me voice

the wames magazine

october 2017, no.19

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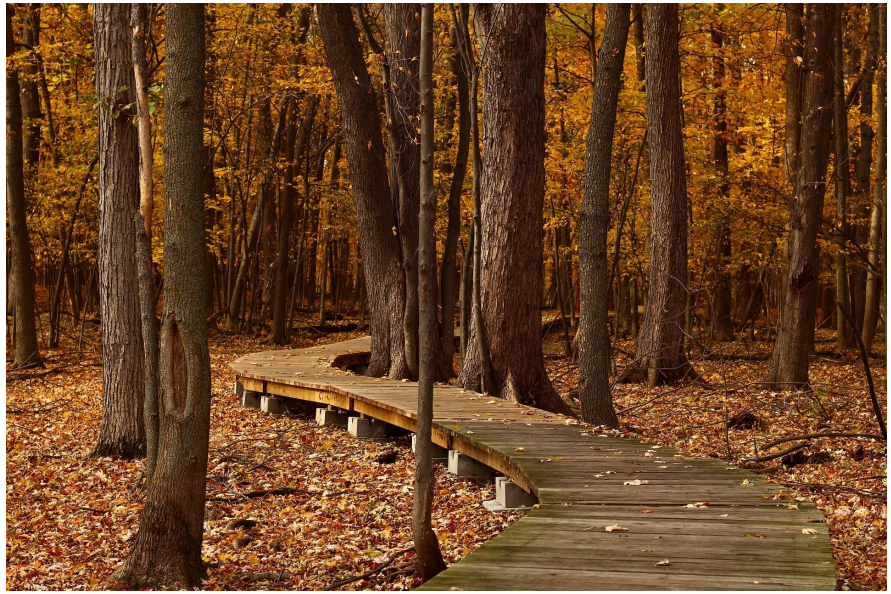

me voice

is published up to 4 times a year. You can subscribe to the paper copy for £10 p.a., or receive it free by email, or read and/or download it from www.wames.org.uk

Contact:

tony@wames.org.uk
WAMES Subscriptions,
The Coach House, Frongôg,
Aberystwyth, SY23 3HN

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

the wames information exchange

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

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

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wames on the web

www.wames.org.uk
twitter: WAMESMECFS
www.facebook.com/WAMESMECFS

Cover photo: #TimeForUnrest, see page 5

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: 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 07530 870024
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: 029 2076 2347 mesigwales@gmail.com
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group
Meets in Montgomery every few months.

Contact: Donna Teague,
dateague@hotmail.co.uk, 07413-529994
Next meeting is on the 25th October at 2.30pm for an hour, then 22nd November and 3rd January. Check before you go.

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: Rhian 01745 508524 or Rebecca.Chamberlain@stroke.org.uk
[Hosted by the Stroke Association]

Ystradgynlais Neuro Café
Open to all with neurological conditions or symptoms. Usually meets at St. Cynog's church hall, Ystradgynlais, between 1—4pm. Check before you go.

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.

me voice

editor: Jan Russell

publisher: Dr Tony Thompson

admin@wames.org.uk

wames news

me voice

Apologies for a reduced version of ***me voice***.
A lot of our time is still being taken up with writing funding bids to enable the work of WAMES to continue into the future.

So far our bids have been unsuccessful, but as soon the money starts pouring in (ever hopeful!) we will be relieved to spend more time on our key activities of campaigning, raising awareness, supporting and informing.

The team has also had a busy summer with commitments and crises, so if you have been unable to get in touch with any of us, please try again.

£1 to Keep WAMES campaigning!

13,000 people in Wales could have ME
If every family with ME in Wales gave £1, WAMES could get back to work!

