



me voice

the wames magazine
august 2015, no. 13

WAMES
Welsh Association of ME & CFS Support

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Senedd Building, Cardiff Bay

me voice

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Contact:

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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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support

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

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

Brecon Area Contact

Richard Jones 01874 622310
richard.j5@btinternet.com

Carmarthenshire ME Group

Meets in Coleshill Social Centre, Llanelli every 2 months.
Next Meeting: 3 Oct, 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: 4 Sep 10-11.30,
19 Sep 7-8.30,
2 Oct
Contact: Beth 07974 543874
www.cwtch-pembrokeshire.co.uk
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: 1 Sep, 15 Sept (Carers Social) 6 Oct, 20 Oct.
fibrowestwales@hotmail.com
<http://fmmecfswestwales.jimdo.com>

ME Support in Glamorgan (MESiG)

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

Next meetings:
10 Aug 2pm (Tea in Roath Park)
7 Sep (Art workshop)
12 Sep (Fundraiser day) at Maes y Coed Community Centre, Heath 12-4pm

Contact: Christalla Bailey,
029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group

Meets in Montgomery every few months.

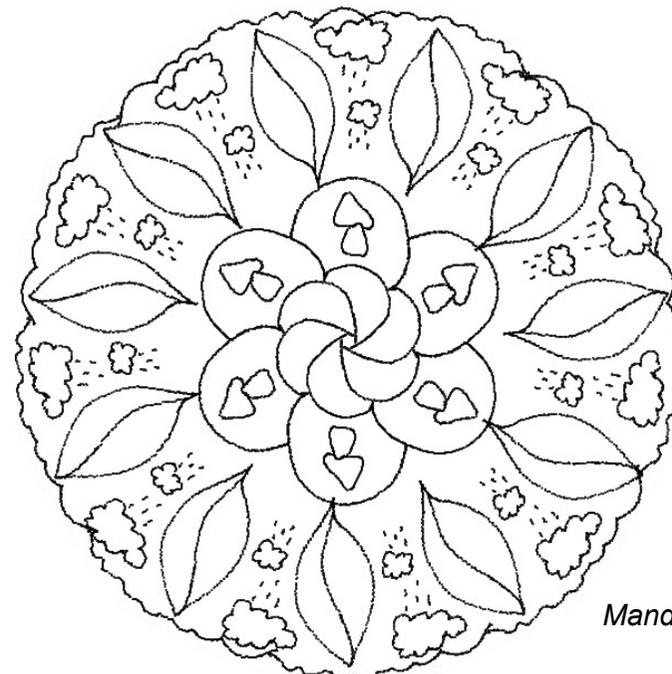
Next meeting: late August
Contact: Mike or Karen
0796 9665419 (between 2-4pm)
karen@kandm46.plus.com

Ystradgynlais Neurological 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)



Mandala

Colouring-in has become a popular method of relaxation. People who colour mandalas often experience a deep sense of calm and well-being.

Mandalas not only focus your attention, but allow you to express your creative side, which many of us neglect in our daily lives.

Mandala means circle in Sanskrit

3rd Wed (education/info sessions)
Next meetings: 2 Sep, 16 Sep,
14, 28 October
Contact: Caroline Bull 01639 849 192
cbullyvc@gmail.com

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

wames news

New secretary for WAMES

WAMES welcomes Kishli Laister Scott to the committee. She is a part time charity worker who believes admin is important – an ideal secretary!



Kishli says:

I first became ill when I was around 13, but it took several years and many trips to the doctor to finally get a diagnosis of ME.

When I was first diagnosed, there was still a great deal of stigma attached to ME, and no-one could offer any treatment or advice, and I was given no extra support in school, but managed to pass my GCSEs and A-levels, and started a degree in

English Literature in Cardiff University.

The first year was a massive struggle, as it involved a long bus journey and 30 minute walk each way from the bus stop to university, but during the second year I noticed an improvement in my condition (for reasons I could never fathom – it certainly wasn't the diet!).

The improvement was so dramatic that I assumed that I had grown out of ME (as all the doctors had said I would) and started a part-time job alongside my studies. I was in good health for a number of years, but then in 2005 I experienced my first relapse, followed by two more serious ones, each of them triggered by a virus and lasting months rather than years (for which I am grateful).

Since my initial diagnosis over 20 years ago, I have seen improvement in how ME is treated by my doctors, and I am lucky to be currently under the care of a supportive doctor, but I have been frustrated at the lack of real progress in terms of research and treatment, and the inconsistencies of services, which led to me joining WAMES.

We have a real chance of achieving a step-change in how ME is treated by the NHS in Wales, and I am very excited to be part of such an important movement.

Lucy joins the editorial team

Lampeter University Student Lucy Fox will be editing the pages of **me voice** for people "Under 21". Find out more about her at page 17.

Can you help?

Welfare editor needed

Do you keep up to date with benefits and disability issues?

We are looking for someone to edit the Welfare section of **me voice**.

This would involve selecting the key stories of interest for people with ME, since the last issue, and supplying items for the newsblog. No experience of magazine production is needed.

Contact Jan for more information.

Fundraise

Help us to meet the costs of the Health services campaign so we can raise awareness of ME in every corner of Wales.



Easy fundraising

Raise money effortlessly every time you shop online from any of the above, and lots of others.

www.easyfundraising.org.uk

Paddy says, "Mick, I'm thinking of buying a Labrador." "Really?" says Mick. "Have you seen how many of their owners go blind?"

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."

