their MR back in two weeks.

During this period people are meant to be able to claim job seekers allowance (JSA) but CAB are seeing many who are finding this impossible.

Citizens Advice policy recommendation:
Continue to pay people ESA at the assessment rate during the mandatory reconsideration phase. This would prevent unnecessary hardship and allow DWP the time to get additional evidence they need. It would also save £162 in administration costs for every claimant who claims Jobseekers Allowance (JSA) and goes onto appeal.

Briefing: http://www.citizensadvice.org.uk/mandatory_reconsideration_brief_final.pdf

Over 10,000 people have signed the CAB’s petition supporting this proposal.

Petition: hhttp://tinyurl.com/pr9rfs7

Mentally ill benefits to be cut?

Hundreds of thousands of benefit claimants face being stripped of their state allowances if they refuse to undergo treatment for anxiety and depression, under radical plans being drawn up by ministers.

Existing welfare rules mean it is not possible to require claimants to have treatment, such as therapy or counselling, as a condition of receiving sickness benefits.

Trials have begun in England looking at combining “talking therapies” with employment support. Four jobcentres are taking part.

Norman Lamb, the Lib Dem health minister, said mandating mental health treatment for benefit claimants would not work and was “*not a sensible idea... The idea that you frogmarch someone into therapy with the threat of a loss of benefits simply won’t work. It is not a question of whether tough love is a good concept. You actually need someone to go into therapy willingly.”*

More info:
http://tinyurl.com/mf6ks2d

A £650,000 funding boost to improve access to psychological therapies for people with mental health problems in Wales was announced by Health Minister Mark Drakeford in June. It will be shared by Health Boards (not Job Centres) to provide CBT, mindfulness etc.

http://wales.gov.uk/newsroom/healthandsocialcare/2014/140618psychological-therapies/?la

A Polish immigrant went to apply for a driving licence. First, he had to take an eyesight test.

The optician showed him a card with the letters ‘C Z W I X N O S T A C Z.’

‘Can you read this?’ the optician asked. ‘Read it?’ the Polish man replied, ‘I know him!’

When you’re right, no one remembers. When you’re wrong, no one forgets.

If you receive an email from the Dept of Health telling you not to eat tinned pork because of swine flu – ignore it.

It’s just spam

Social enterprises – businesses with a difference

Are you looking for a job that fits in with your ME?

Want to do something that helps others e.g. people with ME or your local community?

Why not set up a social enterprise!

What is a social enterprise?

a private business with a social conscience

A social enterprise (SE) is a business with social objectives. The left-over profits are reinvested for that purpose in the business or the community, instead of raising profit for shareholders and owners.

An SE competes in the marketplace like other businesses, using business skills to achieve social aims. Like other businesses, a social enterprise aims to sustain the business and make profits. The difference is what is done with the profits.

1. Do you want to start your business with a number of other people?
2. Is the business going to reinvest the profit into the business or for the good of the community?
3. Do you want the business and assets to be owned by all of the people involved in the business, (the members)?
4. If you end the business will you give the assets to a business/ organisation that does similar work to yours?
5. If the answer is yes to the above questions then it is highly likely that you will want to set up a social enterprise.

Examples of social enterprises

There are a wide range: cafés, laundrettes, crèche/nursery facilities, activity and adventure holidays, bookshops, training providers, community centres, complementary health centres, art and craft shops, galleries and garden centres to name but a few.
Some well-known examples include:

- **The Big Issue** – a magazine aiming to give homeless people a chance to earn an income, and use the content of the magazine for campaigning http://www.bigissue.org.uk/
- **Eden Project** – supports environmental conservation projects locally and overseas and runs training programmes on sustainability http://www.edenproject.com/
- **Fifteen** – Jamie Oliver’s restaurant chain which employs young people on an apprenticeship programme, giving them a chance to learn new skills and gain an experience of working in the competitive restaurant industry. http://www.fifteen.net/
- **Cafédirect** – gives a fair price to small coffee and tea growers and reinvests in sustainable communities http://www.cafedirect.co.uk/

See some Welsh examples at http://supportsocialenterprise.org.uk/casestudies/

Getting started

1. Decide what difference you want to make and who you want to help.
2. How can you achieve this – you need a project that will be self sustaining.
3. Find advice and support from people who care and understand.
4. Choose a legal structure for your business (charity, social firm, cooperative etc) and learn about the admin and financial requirements.
5. Work out what money, equipment etc you will need over the short, medium and long term.
6. Always remember your core objectives and keep them at the centre of the project.

Finding funding

Setting up any type of business requires money. If you don’t have a healthy bank balance of your own you will need to consider:

- Grant – there are a number of grants to help people (sometimes specifically young people) get started in business or develop projects which will benefit the community or the environment.
- Loan - there are schemes which lend to social businesses but the money must be paid back.

young people

- Crowdfunding – where a number of different people and organisations contribute money for a cause they believe in.

Attracting money requires a well thought out business plan and the ability to market it effectively.