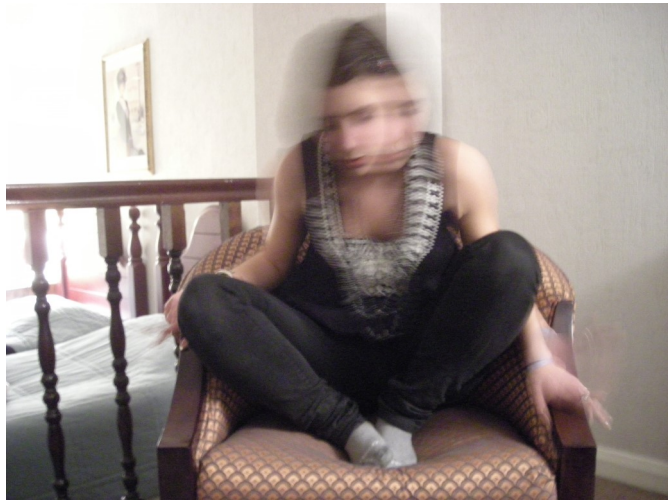
Donate online
https://mydonate.bt.com/charities/wames

OR Donate by cheque
to the treasurer at:
Cornerstones,
Clinton Road Lane,
Penarth,
CF64 3JD

ME and my World photo project

ME is a complex and often misunderstood illness.

Though a series of portraits and snapshots the 'ME and my world' project aims to show others just what living with the illness is like. We want to show what your ME world is, what happens when things are really bad, the small things you do to keep yourself going and the interests you have that help get you through.



We want to show the way ME affects people's lives and how it affects their world and those around them.

If you would be willing to be photographed or send in your own pictures that you feel illustrate your struggle with ME then please email us at WAMES admin@wames.org.uk

Tom Martin,
photographer and person with ME

Are you good with figures?

Liz Chandler has been our treasurer for over 10 years, but now needs to step down.

The role of the treasurer is to:
- Maintain an overview of WAMES' financial affairs and advise the committee on budgets
- Ensure that proper financial records and procedures are maintained

To find out more contact Jan jan@wames.org.uk
Please note:

- Training can be arranged
- Most tasks can be carried out from home
- The post is available as 'role share'
- You don't have to be knowledgeable about ME

Your work will be critical for continued campaigning and awareness raising in Wales!

WAMES medical advisor Dr Speight

Dr Nigel Speight has resumed his post as Medical Advisor for WAMES. The General Medical Council, unsurprisingly, closed the case against the retired paediatrician in July, with no action being taken. WAMES is grateful for all the support he has given to families in Wales over the years.

Thank you

to all who have responded to our plea for money. Could more of you help?

wames news

#TimeForUnrest campaign

WAMES will be supporting the international **#TimeForUnrest** campaign over the next year alongside our own Wales specific campaigns, such as this year's **#BeMEaware** campaign and a creative arts project.

#TimeForUnrest

is a global campaign to grow and strengthen the global movement for equal recognition, education, research, and funding for ME.

Unrest – the film

WAMES will be organising a few screenings of Jennifer Brea's award winning film *Unrest* and offering support to local people throughout Wales who would like to bring the film to their area.

About the film

Twenty-eight year-old Jennifer Brea is working on her PhD at Harvard and months away from marrying the love of her life when she gets a mysterious fever that leaves her bedridden and looking for answers.

Disbelieved by doctors yet determined to live, she turns her camera on herself and discovers a hidden world of millions confined to their homes and bedrooms by ME, commonly known as chronic fatigue syndrome.

At its core, Unrest is a love story. Together, Jen and her new husband, Omar, must find a way to build a life and fight for a cure. Their struggle to forge their relationship while dealing with her mysterious illness is at once heartbreaking, inspiring and funny. Watch the trailer**:** https://www.unrest.film/trailer/

WAMES can help you organise a screening by:

- putting you in touch with other people with ME in your area
- helping in the search for a suitable venue
- providing guidelines for organising a screening
- offering suggestions for funding it (the licence costs £200)
- helping to advertise the film
- providing publicity materials suitable for Wales help with setting up a display or exhibition to support the screening

Get involved on social media

- Post a picture of yourself holding the It's #TimeforUnrest because…
- sign and use the #TimeforUnrest hashtag on Facebook and Twitter.
- Encourage your friends and family to do the same!