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

It's just spam

wames news

Severe ME day

This year WAMES joined with the 25% ME Group on Sat 8th August to raise awareness of the home care needs of people with severe ME.

Helplines run by WAMES and local groups in Wales receive many distressing calls from people who find that doctors, nurses and social services don't believe they can be as ill as they are. This has sometimes led to a refusal to provide support and aids.

Carers and care givers can be told to encourage patients to do more for themselves, without 'props'. This leaves the person with severe ME feeling unsupported and vulnerable, and sometimes even wondering if their life is worth living.

Helen Brownlie of the 25% ME Group describes the problem:

It's become mainstream thinking to imagine that, instead of responding to need by providing ongoing care provision, people seeking support can and should be 're-abled'. The 'thinking' goes something like this:

Ongoing care support = 'dependence' = bad
'Re-ablement' = regaining 'independence' = good

WAMES asks health and social care professionals to **listen** to their patients with severe ME:

Believe me

- I really am very ill and can become more ill if I do too much (post-exertional response).

Work with me

- don't push me to do more before I am able. Help me to find the best approach and speed of change for me.

Please don't blame me

- if I don't recover as quickly as you think I should. I haven't chosen to be ill and I do want to get better.

More info: *Home care is the theme for Severe ME Day* on August 8th, by Helen Brownlie
<http://phoenixrising.me/archives/27607>



Severe ME

“Not sick enough for acute care hospitals, too sick for nursing homes or rehab, sometimes too ill to be at home with care, too ill to be in an independent living facility and I don't have cancer or AIDS so hospice is out.”

**From "The Bardo of ME"
by Liisa Priyanka Lugas.**

news from wales

tell your me story to nhs wales

Would you like to help shape healthcare for people with ME?

At the last ME-CFS and FM Implementation Group meeting, some Health Boards in Wales reported that they are now beginning to organise *stakeholder meetings*, where people with an interest in services for ME, CFS and FM come together to discuss how to improve services.

Planning is more advanced in some HBs than others (see p7 for more info about your HB), but all will eventually be looking for patients and carers to contribute their story of:

- what it is like to live with the illness
- the good and bad experiences you have had finding a diagnosis and accessing services in the health board area.
- which services would be most helpful

Some health boards will invite people to an open meeting to hear their views and stories.

Some are asking for written or video stories to be used by the planning group or in training sessions.

NHS staff will be forming planning groups to develop pathways and services and it may be possible for a small number of patients or carers to be involved with this. Each HB stakeholder group will decide what information they need and how they will gather that.

How to take part

Please let Jan know how you would be willing to take part, by emailing, ringing or writing to her.



She will need your contact details but will keep your identity hidden from the HB, if you wish.

This is a great opportunity to influence services so pass the word around. We must however be realistic and accept that for the moment all Health Boards are struggling to staff services and balance their books, so changes will take place gradually.

The biggest impact we can have in the short term is to help improve the understanding of ME throughout the NHS.

Can you:

- Tell your story in person in a meeting of professionals, patients and carers?
- Take part in discussions about ME at a meeting?
- Write or record your story of ME and accessing health & social care?
- List some key points you wish the Health Board to know about?
- Work with others in a planning group to find the best way of delivering care using existing resources?
 - Be part of an e-group to review documents such as action plans, pathways, reports?



When?

Powys and **ABMU** health boards expect to hold their first stakeholder meeting in early September so please send stories from Powys, Swansea, Bridgend and Neath Port Talbot as soon as possible.

Once you have told Jan how you wish to take part she will let you know as soon as she has more information about your Health Board's plans.

Contact:

Jan Russell enquiries@wames.org.uk

01970 636515

The Coach House, Frongog, Aberystwyth

Images courtesy of Photostock & num_skyman at FreeDigitalPhotos.net

news from wales

nhs services update

The *ME-CFS & FM Implementation Group*, chaired by Prof Jonathan Richards, has met twice during the first half of 2015. This Group gives Health Boards (HBs) a chance to share experiences and encourage each other in implementing the recommendations of the Government's Task & Finish Group Report. Patients are represented by Jan Russell for ME and Carol Ross for FM.

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.

Next meeting of Implementation Group: November 2015

More info: Task & Finish Group Report <http://tiny.cc/gbcf1x>

2015 Health Board goals:

- appoint executive lead to oversee service development & be an advocate at Board level
- appoint clinical lead/s to implement Report recommendations
- identify HB healthcare 'speciality' with responsibility
- develop a 3 year action plan
- begin to hold stakeholder group meetings

Progress to date:

Hywel Dda University Health Board

(Ceredigion, Carmarthen, Pembrokeshire)

Executive lead: Kathryn Davies Director of Therapies & Health Sciences

Clinical Lead: Medical Consultant to be confirmed

Reports to: Musculo-Skeletal Population Group

Activities: Stakeholder (Pathway) group set up 2013
Draft action plan, draft adult pathway overview, GP guide

Powys teaching Health Board - PtHB

(Montgomeryshire, Radnorshire, Brecknock)

Executive lead: Amanda Smith, Director of Therapies & Health Sciences

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

Fatigue Management Service

Reports to: Neurology Steering Group

Activities: Stakeholder groups planned for Sept, Draft Action Plan

Abertawe Bro Morgannwg University Health Board - ABMUHB

(Swansea, Bridgend, Neath Port Talbot)

Executive lead: Hamish Laing, Medical Director

Clinical lead ME: Clare Clark, OT Advanced Practitioner

Reports to: To be confirmed

Activities: Stakeholder group planned for September 2015,
Draft action plan, GP questionnaire