Sources of help
You can start a SE at any age but a useful introduction is *How to Understand Social Enterprise for Young People*

http://tinyurl.com/qjv29vk

The Wales Cooperative centre offers free help and business advice to social enterprises and co-operatives in Wales. http://www.walescooperative.org/how-we-can-help
0300 111 5050

A social enterprise won't make you rich, but it could provide you with an adequate income and a sense of having done something worthwhile!

Job, education or training?

Not sure what to do? Careers Wales provides information.

Careers Wales provides info about finding jobs and work experience, developing a career, courses and training.

0800 028 4844
The Careers Wales Connect helpline is open between 9am and 7pm Monday to Friday.
http://www.careerswales.com/

Local information centres can be found around Wales and are listed at http://www.careerswales.com/en/contact-us/our-centres/

Skills Cymru

Is holding events in October which will have hands on activities, demonstrations and exhibitions.

The events will motivate you to try out new skills, discover your hidden talents and explore future work, learning, skills and careers. By visiting an event you'll have a great start to your career exploration, helping you make the right decisions based on impartial information.
The events are free for Individuals and families.

8-9 Oct. Venue Cymru, The Promenade, Llandudno, LL30 1BB

22-23 Oct Motorpoint Arena, Mary Ann Street, Cardiff, CF10 2EQ

More info: 01823 362800
visit@skillscymru.co.uk
http://www.skillscymru.co.uk/

Need a grant for your project?

In each county in Wales, Youth Volunteering Advisors have supported the set up of Local Youth Led Grant Panel's. These are groups of young people from the local area who are allocated up to £5,000 to distribute through grants to local youth led volunteering activities.

Every area is led by the ideas and needs of young people and the panels themselves decide on the criteria for the grants, the priority groups and the application process but they are all aimed to develop youth volunteering and seek applications from projects lead by young people themselves

Previous successful applications secured funds to: create a community garden, hold a fund-raising event to raise money for a village hall; open up a footpath for local people and making it accessible for people with mobility disabilities; run a peer-led first aid course; train young volunteers. The applications have to be written by young people.

Talk to Jan if you wish WAMES to support your application for funding for your project.

Good practice guide to education

Tymes Trust has published a guide to education for children with ME aimed at schools, families and GPs.

GP Dr Nigel Hunt writes: 'Children and families have rights to suitable education, but without medical backing they have difficulty in convincing schools that serious modifications to education are necessary to protect their health and recovery, and to comply with education law. We know of many tragic and severe relapses due to the misguided drive to put children with ME into classrooms before they are well enough.'

Order a set of three printed copies for £3.85 including post and packing. Send a cheque to Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE or pay online:

http://www.tymestrust.org/donations.htm
or download from the website :
http://www.tymestrust.org/pdfs/gpguidev2.pdf

Hormone imbalance

Hypocortisolism has been found in the past in adults with ME but new research has now confirmed that it is also present in adolescents.

Cortisol is a major hormone which:
- increases the amount of energy (glucose) when stressed
- regulates the immune system
- reduces inflammation

Hypocortisolism or low levels of cortisol are not just found in ME and CFS, but also in conditions like Fibromyalgia, post traumatic stress syndrome (PTSD), asthma and allergies. The reason for it is unclear. Some have suggested that it is a key cause of the problems in the body. Others have suggested that it builds up the longer patients are ill or that it is a way for the body to protect itself from more serious problems. It is uncertain whether prolonged low cortisol levels could be serious.

In this study researchers from the Netherlands measured the levels of cortisol in 108 young people with 'CFS' and 38 healthy people. The CFS patients had significantly lower levels than the others and levels were related to the amount of sleep people received.

The participants were then put through a computer based psychological treatment programme (CBT or Cognitive Behavioural Therapy) called FITNET and measured 6 months later. Many had improved.

[**NB** Previous research found that improvements following the use of FITNET were not maintained at 2.5 years later, so these research findings cannot be used to recommend the programme. In one study of adults the levels of cortisol were raised by doses of hydrocortisone but the CFS remained]
http://www.sciencedirect.com/science/article/pii/S0306453014000420

What's on in Wales this summer?

CLIConline is an online channel offering information, news and advice for all young people aged 11 to 25 in Wales on a wide range of subjects and issues, including where to get support in your area.

The focal point of *CLIConline* is interactive websites which allow young people and the organisations that work with them to upload articles, pictures, videos and themes, and to publicise events and activities.
http://www.cliconline.co.uk/

Cartoon Characters

Answers on page 12. Created by *Puzzlemaker* at DiscoveryEducation.com

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

severe me

Severe ME/CFS - new clinical study

Around 10 to 25% of ME/CFS patients are reported to be housebound or bedbound, yet we still understand very little about the origin and outcome of their severe illness. We know, however, that severe illness predisposes patients to secondary medical conditions, and that the cumulative impact of severe illness over many years, where there is no sense of improvement, can be profound.

Because of all this, it is astonishing that the most basic clinical and experimental scientific work has not been carried out on this important subgroup of people with ME/CFS (discussed more fully in our essay, *Severely Overlooked by Science* http://www.meresearch.org.uk/information/publications/severely-overlooked-by-science/).

