



# me voice

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the wames magazine  
october 2015, no. 14

**WAMES**  
Welsh Association of ME & CFS Support

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## me voice

is published 5 times a year. You can subscribe to the paper copy for £11 p.a., or receive it free by email, or read and/or download it from [www.wames.org.uk](http://www.wames.org.uk)

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We welcome news items, articles, cartoons, jokes, poems, suggestions etc. We will include them whenever it is appropriate. Please send them to [admin@wames.org.uk](mailto:admin@wames.org.uk) or to the WAMES Subscriptions address above.

## the wames information exchange

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

**News** blog on website **Magazine** **Facebook** **Twitter**

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twitter: WAMESMECFS  
[www.facebook.com/WAMESMECFS](https://www.facebook.com/WAMESMECFS)



# support

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

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

## Brecon Area Contact

Richard Jones 01874 622310  
[richard.j5@btinternet.com](mailto:richard.j5@btinternet.com)

## Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months.  
Next Meeting: 28 Nov  
Contact: John James (pm)  
01267 233793

## Cwtch, Haverfordwest

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

Next meetings: 16 Oct, 20 Nov 7-8.30, 6 Nov 10-11.30,  
28 Nov Letterston Christmas Fete

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

## FM/ME/CFS Support Group West Wales

Meets in Milford Haven, Pems at Milford Haven Christian Fellowship on the 1st and 3rd Tuesday of every month 10.30-2pm.

Contact: Gary or Cathy  
0844 887 2385  
Mob: 07867 482 929

Next meetings: 3 Nov, 1 Dec (Carers Social) 20 Oct, 17 Nov  
[fibrowestwales@hotmail.com](mailto:fibrowestwales@hotmail.com)  
<http://fmmeccfswestwales.jimdo.com>

## ME Support in Glamorgan (MESiG)

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

Next meetings: Nov 2, Dec 7  
Contact: Christalla Bailey,  
029 2076 2347  
[christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)  
[www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk)



## Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

Next meeting: mid November  
Contact: Mike or Karen

0796 9665419 (between 2-4pm)  
[karen@kandm46.plus.com](mailto:karen@kandm46.plus.com)

## Ystradgynlais Neuro Café

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

1st Wed (games, informal social time & a cuppa)

3rd Wed (education/info sessions)  
Next meetings: 21 Oct, 4 & 18 Nov, 2 & 16 Dec

Contact: Caroline Bull 01639 849 192  
[cbullyvc@gmail.com](mailto:cbullyvc@gmail.com)  
Jan will be speaking at the meeting on 18 November

## Live near the border?

*An English group may meet closer to you:*

## Shropshire

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

## Chester

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

## Ross on Wye

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

## me voice

**editor:** Jan Russell

**U21 editor:** Lucy Fox

**publisher:** Dr Tony Thompson

## Your ME stories

Thanks to all who have contributed stories of their experience of ME and accessing services in Wales.

Keep them coming as we can use them to influence service development and in many training situations.

See the last issue for more info about what your story can contain, or contact Sylvia

## Easy Fundraising total £81.29

Thanks to the 5 supporters raising money for us as they shop online.

Christmas is a coming, so why not join us and push that total higher. It won't cost YOU a penny!

[www.easyfundraising.org.uk/](http://www.easyfundraising.org.uk/)

## Change of email

Please note change of email address for Jan. Emails to the old enquiries address will continue to be read and responded to by a member of the team.

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

## NHS Services update

Following the last meeting of the ME -CFS and FM Implementation group at Government offices in Cardiff one Health Board has called a stakeholder meeting.

### Abertawe Bro Morgannwg UHB

(covering Swansea, Bridgend and Neath Port Talbot) met on 1st September. Staff representing GPs, neurology, rheumatology and therapists attended. Jan Russell from WAMES represented people with ME and CFS.

Plans are being developed for a pathway, pilot service for ME & CFS and website providing information for staff, to begin in early 2016. WAMES will be contributing information in an attempt to make this as patient friendly as possible.

**Powys tHB's** stakeholder meeting planned for September has been delayed.

### Implementation group

Representatives from Health Boards and patient groups will meet again in early November to share progress and their 3 year action plans.

## One Word Films

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

Apocalypse  
Braveheart  
Cato  
Damian  
Esiotrot  
Heidi  
Jumanji  
Matilda  
Pinocchio  
Requiem

Atonement  
Brewster  
Cinderella  
Elemental  
Frankenstein  
Jaws  
Macbeth  
Nevermore  
Rebecca  
Twilight

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

# news from wales

## Disabled People's Manifesto

Disability Wales, on 17th September 2015, presented its Manifesto in the Senedd calling for **an Enabling Wales** where disabled people, as citizens of a modern inclusive nation, truly experience their rights, equality and independence, and are able to contribute fully to its social and economic success.

Rhian Davies, Chief Executive of Disability Wales, states:

"Disabled people make up over 20% of the population in Wales, which has a higher proportion of disabled people than other nations and most regions of the UK.

On the 5th May 2016, disabled people, their families, friends and carers across Wales will cast their votes in the National Assembly for Wales Elections. Disability Wales calls on all political parties to evidence their full commitment to disabled voters in their party Manifestos."

The Manifesto calls upon the Welsh Government to:

- include an **Independent Living (Wales) Bill** in the Legislative Programme for the Fifth Assembly

2016-21 (modelled on one ``proposed by the late Lord Jack ``Ashley in 2006)

- fully implement the **UN Convention on the Rights of Disabled People** (UNCRPD) across government policy and legislation
- establish a **Commission of Inquiry** involving disabled people and their organisations to consider options to strengthen the enforcement of disabled people's rights, equality and independence in Wales, including devolving powers over equality legislation to Welsh Government
- **eradicate disability poverty** in Wales by 2030
- tackle **Disability Hate Crime**

The Disabled People's Manifesto has been produced in consultation with disabled people and their organisations from across Wales.