Read more about the campaign at https://www.unrest.film/time-for-unrest/

Current 'Unrest Screening Workgroups' :

- Welsh Government
- Cardiff MEDSOC (medical students)
- Aberystwyth – Jan Russell
- Cardiff – MESiG

Please get in touch with Jan if you would like to know more. Email her in the first instance jan@wames.org.uk

Sudoku

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	5			6	
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news in brief...

NICE guidelines to be updated!

In July the National Institute for Health and Care Excellence (NICE) announced they would not be updating the CFS/ME guidelines and invited stakeholders to give their views.

There was a stampede of responses from 39 organisations, only 9 of which agreed that it should remained unchanged.

WAMES challenged the omission of a number of key issues, the inclusion of potentially harmful guidance, a misleading portrayal of the condition and the decision to overlook the failings of the PACE trial.

In September NICE announced that 'a full update with modified scope is necessary for this guideline.'

Then the NICE director Prof Nick Baker surprised many in his blog saying that the NICE guidelines were not obligatory instructions but suggestions – 'guidelines not tramlines'.

Read more:
WAMES response to the consultation:
https://tinyurl.com/y8xoseyk

NICE decision: https://tinyurl.com/y8vt48p6

NICE director's blog post:
https://tinyurl.com/y9jype83

UK All-party parliamentary party ends

The Countess of Mar, former Co-Chair of the APPG, says, "It is extremely challenging to ensure that MPs and peers reliably commit to attending APPG meetings. Despite the best efforts of the Secretariat and charity partners, there has simply not been the momentum needed to drive the changes we want to achieve.

"I believe we can exert more influence by inviting parliamentarians to attend Forward M.E. meetings, where we focus on specific and urgent issues such as the NICE guideline and provision of NHS services. In addition, I have asked to join the well-established APPG on Disability, and will strive to ensure that it considers the needs of people with M.E., including the severely affected, in its work."

Read more: https://tinyurl.com/ycqp7gur

PACE trial special issue

The Journal of Health Psychology issued a special issue of critical articles on the PACE trial in July.
https://tinyurl.com/yayodha4

Can you help design a Patient Reported

Experience Measure (PREM) for neurological conditions?

If you have, or are affected by, a neurological condition, the Wales Neurological Alliance wants your views on how best to capture health care experiences of people who are affected by neurological conditions through creating a fit-for-purpose, Wales wide survey.
Deadline: 30 Oct 2017
https://tinyurl.com/yaewm28n

ME costs UK economy £3 billion+

AfME published a report in September of a thinkhealth2020 study into the cost of CFS/ME to the UK. **Read more**: https://tinyurl.com/ycscso7x

£14 Million
UK NHS spends on dedicated specialised CFS/ME services

£542 Million
Total UK Health Service spend on people with CFS/ME

£3.3 Billion
Annual cost of CFS/ME to the UK

In memoriam

Dr Bruce Carruthers, editor of the influential Canadian Guidelines died in Vancouver in July. Read the tributes: http://wames.org.uk/cms-english/2017/07/in-memory-of-dr-bruce-carruthers/

Open Medicine Foundation

Their Pediatric ME/CFS web page contains information about ME for parents, doctors and educators from a US perspective, but much is helpful in the UK
http://wames.org.uk/cms-english/2017/09/omf-resources-for-parents-of-children-with-mecfs/

news in brief...

ME Research Conference Videos

Lectures of talks by top researchers can be viewed or purchased online:

CFS/ME Research Collaborative conference, September 2017 https://tinyurl.com/y9b9ay43

Community Symposium on the Molecular Basis of ME/CFS, August 2017 https://tinyurl.com/ya66kmpm

12th Invest in ME Research International ME Conference, June 2017 - order conference DVD https://tinyurl.com/y7yf4hr8