For many years, ME Research UK and Prof. Julia Newton and colleagues at Newcastle University have been concerned about the chronic lack of research interest into severe ME/CFS, and the serious void that exists in the scientific knowledge-base about this group of patients. So, as part of a Programme Grant ME Research UK awarded to the researchers in 2014, it was decided to initiate a specific project investigating housebound or bedbound individuals who are unable to attend clinics or take part in research projects (which often require hospital attendance and multiple visits).

This aim of this exploratory study is to raise the curtain on this severely overlooked group of patients, defining their clinical characteristics, gauging the level of unmet clinical need, and determining the relationship, if any, between autonomic nervous system dysfunction and other clinical variables.

Subsequent progress will depend on what these investigations uncover and where the science leads. The two-year project will be conducted day-to-day by the newly funded ME Research UK Research Associate, and further details are at http://www.meresearch.org.uk/our-research/ongoing-studies/severely-affected-me-patients/

Perversely dark - Norwegian film

Perversely Dark is Pål Winsents' ninth documentary film and his second thematic ME/CFS film uniquely exploring the lives of severely affected people with ME/CFS, a little known patient group and bringing their stories and voices into society's light.

His first ME/CFS themed film *Få Meg Frisk* (Heal Me!) featured partially functioning Anette Gilje, ME/CFS patient and former General Secretary of the Norwegian ME Association, through her desperate journey for treatment and proactive steps.

In *Perversely Dark* Pål Winsents ventures even further and captures the anguishing worse case stories of two full-time ME/CFS bed ridden patients and their families' struggles.

View the trailer http://www.syktmorkt.no/#!in-english/con6

Order the movie online :

- OnDemand See the movie online soon $50 US (c. £29)
- DVD for private use only - Shipped within 7 days $60 US (c. £35) & P&P $7 (c. £4)
- DVD public use - Shipped within 7 days. $117 (c. £68) & P&P $7 (c. £4) http://www.syktmorkt.no/#!kjp-filmen/c1g2c

Advice for carers

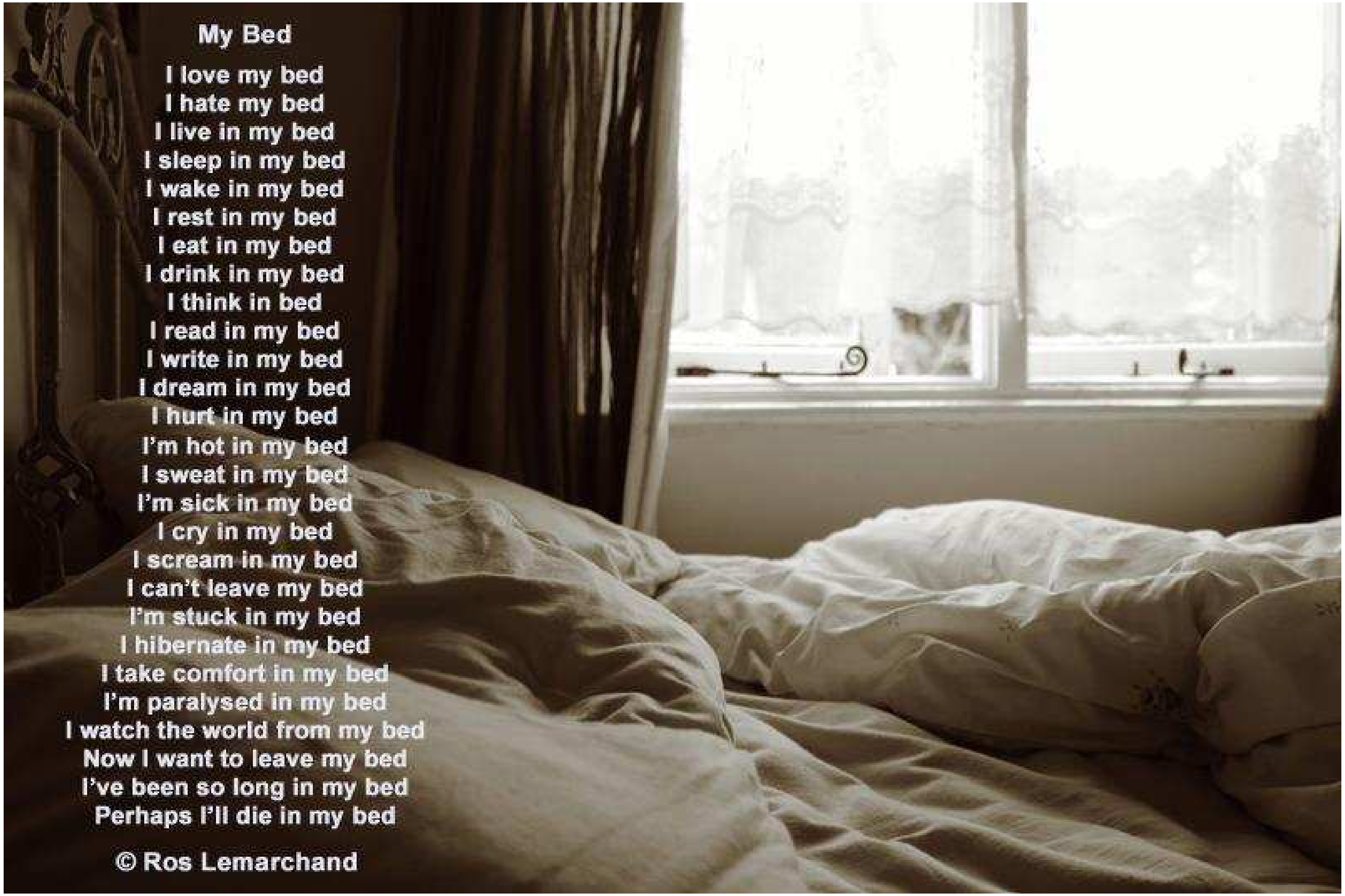
Supporting someone with severe ME: care sheets