A four month period of engagement was undertaken in order to inform and help shape the Calls to Action. Over 200 people took part in the development of this Manifesto.  
[www.disabilitywales.org/calls-for-action/](http://www.disabilitywales.org/calls-for-action/)

## Are people with ME disabled?

Many people with ME are considered to be disabled because the Equality Act 2010 defines disability as having a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

<http://tinyurl.com/ovidz3o>

### Social Model of Disability (SMD)

The Social Model of Disability makes the important difference between 'impairment' and 'disability'.

Our impairments or bodies are not the problem. Social barriers are the main cause of our problems.

These barriers include people's attitudes to disability, and physical and organisational barriers.

### Impairment

An injury, illness, or congenital condition that causes or is likely to cause a long-term effect on physical appearance and / or limitation of function within the individual that differs from the commonplace.

### Disability

The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers. Disability is shown as being caused by 'barriers' or elements of social

organisation which take no or little account of people who have impairments.

*[Info from Disability Wales website. DW aims to promote the understanding, adoption and implementation of the Social Model of Disability throughout Wales]*

### Video illustrating the SMD

The premise is a town inhabited by wheelchair users. They have built everything to be practical for them which is great until non-wheelchair users start moving in...

Solutions need to be found for the "disabled able-bodied people..." Poignant and funny!

<https://youtube/9s3NZaLhcc4>

## Disability Wales

Disability Wales is an independent membership organisation of disability groups and individuals from across Wales.

They champion the rights, equality and independence of all disabled people regardless of impairment.

Their website gives info on rights, assistive technology, campaigns, benefits etc.

[www.disabilitywales.org](http://www.disabilitywales.org)



# news from wales

## Help for struggling GP practices

NHS Wales has now agreed with the General Practitioners Council a framework for assessing the sustainability of GP practices in Wales. The aim is to create a stronger, highly-trained primary care workforce, which can deliver a wide-range of services in local communities, reducing dependence on hospital-based care.

The new sustainability framework will enable GP practices at risk of closure can apply for support, as part of the reform of primary care.

In addition a £34m funding package has been invested in the Wales NHS to train more nurses, attract more GPs to North Wales, and provide 24-hour healthcare closer to people's homes. <http://tiny.cc/v0pk4x>



## Nest - free home improvements

Nest – the Welsh Government's warm homes scheme has made changes to the eligibility criteria.

The scheme will benefit more low income households in Wales who are struggling with their energy bills.

Households in receipt of a means tested benefit and living in privately owned or privately rented properties could now be eligible for free home improvements if their home has an energy rating of EPC E or below.

If you call Nest it would be useful if you could have a range of information available.

There is a list of the Home Energy Check questions on the website but most importantly have the following to hand – household income, benefit award letter, utility bill costs, and tenancy agreement or mortgage statement.

Freephone **0808 808 2244** Mon-Fri 9-7pm <http://www.nestwales.org.uk>

## Online help

### Law Wales

A new website which provides an overview of an overview of Welsh law and explains how devolved laws are in specific areas such as health, social care, education etc.

<http://law.gov.wales>

### Dewis Cymru

Dewis Cymru is an online directory providing information about wellbeing in Wales from a network of social care, health and third sector organisations (including WAMES).

It is adding info for adults in North Wales during 2015 and will add info for children and the rest of Wales during 2016. <http://www.dewis.wales>

It includes voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives.

## WHAT IS THE THIRD SECTOR?

'Third sector organisations' is a term used to describe the range of organisations that are neither public sector nor private sector

## Say no to Ageism

This campaign aims to change the way society thinks about older people and highlight their huge contribution to communities across Wales.

Older people can sometimes feel their needs and desires are not taken as seriously as those of younger people, in a wide range of situations: health, social care, housing, transport, employment etc.

*'Why does it matter that society changes the way it thinks about and perceives older people?'*

*It matters because a stereotypical image of frailty, decline and dependence, together with a lack of understanding about the vital role that older people play across society, not only demeans the people we care about and undermines their self-worth, but also fuels ageism.*

*And ageism, like sexism, racism, homophobia and all other forms of discrimination can destroy individuals and diminishes us all.'*

**Sarah Rochira**, Older People's Commissioner for Wales

<http://tiny.cc/xgqk4x>

# news from wales

## Samaritans free phone number

New free-to-caller number:  
116 123 (24 hours a day, 7 days a week)

Welsh: 0300 123 3011 (from 7pm - 11pm only, 7 days a week—local rate, not free)

More info: <http://tiny.cc/p5tl4x>

## Hywel Dda HB central contact number

Patients will be able to experience greater choice and reduced waiting times for hospital appointments, thanks to the launch of a new central contact centre, which is rolled out to Ceredigion and Pembrokeshire today following a previous launch in Carmarthenshire.

Anyone who would like to arrange, confirm, alter or cancel an outpatient appointment in the Hywel Dda area can contact the new central number on **0300 303 9642**.

More info: <http://bit.ly/1QsXPgR>

## Want to leave your body to science?

From 1 Dec 2015 people in Wales will need to opt out of organ donation. However it is a bit more complicated for people with ME.

The Organ Donation Legislation Office told WAMES:

### Donating tissue

People with ME/CFS cannot donate tissues unless their condition has been resolved. People with ME/CFS could potentially donate their organs given the right circumstances, but this would be determined at the point of their death by an appropriate medical professional.

### Donating brains

Contact the research centre in question to ask whether they accept brains from people who have donated other organs - many medical research facilities do not accept bodies where organs have already been donated.

### Organ donor register

A person can be on the Organ Donor Register and also have agreed to donate their body to science. Organ donation is an incredibly rare event (71 people in Wales donated their organs last year) so

in the vast majority of circumstances it would not be a possibility and the body could be donated to science. However, if a person's main wish is to donate their brain to science they should register a decision not to be a donor.

### ME/CFS donors

The Joint United Kingdom (UK) Blood Transfusion and Tissue Transplantation Services Professional Advisory Committee guidance makes it clear that a person with any illness with unknown aetiology cannot donate tissues. This includes ME/CFS.

People with ME/CFS could potentially donate organs but each person would be assessed individually at the point of donation.