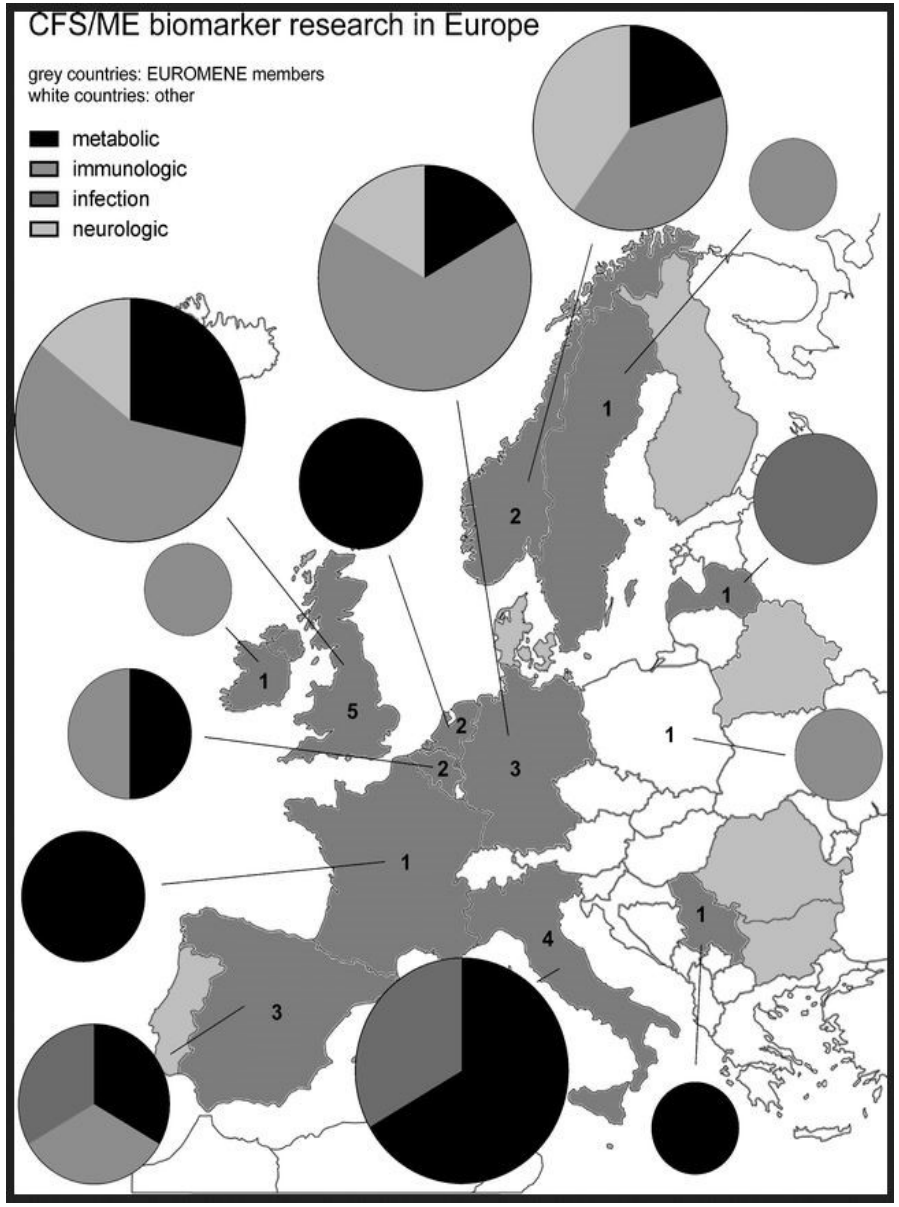
New research projects

The UK ME/CFS Biobank gets £1.57m from the US to measure changes in the immune system https://tinyurl.com/y9agh4wn

Irritable bowel & ME study is to be funded by ME Research UK http://www.meresearch.org.uk/our-research/ongoing-studies/gut-immune-and-microbiome-changes/

AfME invites PhD proposals for biomedical research pilot projects by 27 Nov 2017. They will pay 50% of the cost. http://wames.org.uk/cms-english/2017/10/afme-invites-phd-proposals-for-biomedical-research-pilot-projects/

The European ME/CFS Biomarker Landscape project - the EUROMENE network of European researchers and clinicians aims to promote cooperation and advance research on ME/CFS.



