



me voice

the wames magazine
may 2017, no.18

WAMES
Welsh Association of ME & CFS Support

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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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'Fishermen, Swansea'



me support



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

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

Brecon Area Contact

Richard Jones 01874 622310
richard.j5@btinternet.com

Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months.
Next Meetings: 10 June; 12 Aug; 14 Oct; 2 Dec

Contact: John James (pm) 01267 233793

Cwtch, Haverfordwest

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

Contact: Beth 07974 543874
www.cwtch-pembrokeshire.co.uk
cwtch@live.co.uk

ME Support in Glamorgan (MESiG)

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

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

Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

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

Neuro-Café Brecon

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

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

Ystradgynlais Neuro Café

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

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

headwaysouthpowys@hotmail.com
<https://www.facebook.com/HeadwaySouthPowysNeuroCafe/> 01792 529615

Live near the border?

An English group may meet closer to you:

Shropshire

www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester

www.chestermesh.org.uk
Joan Crawford 01244 370988

Ross on Wye

Gill Suttle 01600 890730
mesupport@gillsuttle.co.uk

For other support groups in the UK:

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

Disclaimer:

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

me voice

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publisher: Dr Tony Thompson

admin@wames.org.uk

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wames news

me voice

2016 was such a busy year for WAMES that, combined with a fluctuation in health, we only managed to produce 2 issues of *me voice*.

It has also been a busy start to 2017 so we are pleased to have found time to send out a May issue, even if it is shorter than usual. We would have liked you to receive information in time for ME Awareness week, but as everybody with ME knows, we have to accept that we can only do the things we can, not those we wish!

If you would like to get involved with any aspect of the magazine – articles, poems, news gathering, photos, layout, printing etc., please get in touch with any member of the Team. You don't need to be an expert, just willing to learn.

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

WAMES activities 2017, so far...

Grant applications

Our number one priority has been to ensure we have enough money to continue our work of campaigning, supporting and informing about ME over the next few years.

Completing grant applications is very time consuming as they usually require the preparation of supporting documents. Our grant application last year was unsuccessful. We have now submitted a bid for funding for a part-time project worker to help us tackle the workload. We won't hear whether we are successful until August, so

we are also preparing a number of other applications.

Competition for grants is fierce so we are taking advice on how to make our applications stand out from the crowd.

More about money on p6.

The search for volunteers

Our number 2 priority is to attract more volunteers to join us in taking advantage of all the many opportunities for campaigning and awareness.

We have been developing a plan to recruit, train and support volunteers with a wide range of abilities and knowledge about ME. Adverts have been placed with Volunteer websites and bureaux.

We are pleased to welcome a new volunteer who is keen to raise funds and contribute to communication and awareness activities.

Consultations

As usual we have been able to contribute the ME person's perspective in a number of consultations, some of which have required attending meetings. Topics covered include education, transport, health & social care.

Support for our Medical Advisor Dr Nigel Speight

We were very happy to provide a testimonial for Dr Speight in March, as the General Medical Council (GMC) continues to investigate complaints against him. We have always found Dr Speight professional, considerate and willing to provide diagnosis and advice based on biomedical

research and what is best for the child, so we hope the GMC clears him soon.

Awareness week

During Awareness week this year we launched a challenge to NHS Wales to provide training for health professionals, to help them understand ME and support patients and carers more effectively. We are inviting all Welsh residents to join through social media. **Read more** about the campaign on p8.



Wales Pharmacy review

An article by WAMES chair Jan Russell was published in the journal for pharmacists in Wales, highlighting the latest research into treatments for ME-CFS. We are hoping this will help to raise the profile of neurological ME in NHS Wales. Download a copy and pass it on.

A miracle drug for ME-CFS? by Jan Russell in *Welsh Pharmacy Review* issue 32, 2017, pp30-32 [published April 2017]

<http://waleshealthcare.com/miracle-drug-cfs/>

My Son's #1 Concern

When my three-year-old was told to pee in a cup at the doctor's office, he unexpectedly got nervous. With a shaking voice, he asked, "Do I have to drink it?"

wames news

WAMES signed open letter to retract PACE

WAMES joined 51 other organisations and 92 professionals from around the world in calling for the journal Psychological Medicine to retract the misleading findings that participants in the PACE trial for ME/CFS had “recovered” from cognitive behaviour therapy and graded exercise therapy. Prof David Tuller, An American public health lecturer organised the letter and enlisted the support of top names in ME research as well as practitioners and professionals from outside the ME community. <https://tinyurl.com/mtbkjxa>

NHS Services Task & Finish Report Implementation

WAMES continues to be involved in the All Wales Implementation Group (AWIG), attending meetings and providing information for the group and the Cabinet Secretary for Health. The Group met in Cardiff 3 times last year and once in 2017 so far.

We have also been busy working on pathways and other documents for the Hywel Dda ME-CFS ME-CFS Planning & Delivery Group, which meets in various locations around Carmarthen-shire and Ceredigion. *More information on p7.*

AGM

The WAMES AGM was held on April 6th.

The committee was re-elected:

Chair: Jan Russell
Secretary: Kishli Laister-Scott
Treasurer: Liz Chandler
Youth & Care Officer: Sylvia Penny
Young People's Contact: Michelle Penny
Website & Publicity: Tony Thompson

2016 Finances

Opening balance:	£2019.56
Income:	£946.61
Expenditure :	£1805.88
End of year balance	£1160.29
Draft Budget for 2017	£3155

Because of our low income in 2015 we economised on many activities in 2016 but if we want to maintain and develop our activities in 2017 we will need to attract much more funding. Our accounts have been ‘externally examined’ (at a cost of £100) so we can prove good financial management to prospective funders.