### More info:

<http://organdonationwales.org>

## Blood donation

From the Welsh Blood Service: In the past, donors with a history of ME/CFS could give blood, provided they had completely recovered and were feeling well. However, as ME/CFS is a condition where people can relapse and become ill again, donor selection guidelines are being changed as a precaution to protect the donor's safety by ensuring the condition is not made worse by donating blood.

<http://tiny.cc/vdul4x>

## Double Bubble

LOLWA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VIEDR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ASHEK	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEABT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ADIE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ETDYI	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Unscramble each of the clue words.

Take the letters that appear in ☐ boxes and unscramble them for the final message.

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



# news from wales

## Food Co-ops

There are around 300 community food co-ops running across Wales in schools, community centres, church halls and workplaces.

Produce sold through food co-ops comes directly from local suppliers such as farmers, retailers or wholesalers, who select fresh fruit and vegetables according to seasonality, availability and value.

Customers order and pay one week and collect the next. As well as helping you eat more healthily, you can also save money. On average a regular customer saves around £220 a year!

Find a coop near you  
[www.foodcoopswales.org.uk](http://www.foodcoopswales.org.uk)  
(no address or phone no. available)

## Dr Myhill videos

Dr Sarah Myhill's talks at the Biocare Summer 2015 Conference in July are now viewable online.

"Diagnosis and Treatment of Chronic Fatigue Syndrome" (4+hours)  
<http://tiny.cc/a30l4x>

## Are you online?

The National Survey for Wales: 2014-15 confirmed that 19% (approximately 473,959) of the Welsh adult population (aged 18 or over) do not regularly use the internet.

Disabled consumers are less likely to have internet access than people who do not have a disability, according to research by Ofcom. People without internet access and skills are sometimes viewed as 'disempowered' so the Welsh Government are pushing forward with plans to bring broadband to all areas of Wales and to get people online, i.e. the digital inclusion plan. They are funding training for older people,



people with disabilities, unemployed people, social housing tenants or families in poverty from all backgrounds across Wales.

Find out what is happening in your area by contacting your local library.

## Get online week 12-18 Oct 2015

### Make life easier online!

Contacts:

<http://digitalcommunities.gov.wales/resources/>  
<http://tinyurl.com/pm7u687>

## Beyond 110 blog

25 year old Lizzie Horgan lived life at 110mph until "an unexpected onset of ME/CFS hit me out of the blue, and derailed my everyday life as I knew it". "And then I got a bit fed up with being told about my new limited lifestyle". So Beyond110 was born.

"I'm sharing my journey and all that I'm learning, as I discover life beyond living it at the old 110mph. I'm no expert, but my aim is to help brighten someone else's day. And to get ME recognised as a hot health topic.

### Testing patience 22 Sep 2015

You may have guessed that this week, my experience of ME/Chronic Fatigue Syndrome is testing my patience.

I'm reassured by my Dr. that this is a good sign; "You're frustrated! You didn't have the energy to be frustrated a few months ago". It's a real seesaw.

The fact that I'm sitting here, with a laptop in front of me, a hot water bottle on my lap, and glasses (yes, still specky) confirms that I am a privileged human being.

But there is the other part, where today I walked into the supermarket in my loosest, all white PJ bottoms (because genuinely any other trousers feel just too damn tight on achey legs), caught my reflection and realised that I bore an uncanny resemblance to a character stepped out of *One Flew Over The Cuckoo's Nest* (another great read). Fairly dramatic, but let's not forget it was only a few weeks ago that I was in the veg aisle with my slippers on.

So during the car ride home I felt fairly irritable and like I could really do with clomping around the house if my bod let me.

And then one small thing happens, one moment of brilliance and you realise. This isn't so bad, it's all going to be ok..."

Read more from Lizzie's blog at [www.beyond110.co.uk](http://www.beyond110.co.uk)





# making the most of your gp appointment

**With the difficulties of recruiting medical staff to many parts of Wales, GPs are under increasing pressure.**

**Nia Francis-Scrutton from the Stockport ME group suggests ways to make the most of your GP's time.**

Getting on well with your doctor can make a positive difference to your health.

Being prepared for your visit and thinking about what you want to get out of it will help both you and your GP (or any healthcare worker who you have an appointment with.)

## **Visit or phonecall?**

You can either make an appointment to visit the surgery or you may feel that a telephone consultation would be easier. Around 25% of consultations now take place over the phone which saves time for both you and your GP.

## **10 minutes or more?**

Your appointment is likely to last 8-10 minutes, so it is advisable to be well prepared. If you think you need more time explain this to the receptionist,

they may be able to schedule a slightly longer appointment time for you.

**1. Try to get straight to the point:** describe the symptoms you are concerned about or the help you need. Don't wait until the end of your appointment before voicing your main concern.

**2. It may help to write down your symptoms or the problem** which is concerning you and give it to the GP at the start of the consultation.

**3. Always mention any non-prescription medication,** supplements or herbal remedies you are taking.

**4. Make a list of any questions** you want to ask e.g.

- What are my treatment options?
- Will I need to have any tests?
- What is the next step?
- Where can I get more information?
- What should I do if I start to feel worse?

**5. If you feel you may not remember everything your GP has said to you, maybe take someone with you.** Most of us forget up to 50% of what the doctor says. Ask about anything



you don't understand. Ask for important words to be written down and explained, take notes or ask someone else to take notes for you.

**6. Dress appropriately:** your practitioner sometimes needs to see and feel the parts of the body in question. Time spent dressing and undressing is time you could be spending face to face with the doctor.

**7. Be honest**—if the doctor asks you to do something you'll find difficult, feel free to say so. For example, you could say: "I know that taking these tablets is important, but I find it difficult to take them four times a day." This gives the doctor a chance to help you solve the problem.

**8. When you get home,** spend some time thinking about the appointment, either alone or with the person who went with you. This is a good time to look back at how the appointment went. You could do this by asking a few questions:

Did I get what I wanted out of the visit?

What worked and what didn't?

What will I do differently next time?