Recent research results

Biomarkers indicate CFS severity
Researchers at the Stanford University School of Medicine have linked chronic fatigue syndrome to variations in 17 immune -system signaling proteins, or cytokines, whose concentrations in the blood correlate with the disease's severity https://tinyurl.com/y9a2apdq

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SMILE trial – Lightning Process
Dr Crawley's trial of LP in teenagers concluded:

- At 6 months, children who received LP in addition to SMC had better physical function, less fatigue and anxiety.
- At 12 months, children who received LP in addition to SMC had less fatigue, anxiety, depression and better school attendance.

Adding LP is probably cost-effective but not all children wish to take part.

Read more about the trial & LP on p 9. Criticisms abounded in the media: https://tinyurl.com/y98donx2

ME in young people

Dr Nigel Speight is one of the contributors to new guidelines on ME in young people:

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: a Primer
https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full

news in brief...

United Nations chastises UK government

In 2015 the United Nations began to investigate allegations that the UK were violating the rights of disabled people enshrined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), through welfare reform and austerity measures.

In 2016 the UN issued a report with 11 recommendations condemning UK government actions and calling on them to carry out a study of the cumulative impact of all spending cuts on the disabled & to ensure human rights of the disabled.

The Government rejected the findings of the UN report that austerity measures have disproportionately affected ill and disabled people, in spite of continued lobbying by disability rights groups for them to implement the recommendations.

In early 2017 disability rights groups submitted a "shadow report" to the UN Committee highlighting the continued failure to comply and in June the UN committee announced that it had found the UK government's breaches of the human rights treaty were both "grave" and "systematic".

At the end of August the Committee released damning Concluding Observations on the UK, following its first Review of the government's compliance with the Convention.

The highlights of the press conference held by the UN Committee on the Rights of Disabled People at this afternoon are:

- The Committee has made the highest ever number of recommendations to the UK.
- The UK's retrogression in ensuring Independent Living is a major concern. There is not adequate funding, resulting in too much institutionalisation.
- There is a significant problem with Deaf and disabled people's standard of living.
- Disabled people continue to be disadvantaged in employment, and are not adequately compensated for disability by the state.

The big question is what next? The government continues to show no sign of caring about the consequences of its political agenda for the most vulnerable in society .
https://tinyurl.com/y8q6aoy4

Ill & disabled in the workplace

Offering flexible hours to all job applicants will help combat pay disparities and increase job opportunities for disabled people, according to a new report by the Equality and Human Rights Commission.

Fair opportunities for all:
https://tinyurl.com/y8o2499n

Action for ME's ***Support, Empower and Employ people with M.E. (SEE M.E.)*** was a pilot project that transformed employment outcomes for people with ME in the South West of England.

By responding directly to the needs of people with ME, and those that support them, *SEE ME* provided crucial tailored and expert support, empowering people with M.E. to stay in work, return to work or leave work well.
https://www.actionforme.org.uk/living-with-me/managing-work/see-me-project/

Are you self-employed?

If you have ME and have set up your own business, tell us about your experiences so others can learn more and decide if it is for them.

AUTUMN WORDSEARCH

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Breezy·····Poppies
Changing·····Raincoat
Crunchy·····Robin
Fireside·····Rust
Halloween·····Scarecrow
Harvest·····Season
Hibernation·····Thanksgiving
Leaves·····Umbrella
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Created by Puzzlemaker at DiscoveryEducation.com

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

SMILE trial

The results of Dr Esther Crawley's controversial study of the Lightning Process in young people was published in September.

She concluded that: *The LP is effective and is probably cost-effective when provided in addition to Specialist Medical Care for mild/moderately affected adolescents with CFS/ME.*

ME experts are still not convinced and even Dr Crawley admits there are many questions still to be answered. She says:

"I'm not advocating people go out and get the Lightning Process. And we don't know if it works for adults and we don't know if it works for primary school-age children."

What is the Lightning Process?

The Lightning Process (LP) is a three-day personal training programme developed by British osteopath Phil Parker. It claims to be beneficial for various conditions, including Chronic Fatigue Syndrome, depression and chronic pain.