Aneurin Bevan Health Board

(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: Draft action plan

Cardiff & Vale University Health Board - CVUHB

Lead: Jane Boyd, Clinical Director for Psychology and
Counselling Services

Activities: plans to develop joint action plan with Cwm Taf UHB

Cwm Taf University Health Board

(Merthyr Tydfil and Rhondda Cynon Taf)

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

Clinical lead: Prof Jonathan Richards, Visiting Professor of Primary Care,
University of South Wales and Locality Clinical Director,
Cwm Taf UHB

Reports to: to be confirmed

Betsi Cadwaladr University Health Board - BCUHB

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

Executive lead: Prof Matthew Makin, Director of Primary Care

Clinical lead: Simon Neal (to be confirmed) Consultant Clinical
psychologist & Head of North Wales CFS/ME service

Reports to: Neurology Network

Activities: Draft Action plan

news from wales

Healthcare in the news

Discussions about ME health service improvements are taking place in Health Boards, which are facing many other challenges.

The news headlines over the last few months have included:

People in Wales have less confidence in the NHS than across the border in England, a new survey has found.

(29 June *Walesonline*)

Three-quarters of hospitals, GP surgeries and dentists needed improvements last year to ensure 'safe and effective' care.

(23 July *Walesonline*)

Doctor shortages at Pembrokeshire hospital means hundreds of patients will be diverted to another county.

(17 July *Walesonline*)

New plan to recruit and retain GPs in Wales and boost primary care services is unveiled by the Welsh Government .

(17 July *Walesonline*)

Welsh NHS spent nearly £190m on agency doctors and nurses in the past four years, new figures reveal.

(31 July *Walesonline*)

Betsi Cadwaladr University Health Board (BCUHB) placed in special measures (8 June)

Mental health ward slammed for 'inadequate' health and safety recording, 'dirty' utility rooms and lack of beds. Despite good examples of patient care, Healthcare Inspectorate Wales (HIW) said urgent improvements needed to be made at the Heddfan unit at Wrexham Maelor Hospital.

(15 July *Walesonline*)

Betsi Cadwaladr spent £72m on locums and agency staff over four years.

(31 July *Daily Post*)

Severe staff shortages leave GP out of hours in BCUHB in crisis (31 July 2015)

Patients stuck in ambulances outside Welsh hospitals for 9 hours. (19 July)

Ambulance response targets scrapped by Welsh Government in overhaul .

(29 July *Walesonline*)

£600m shake up of hospital services for south-west Wales revealed.

(27 July *Walesonline*)

New five-year plan launched to tackle suicide and self harm in Wales. Each year in Wales between 300 and 350 people die from suicide - about three times the number killed in road accidents (16 July 2015 *Walesonline*)

One in seven cancer patients in Wales are still waiting too long for treatment, new figures reveal.

(15 July *Walesonline*)

Further info: www.walesonline.co.uk/

Consultations

Betsi Cadwaladr seeks service users views

Since Betsi Cadwaladr Health Board was placed in special measures they have been asking service users for their views on what needs to be done to improve services.

You can meet NHS staff at public events, email or ring them take the online survey by 30 Sep 2015.

www.nwwaleshaveyoursay.org

0800 169 3142 (Mon – Fri 9-5)

NWalesHaveYourSay@wales.nhs.uk

Living Healthier, Staying Well
FREEPOST, RSZZ-SGX



Do you care for a family member or friend?

BCUHB is seeking carers to become involved in a North Wales Carers Reference Group. The aim of the group will be to offer advice and feedback to the Health Board on the impact of services on carers and help create a culture of carer involvement at all levels within the Health Board.

The group will meet at least twice a year at locations across North Wales. The Health Board will reimburse reasonable travel costs, respite, child care or other expenses incurred by Carers through attending the meetings.

Contact:

Jane Berry, Carers Measure
Project Manager on 01745 448740
Ext 2492

news from wales

Health Green Paper

The Welsh Government is seeking your views on how they can improve quality and governance in the NHS.

Green Paper: Our Health, Our Health Service

Deadline: 20 November 2015

<http://tiny.cc/d0bi1x>

HQDmailbox@wales.gsi.gov.uk

Matthew Tester

Healthcare Quality Division

Department of Health and Social Services, Welsh Government

Cathays Park, Cardiff CF10 3NQ
029 2082 6498

Non Emergency transport

The Welsh Ambulance Services Trust (WAST) is looking at ways they can improve the Non Emergency Patient Transport Service (NEPTS) in Wales. Let them know what you think:

ppi.team@wales.nhs.uk

01792 776252 Ext 45400

More info: <http://tiny.cc/yzci1x>

People in the welsh news

Cash for Milford Haven ME group

A support group helping people with ME/CFS and FM, and their carers, will receive £240 towards stationery, fuel and room hire costs. *Western Telegraph (Pembroke), p 42*

Gwyn Hopkins

Walked for 12 days across Wales, covering 150 miles in June and raised over £1,000 for ME research.

<https://www.justgiving.com/GwynethHopkins/>

Stephen Forward

from Newport Gwent talked about his flu like symptoms following many years of working with sheep dip chemicals. His MP Jessica Morden demanded answers from the government about at least 500 suspected cases of sheep dip poisoning during a debate in parliament.