WAMES supports proposal to classify ME as neurological

WAMES has submitted our comment on proposals for the revision of the World Health Organisation's International Classification of Diseases (ICD).

The proposals recommend:

- that the terms should be retained in the neurological chapter (*Chapter 08: Diseases of the nervous system*);
- that the terms should be retained under the parent class: *Other disorders of the nervous system*;
- that ME and CFS should each be assigned separate codes;
- that PVFS is not an appropriate title term for ME to sit under (*not all cases of ME are preceded by a virus*);
- reciprocal exclusions for “*Bodily distress disorder*” and for general *Fatigue*;
- that the designation “*Benign*” should be dropped for ICD-11.

WAMES supports the proposal for the ICD-11 revision submitted by Chapman and Dimmock on 27th March 2017.

See the proposals at <https://tinyurl.com/kyq65zi>

See the full response from WAMES at <https://tinyurl.com/ktpk9k4>

Other support:

- 549 individuals or organisations have agreed with the proposal
- over 380 comments have been submitted
- 53 organisations from around the world have responded

More information:

<https://dxrevisionwatch.com/icd-11/>

#patientsneedprotection support proposal for ICD-11

Twitter @dxrevisionwatch

Answers to the hairstyle crossword on page 7:

Across:
2. Conk
5. Rattail
6. Fauxhawk
7. Pageboy
11. Ringlets
12. Mullet
13. Queue
14. Undercut

Down
1. Mohawk
3. Wings
4. Plaits
7. Princeton
8. Beehive
9. Bangs
10. Waves

wames money

WAMES Money matters – boring but essential!

Almost everything we do costs money!

Volunteers' generosity

WAMES is active in Wales because volunteers share their time for no payment and share their household resources (phones, computers etc.). They donate small sums of money and fundraise among their friends and acquaintances. We are very grateful for their generosity. With their help we can continue to 'tick over'.



A BIG THANKYOU to Team Shareth

In December Sharon Price and Gareth Williams, aka Team Shareth, took on the challenge of doing a Sponsored Swim of 5 miles between them in aid of WAMES.

On the 30th January Sharon and Gareth completed their swim and with the help of many sponsors raised over £500.

However volunteers also *cost* money. Insurance costs nearly £300 a year. Training is often essential, costing £10-50 a session, plus transport costs. Volunteers might need a more 'up to date' computer than the one they own. Phone calls, stationery, broadband etc. cost extra. Transporting a display to a conference or contributing the ME point of view at a focus group requires travel, often expensive in rural Wales.

WAMES would like to be in a position to involve people as Volunteers whatever their financial resources!

Grants

Grants can be an invaluable source of money. The Big Lottery paid for the WAMES website, publications, translation, display equipment and much more. But...applications are hard work to prepare. It can take 30 – 200 hours+ to prepare and/or update all the paperwork for an application!

Grants are only available for some activities. Projects with a start and finish date are the favourite. Few offer money for running costs and campaign costs. The money has to be used for the specified purpose within a specified time, and then we need to spend time justifying the way the money was spent, after the project has finished.

Success is not guaranteed because there are too many applications for the money available. WAMES is also competing against charities with healthy professional fundraisers!



Join



Shop



Raise

Collect **FREE** funds for us
any time you shop with  **easyfundraising**
feel good shopping

Sign up
now



We need *your* help to find more money

If you cannot donate money, you can still help in other ways.

- **Tell us** about the problems ME patients and carers face, and tell us how WAMES has helped you. We add anonymised quotes to applications because Funders like to see illustrations of why our cause or project is worth supporting.
- **Tell us** about any sources of money you come across or are involved in. e.g. organisations and companies, schools, professional associations often support an annual cause or project.
- **Ask** friends and family to put on an event or take part in a sponsored event. Contact us or check the website for ideas.
- **Share your expertise** with us if you have experience in financial, fundraising and project planning.
- **Ask** your local shop or centre to display a collection tin. Contact us for tins.
- **Raise money effortlessly** every time you shop with www.easyfundraising.org.uk/causes/wames/

wames money

WAMES Fundraising challenge – be a regular donor

We need income we can rely on long term – we need a sustainable income.

We wish to avoid taking time out from fundraising, updating the website, producing the magazine etc. *every year*, to look for money to cover costs that Funders don't offer grants for:

Running costs: 20% of WAMES expenditure

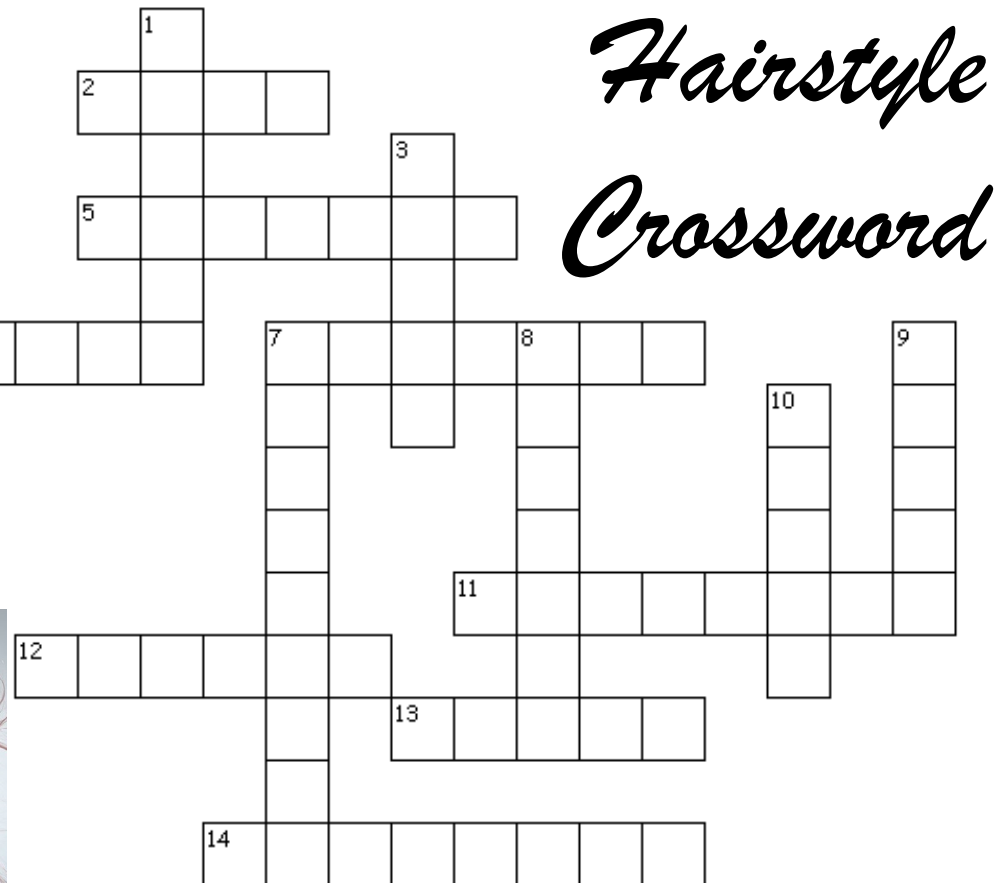
Campaign costs: 45% of WAMES expenditure

Could you become a regular donor?

- set up a Direct Debit with your bank – large or small



- organise an annual fundraising activity—donate a percentage of earnings from your hobby e.g. sale of cakes or fudge, greeting cards, plants, babysitting, tutoring.



Across

- 2 Slang for nose
5 This helps a rodent regulate its body temperature
6 A fake bird of prey
7 Male attendant at a wedding
11 A brown butterfly with wings bearing eyespots
12 Phrase – stunned
13 A line of people waiting to enter a venue
14 Offer to charge less for goods or services

Down

- 1 A member of an American Indian people
3 They enable you to fly
4 Can be a decorative edging made of lace etc
7 'Ivy League' university in New Jersey
8 A box like structure in which bees are kept
9 Loud noises
10 They break on the sea shore

Answers on page 5

wames news

WAMES asks NHS Wales to help staff become 'ME aware' #HelpNHSbeMEaware

On behalf of an estimated 13,000 people affected by ME-CFS in Wales WAMES is asking NHS Wales to commit to raising awareness of ME-CFS amongst its staff.

Patients tell us that while doctors and their colleagues recognise the name, many do not understand the key characteristic of Myalgic Encephalomyelitis – the post-exertional response. Nor is ME-CFS treated as a complex debilitating condition, like other neurological conditions, with appropriate care and long term support.

Government Report

In 2014 the Task & Finish Group Report on ME-CFS & FM made recommendations to Health Boards aimed at 'improving NHS services and patient experience'.

Recommendation 5:

Each Health Board should undertake work to raise awareness of ME/CFS and Fibromyalgia in primary care, to support timely diagnosis and effective management of both children and adults



So far this hasn't happened. In fact no Health Board has allocated any money for awareness and training, and few Health Boards have doctors with enough experience of the condition to run training courses. Outside help will be needed, even if that costs a little money. The benefits will far outweigh the cost. The development of effective services depends on patients getting an accurate diagnosis and on service planners understanding patients' complex needs.

All-Wales Implementation Group (AWIG)

This Group of Health Board and patient representatives meet in Cardiff 3 times a year to look for ways Health Boards can implement the T&FG Report's recommendations, without funding. During 2017 the Group are encouraging Health Boards to survey their GPs, to find out what resources they use and what help they need with diagnosing and treating ME. The need for training is being revealed.

The task now is to find a cost effective way to deliver training that is much more than opportunities to share questions and lack of knowledge!

WAMES challenges the Welsh Government and Health Boards to develop an awareness and training programme using experts e.g.:

- Patients' and carers' experiences of living with ME-CFS
- Webinars with CPD points for clinicians
- Research conferences with CPD points

- Online videos & clinical sources
- Masterclasses with visiting experts

Join us in issuing this challenge!

Although the challenge was launched in Awareness week, it won't end until something changes.

Do you wish NHS staff knew more about neurological ME?

Have you had a bad experience because your doctor, nurse, paediatrician etc. didn't know enough about ME?

Let your Health Board know in one of the following ways:

- Email Chief Executive and Executive lead for ME-CFS with the challenge and tell them about your experience. Include the link to the blog post and keep it short!
- Tweet the NHS staff you follow, with e.g.
 - ◇ *My GP (or nurse or paediatrician etc.) doesn't understand neurological ME & #postexertionalmalaise. Please provide training! #HelpNHSbeMEaware*
 - ◇ *Please give training about ME and #postexertionalmalaise to NHS staff #HelpNHSbeMEaware #BeMEaware*
- Write to the Chief Executive and Executive lead for ME-CFS at their HQ address

Add a # BeMEaware poster, available for download:
<https://tinyurl.com/k4x2bo2>
<https://tinyurl.com/mslInn73>

Addresses & links: <https://tinyurl.com/mq8bvp4>

More info: contact Jan, or Sylvia on the helpline

news from wales

Task & Finish Group Health Services improvement Implementation

All Wales Implementation Group

AWIG is making slow progress in encouraging health boards to implement the recommendations of the Task & Finish Group Report, which are aimed at improving health services for people with ME, CFS and FM.