This 9 page booklet looks at the symptoms experienced, the impact on the patient, how to approach and care for that person.

Contact WAMES helpline for a copy of the booklet or download from: http://www.stonebird.co.uk/Care%20Sheets.pdf

Answers to puzzle on page 11

ANDY PANDY
BART SIMPSON
BETTY BOOP
BILL and BEN
BUGS BUNNY
BUZZ LIGHTYEAR
CASPER
DAFFY DUCK
DIPSY
DONALD DUCK
FIREMAN SAM
FLORENCE
FOGHORN LEGHORN
GARFIELD
JESS
MILHOUSE
PATRICK
PINK PANTHER
PLUTO
POKEMON
PONGO
POPEYE
PORKY PIG
RHUBARB
SCOOBY DOO
SPONGEBOB
TOM and JERRY
TOPCAT
TWIZZLE
WALLACE and GROMIT
WILEE-COYOTE



My Bed

I love my bed
I hate my bed
I live in my bed
I sleep in my bed
I wake in my bed
I rest in my bed
I eat in my bed
I drink in my bed
I think in bed
I read in my bed
I write in my bed
I dream in my bed
I hurt in my bed
I'm hot in my bed
I sweat in my bed
I'm sick in my bed
I cry in my bed
I scream in my bed
I can't leave my bed
I'm stuck in my bed
I hibernate in my bed
I take comfort in my bed
I'm paralysed in my bed
I watch the world from my bed
Now I want to leave my bed
I've been so long in my bed
Perhaps I'll die in my bed

© Ros Lemarchand

This poem is from Ros LeMarchand's book of 50 poems: My A-Z of ME **Photo by Julia Cottam**
(NB book is not illustrated)

More info: http://mecuperate.co.uk/my-a-z-of-me-by-ros-lemarchand/

Available to buy as Kindle book in aid of Invest in ME http://www.amazon.co.uk/My-A-Z-M-E-Myalgic-Encephalomyelitis-ebook/dp/B00EYXX1NW

ME Cover Up!

Severe ME Awareness Day, 8th August. The theme for 2014 is ME Cover up!

The website will include photos of people with ME 'covered up' to raise awareness of the cover up of our serious neurological disease.

The 25% ME group and Stonebird want to create a powerful visual impact to shock and shame and show for August 8th, Severe Myalgic Encephalomyelitis Day!

More info: Poster at
www.wames.org.uk
http://www.stonebird.co.uk/

http://25megroup.org/campaigning_Severe_ME_Day.html

25% ME Group,
21 Church Street,Troon,
Ayrshire KA10 6HT
01292 318611

Office Hours 9.30 to 5pm - Monday to Friday

enquiry@25megroup.org

carers

Public ignorance of the role of carers

The Carers Week poll published in June found that adults of all ages drastically underestimate the issue, with only a tiny fraction (8%) of Welsh adults correctly stating the true scale of unpaid, family care. In reality 370,000 in Wales are already caring for a family member or close friend who is frail or facing long-term illness or disability.

Only a quarter of adults in Wales who are currently not carers (25%) believe it likely they will become carers in the future, the survey found. From previous research we know that over a third of carers will start caring every year and over a third will cease which would equate to 123,000 new carers in Wales each year.

The survey also asked what would be of greatest concern if a loved one did come to need care.

Wales' Top 3 Caring Worries are revealed as:

- Money worries - Being unable to cope financially
- Emotional strain - Finding it too stressful/upsetting
- I wouldn't know how - Not having the experience or skills to be a carer

The views of current carers gathered through the same poll, reveal carers across the country are struggling behind closed doors without adequate help. Worryingly, over half (53%) of carers polled across the UK said they were not receiving enough support. http://tiny.cc/lsojjx

> "*The reality is that all of us, at some point in our lives, will either be carers or need the help of carers. This survey is a wake-up call, clearly and alarmingly showing that as a society we need a much wider understanding of the realities of caring.*"
>
> **Keith Bowen**, Director of Carers Wales

Carers virtual strike

On 21 June carers were invited to go on virtual strike by signing a petition which asked for:

- Carers Allowance for all live-in carers, irrespective of age or employment, just as DLA/PIP is given to those we care for.
- A state-funded occupational pension scheme for each fulltime carer to reflect what we might expect to have if we were working, say, only an 80 hours a week at minimum wage.
- Solid practical careers advice and training for working-age carers to help us train for and sustain appropriate work within our environment and to provide us with the luxury of a working life should our caring duties finish
- Social housing to recognise the requirements of disability and caring in the allocation of rooms. Sufficient appropriate accommodation purpose-built for the disabilities of the local population – because if it is not provided this is a huge stress on carers.
- State money ONLY given to organisations that offer properly targeted transport-accessible fit-for-purpose help for every carer who needs it.