<http://tiny.cc/s4ci1x>

Ashleigh Johnstone

A psychology student with CFS graduated from Bangor University with 1st class honours

<http://tiny.cc/z5ci1x>

News from the alliances

WAMES works with many patient alliances because we can have a greater impact when campaigning with other patient groups on issues

we have in common.

If you would like to represent WAMES and ME in your area, contact Jan.

C&VLTCA

Cardiff & Vale Long Term Conditions Alliance

<http://tiny.cc/egdi1x>

Next meeting: 9 Sep 2015, 10-12

MANGO

The Montgomeryshire Neurological Alliance has folded due to shortage of officers. This coincides with the departure of their project worker. Once a new organisation takes over the *Neuro Voice Powys* (NVP) project a replacement project worker covering all of Powys will be recruited.

In the meantime Jan Russell will represent NVP on the Neurological Delivery Plan steering group for Powys.

www.nvp.org.uk

SGLTCA

South Gwynedd Long Term Conditions Alliance - The Good Health Event this year will be held on Friday October 16 (10am-2:00pm) at the Glan Wnion Leisure Centre, Dolgellau

www.southgwyneddlitca.org.uk

SWWNA

The South West Wales Neurological Alliance has been involved with the Neurological Delivery Plan and

carrying out pilot trails of a Health Passport and Medic Alert ID bands.

www.swwna.com

Next meeting: 23 Sep 2015

WWNA

West Wales Neurological Alliance operates in the Hywel Dda area of Ceredigion, Carmarthenshire and Pembro.

www.wwna.org.uk

WNA

The Wales Neurological Alliance brings together organisations representing people affected by neurological conditions in Wales to improve services. This is done by influencing policy, raising awareness and developing services. Recent work areas include:

- Cross-Party Group
- Neurological Delivery Plan
- Wheelchair and Posture Partnership
- Brain Repair And Intracranial Neurotherapeutics (B.R.A.I.N) Unit
- Patient Reported Experience Measures (PREMS)
- The North Wales Neurosciences Network

www.walesneurologicalalliance.org.uk

Social care information

The website, My Local Health Service, launched in September 2013 with information on health boards, hospitals and GP surgeries, has been re-launched as *My Local Health and*

crossword

TV Quiz Gameshow Programmes

Across

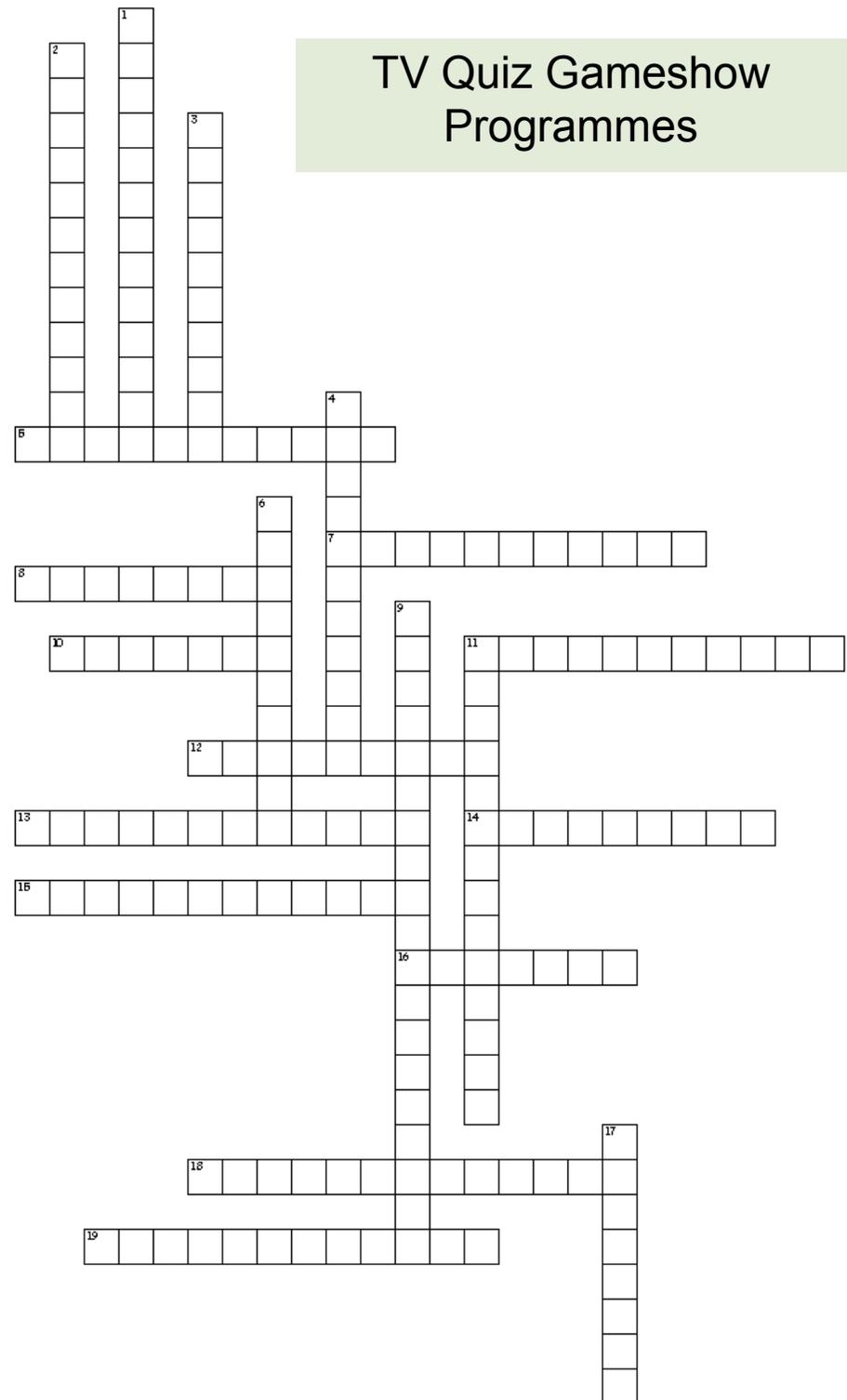
5. Famously known for the hosts wink at the end of each show.
7. Involves travelling through 4 zones to the dome.
8. General knowledge quiz show on BBC2 hosted by Jeremy or Dermot.
10. A square hosted by Phillip Schofield
11. Game show where contestants 'say what they see' hosted by Stephen Mulhern.
12. The aim of the game is to score zero.
13. Square box compulsion or game show from 80s hosted by Noel Edmunds.
14. Game show using a mix of consonants, vowels and numbers.
15. Famous for the big red balls.
16. Jump in a taxi, answer some questions and win some dough.
18. Chemical with atomic no. 36 and another word for reason.
19. 80' game show hosted by Bob Holness where contestants are 6th formers.