*[based NHS UK website and the MEA leaflet "How to deal with your doctor."]*

## **NHS Wales**

### **NHS Direct**

health advice and information service available 24 hours a day, every day 0845 46 47  
<http://www.nhsdirect.wales.nhs.uk>

### **My health online**

Some GP practices have signed up to this service where you can communicate with your GP and surgery online.

<http://tiny.cc/wyvl4x>

### **Choose well**

The NHS Wales campaign to help you decide who to contact when you need healthcare advice.

[www.choosewellwales.org.uk](http://www.choosewellwales.org.uk)



# research

## Post exertional malaise

Post exertional malaise (PEM) is the characteristic feature of ME, but researchers have been slow to investigate it. There are signs this is changing with a number of research studies published during 2015 and more to come.

### What is PEM?

“There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period—usually 24 hours or longer.”

[from Canadian guidelines p2 <http://tiny.cc/21i04x>]

### Dr Charles Shepherd describes it as:

“Post-exertional malaise (PEM), or post-exertional symptom exacerbation, describes a delayed and significant exacerbation of ME/CFS symptoms that always follows physical activity and often follows cognitive activity. PEM is a highly characteristic clinical and diagnostic feature of ME/CFS. In some respects, PEM is an illness within an illness.” <http://tiny.cc/n4i04x>

### Is there a better name for it?

Not everyone feels that malaise is the best term to use to describe the range of symptoms experienced following exertion. Like the word fatigue, it seems inadequate, called by some a ‘powder puff term’. The International Consensus Primer prefers: Post-Exertional Neuroimmune Exhaustion (PENE) as this focuses on measurable physical dysfunction.

[International Consensus Primer: <http://tiny.cc/0ej04x> p2]

### How have scientists researched PEM?

Researchers have used patient questionnaires, cognitive tests, gene expression, cardiopulmonary tests over 2 days (test/retest), fMRI (brain scans), measurement of lactate levels.

Dr Dane Cook talks about PEM in a YouTube video: <http://tiny.cc/2hj04x>

### Some research discoveries:

1. Slow muscle recovery following physical exercise
2. Exercises causes specific muscle abnormalities
3. Pain increases following exercise
4. Cognitive processing ability decreases
5. Symptom exacerbation follows mental activity as well
6. General, mental, and physical fatigue increased following cognitive testing
7. Reaction to and recovery from exertion is delayed
8. Tests on consecutive days show decrease in oxygen consumption
9. Wide range of symptoms affected by exercise
10. Exercise feels harder to people with ME
11. The immune system is altered following exercise

More about latest research discoveries on WAMES website news blog

### What next?

- Belgian researchers are looking at the role of autonomic dysfunction in PEM
- English researchers are looking at what happens to immune function before and after a cognitive challenge and an exercise challenge.
- The Medical Research Council (MRC) funded neuroimaging study will look at what happens to brain networks before and after an exercise challenge.

More about these studies: <http://tiny.cc/ykj04x>



# carers

## Carers are missing out on NI credits

The Minister for Pensions is calling on all carers to check they are getting what they are entitled to. Nearly 200,000 people with caring responsibilities could receive a boost to their pension by claiming Carers Credit. Only an estimated 5% of those eligible are signed up to receive these additional National Insurance contributions.

Carer's Allowance is available to those who care for 35 hours a week or more, subject to eligibility, whereas Carer's Credit is for those who care for at least 20 hours a week. Income, savings or investments do not affect eligibility for Carer's Credit. If you get Carer's Allowance, you are already automatically getting Carer's Credit.

Minister's talk: <http://tiny.cc/q70l4x>

About Carers credit: [www.gov.uk/carers-credit/overview](http://www.gov.uk/carers-credit/overview)

## Young adult carers website

*Matter* has been created by Carers Trust to provide an online space for young adult carers aged 16–25 to

connect, share their experiences, and access trusted support.

The vision of the site is to bring together young adult carers from across the UK, as well as those who work with young adult carers, via an online space which is safe, fun, and most of all, inspiring. There is an online community team on hand to provide support as and when needed, by messaging or email.

If you're aged 16–25 and are caring for a family member or friend, *Matter* is a platform for you to share your story with others and to hear the stories of those with similar experiences to your own. Your thoughts, your world, matter.

<https://matter.carers.org>

## Local Ambassador Volunteers

As a carer you'll know how caring can cut some people off from the outside world. It's hard to meet other people who know what you're going through and it's hard to find out what help is out there in your local area.

That's why Carers Wales are creating a network of Local Ambassadors who use their knowledge and expertise to help



other carers. They want a team of skilled volunteers who understand what caring is like in order to reach out to carers, raise awareness of carers' issues and improve local services.

If you would like to know more or would like to apply to be an Ambassador for your local area visit <http://www.carersuk.org/how-you-can-help> or contact Julie Skelton [Julie.skelton@carerswales.org](mailto:Julie.skelton@carerswales.org) 029 2081 1370 or 07930 404858

*I like long walks...*

Especially when taken by people who really annoy me!!!

## Hynt—free theatre ticket for carers & PAs

- a **card scheme** that entitles cardholders to a ticket free of charge for personal assistants or carers across participating theatres and venues in Wales. If you don't meet the eligibility criteria but still feel you need additional support, you can have your application assessed by an arbiter with the help of Diverse Cymru.
- a **website** where you can find information about accessible performances at venues across Wales and you can also read our access guides to help you plan your visit.
- a **network**, working with the 30+ participating theatres and arts centres to improve accessibility and understanding through professional development, research and sharing of good practice.

### More information:

[www.hynt.co.uk](http://www.hynt.co.uk) or [www.hynt.cymru](http://www.hynt.cymru)

Hynt Card, Network House, St Ives Way, Sandycroft, Flint CH5 2QS  
help desk 0344 225 2305  
text relay service 18001 0344 257 8858



# carers

## Project Cariad Swansea

This project aims to improve the health & wellbeing of carers and former carers by offering a variety of different training sessions & holistic therapies. They offer a range of tasters, workshops and courses, such as Stress Control, Emergency First Aid, Body Confidence, Tai Chi, Looking After Me – A Course for Carers, Sleep & Relaxation Techniques...check out the calendar!