The petition collected 988 signatures out of a potential 6.5 million carers in the UK (probably as the result of poor advertising). More information http://www.caretostrike.co.uk/

Social Care Jargon Buster

The Care and Support Jargon Buster is a plain English guide to the most commonly used social care words and phrases and what they mean. The definitions were developed and tested by a steering group that included people who use services, carers, representatives from local authorities, information providers and key stakeholders from across the social care sector.

Use the database online http://tiny.cc/vxojjx or download the booklet from the Think Local Act personal website http://tiny.cc/pyojjx

Example from Jargon Buster
Carer - a person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or disabled and could not manage without this help. This is distinct from a care worker, who is paid to support people.

Helpline for Older People

The Silver Line is a new free confidential helpline providing information, friendship and advice to older people.

It is open 24 hours a day every day of the year. ww.thesilverline.org.uk

Writing competition about caring

Carers UK creative writing competition invites entries from both experienced writers and first timers.

Theme: family, friends and caring
Open to everyone, the competition is a great opportunity to raise awareness about caring.

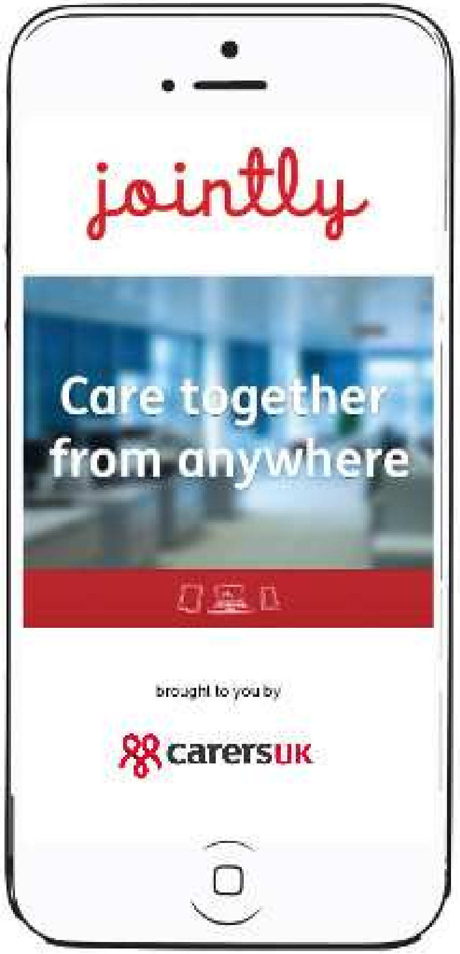
The winning entries will be published on the Carers UK website in the autumn and maybe in an e-book.

How to take part

1. Submit up to three poems, each being no longer than 40 lines and/or one short story, of up to 1,000 words. Entries must be unpublished, in English, and not a translation of another author's work.

> **Award-winning poet Cheryl Moskowitz is judging the competition.**
>
> *"The role of carer can be all consuming. Could it be that carers put all their creative energy into their caring role leaving the world bereft of the poems and stories they might have to tell? It is time to change all that. Get writing!"*

2. Email your entry as a Word document attachment to writingcomp@carersuk.org Your covering email should contain your name, email address, phone number, postcode, the titles of entry and the category you are entering.



Alternatively post your entry to:
Creative Writing Competition
Carers UK 20 Great Dover Street
London SE1 4LX

Please remember to put your contact details, category and poem titles on a separate page.

Closing date: Friday 1 August 2014
More info:
writingcomp@carersuk.org
https://www.carersuk.org/how-you-can-help/writing-competition

Jointly – an app for carers

Jointly is an innovative mobile and online app from CarersUK.

It is for:

- People who share the care with others
- People who juggle work and care
- People with smartphones, tablets or access to the internet
- Organisations who employ them or deliver services to them

Key features:

- Communicate with everyone in your Jointly circle by posting a message or uploading an image.
- Keep organised by using tasks and task lists. Simply create a task and assign it to any member of your Jointly circle, including yourself, and monitor its status.
- Create date/time specific events and invite people.
- Store useful information about the person you are looking after and have it available to access any time at a click of a button.
- Keep track of current and past medication of the person you are caring for.
- Store useful contact details

It is available to download as a mobile app from Apple and Google Play stores. Available online at www.jointlyapp.com

Be job smart

From 30 June 2014, all employees have the legal right to request flexible working - not just parents and carers. For more information visit the UK Government website: https://www.gov.uk/flexible-working

Crossroads Care Cardiff

closed on 11 June 2014. Crossroads Care Cardiff and the associated Cardiff Carers Centre has closed. Crossroads Care in the Vale is separate and still provides services.

Answer to puzzle page 6

Always bear in mind that your own resolution to succeed is more important than any other one thing

living with me

Eternally grateful – a story of healing

After 23 years of battling ME, along with Fibromyalgia and multiple chemical sensitivities, I am now completely better.