More info: Task & Finish Group Report

<http://tinyurl.com/maksqsg>

Claire Hurlin from Hywel Dda UHB took over as chair in 2016 and there have been other changes in personnel representing Health Boards and in the civil servants representing the Cabinet Secretary for Health, Vaughan Gething AM.

The Group continues to meet 2-3 times a year. 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.

Hywel Dda University Health Board

(Ceredigion, Carmarthen, Pembrokeshire)

Executive lead: Jill Paterson, Director of Therapies & Health Sciences

Clinical Lead: To be confirmed

Support: Claire Hurlin, Chronic Conditions lead

Reports to: Health Strategy Group

Activities: Delivery & Planning group consisting of staff, patients and carers is developing a pathway and awareness strategy, GP survey.

Powys teaching Health Board - PtHB

(Montgomeryshire, Radnorshire, Brecknock)

Executive lead: David Murphy, Director of Therapies & Health Sciences

Clinical lead: Owen Hughes, Consultant psychologist & Head of Centre for Long Term Condition Management

Reports to: Neurology Steering Group

Activities: Action plan and pathway has been drawn up focusing on the clinic's services, but there has been no engagement with patients and carers about medical care for ME.

Abertawe Bro Morgannwg University Health Board - ABMUHB

(Swansea, Bridgend, Neath Port Talbot)

Executive lead: Hamish Laing, Medical Director

Clinical lead ME: Nick Brace, Psychologist, Chronic Pain Service

Reports to: Long Term Conditions Group

Activities: GP survey; draft pathway and service development; no patient engagement. Draft rehab service drawn up.

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 & GP survey. GP survey.

Cardiff & Vale University Health Board - CVUHB

Executive lead: Fiona Jenkins, Director of Therapies

Clinical lead: Dr Bethan Lloyd, 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; Engagement with patient group. Draft rehab service drawn up.

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: Evan Moore, Medical Director

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 the Implementation group, passing on relevant information about research, PACE trial, UK conferences etc. and continues to emphasise the need for patient engagement and staff awareness and training.

news from wales

Congratulations

The Carmarthenshire ME Support Group and Cwtch-Pembrokeshire support group received awards from the High Sheriff of Dyfed for service to the community at a reception in Carmarthen on 15 February 2017.

Western Telegraph, 21 Feb 2017: CWTCH Pembrokeshire's outstanding contribution recognised by Professor Medwin Hughes DL, High Sheriff of Dyfed. <https://tinyurl.com/mon2to3>



Carmarthen Journal, 25 February 2017: Shrievally Awards – Carmarthenshire ME support group (Left to right: Rob Messenger, John James, Prof Medwin Hughes – High Sheriff)

Every crisis holds not only its dangers but also its opportunities. *Martin Luther King*

God does not send us despair to kill us; he sends it to awaken new life in us.

Herman Hesse

Inquest into death of woman with ME in North Wales

The Daily Post reported on the inquest into the death of mother-of-four Sarah Ann Tyler from Wrexham, who killed herself in the hospital's emergency department in January 2016, where she had been on a trolley for about eight hours, having been admitted after taking an overdose of paracetamol.

Ms Tyler was found unconscious with a ligature made of an ECG cable around her neck in the early hours of February 9, 2015.

The hearing was told that she had been suffering from depression and severe ME (myalgic encephalomyelitis) which had left her bed-bound. In a statement read at the inquest her partner, who was father to her four children, said she was virtually unable to move and was upset at being unable to care for her children. He said she was convinced that the ME, not a mental health issue, was her main problem and she felt she was not receiving the specialist treatment for her condition.

The coroner recorded a conclusion of accidental death on Ms Tyler as he was not persuaded that she wanted to kill herself because she had taken the action in a place where she could expect to be found. He also believed steps had been taken to improve observation of vulnerable patients but he remained concerned about the severe problem of finding beds for patients, even though he did not believe it played a part in Ms Tyler's death.

<https://tinyurl.com/m7om7pk>

Art For Well Being

Art for Well Being workshops are aimed at individuals and carers who may be recovering or living with illness, either physical or psychological.



Location: Mid Wales Arts Centre, Maesmawr, Caersws, Newtown SY17 5SB

Cost: £25, booking essential

To find out future dates and to book: Pauline on 07531 713272 /

pauline@fordeassociates.co.uk

or info@midwalesarts.org.uk

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

Celf-Able

A new art group and network by and for disabled artists in Powys and across Wales.

<http://www.celf-able.org/> 01938 810058

<https://www.facebook.com/pg/celfable/>

May 30, The Institute, Llanfair Caereinion, 10-2

June 13, The Institute, Llanfair, 10-2.

news from wales



Storytelling for Health

This international conference will acknowledge and celebrate the importance and growth of storytelling for health and to understand and promote good practice and new research. It takes place over 3 days and includes lectures, storytelling, an exhibition, children's workshop and poetry session.

Thu, 15 Jun 2017 19:00 – Sat, 17 Jun 2017 17:00

Several town centre venues, Swansea

Saturday children's workshop - free

Saturday evening music and poetry £5

Friday or Saturday only £40

Full ticket £75

Students or unwaged can work as a volunteer on the conference in exchange for a free place.

More info: www.artsinhealth.wales/conference



New 111 number for Carmarthenshire patients

From May 2nd patients living in Carmarthenshire are able to dial 111 to access their GP Out of Hours service and NHS Direct Wales.

The free-to-call phone number, launched on 2 May, will make it easy for people in the county to get urgent healthcare support if they are feeling unwell or if their own surgery is closed.