They can help with FREE respite, replacement or alternative care. This means they may be able to pay your existing care provider or reimburse the time of a friend, neighbour or relative at an hourly rate.

All training workshops and holistic therapies are FREE to any carers aged 16+ who live in the Swansea area.

**More info:** contact Ali or Marta  
01792 653344

[ali@swanseacarerscentre.org.uk](mailto:ali@swanseacarerscentre.org.uk)  
<http://tiny.cc/vm1l4x>

## CRYF Wrexham

### Confident Recognised Young Future

Do you help or support someone with an illness or disability?

Project CRYF is a new project supporting Young Adult Carers (aged 18-25) around education and employment. This could be help with job/college applications, sourcing grants for travel expenses or driving lessons, or signposting to other advice & support such as advocacy or benefits.

**More info:** 01978 318812/ 0800 276 1070 [projectcryf@avow.org](mailto:projectcryf@avow.org)  
Facebook & Twitter

## Pharmacists - 'Here for Carers'

During October pharmacists throughout Wales will be encouraged to focus on the help they can give unpaid carers.

Carers are often required to administer medicines, and to order and collect prescriptions on behalf of the person they care for. Pharmacists can provide vital services such as Medicine Use Reviews, advice on treatment for minor ailments and the flu vaccine, and signposting carers to relevant services that could benefit themselves and those they care for.

A free booklet 'A Carer's Guide to Managing Medicines' / Canllaw i Ofalwyr ar Reoli Meddyginiaeth will

be available from all pharmacies in Wales. And can be downloaded from  
<http://tiny.cc/qg1l4x>  
<http://tiny.cc/rr1l4x>



## Carers Rights Day 20 November

Having the right information at the right time can make a huge difference when you are looking after someone.

Find out about Information events in your area from your local library.

The Carers Rights Guide outlines carers' essential rights and signposts what financial and practical help is available. A new edition will be launched on Nov 20<sup>th</sup>.

Download <https://www.carersuk.org/help-and-advice/get-resources/carers-rights-guide>  
or contact 029 2081 1370  
[info@carerswales.org](mailto:info@carerswales.org)

## A Smile is a Funny Thing (sung to *Auld Lang Syne*)

A smile is quite a funny thing  
It wrinkles up your face  
And when it's gone, you'll never find  
Its secret hiding place  
But far more wonderful it is  
To see what smiles can do  
You smile at one, she smiles at you  
And so one smile makes two

He smiles at someone, since you smile  
And then that one smiles back  
And that one smile smiles until in truth

You fail in keeping track  
And since a smile can do great good  
By cheering hearts of care  
Let's smile and not forget the fact  
That smiles go everywhere

## 5 portions of fun a day for CFS

During a phone-in with a man who was diagnosed with a life-threatening brain tumour, Dr Phil Hammond said:

*"I treat young people with a nasty illness called chronic fatigue syndrome at the moment, and when they're feeling at their lowest I say 'you still need five portions of fun a day.' Whatever energy you've got in the tank, you need to do something every day that gives your life purpose and meaning."*

# living with me

## National Disabled Identification Card

The aim of the National DID Card is to remove the need for individuals to carry their paper documentation with them at all times. The card will have a photograph of the cardholder and will only be issued to disabled people who are in receipt of some form of disability allowance.

The card can be used as proof that they are in receipt of an eligible benefit and therefore entitled to gain entry at concessionary rate. Many establishments, theatres, museums, attractions, leisure facilities etc. offer concessionary prices for disabled people and in some cases offer free entry to another person assisting the disabled person.

**More info:** [www.did-card.co.uk](http://www.did-card.co.uk)  
DID Card, PO BOX 3105, Reading, Berkshire RG1 9ZS

## Make your Blue Badge international!

There is now something else you can do to ensure worry-free parking – print out a translation of your parking entitlement in the language of the European country you are visiting.

The single sheet simply explains that you are a traveller with a disability, and that your Blue Badge should enable you to use the same concessionary parking facilities as residents of the country.

Print whichever language versions you need at:  
[www.icarhireinsurance.com/disabled-driving-in-europe](http://www.icarhireinsurance.com/disabled-driving-in-europe)

Please remember that this translation should be displayed alongside your Blue Badge – it isn't a substitute.

## Online guidebook for PAs

Personal assistants are employed by many people, including people severely affected by ME, to provide care and support known as 'personalised care'.

This guidebook aims to increase understanding of the role of personal assistants in Wales. It is not a training course, but it should give PAs and employers a good basis of knowledge about the job.

<http://pasonlineguidebook.blogspot.co.uk>



- flashing light-up casters
- spoke guard protector skins
- cup holder and tray
- colourful seat cushion
- wheel pouch
- spoke wheel safety light
- iphone cradle
- attachable umbrella

## Accessorise your wheelchair

Here are a selection of practical solutions, that also make great gifts:

- underseat Bag
- back or handlebars bag
- armrest bag
- wheelchair slippers & socks - Wheelchair Slippers cover the rear tyres. Wheelchair Socks cover the front tyres. They are machine washable, prevent slippage and keep your carpets clean.

Ask at your local mobility shop or try these online sites:

[www.amazon.co.uk](http://www.amazon.co.uk)  
Wheelchair accessories  
[www.betterlifehealthcare.com](http://www.betterlifehealthcare.com)  
free catalogue 0333 331 7584  
<http://epc-wheelchairs.co.uk>  
01252 547939  
[www.pimpyourchair.co.uk](http://www.pimpyourchair.co.uk)  
01543 306 644 also on ebay

My daughter asked me for a pet spider for her birthday, so I went to our local pet shop and they were £70!

"Blow this," I thought, "I can get one cheaper off the web."



# living with me

## An end to sex?

@satonmybutt shared a great blog post on Twitter called “An end to sex?”

**SatonmyButt** suffers from CRPS (Complex regional pain syndrome) and ME, and writes a blog called *Sat on my Butt*, which among other things describes changes in his life since becoming a “Spoonie”.

**A spoonie** is a person living with a chronic illness who measures their ability to deal with daily activities by how many spoons it will require of them – spoons are a finite resource which are sometimes in abundance and sometimes lacking.