Down

1. -----
2. Start with 3 x 5 then a word and end with the first number.
3. Roman soldiers.
4. Epigraph to E. M. Forster's 1910 novel 'Howards End'.
6. Young sir plus ---- over matter.
9. Higher education competition.
11. A game of noughts and crosses.
17. Married male and female titles.

Created by Puzzlemaker at DiscoveryEducation.com

Answers to the Crossword and Cryptogram on page 15



carers

Time to be heard

Ground breaking new research by the Carers Trust shows the shocking impact of caring unpaid for a family member or friend on young adults in their education and when looking for work.

The first large-scale survey of carers aged 14-25 shines a light on the lives of some of the 375,000 young adults in the UK, young people who pick up the pieces when their families with care needs are left without adequate support.

Key findings are that young adult carers:

- Miss or cut short multiple days of school, college, university or work each year because of their caring role.
- Have higher rates of poor mental and physical health than the average young person.
- Rarely receive the assessments they are entitled to, with only 22% of those surveyed receiving a formal assessment of their needs by the local authority.

Carers Trust is recommending that:

- The Government should provide sufficient funding and monitoring of the implementation of the Care Act 2014 and Children and Families Act 2014.
- Young adult carers and their families should receive appropriate assessments and the care needs of the whole family should be met.
- Young adult carers should not be unduly relied on to provide care.
- The Government should include young adult carers in additional financial support programmes, such as Pupil Premium, the 16–19 Bursary Fund and the criteria for university access agreements so that young adult carers are



identified and given the support to do well in their education.

- The NHS and local government should support a national network of young adult carer services to improve young adult carers' wellbeing, ensuring their rights to assessment and support are respected. This is also necessary so that their views are represented within local and national decision making.

Careers guidance, training and employability programmes should recognise young adult carers as a vulnerable group and provide sufficient information for them to plan for training and/or employment

More info: CarersTrust
www.carers.org/timetobeheard

Report: *Time to be heard*
<http://tiny.cc/vw6p1x>

Carers Allowance Digital Service (CADS)

This bilingual service enables carers to make claims or report changes of circumstances online.

The process is user friendly and feedback so far is that it yields speedier results than filling out a form by hand and then sending it through the post.

www.gov.uk/carers-allowance/

NB the earnings threshold for Carers Allowance increased to £110 a week in April 2015.

Carers and the Budget

Following press speculation of a cut to **Carer's Allowance**, carers will be relieved that it has not been cut.

It will increase in line with the Government's measure of inflation, the Consumer Price Index. The Carer premia on other benefits will also rise with inflation even where the rest of the benefit is frozen.

Disability benefits and related premia will also rise with inflation.

The protection of carers and disability benefits is welcome, but carers receiving other working age benefits such as income support will see at least part of their income affected by this freeze.

From April 2016, a new **National Living Wage** of £7.20 an hour for the over 25s will be introduced. This will rise to over £9 an hour by 2020.

National Minimum wage rates are usually updated every October. The Government has announced a review to align it with the tax year.

Whilst this increase is welcome in itself, it threatens to cause significant difficulties for carers over 25 who are currently entitled to Carer's Allowance. To be entitled, a carer can earn a

carers

maximum of £110 per week after deductions.

The National Living Wage will take those working 16 hours or more (the minimum requirement for many to receive WTC) over this threshold meaning they will have to choose between cutting their hours (if that is an option) and missing out on WTC or lose out on Carer's Allowance.

Carers UK believes the right long-term solution is to remove this 'cliff edge' earnings limit altogether and introduce an 'earnings taper' so that the benefit is gradually reduced with earnings. For those receiving **Working Tax Credits**, the National Living Wage increases will be partly offset by reductions in the amount of Working Tax Credits.

[From *Carers UK Policy briefing*]

Few carers go on holiday

More than two thirds of carers questioned by the Carers Trust for their latest research said that they wouldn't be going on holiday this year; half haven't had a holiday for between one and five years, while a further quarter haven't been away in the last five years at all.

Some statistics:

- 68% of carers won't have a holiday this year
- 30% never get any sort of break
- 7% get a daily break
- 63% spend their break time doing chores
- 20% simply sleep when they get a break. Of those carers who never get a break, more than half say that there is no-one else to take over from them. 41% couldn't take a holiday because they can't afford it, and almost a third (30%) had no-one to pick up responsibility for the person they care for if they went away.