It all started following the birth of my daughter when I caught Glandular Fever. Prior to this I was a very active person. Into sport, keep fit, dance and running a business.

I was 5 years undiagnosed, until I collapsed one day from the constant pushing through the pain etc. The doctors kept telling me I was stressed or depressed, which was far from true. I ended up concluding the illness was in my head. The more symptoms I developed the more I threw myself into work etc. to forget but the worse I became until the point of collapse.

If you are in the early stages of ME please hear this warning, do not push through, take away all stress and pressure, physical, emotional, spiritual. Give your body a chance to recover. Give it good, healthy food, rest, deal with the rubbish.

I had a marriage break up, so ended up a single parent with 2 small children. I was reliant on carers. Consequently I now have 2 capable and independent grown up children and a wonderful husband by my side who saw me through thick and thin.

The ME fluctuated quite drastically. Twice I was near death. In the year 2000, I ended up in Harold Wood hospital in Essex. They set up more care at home and adaptations which made my life much easier.

The last two years of ME my life was slipping away. I kept fainting on any exertion, I had become reactive to all chemicals and food. My digestion had shut down through exhaustion and consequently lost a lot of weight. My heart was struggling, I would turn blue and the medics were called out regularly through the nights.

My son was having anxiety and panic issues through the worry, and my now husband was on the verge of a breakdown from being on call day and night with no sleep. No one could or would help us. Drs, social services etc all closed ranks.

A friend lent me a book called ‘the grace outpouring’ by Roy Godwin about a place called ‘Ffald y Brenin’. This book changed my life. It filled me with hope and possibilities. The book is full of real life stories of people being healed from all sorts. Ffald y Brenin is a Christian retreat. My journey with ME led me to God. It was a gradual journey after searching in lots of places for answers. I kept finding Christians on my path. My only experience in this area was being dragged to Greek church for Christmas and Easter, where I didn’t understand a word. When I read the book, I wanted to go straight there but I let practicalities get in the way. Then as things went from bad to worse, I knew I had to go there.

My other half put me in the car and took me there. He had been praying over me night after night as didn’t know what else to do. The healing started in the car, I put on a CD and a song called ‘The River’ came on. I started to cry but wasn’t crying. It was like something had completely taken over and all I could do was surrender. When I got there, there were about 100 people gathered. I sat down and my heart started to over run. This would normally escalate until I lost consciousness. I sat there wondering what I had done, when my thoughts were interrupted by Roy saying that ‘somebody here today, has been crying out to God for healing. The word is for you, it has been done’. All the life threatening reactions stopped instantly, my heart slowed back down. This had not happened before. At that point I knew the words were for me. I got through the whole day there, which was a worship day, they hold once a month. This was impossible for me to do at the time as I couldn’t even sit in a chair due to extreme weakness and loss of balance and pain.

I slept that night and woke full of joy and energy, the tight band in my head was gone, fog gone, pain gone, weakness gone. I put on my trainers and went walking in the fields. I can’t even begin to explain what that felt like. The green was so green and the blue so blue. I was singing and dancing with the joy.

My other half, who was also my carer, was asleep downstairs. He came up to get my breakfast, saw I was missing and thought the medics had come in the night and taken me to hospital. This was a regular occurrence at that time. I came bounding through the door, to his relief.

It took the family a while to adjust and believe what had happened. It was so extreme, going from totally incapacitated to mobile and able. I couldn't even have got myself to the toilet before the miracle happened. They kept expecting the relapse that so often happened after any improvement. This didn't and hasn't happened.

For a week after Ffald y Brenin, I had like a fluttering in my heart area, I believe my heart was being physically healed. It took a year of training to build up my muscles and each month another symptom would leave me. The final thing was the reaction to foods. I can now eat anything.

You might read this and think that I didn't have ME in the first place, I want to reassure you that I did. I was diagnosed by professionals in ME as grade 4 severe ME. I also had a test done in Breakspear hospital which proved all the abnormalities that were present in my body.

I also want to clarify that ME is an illness with a physical cause. It is a neurological condition. It is a real illness as documented by the World Health Organisation. The only explanation is that Jesus is alive and still in the business of healing. That's why He died on the cross. By His stripes I am healed. For which I am eternally grateful.

Christalla Bailey, Cardiff

Can God help ME?

Another story of Christian healing, which explores the spiritual dimensions of having ME, as well as the physical and emotional dimensions is *Can God help ME?* Author Liz Babbs also discusses general questions of suffering and healing.

Liz is a 'creative communicator' who writes meditation and worship materials and is a professional speaker and performer. You can buy or download her publications from her website: http://www.lizbabbs.com/ though some can also be bought on Amazon or ordered from major booksellers.

Can God Help ME?: Breaking through the darkness of ME and Chronic Fatigue Syndrome Author: Liz Babbs Publisher: Eagle ISBN-10: 0863472621 £9.99 +P&P or £8.27 Amazon

Tell people about ME

Give them this book! At last there is a book we can give people which will explain what it is like to have ME that is easy to read!