In this particular post he describes the worries he experienced because of being in too much pain to continue having what he considered a “normal” sex-life.

However, since deciding to focus on the things he can do rather than the things he cannot, he is pleased to report that he and his wife now have a very satisfying sex-life.

You can read the full blog post here <http://tiny.cc/wq5w4x>

Focus on the things you  
*can* do!

**Not much is written about the affect of ME on sex but how do people with other debilitating illnesses deal with these problems?**

### Arthritis Care booklet

AC recommends various positions for people suffering from joint pain in their booklet *Relationships, intimacy and arthritis*

<http://tiny.cc/tq2l4x>

0808 800 4050

[info@arthritiscare.org.uk](mailto:info@arthritiscare.org.uk)

[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

### Pain Concern

information on sex and chronic pain can be found on their website or posted out for a small donation.

<http://painconcern.org.uk/sex-and-chronic-pain/>

*The illustrated guide to better sex for people with chronic pain* by Robert W Rothrock and Gabriella D'Amore, can be bought from them

<http://painconcern.org.uk>

Unit 1-3, 62-66 Newcraighall Road, Edinburgh EH15 3HS



### Body mapping

The MS Society recommends trying body mapping as a way of helping you feel more aware of your body and to work out what feels good.

Body mapping with your partner can also increase intimacy. This is a simple self-exploration technique in which you set aside time and gently touch all parts of the body to identify what results in sensual pleasure, discomfort or sensory change.

<http://tiny.cc/Ou2l4x>

Leaflet: Sex, intimacy & relationships

0131 669 5951

[info@painconcern.org.uk](mailto:info@painconcern.org.uk)

### Outsiders forum

A frank forum for discussing sex and disability, provides info on its website and runs a sex and disability helpline.

[trust@outsiders.org.uk](mailto:trust@outsiders.org.uk)

07074 993 527

WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE

SEX AND DISABILITY HEPLINE

07074 993 527

11am-7pm weekdays

[sexdis@Outsiders.org.uk](mailto:sexdis@Outsiders.org.uk)

### Action for ME articles

*Let's get physical*

<http://tiny.cc/cx2l4x>

*Let's talk about sex*

<http://tiny.cc/1y2l4x>

Life is an endless process of self  
discovery

John Gardner

# welfare

## Impact of welfare reforms in Wales

The Welsh Government has published the final part of its report begun in Feb 2012.

It includes the impact of the Summer budget cuts, personal tax reforms and changes to the national minimum wage for those aged 25 and over.

<http://tinyurl.com/px4syzt>

## ‘War on welfare’ petition

A new WOW petition attracted nearly 5,000 signatures on parliament’s e-petition website within four days of going live, and has backing from the Greens, the SNP, and MPs from Labour and Plaid Cymru.

The petition calls on the government to assess the full impact of all of its cuts to support and social care for disabled people. Signatures now approaching 21,500.

<http://tinyurl.com/pylqk93>

Petition runs until Feb 2016  
<https://petition.parliament.uk/petitions/106068>

## Crowdsourcing alternative to WCA

Much has been said about the many failings of the welfare to work reforms and the ways in which ESA (Employment Support Allowance) and WCA (Work Capability Assessment) are failing people with disabilities and long-term health conditions.

Now, you have an opportunity to get involved with a project designed to come up with an alternative system.

Ekklesia have recently launched a survey to canvass the best ideas about what proper support and assessment should look like.

They are working on the principle that the people best able to help achieve the necessary change are the ones who are affected, those with long-term illnesses and/or disabilities. Complete the questionnaire online or download and post.

### More info:

<http://tinyurl.com/oer25s5>

## Manage your money

Budgeting skills are not something we are all blessed with, but they can be learnt.

The Payments Council has recently released some research showing that half of benefits recipients fear that they will have problems managing their money, once they move onto Universal Credit.

Nearly as many have given no thought to what they will need to do differently, once their benefits arrive in a monthly lump sum, rather than at more frequent intervals.

**Pay Your Way** is the Payments Council’s consumer education campaign, and they are hoping to catch the attention of everyone who could do with brushing up their money management, not just those receiving benefits.

Check out the Money Advice Service’s **online budget planner**, which helps you to organise your monthly commitments.

One piece of advice for everyone is to prioritise your rent (or mortgage payment). This is what keeps a roof over your head, so it should take precedence - but often people make different decisions, when faced with more assertive creditors, whose demands might seem more urgent.  
<http://www.payyourway.org.uk>  
<http://tinyurl.com/o9zcy45>

## Christmas money planner

Will your Christmas spending outweigh your Christmas budget?

The Money Advice Centre have an online planner to help keep you in the black. <http://tiny.cc/pfhn4x>



The website also gives lots of independent information about all financial matters.

## UN inquiry

The United Nations is carrying out an unprecedented inquiry into “systematic and grave violations” of disabled people’s human rights by the UK government.

The inquiry was triggered by the grassroots campaigning organisation Disabled People Against Cuts (DPAC), which had grown increasingly concerned by the disproportionate impact of the coalition’s cuts on disabled people.

If you are distressed by anything external, the pain is not due to the thing itself, but to your own estimate of it; and this you have the power to revoke at any time.  
*Marcus Aurelius*

# welfare

## Lifetime DLA to PIP

The Department of Work & pensions (DWP) have confirmed that any working age DLA claimant with a lifetime award can now be 'invited' to claim DLA instead of PIP, regardless of where they live.

This means that the pilots are over, and any DLA claimant can be chosen at random between now and September 2017.

<http://tinyurl.com/ocdrewf>

## PIP to merge with ESA?

Iain Duncan Smith has now told the Guardian that he's considering merging PIP and ESA into a single benefit. Or at the very least having a single assessment for both benefits – meaning that one badly trained 'health professional' could lose claimants both benefits in a single interview.

<http://www.theguardian.com/politics/2015/oct/02/iain-duncan-smith-interview>

## Worrying MR stats

Latest statistics on PIP show that since PIP has started to replace DLA in 2013, mandatory reconsiderations (MR) are often unsuccessful.