Carers Trust are trying to provide breaks and support for unpaid carers.

Carers Trust wants "Britain's Best Breakfast" to raise money to support all unpaid carers and give them a break from their caring role through its network of carer centres and schemes.

More info: text egg to 70660
www.britainsbestbreakfast.org



Being Heard: a self-advocacy toolkit for carers

Self-advocacy is about enabling someone to get their own voice heard. For carers, this means speaking up for ourselves and for the person we're caring for.

The Carers Self-Advocacy Toolkit is a group of integrated resources to help carers get their voices heard.

The *Being Heard* guide provides information and suggests techniques to help carers advocate for themselves.

The Toolkit also features separate satellite resources, designed to enable carers to take a deeper look at different techniques or aspects of self-advocacy e.g.

- About loss
- Behaviours & body language
- Being objective
- Complaints
- Dealing with anger
- Dealing with anxiety
- Email etiquette
- Extrovert or introvert
- How assertive are you?
- How do you communicate?
- How do you see your own needs?
- How to be more assertive
- How to manage your stress
- Mind your language
- Mindfulness
- Optimist or pessimist?
- Preparing to negotiate
- Reflecting on events
- The drama triangle

Download: <http://tiny.cc/d0bi1x>
0808 808 7777
info@carerswales.org

A mummy covered in chocolate and nuts has been discovered in Egypt .

Archaeologists believe it may be Pharaoh Rocher.....

welfare

Summer budget

The Chancellor set out savings of £17bn, with £12bn coming from welfare cuts and £5bn coming from tax evasion/avoidance measures.

Further savings will come from departmental budget cuts, to be set out in the Autumn.

Welfare cuts

The £12 billion savings to the welfare bill are to be gained from a number of different areas including freezes to many benefits, a lowering of the benefit cap, significant changes to Tax Credits and a number of changes to support with rent and some changes to mortgage payments for householders.

There were changes to maintenance grants for those in higher education, which will become a loan based system. The Chancellor also announced a new 'National Living Wage' for those over 25 years old.

Benefits freeze

Most working-age benefits will be frozen for four years from April 2016. This will apply to Jobseeker's Allowance; Employment and Support Allowance; Income Support; Child Benefit; applicable amounts for

Housing Benefit; and Local Housing Allowance rates, with provision for high rent areas.

It **excludes** Maternity Allowance; Statutory Sick Pay; Statutory Maternity Pay; Statutory Paternity Pay; Statutory Shared Parental Pay; and Statutory Adoption Pay; disability, carers and pensioners' premia in the frozen benefits; the Employment and Support Allowance Support Group component; and other disability, carer and pensioner benefits, which will continue to be updated in relation to prices or earnings as applicable.

<https://www.gov.uk/government/topical-events/budget-july-2015>

Compassionate Britain

Compassionate Britain has been founded by Christians, inspired by Jesus' compassion, who are campaigning with other organisations to protect the most vulnerable and petition the government to stop the cuts falling disproportionately on disabled people.

They ask people to sign their petitions, sign up for campaign updates, write to your MP, write for them or tell your story.

<http://compassionatebritain.org.uk>

PIP

The UK government announced that the DWP started to invite all remaining claimants of Personal Independence Payment (PIP) from 13 July. This means people who currently have a long-term or indefinite award of DLA.

By late 2017 all existing DLA claimants (aged 16 to 64 on 8 April 2013) will have been invited to claim PIP'.

Disability poverty rises

The proportion of disabled people living in poverty rose sharply in the fourth year of the coalition government, according to official figures.

The figures show that – after housing costs are taken into account – the percentage of people living in households where at least one member was disabled who were in “absolute poverty” rose from 27 per cent in 2012-13 to 30 per cent in 2013-14, an increase of about 10 per cent in just one year.

And they show that the number of people in “disabled households” who were living in absolute poverty rose by 300,000 in that one year.

Once income received through disability living allowance, attendance allowance and personal independence payment is excluded

– as income from these benefits is supposed to meet some of the extra costs of disability – the number of disabled people living in poverty will have risen even further.

<http://tiny.cc/ijlo1x>

Welsh Independent Living Fund

Existing recipients of the ILF Benefit will continue receive money from a Welsh Government fund which began on July 1st 2015. It will run until March 2017.

New DWP guidance on ME

The Department of Work and Pensions (DWP) has updated its advice on CFS/ME for healthcare professionals carrying out Work Capability Assessments (WCAs).

Action for ME, Forward ME, the APPG on ME, Dr Alastair Miller and Prof Julia Newton contributed to the improved version.

<http://tiny.cc/rklo1x>

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

living with me

The MINI energy diary

Staying creative is always a challenge, especially so when we're low on energy. One of the first tools Michael Nobbs (an artist with ME) used was an Energy Diary.

In his latest newsletter he writes:

I'm still an advocate of the Energy Diary—but I'm very aware for many people the keeping of the diary is a significant drain on energy and can make people feel defeated before they've started (or having seen any of the benefits).

Instead of implementing a full scale Energy Diary, how about trying a mini version instead?

I'd like to encourage you to make a brief note every day of how you feel and what you've achieved. Keep it as simple as you like, use a shorthand for activities and a rating system for how you're feeling.

Helping you stay positive

Remember to include how you feel both emotionally and physically (they're often not the same and it's very useful to make a distinction) and the major things (or things) that you've done that day.