The scheme will be rolled out across Carmarthenshire initially, followed by **Pembrokeshire** and **Ceredigion** at a future date.

People calling 111 will firstly speak to a specially-trained call handler who will ask a series of questions. Depending on the urgency of their condition, callers will get a call back from a nurse, doctor or pharmacist advising them what to do.

<http://www.wales.nhs.uk/sitesplus/862/page/91415>

The Powys Community Health & Wellbeing Coordination Service

This service helps people in Powys (aged 18+) and their families or carers, to access community-level services and activities that will help them maintain independent lives and which help prevent their circumstances deteriorating to a point where they might need higher level health or social care services.

The service can also help support people when they return to home from hospital by helping other Third Sector services, such as Red Cross, identify additional local services that may be needed. You can access the service:

Powys People Direct on 01597 827666
Community Health and Well-Being Coordination Service 01597 828649 or
community.connectors@pavo.org.uk

Your locally based *Community Connector*
More info: <https://tinyurl.com/l5j8cux>

Welsh Government Survey – Framework for action on independent living

This survey will help the Welsh Government to check that future plans will address the barriers to independent living that are the most important to disabled people. The closing date for responses is 31 May 2017.

<https://tinyurl.com/kkd7bm2>

Tech angels Gwynedd & Anglesey

Tech Angels are Digital Communities Wales trained volunteers, providing support with technology to older people in their homes, helping them to:

- Use Skype to see/speak to family
- Make online health appointments
- Use money saving comparison sites
- Bank online
- Know how to stay safe online
- Only travel expenses are charged.

Contact: Dan Scrase, Service Manager, Good Neighbours Service
30 Dean Street, Bangor, LL57 1UR
01248 661915, 07867341744

daniel.scrase@royalvoluntaryservice.org.uk
Facebook & Twitter: @RVSGwyneddaMon

news from wales

Online prescription services warning

People should be wary of buying medications on the internet after an investigation found “widespread failings” at some online providers, the Care Quality Commission (CQC) has said.

The Welsh Government has said all private clinics with a base in Wales must be registered.

The CQC tips for things for the public to check before they click and buy are:

- An online doctor service is registered with the **CQC** or, if an online pharmacy service, with the **General Pharmaceutical Council** using the EU common logo
- Their address and where you can contact them
- How much the service will cost
- Who works there - are they based in the UK or overseas and are they registered?
- You have been given clear information about the medicine prescribed

New:
EU common logo



More info: <https://tinyurl.com/kv3e4xn>
<https://tinyurl.com/kgbotn4>

Online wellbeing library helps people to help themselves

An ‘electronic library’, a series of online self-help guides is designed to offer information and advice on a wide range of subjects, help users to make sense of emotional and wellbeing issues and signpost to appropriate services if further support is needed.

Guides are available in both Welsh and English: www.selfhelpguides.nth.nhs.uk/abmu



Choosing Wisely Wales

Patients in Wales are being urged to take more control of decisions about the care and treatments they receive, as part of a new medical movement.

Choosing Wisely Wales aims for a more equal doctor-patient relationship
<https://tinyurl.com/kkrrn9y>

Central to the idea are four questions a patient needs to ask:

Four questions to ask the doctor

- What are my options?
- How likely is it to harm or benefit me?
- Do I really need this?
- What can I do to help myself?

More info:

<https://tinyurl.com/jrzvp9a>
<https://tinyurl.com/kqu3zhd>

Sudoko - ah, so!

6		3	2		1
2			4		
4		6	3		2
3			6		

living with ME

My disappearing 'automatic pilot'

Brain fog is listed as a potential symptom of ME. To me that sounds like an external problem which the active brain has to negotiate through, rather than a description of how the brain doesn't work properly.

A regular occurrence for me is when my brain's automatic pilot (AP for short) goes on the fritz.

All the actions and knowledge I have learned over the years and that I thought had become 2nd nature, either disappears or becomes hazy. In the early years of my illness it was a permanent, if fluctuating, state. More recently my AP can go AWOL without notice, leaving me in a pickle.

The simplest of activities become a struggle - who knew how many decisions and judgement calls have to be taken just to make a cup of tea! A lot of concentration is required when the AP goes on holiday.

Making tea without AP

1. Locate the kitchen - no it hasn't moved, but going by the number of bruises on my arm I am sure the door frame is narrower.

2. Fill the kettle - from which tap? Hot, cold, or that new filter we had installed only 20 years ago.

3. Oops, the kettle is overflowing. I only need enough hot water for two mugs.

4. Why am I standing at the sink? Oh yes, I need to find clean mugs. Not that cupboard. We moved them to a cupboard nearer the kettle 5 years ago.

5. Carefully remove the mugs without knocking any others out.

6. What's that noise? Oops again. I didn't actually drop the mug, (my knuckles were white with the effort of holding on to it) but somehow it knocked against something that got in my way. Oh well, I'll tidy up the pieces later. Must move on or it will be lunchtime before I have drunk my tea.

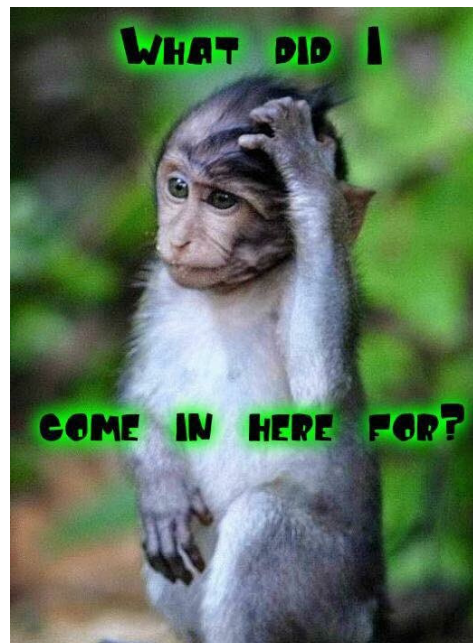
7. Ow! One of the shards must have fallen on to the floor and is now embedded in my foot. Where are my slippers...