What is mandatory reconsideration? Before you can appeal a decision about your benefits application, you have to request it is looked at again, usually by a different decision maker.

If you have been found to be capable of work, you also will not be able to get any rate of ESA whilst the process is taking place.

Once you receive the mandatory reconsideration notice, telling you whether the decision has been changed and, if so how, you can then appeal if you are still unhappy. At this point you will be able to go back onto the assessment phase rate of ESA.

It has become even more important to seek help to appeal.

Appeals have dropped by around 80% since MRs were introduced. Other stats show that PIP is the largest area of benefit appeals, with ESA close behind.

<http://tinyurl.com/peunfm8>  
<http://tinyurl.com/nvopuw4>

## Independence at risk says CAB

The Citizens Advice Bureau says people's ability to live independently is at risk due to PIP failures. People are experiencing problems with every part of the PIP application process, causing a huge amount of stress and anxiety for those going through a very difficult time....

ESA has proved a huge challenge with people complaining of problems with the application process, medical assessments and delays to awards.

With PIP now the number one problem people come to Citizens Advice with, the CAB want the UK government to avoid repeating the mistakes made with ESA and focus on its safe and steady implementation...

The top three PIP problems reported to Citizens Advice in the last year are:

- over 100,000 queries about eligibility for PIP.
- over 50,000 making and managing a claim issues, including problems with delays.

PIP challenges and appeals issues have increased, now standing at over 20,000.

More claimants are having their DLA assessed under PIP rules all the time, with the government targeting a reduction of 500,000 in DLA claimants compared to PIP.

<http://tinyurl.com/nffdtfrf>

## PIP award numbers falling

Successful new claimants represent well under half of all applications – 42% in July, which compares with 43% in June and 46% in May.

Even amongst those who were previously receiving Disability Living Allowance (DLA) and are now being reassessed for PIP, just over two thirds of claimants were awarded the new benefit in July, as against nearly three quarters in May.

An added concern: there are extremely wide variations around the country, turning a PIP application into a postcode lottery.

<http://tinyurl.com/oeqdlu9>



# welfare

## PIP 20m legal challenge fails

The Court of Appeal have rejected the appeal in Sumpter vs Secretary of State for Work and Pensions.

This was an appeal against last year's High Court ruling rejecting a judicial review challenge to the fairness of the Government's consultation process on the introduction of the Personal Independence Payment (PIP) 20 metre eligibility criteria.

Under PIP you can get an enhanced mobility component if you are only able to move up to 20 metres aided or unaided.

Previously, under Disability Living Allowance (DLA), the equivalent higher mobility award was given to those who could only manage to walk up to 50 metres.

The Court of Appeal found that the PIP consultation had been conducted fairly, if not exactly flawlessly and upheld the earlier High Court decision.

## Suicide following WCA

A coroner has demanded that the government takes action to prevent future deaths of disability benefit claimants, after concluding in a "ground-breaking" inquest verdict that a disabled man killed himself as a direct result of being found "fit for work".

<http://tiny.cc/2lqy4x>

## Thousands have died after being found fit for work

Nearly 90 people a month are dying shortly after being declared fit for work, according to new data that has prompted calls for an overhaul of the government's welfare regime. Statistics released by the DWP reveal that 2,380 people died between December 2011 and February 2014 within 14 days of being taken off ESA because WCA had concluded they were able to work.

The total figure is 81,140 people who died between December 2011 and February 2014, to which must be added the 10,600 deaths already reported between January and November 2011. This is an

average of 99 deaths per day, 692 per week, and contrasts with figures for the previous period where comparable figures are available of 32 per day, 222 per week.

The DWP correctly emphasises that "any causal effect between benefits and mortality cannot be assumed from these statistics".

They also state that "these isolated figures provide limited scope for analysis and nothing can be gained from this publication that would allow the reader to form any judgement as to the effects or impacts of the Work Capability Assessment".

Nevertheless, the significant increase in the death rate does seem sufficient reason to look more closely at the way in which the system of incapacity benefits is operating. <http://tiny.cc/2pqy4x>

## Universal credit

'7 Waiting days' - these are now introduced from the start of UC claims for some claimants. Click here for some guidance from the DWP which covers exceptions and more details.

<http://tiny.cc/psqy4x>

**Tranche 3 starts to roll out** - Haven't got Universal Credit yet? Tranche 1 and 2 have already rolled out so that half the country are now taking UC claims. Click here for a list of when tranches 3 and 4 will come on stream, in your local authority area.

<http://tiny.cc/psqy4x>

## Glossary

**CAB** Citizen's Advice Bureaux

**DLA** Disability Living Allowance

**DWP** Department of Work & Pensions

**ESA** Employment Support Allowance

**MR** Mandatory reconsideration

**PIP** Personal Independence Payment

**UC** Universal credit

**WCA** Work Capability Assessment

# U21

This edition of U21 has a definite autumn theme. Featuring articles on education, research news and the new 'Things to look out for' Page.

I've been designing charts like the one you can see on the other side of the page and speaking with the Director for Education in Carmarthenshire (see 'Back to School?').

Until next time,  
Lucy



## What you can't see about ME

I've put together MEL (The ME Labelling Lady) to point out the symptoms that directly affect people with ME but which those around us can't see. For each of us this list is just a pic n' mix of symptoms but you can make it your own by colouring in those that affect you to show your friends and family so they understand what you are feeling. Missed out something that affects you? Let me know!

# U21 Back to School?



Last week I spoke to the Director of Education in Carmarthenshire. But before I tell you more let me tell you a story...

**My Story:** When I was 14 I was too unwell to go to school but my local council had a plan.



As soon as I received a diagnosis I was allocated work to be sent home and from there I built up to an hour of home tuition three times a week to study English, Maths and Science. This increased and decreased with my health and I was never made to do more than I could.

When I returned to school the following academic year I did all my work from the flexible learning centre and managed to build up from 2 hours twice a week to 2 hours four times a week. I also had a special pass to leave and move around school comfortably. This meant I could avoid crowds and didn't overdo it.