Whilst you're not going to have the richness of data that the full blown Energy Diary would give you, this mini version is still very useful. In the moment of making it (which could take less time than brushing your teeth) it can help you stay positive and show you that you're on creative track and, over time, it can build into useful reference material that could help you start to make connections between things that affect your health and wellbeing in both positive and negative ways.

Helping me see changes I need to make

I combine this mini version of the energy diary in my (mostly) daily journal. Over the last couple of weeks I've noticed that my midweek habit of doing my washing and having a baking session has left me exhausted.

Not directly following it—I tend to feel very upbeat and almost on a high when I smell my fresh clean washing and newly baked pie (!) — but rather over the following two or three days. Because I've noticed this, I'm experimenting with baking at a different time of the day and doing my washing on a different day.

Staying aware

Staying aware and noticing is an important part of being able to stay sustainably creative and the mini energy diary is a great way of staying aware and noticing.

When you feel ready, go further Perhaps after you've done this for a while (and hopefully seen some benefits!) you might even feel that you'd like to give the mini diary's big sister a try!

www.sustainablycreative.com

Accomable

Holiday at home or abroad with your wheelchair. This website lists accessible homes, apartments, swaps and holiday rentals available around the world. www.accomable.com
editor@disabilityhorizons.com

Euan's guide

This website features disabled access reviews from disabled people and their friends and families to help you find out the real access issues with tourism and entertainment venues. www.euansguide.com



0131 510 5106,
helo@euansguide.com

Crossword answers

Across:

5. Weakest Link
7. Crystal Maze
8. Eggheads
10. The Cube
11. Catchphrase
12. Pointless
13. Telly Addicts
14. Countdown
15. Total Wipeout
16. Cash Cab
18. Krypton Factor
19. Blockbusters

Down

1. Blankety Blank
2. Fifteen to One
3. Gladiators
4. Only Connect
6. Mastermind
9. University Challenge
11. Criss Cross Quiz
17. Mr and Mrs

Cryptogram answer

"Be who you are and say

what you feel, because those who mind don't matter, and those who matter don't mind."

research

Take part in research

Use your 'pyjama power' and sign up to take part in research from the comfort of your home.

Mendus is an online research lab where patients can take part in research trials and even suggest topics for study.

The aim of Mendus is to bring research within reach of those who need it. Patients can unite, discuss, and with the guidance of experienced research scientists, conduct their own research.

There are currently 5 studies for people with CFS and ME:

- CFS Diet
- D-Ribose
- Chocolate
- Whey protein
- Coenzyme Q10

How to get involved:

1. Register anonymously on the site – all you need is an email address
2. You will be asked to complete the DePaul Symptom Questionnaire (devised by Dr Leonard Jason from the DePaul University, Chicago)

3. You will be given an ID number and you can begin a study at any time, though may have to purchase items in order to take part.

More info:

www.mendus.org

Potential new treatments

CoQ10 with NADH

Coenzyme Q10 (CoQ10) and nicotinamide adenine dinucleotide (NADH) supplementation for 8 weeks was safe and effective in reducing max heart rate during a cycle ergometer test and fatigue in a small trial.

<http://tiny.cc/b3ko1x>

Brincidofovir

The anti-viral known as Vistide has been repackaged to reduce the side effects and is being marketed for a number of viruses. It could be a useful treatment for an ME subgroup. <http://tiny.cc/83ko1x>

Rituximab

The pilot trial success has been replicated in this Norwegian study of 29 people. The significant improvement in 18 participants suggests it could be a potential treatment for a subgroup.

<http://tiny.cc/45ko1x>

SEID v CFS

The US Institute of Medicine's report on ME/CFS in February 2015 recommended a new name to replace CFS - **Systemic exertion intolerance disease (SEID)**.

The name and new diagnostic criteria aim to better represent the "real" underlying biological abnormalities.

"ME/CFS is a serious, chronic, complex systemic disease that often can profoundly affect the lives of patients".

Summarizing the committee's deliberations, Ganiats said that the illness *"is not, as many clinicians believe, a psychological problem,"* while emphasizing that psychiatric comorbid conditions occur in some patients with ME/CFS and need to be diagnosed and treated.

Response to the new name in the following months has been varied. Some welcome this contribution to the debate and the attempt to highlight the physical dysfunction.

Others ask why a name was chosen without widespread consultation, especially with patients and families.

An international team compared the new criteria to existing guidelines (Fukuda, Canadian etc.) and found it included patients who have less impairment and fewer symptoms than several other criteria.

Fink and Schroeder believe the new diagnostic proposal does not answer the important question of whether patients who have multi-symptomatic ME/CFS have the same illness as patients with few symptoms. Is ME/CFS a distinct syndrome or part of a spectrum? They say the answer to that is more research, not new name and criteria.

More info: WAMES website new blog

Keep up to date with research papers, news and events on the news blog on the WAMES website, Facebook or Twitter

Science Quote

from (a not very learned) child

When they broke open molecules, they found they were only stuffed with atoms,

but when they broke open the atoms, they found them stuffed with explosions.

U21

Introductions...

Hi everyone,
I'm Lucy, your U21 editor.

I'm a philosophy student
at the University of Wales
and I love to write.

I've had ME for 6 years.
This issue is full of infor-
mation and is the new ver-
sion of the 'young people'
section.

You'll find the same sort of
recommendations, activi-
ties and things to do as
well as some new twists
and ideas.

On this page we have my
top summer recommenda-
tions.