The book describes a fictional family where Molly, the mother, has ME. It gives us her perspective and also that of her husband and children, on the impact ME has on their lives. In a few simple chapters, it conveys everything we need our friends and loved ones to know and understand. The book is also short (64 pages), snappy, jargon-free, uses light-hearted graphics and is even child-friendly so the whole family will have no difficulty reading it.

The author has had ME for 20 years and has also written some Quick Reads (see next news item).

The book is one of a series of simple introductions to a wide range of medical conditions.

Can I Tell You about ME/Chronic Fatigue Syndrome? A Guide for Friends, Family and Professionals

Author: Jacqueline Rayner Illustrator: Jason Lythgoe-Hay: Publisher: Jessica Kingsley Pub (21 Feb 2014) ISBN-10: 1849054525 Paperback £6.41 - £8.99 Kindle £4.63

It is available most cheaply from Amazon http://tiny.cc/c0mjjx but can also be ordered from major bookstores for a few £s more.

Quick reads

Quick reads are short books that are specifically designed to be easy to read and are mostly written by big name authors such as Ian Rankin, Alexander McCall Smith, Archer, Barbara Taylor Bradford and James Paterson.

They are sold through major retailers, online booksellers and are loaned from libraries. (Jacqueline Rayner's Quick Reads are Dr Who stories.) Prices vary but on Amazon prices start at £1 per paperback or £0.20 for a Kindle version http://www.quickreads.org.uk/

news

Videos about ME

Prof Julia Newtown joins Dr Charles Shepherd and many other experts on the Dutch ME group Youtube site. She talks about muscles, blood flow and neurocognitive problems. http://tiny.cc/icnjjx (look down the list of links)

Prof Anthony Komaroff gives a 45 minute lecture on the Biology of CFS to fellow medics at Stanford School of Medicine, USA. http://tiny.cc/76mjjx

Research conference Sep 2014

The UK CFS/M.E. Research Collaborative (CMRC) is holding its first annual science conference in Bristol on Mon 1 and Tues 2 Sep 2014.
The conference aims to stimulate research collaboration and is being supported by the Medical Research Council (MRC). There will be a free session for anyone with an interest in ME/CFS, including patients and carers on the 1st (2-6.30pm), to encourage cooperation between researchers and the wider M.E. community.

Read an interview with Prof Stephen Holgate, chair of the CMRC about the importance of the conference and book your place:

- at http://tiny.cc/2anjjx
- through Action for ME
- or ring 0117 927 9551

Prof Ian Lipkin

3 Sep, London. Prof Lipkin will speak about his work on infection and ME/CFS in a seminar in London at the offices of Allen & Overy, at One Bishops Square, London E1 6AD from 10am-12pm Cost is £5 and includes refreshments at 9.30 (tea, coffee, biscuits - incl. dairy/ gluten-free - and fruit).

Book place at seminar:

- https://www.surveymonkey.com/s/lipkinseminar
- Debit/credit card payment (can be taken over the phone by Matt Parker, Finance Officer, Action for M.E.). Tel: 0117 937 6632
- Cheque - send to Prof Lipkin Seminar, Action for M.E., 42 Temple Street, Keynsham BS31 1EH

More about Ian Lipkin:

- http://cfinitiative.org/lead-researchers/w.-ian-lipkin/
- http://tiny.cc/qenjjx
- http://tiny.cc/gfnjjx

IACFS/ME primer new edition

The International Association for CFS/ME (IACFS/ME) has produced a revised version of their primer for clinical practitioners. It can be downloaded from their website or ordered from the US with a cheque for $20. http://iacfsme.org/Home/Primer/tabid/509/Default.aspx

Interview with author Maria Mann

This is available on the Squidoo website. Maria is the author of the popular *Verity Red's Diary: A story of surviving M.E.* and Love & best witches. Both books deal with living life as an ME sufferer, but with magic, fantasy and humour. They can be bought from Amazon or major bookshops.
http://tiny.cc/zgnjjx
Maria's website:
http://www.inter-netti.co.uk/

Is CFS a meme?

A meme is a dysfunctional culturally-transmitted idea-infection, first coined by Richard Dawkins in his book The selfish gene.

Dr Peter White caused a stir in 2004 by suggesting CFS was a meme and the discussion been re-awakened by Drs Antony Collings and Brian Newton in the BMJ (British Medical Journal) online. Letters for and against the idea have been posted at http://tiny.cc/ninjjx .

NICE admits failings of CFS/ME guideline

On June 25th 2014 the Forward ME Group met with Prof Mark Baker, Director of the Centre for Clinical Practice at the National Institute for Health and Clinical Excellence (NICE).

The minutes report that talking about the guideline” the Professor said that it did not meet our needs and it did not meet theirs (NICE's) either… It did serve a purpose because it was the only bit of guidance in the NHS on ME/CFS, but it was limited in its scope. It was designed to get patients seen and helped, but it assumed there were specialists who knew what to do – and there were not.

In summary, Prof Baker said:

- He sympathised with the position we were in.
- The Guideline failed to address the real issues in ME/CFS
- It does not promote innovation
- It had a disappointing impact on specialist care and commissioning issues.”