8. Why are the teabags so far away from the mugs? Oops, why was that sugar bowl perched in front. I'll clean the cupboard later.

9. I've successfully torn apart 2 conjoined teabags without breaking them. Relief!

10. Now pour the boiling water onto the teabag without spilling it onto my hand. (Did I buy more burn cream?)

11. Thank goodness I don't take milk. It is so easy to confuse the milk carton with the apple juice



carton – my husband doesn't like the taste when I do that!

12. Now, do I drink my tea here or risk carrying it into the living room where there's a comfortable chair, light coloured carpet and lots of soft furnishings that don't need any more stains?

13. The living room it is. I need to put my feet up before I embark on the next challenge - remembering to drink the tea once it is cool enough, but before it goes stone cold.

14. Oh dear, I hear expletives pouring out of the kitchen. I think my husband may have found the mess I made!

The absent automatic pilot is responsible for many amusing, embarrassing and dangerous situations in my life. I remember the people I have caused to laugh, become bored or offended at social events or in meetings, many minor accidents and even a few narrowly missed major accidents while cooking, driving or just walking.

When my AP was absent all the time it was frustrating, but I knew what to expect. Now I need to be on the look-out for the warning signs that AP is packing his bags, so I can modify my plans and behaviour, and avoid chaos. In fact, I have written a number of checklists to remind me how to proceed when I am AP-less.

I wonder where I stored them: in paper lists; or in a Word file on my laptop; or maybe in a memo on my mobile phone... I'll look for them later, if I remember....

Jan Russell

living with ME

Alternative to Motability

Many people with disabilities are losing their Motability vehicles as they are reassessed from DLA (Disability Living Allowance) to PIP (Personal Independence Payment).

It is now possible to retain your vehicle, while you are appealing the decision, but there is also an alternative which doesn't depend on being eligible for enhanced rate PIP mobility.



OSV (in partnership with Mobility charity MASIS) have developed a scheme to help people with disabilities or who have long-term health conditions, as well as for individuals assisting disabled people.

The scheme is also suitable for those who are employed, have a private income and, in certain circumstances, for those who are on long-term benefits.

Everything is done from the comfort of your own home.

Your vehicle is ordered over the phone, by email or by post. There's no need to go to a showroom. Lease a brand-new car for a fixed monthly payment, with no worries about maintenance and servicing in the future.

Approval is subject to a credit search and affordability.

A franchised dealer will deliver directly to your home on a pre-arranged day at no cost to you.

More info: <https://www.osv.ltd.uk/masis/>
01903 257155 sales@osv.ltd.uk

Accessible transport in Wales

Find answers to bus and train transport queries from Traveline Cymru:

Online <https://www.traveline.cymru/travellers-with-a-disability/>

Phone - Call the bi-lingual Contact Centre on freephone number 0800 464 0000, 7am - 8pm daily most days.

Email - feedback@traveline.cymru

Post - Traveline Cymru, PO Box 83, CF11 1NA

Accessible travel in London

Plan a short break in London with the help of London Transport's guides: e.g.

- Large print tube maps
- Step-free Tube guide (including Docklands Light Railway and London Overground)
- Avoiding stairs Tube guide
- Tube toilet map
- Guide to River Thames boat services
- London Overground - Making rail accessible

- Assisted transport services
- Dial-a-Ride application form

See the full range and download or order online at <https://tfl.gov.uk/forms/12387.aspx>

Transport for London (TfL) has the following step-free stations:

- 71 Tube stations
- 57 London Overground stations
- 6 TfL Rail stations
- All DLR stations are step-free



More news can be found

on the WAMES' website's news blog, with additional items on twitter and Facebook.

Open a Facebook or twitter account to follow the WAMES FB and twitter pages, You don't need to post anything yourself, but you can add your comments to others' posts.



living with ME

Do you employ a care worker?

Social Care Wales (previously known as Care Council for Wales) has published a leaflet outlining what you and your family should expect from social care workers who give personal care in your home.

What the Code says:

To provide you with the best of care, social care workers must:

- Respect your views and put your needs first.
- Gain your trust and confidence.
- Help you be safe and healthy.
- Respect your rights while keeping you and other people safe.
- Be honest with you.
- Make sure they have the knowledge and skills to do their job well.

What to do if you feel you or your family are not receiving this standard of care

If you feel you are not getting the right standard of care and support you should:

- Read through the Code of Professional Practice for Social Care: *Our Code is not a secret* <http://www.ccwales.org.uk/code/>
- Talk to your social care worker's employer, share your concerns that the Code of Professional Practice is not being met and ask them how they will address your concerns.
- If you are still not happy and your concerns have not been dealt with, ask for a copy of their

complaints procedure to guide you on what to do next.

- If you are still concerned and the worker is registered with the Care Council for Wales, you can contact their Fitness to Practise team
- If you are concerned about the standard of care provided by a company or organisation, please contact the Care and Social Service Inspectorate Wales (CSSIW)

More info:

Social Care Wales, South Gate House, Wood Street, Cardiff, CF10 1EW

Social Care Wales, Unit 19, St Asaph Business Park, Glascoed Road, St Asaph, LL17 0LJ

info@socialcare.wales 9am-5pm 0300 30 33 444

Fitness to practice team:

<https://socialcare.wales/fitness-to-practice>

CSSIW National Office, Welsh Government, Rhydycar CF48 1UZ

<https://tinyurl.com/n2cyh8w>

0300 7900 126 CSSIW@wales.gsi.gov.uk

Need help to go to the cinema?