If you want to get in
touch, you can e-mail me:
u21@wames.org.uk

Keeping Cool

A great way to keep cool is to freeze or refrigerate an ice pack made with Gel (so that you can decide the ideal temperature).

Pete Panda Ice Pack £1 Primark



Get creative

If the heat is too much or the rain is too heavy check out AIRFIX
(<http://www.airfix.com/uk-en/>)

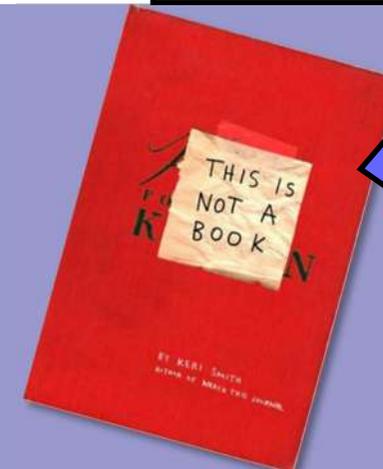
There are so many great miniature projects out there from planes to castles and you can do as much or as little as you like at a time.



Keri Smith-This Is not a book.

100s of pages of instructions of the most random fun things to do and create, some with just a pen or pencil.

For boys and girls, this book is awesome!



I love art and this is one of my favourite things to do if I'm out of ideas or a blank page just feels too big!



Surviving Summer

Long days, stifling heat and an extra case of brain fog...now what was I saying? Oh, that's it. I'm introducing my 'what to do guide' to fighting boredom this summer. My top three tips are:

1. Take advantage of Technology

The world is full of apps and websites. My top picks include Instagram, Duolingo (www.duolingo.com) and Club Penguin (www.clubpenguin.com). If you want something educational, try Coursera (www.coursera.org) or why not learn or improve your Welsh (www.bbc.co.uk/wales/learning/learnwelsh).

Into Gaming? Check out steam (<http://store.steampowered.com>). If none of that appeals try or Stumbleupon (www.stumbleupon.com) which is great to tailor to your individual tastes.

2. Make the most of what's around you

In Wales you are never far from something you can paint, photograph or just sit and observe from small towns to countryside or even your own garden.

3. Don't let rain put you off

Why not grow something, keep a diary of ideas and photographs or check out your local library. Pinterest and Tumblr are great sources of general inspiration and ideas.

Happy Summer! :)

What's going on in Wales?

If you're looking for a day out there's plenty going on. From medieval life to the Solarsphere check out:

www.visitwales.com/things-to-do/whats-on/events/august

Maybe the film industry is more your thing, try Zoomcymru which is an essential place to look for events and film council news.

(<http://zoomcymru.com/>)

If you want to get involved with politics or stay up-to date then Young Wales is the place for you: www.youngwales.wales

Hwb is a specific website for digital learning with a wide range of topics, materials and information. <http://hwb.wales.gov.uk>

If you're thinking about the future and love music BBC Wales music have put together a great guide in how to get involved in the industry as well as information about events. (www.bbc.co.uk/wales/music/sites/how-to)

Have an interest in reducing your carbon footprint? there are loads of great places to visit, why not show this to someone at home: www.visitwales.com/holidays-breaks/green-sustainability/eco-friendly-places-to-visit

(Don't forget to check out local newspapers and noticeboards.)

Know of anything we haven't mentioned? Tried any of these things and want to share your reviews or experiences. Feel free to get in touch, I'd love to hear from you.

u21@wames.org.uk

U21

My Story

I tried the Activity rest and sleep diary when I first became ill at 14 and continued to follow it until I reached 17.

The idea is that you first monitor your health condition and document what patterns you do or do not follow.

After this you have to slowly implement a routine over the course of weeks so as not to overdo it.

After this, once you have achieved a basic routine you can reduce activity as much or as little as you feel comfortable with.

I gradually increased over the first two years and after that I had developed the ability to monitor my health without the charts which enabled me to learn a lot more about my condition as well as improving it.

Although I had the guidance of a nurse I only had to do what I felt comfortable with, which reduced the risk of relapse or getting worse. Unlike many common treatments, this one is in your hands.

Lucy

The Activity Rest and Sleep Diary

Simply Fill in the boxes with the colours outlined below to monitor your daily progress and take any notes you need to in the section

 High Energy Activity	 Low Energy Activity	 Rest/Relaxation	 Sleep																					
	Morning a.m.											Afternoon/Evening p.m.												
Date:	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								
Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday																		
Notes:	Notes:	Notes:	Notes:	Notes:	Notes:	Notes:																		

The chart above is a simple example of one of many variations of the system but all are used to document the different levels of activity and sleep using a simple colour coding idea.

It offers no instant or miracle cure but it is a good way to get to know more about how the condition affects you if nothing else. If you're interested I'd recommend speaking to a trusted medical professional and if you want to get in touch then I am happy to answer any questions.

ANY ONE TRIED THIS? DON'T BE AFRAID TO GET IN TOUCH AND LET US KNOW HOW YOU FOUND IT.

U21



Activities

Colouring pages are known for encouraging mindfulness and relaxation so here is one very fitting for WAMES.

You might be wondering why this is classed as therapeutic, well check out this article from the Guardian:

www.theguardian.com/books/2014/jun/29/colouring-in-books-therapy-depression.

Your Space

In future issues I want to hear from you, send in your photos, stories and things you've been doing and have it posted here.

For now it's just a blank space waiting to be filled... Get in touch at: u21@wames.org.uk