Read the minutes at
http://tinyurl.com/nlmumd7
Comment by ME Association:
http://tinyurl.com/kn7nf2o

Orthostatic intolerance

This year a number of researchers have published findings from studies of a type of orthostatic intolerance called Postural Orthostatic Tachycardia Syndrome or PoTS.

According to Wikipedia Orthostatic intolerance (OI) is the development of symptoms when standing upright which are relieved when sitting back down again. Symptoms include light headedness, low blood pressure, dizziness, fatigue, high heart rates etc.

Many people with ME find standing harder than walking and have an overwhelming desire to lie down even if they don't feel tired. Some have also been diagnosed with OI.

OI can be diagnosed with a Tilt Table test (where the patient lies flat on a special table or bed and then is monitored with ECG and a blood presure monitor while the table moves from lying to standing) but one study found that most of the ME/CFS patients that seemed to 'pass' their tilt table tests still experienced worsening symptoms during one. For some people symptoms are the key i.e. if standing immediately brings on dizziness, heart pounding, fatigue, difficulty concentrating and more.

Treatment involves lifestyle changes, diet and drugs aimed at controlling blood vessel width.

Some of the recent research:

1. **Prof Julia Newton** and colleagues from Newcastle University believes that about 80,000 of the 250,000 ME suffers may have the condition. "I would think that around one third of people with chronic fatigue syndrome, if they were properly tested, would have PoTS," she said.

"PoTS is an abnormal response of the nervous system, but it is a spectrum, so some people will feel dizzy on standing, while others will actually black out. It affects the part of the nervous system which is outside our control."

Although doctors are unclear as to what causes the problem, Prof Newton believes it may be caused by a viral infection or hormonal changes. She found that people with PoTS were predominantly young, well-educated and female and that some patients never recover. http://tiny.cc/bxnjjx

2. **Australian researchers** found that 11% of younger adults with ME also had PoTS. It also suggested that heart rate variability was an important marker of fatigue for CFS patients in general.
http://www.ncbi.nlm.nih.gov/pubmed/24206536

3. **Patients with PoTS** reached significantly higher scores in sleep questionnaires, which means that they were more sleepy and had a lower sleep quality. PoTS patients had higher levels of daytime sleepiness and showed a higher proportion of stage 2 sleep than people with sleep disturbances.
http://journal.frontiersin.org/Journal/10.3389/fneur.2014.00118/pdf

4. **Blood flow** - is reduced to the brain following reduced nitrergic nitric oxide http://ajpheart.physiology.org/content/early/2014/05/27/ajpheart.00194.2014 and increased when closely coupled to oscillatory CBFv
http://tiny.cc/o2njjx

5. **One group of American researchers** believe that adolescents could experience full recovery from CFS/POT with multi-faceted treatment. The daily treatment plan should consist of increased fluid and salt intake, aerobic exercise, and regular sleep and meal schedules; some medications can be helpful. Psychological support is critical and often includes bio-behavioural strategies and cognitive-behavioural therapy to help with symptom management.
http://www.ncbi.nlm.nih.gov/pubmed/24819031

6. **American research** published in Feb 2014 believes that the presence of certain agonistic autoantibodies confirmed that POTS is an autoimmune condition.
http://jaha.ahajournals.org/content/3/1/e000755.full

7. **Leonard Jason** and colleagues in the US reviewed research on the cognitive problems in CFS and POTS and concluded they interfered with daily life. They looked at the theories surrounding the cause and concluded more research was needed http://tiny.cc/y4njjx

8. **Blogger Martha Gill** speculated that people diagnosed with POTs would get more sympathy than people with ME because it was more treatable. http://tiny.cc/i8njjx

More info:

Nursing times comment
http://tiny.cc/k9njjx
Phoenix rising article
http://tiny.cc/taojjx
Health rising – search for articles related to POTS

ME Groups

WAMES would be pleased to hear from anyone who runs a small group, no matter how informal, or from anyone who would like assistance in setting up local meetings

Anglesey & Gwynedd Fibromyalgia / ME Group
Contact: Rhian Medi (secretary)
01248 722184
fmsmemonagwy@yahoo.com

Brecon area contact
Richard Jones
richardj5@virginmedia.com
01874 622310

Carmarthenshire ME Group
Meets Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James pm 01267 233793 for further details.

Clwyd ME group
clwydme@googlemail.com
01745 822953
www.clwydme.net
Contact Adrian Jenkins
adrianj15@hotmail.co.uk

ME Support in Glamorgan (MESiG)
Monthly meetings are held on the first Monday of the month, 11am - 12.30pm at The Community Shop, Llangranog Road, Llanishen, Cardiff CF14 5BL
Contact: Christalla Bailey, 029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group
Please telephone Mike or Karen on 0796 9665419 (between 2-4pm only please) or email karen@kandm46.plus.com for more information and the date of the next get-together.

Pembrokeshire Get togethers at 65, Tudor Gardens, Merlin's Bridge, Haverfordwest SA 61 1LB. Tina, 01437 454359, tretiul@talktalk.net

Live near the border? An English group may meet closer to you:

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www.shropshiremegroup.org.uk
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Chester
www.chestermesh.org.uk
Joan Crawford 01244 370988

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