The CEA Card allows you to obtain ONE free ticket for the person who is accompanying you to enable you to visit the cinema, by providing the assistance you require as a result of your disability.

You must purchase a full price ticket for yourself for the same performance of the same film in the same auditorium.

Apply for a card online or by post

You will need:

- photo
- document providing proof of eligibility
- A Cheque or Postal Order payment for £6.00A stamped SAE

CEA Card, PO Box 199, Deeside, CH5 9BW
0344 967 0101 Textphone: 18001 0344 967 0101

info@ceacard.co.uk <https://www.ceacard.co.uk/howtoapply.aspx>



You are not obligated to do everything a healthy person does.

You are not obligated to be an inspiration.

You are not obligated to hide your illness in order to make other people comfortable.

You are allowed to know your limits.

You are allowed to stay in bed if you can't get up to do anything but go to the bathroom.

It is not your fault if other people leave you because of your illness.

It is not your fault that you are sick.

You don't have to apologise for something that is out of your control.

Author Unknown

Retirement on hold for many older carers

A recent Carers Trust report says there is no such thing as retirement for older carers.

Instead of retiring, they have become or will remain lifelong unpaid carers for their sick or disabled partner or adult children.

The Carers trust has launched "*Retirement on Hold*", a new report which highlights some of the challenges the older population are facing.

The report gives a snapshot of the battles some older people are now fighting, including caring for someone else when they have their own age-related illnesses.

- Over half of older carers attending focus groups set up by Carers Trust had at least one health condition themselves, such as high blood pressure, arthritis and heart problems.
- Some carers carried on caring even though they no longer had feelings for the person they cared for. While some felt they were made to feel guilty if they were no longer willing or able to care and were judged harshly by relatives and some professionals.
- Some carers were using their own money to finance personal care services or respite breaks without realising the person they care for should be assessed for the cost.
- Many carers aren't prepared for caring and are struggling to find their way around the social care system, and some say by the time they've re-

ceived vital information it is too late. They say the burden of caring has resulted in them being exhausted, frustrated and becoming sick themselves.



The Carers Trust says:

"We need local authorities and society generally to think and plan ahead to meet the needs of the increasing numbers of older carers who are a vital resource to our stretched health and social care system.

"There are so many things that can be done to improve their situation – better co-ordination of their health care, information about local support at the earliest opportunity and before it becomes too late."

More info & download the "*Retirement on Hold*" report: <https://tinyurl.com/kkhbsyu>

Remember – caring is a paid job many people train for. Don't expect to be able to do everything without support, financial assistance and regular breaks.

Sign up with your local Carers' network – get contact details from your local council or the Dec 2016 issue of me voice.

Find out what support is available. It is up to you if or when you take advantage of it.

"Learn to trust - let go, even a little bit. I tried to see people not as 'helping' with care because I was incapable, but allowing me to care better."
Helen, carer of her father and son.

Support for Young Carers to achieve their life ambitions

Young Carers' awareness day on 26th January this year highlighted the need to ensure young carers are able to make the most out their education so they can achieve their life ambitions.

Carers Trust Wales reports:

- There are an estimated 700,000 children and young people across the UK, who are caring for family members.
- 29,000 Young people in Wales who are caring for family members, according to the Carers Trust.
- 53% of the young adult carers surveyed by the Carers Trust were having problems coping with school work.

carers

Kirsty Williams AM, the Welsh Government Cabinet Secretary for Education, met with the *Young Adult Carer Council* to discuss what schools and colleges can do to support young carers better.

The Cabinet Secretary shared some of her plans to improve the provision of advice and support for young carers in schools, as well as imparting some advice for young carers:

"Your caring role will have developed in you incredible resilience, which will help you in pursuing your chosen career. Never take no for an answer."

Being a young carer can have a big impact on the things that are important to growing up

- It can affect a young person's health, social life and self-confidence.
- Many young carers struggle to juggle their education and caring which can cause pressure and stress.
- In a survey, 39% said that nobody in their school was aware of their caring role.
- 26% have been bullied at school because of their caring role.
- 1 in 20 miss school because of their caring role.

But young people can learn lots of useful skills by being a young carer.



The **Going Higher Wales** project' from Carers Trust Wales' aims to work with all universities in Wales, to encourage them to adopt 'carer-friendly' policies to support young adult carers throughout their time in higher education.

It also aims to work with young adult carers to support them in the process of applying to, and staying at, university.

<https://carers.org/young-adult-carers-wales>
etaylor@carers.org
 02920 090087

Maths Puzzle Answers From Page 20

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	9 =		2 =		9 =
8 =	9	-	(7)	X	(2)
	-		-		-
8 =	4	+	(1)	-	(5)
	+		X		+
4 =	8	-	(6)	+	(3)

	0 =		10 =		5 =
7 =	2	+	1	÷	(5)
	-		-		X
7 =	(3)	+	4	-	(8)
	÷		+		-
8 =	(9)	+	7	-	(6)

Carers Week 12 – 18 June

Carers Week is an annual campaign to:

- raise awareness of caring,
- highlight the challenges carers face
- and recognise the contribution they make to families and communities

Events will be held in many parts of Wales and beyond, including tea and cake, information stalls, walks and other activities.



Contact your local carers' network for more details. Some activities may be included on the Carers week website

<http://www.carersweek.org/get-involved/events-near-you>

Contact details are also in the December 2016 issue of **me voice**.

Win £10 Amazon voucher!