I came out of school with two GCSEs but am about to complete a degree. Education is always an option so don't worry if for now it's not a possibility.

## What you can do:

I spoke to the Director of Education for Carmarthenshire who sent me the list of things the council can put in place. These things can include small amounts of work being sent home, having a teacher come to your house for a couple of hours a week, reduced or flexible learning time in school, morning or afternoon sessions in school and being allocated a quiet space whenever you need it. These are there to make sure you have access to education dependent on how much you can do.

Ask your parents to contact your school, SEN officer or Welfare officer see what options are available to you. For a list of options you can also contact the Additional Needs/SEN Manager at your local education department at <http://www.wlga.gov.uk/authorities> (or ask your parents to do it if you're under 16!).



# U21 Research & News



**Interested in your rights?** Check out this young people friendly, jargonless article from the Welsh government for a clear idea of where you stand and what changes you can make just by speaking up on certain issues.

<http://tiny.cc/ugbx4x>

If you would like a paper copy of this, get in touch at [u21@wames.org.uk](mailto:u21@wames.org.uk)

## Have your say:

The Welsh Government want YOUR input to decide what gets done. If an idea on how to change things, from your school to your area, is important to you then this survey should be!

<http://www.childcomwales.org.uk/en/what-next/>

Closes November 1st 2015!

## In the brain:

**This study looks at attention in children with ME/CFS and how the condition can affect the frontal cortex of the brain. It's a lot of information but definitely something worth bearing in mind.**

<http://tiny.cc/ghl24x>

Check out this page for a look at where the frontal lobe is:

<http://tiny.cc/vjl24x>

**How are you feeling? If you've experienced an increased level of sadness since having ME then you're not alone. A recent study has illustrated that ME can effect various types of development.**

<http://tiny.cc/8nbx4x>

Or for a more detailed look at the study:

<http://tiny.cc/oobx4x>

And for those of you into science:

<http://tiny.cc/xqbx4x>



# U21 Things to Look Out For

## Competition

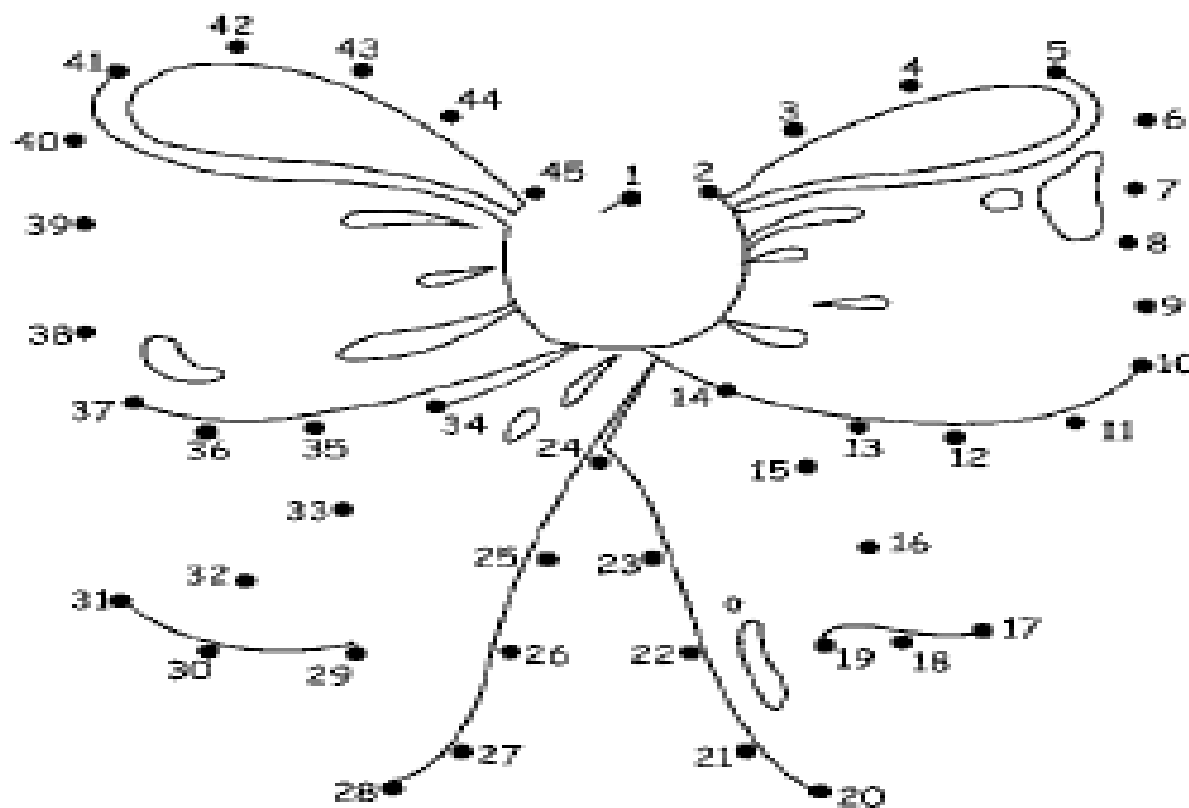
This writing competition for the annual Morgan Parry Foundation Award invites entries from anyone resident in Wales and aged between 16-19 years old.



**What to do:** You can be whoever you want to be, writing either in the present day about what you would do, or from the perspective of 2050 what you would have done, to secure Wales for future generations. The winner will receive £500 to develop the ideas and the actions described in the essay.

**Closing date:** 30 November 2015. The work should be sent via email as an attachment to [rogerthomas53@me.com](mailto:rogerthomas53@me.com) by the closing date. The e-mail message accompanying your entry should state that it is your own original work and should give your full name, date of birth, address and, preferably, a telephone number at which you can be reached. Read more:

<http://www.morganparry.cymru/>



[www.DotToDot.net](http://www.DotToDot.net)

## Dot-to-Dot:

In the last issue I used this page to talk about the benefits of colouring. But after finding puzzles like the one you can see above I have a new fascination I couldn't not share. They're very time friendly! Too easy? If you have a look online you can find many free puzzles that are a lot more complex!