- It is expensive - £620 a course
- It is intensive – 3 long hard days of talks and activities

It uses a combination of:

- osteopathy - moving, stretching and massaging a person's muscles and joints
- life-coaching - teaching ways to confidently face difficult situations and push past emotional barriers
- brain training (Neuro Linguistic Programming or NLP) - techniques to help change patterns of thinking and behaving

People who have done the course say they are told:

- To believe that Lightning Process will heal you
- Tell everyone that you have been healed
- Perform rituals like standing in circles drawn on paper with positive words written on them
- Learn a short rhythm to use whenever you feel the symptoms
- Talk only in positive terms and think only positive thoughts
- If you have symptoms or negative thoughts, stretch your arms with your palm pointing outwards and shout *Stop!*

- You are responsible for having ME yourself. You choose to have ME yourself. But you are free to choose a life without ME if you want to.

The big question is how you can measure if the process works when everybody is told to say it does, even if they feel awful!

Student: I'm not going back to school ever again!
Parent: *Why ever not?*
Student: The teacher doesn't know a thing, all she does is ask questions!!

Teacher: I hope I didn't see you looking at Fred's test paper.
Student: I hope you didn't see me either!

U21 Number Puzzle

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×	■	-	■	+	■	+	■	+	
	×		-		+		+		168
+	■	+	■	+	■	×	■	-	
	+		-		×		+		-172
49		-13		108		409		17	

Created by Puzzlemaker at DiscoveryEducation.com

Try to fill in the missing numbers.

Use the numbers 1 through 25 to complete the equations.

⇒ Each number is only used once.

⇒ Each row is a math equation. Each column is a math equation.

⇒ Remember that multiplication and division are performed before addition and subtraction.

Back to school?

School or college isn't always the best place to be when you have ME.

Even if you have the energy to get there, then there are the lights, noise (often a lot it), chatting, sitting on a hard seat for 45 minutes while concentrating hard, then walking to the next class with a crowd of people pushing and shoving is all too much.

That doesn't mean you have to give up on an education. There are many ways you can learn from home but not be on your own.

Sharon Price explains how she teaches French and German online:

Online tuition - how does it work?
It is just like being in a room for a one-to-one teaching session in person – but via a computer. All you need is a computer/tablet and a webcam and microphone.

The teacher and student can see and hear each other. I generally use Skype, so I can instantly send a student the spelling or phonetic pronunciation of phrases for example, as we talk. Classes can also be recorded to listen to again if necessary. Skype is quick, easy and free to install and use.

Worksheets and audio files can be emailed before, during and after lessons. Homework can also be emailed, and detailed feedback provided.

The great advantage of online learning is that you can learn in the comfort of your own home, or wherever you happen to be, cutting down on travel time if you are busy, or making learning accessible if you have mobility problems or are housebound for any reason. It also means that it is possible to teach anyone, or learn from anyone, anywhere in the world!

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Sharon got ME when still at school but is now well enough to work part time as a teacher, so she understands the score. Find out more about her business at http://www.languagesforliving.co.uk

Which online learning schemes have helped you? Look over the page!
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Other private learning options:
Nisai Virtual Academy https://tinyurl.com/ybsk37uc

Coleg Gwent e-courses
https://tinyurl.com/y878gbr2

Some free resources are available at the BBC to help you sit exams:
BBC Bitesize http://www.bbc.co.uk/education

For a more informal learning experience try the BBC learning zone:
http://www.bbc.co.uk/programmes/p01b8f09

Virtual Reality Headset caution

Virtual Reality headsets are in the news at the moment, with reports that prices will soon be coming down. A caller to the WAMES helpline told us that after using a virtual reality headset for just a few seconds a person with ME reported disturbed vision, extreme nausea, increased brain fog and a worsening of all their symptoms for several days afterwards.

Please be cautious about your use of this type of headset. Let us know if you have had similar problems.

Raising awareness through photography

See page 4 for how you can get involved in the WAMES awareness photography project.

U21