Supercalifragilisticexpialidocious

Who can find the most words using 3 or more letters from this magical word? Anyone can take part.

Send your list to Sylvia by the end of the 31st May. sylvia@wames.org.uk or ring for her postal address 029 2051 5061

U21

u21@wames.org.uk

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

Got something you want to share? U21@wames.org.uk

Want to get connected with others your age in Wales? Contact michelle@wames.org.uk

Tymes Trust magazine

The Young ME Sufferers' Trust publishes a magazine for young people, families and professionals called *Vision*. Past issues can be downloaded free from <http://www.tymestrust.org/tymesmagazine.htm>

AfME & AYME merge

On 3 April the Association for Young People with ME (AYME) closed and merged with Action for ME (AfME). AYME's Chief Executive Mary-Jane Willows is now Head of Children's Services in AfME's new Children's Services Team.

AfME has relaunched their web pages for young people and launched new forums for people up to age 18, 18-26 year olds and parents of young people. <https://tinyurl.com/n7o8qhm>

New Youth Parliament for Wales

Do you want to get involved in Welsh politics?

The new youth parliament could enable you to talk about the things you want, need and the issues that are important to you. Why should you wait until the age of 18 to have your say? The youth parliament aims to campaign and debate on your behalf.



Shape the future of the youth parliament

take the survey to tell them how you think it should work.

<https://www.surveymonkey.co.uk/r/XN9T537>

Consultation ends 30 June 2017.

More info:

<http://www.yourassembly.org/establishing-new-youth-parliament-wales/>

<https://www.youthparliament.wales/>

Raising awareness of ME and CFS

May 12th was International ME Awareness day

Some people spread out their awareness raising activities over a week (6-12th) or over the whole month of May, though it is never a bad time to tell people about ME. Whatever works for you!

ME/CFS Awareness computer game – Robin

Help your friends and family understand what it can be like to live with ME/CFS. Players have to help Robin, who suffers from ME, to get through a long weekend at home. They discover that Robin can only carry out a limited number of activities in a day, and must decide which activities she will carry out.



There are three possible outcomes to the game, and the developers emphasize that there is no 'perfect ending', which may help players to develop a better awareness of life for sufferers of ME/CFS. The game is suitable for all ages and free to download for PC or Mac, from <http://gamejolt.com/games/robin/173478#close>

Other awareness raising ideas:

post your story on a health website, or blog, or make a video story, e.g.

<https://www.youtube.com/watch?v=0YtX0VkgOcM>

U21

Everybody has rights!

The United Nations has compiled a list of 42 rights that children and young people around the world should have. Here are just a few of them:

3. Everyone who works with children should always do what is best for each child.
4. **The government should make sure that all these rights are available to all children.**
5. Governments should help parents to help you to know about and use children's rights as you grow up.
6. **You have the right to life and to grow up to be healthy.**
9. Your right to be with your parents if this is what's best for you.
12. **Your right to say what you think should happen and be listened to.**
13. Your right to have information.
16. **Your right to have privacy.**
19. You should not be harmed and should be looked after and kept safe.
23. **Your right to special care and support if you have a disability so that you can lead a full and independent life.**
24. Your right to good food and water and to see a doctor if you are ill.
25. **Children who are not living with their families should be checked on regularly to make sure they are okay.**
26. The right to extra money if your family hasn't got enough to live on.
27. **Your right to a good standard of living.**
28. Your right to learn and go to school.
29. **Your right to become the best that you can be.**



In 2011 Wales became the first country in the UK to make the UN Convention for Children's Rights part of its domestic law. They have to report to the United Nations every five years on how they are making children's rights a reality in their country.

Unfortunately when we got ME, our needs changed and life became more complicated. Many of us found it was often difficult to find doctors who understood or who would visit us at home, help with everyday tasks, money/benefits to pay for the extra costs, transport, an education or job we could cope with.

Sometimes this is due to discrimination or lack of understanding and we need to persevere to get the same treatment as anyone else.

Sometimes there simply aren't any suitable services to meet our needs. That is when we need to speak out and let the authorities know they are not upholding our rights. The Children's Commissioner's job is to help us by championing the rights of children and young people in Wales.

Children's Commissioner for Wales Investigation and Advice service

The Children's Commissioner for Wales' officers offer help and support if you feel that you have been treated unfairly. They can either point you in the right direction to another organisation or sometimes, look at individual complaints.

- for people up to the age of 18, or 25 in certain circumstances – you can ask a parent or other adult to contact them on your behalf
- for those living in Wales or placed in England by a Welsh local authority
- help with complaints or approaching service provider or organisation (such as a registered child minder, county council, health authority) 01792 765600 advice@childcomwales.org.uk
- free and confidential

Children's Commissioner for Wales, Freepost RRGL XLYC BHGC
Swansea SA7 9FS
Open: Monday to Friday except Bank Holidays from 9am – 5pm

More info : <https://www.childcomwales.org.uk>

Math Cross Numbers

Each of the digits 1 through 9 is used once and only once in each of these two puzzles. Can you figure out where they must be placed so that each of the equations (both horizontally and vertically) are true? Only positive numbers are involved.

(-		+	(= 8
-		+		÷	
)	-		+)	= 7
x		-		-	
(÷)	+		= 7
= 5		= 10		= 0	

(+	(-		= 4
+		x		+	
)	-)	+		= 8
-		-		-	
(x)	-		= 8
= 6		= 2		= 6	

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Roald Dahl Book Titles

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

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

U21

Boy
Esio Trot
Fantastic Mr Fox
Going Solo
Kiss Kiss
Matilda

My Uncle Oswald
Revolting Rhymes
The BFG
The Minpins
The Twits
The Witches

