



October 2014, no. 9

me voice

The WAMES Magazine

WAMES
Welsh Association of ME & CFS Support

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me voice

me voice is published 5 times a year. You can subscribe to the paper copy for £10 p.a., or receive it free by email, or read and/or download it from our website www.wames.org.uk

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The WAMES information exchange

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

- News blog on website
- Magazine
- Facebook
- Twitter
- e-group

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

Making the web links in me voice work in your Browser

Internet Explorer

When you click the *me voice* link, this opens your default pdf reader. The hyperlinks and the email addresses all work.

Google Chrome, Opera, Torch
Hyperlinks and email addresses work correctly.

Mozilla Firefox

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

Read the magazine full screen:

In Foxit Reader click F11 to increase or decrease the size of page.
In Adobe Acrobat press Control+L

Copy dates for the magazine:

24 Nov 2014, 26 Jan 2015

ME get-togethers around Wales

Carmarthenshire ME Group

Meets on 29 November at Coleshill Social Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James [pm] for further details. 01267233793

North Ceredigion Yoga Class

tailored for people with ME and other medical conditions.

Meets on Wednesdays, 2.30-4pm, at Canolfan y Morlan, Aberystwyth. For details contact Cathy Crick on 01570 421 144 or 07748 031614 or cathycrick@hotmail.co.uk

ME Support in Glamorgan

(MESiG) Meeting 11-12.30 3rd Nov at Llanishen Community Shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

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

West Wales ME/FM Group

Meetings on 24 November 11am to 1pm at 65 Tudor Gardens, Merlin's Bridge, Haverfordwest, Pembro SA61 1LB.

Transport can be arranged from the bus or train stations. Parking is available. Contact Tina tretuil@talktalk.net or 01437 454359

Haverfordwest – Cwtch

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

They meet the first Friday of the month during school term time for talks and social activities.

10-11.30 at Furzy Park Community Centre, SA61 1HQ.
Next meeting 7 Nov, 5 Dec.
www.cwtchpembrokeshire.co.uk
Beth 07974 543874
cwtch@live.co.uk

CHAT (Chronic Health All Together) South Wales

All ages, both sexes, partners and carers are all welcome. People with ME, FM and similar conditions meet to catch up, talk about health, have a laugh, general every day chit chat and get to know each other and create a support network.

They meet once a month, dates to be arranged although they are having a Xmas get together on Friday 5th December (time to be arranged). The get-together will alternate between Newport, Cwmbran, Cardiff (so everyone gets a chance to attend one).

More info:

Natasha Trew-Burns 07969994643
panoz8228@gmail.com

wames news

WAMES poll on ME Action plan

The Welsh Government has launched the ME Action Plan for Health Boards – see page 4.

Let us know what you think about it at www.wames.org.uk

Cleaner in Llanelli

A person with ME recommends Pam's spick and span homes podbury123@live.com
01269 860676 07581400 501

Wrexham get-together

Please let Jan know if you would like to join a group in Wrexham so the next get together can be planned.

Christmas shopping online?

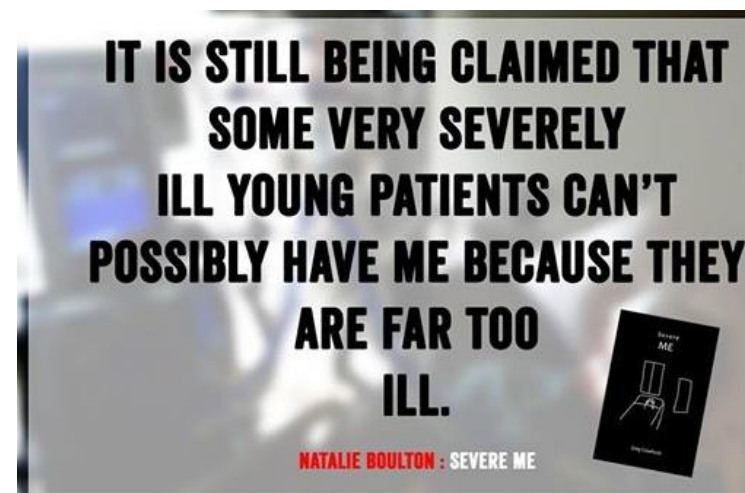
Sign up for an Easy fundraising reminder

Or add easyfundraising.org.uk to your speed dial and raise funds for WAMES every time you shop.

A great gift for the ME campaign in Wales, **but it won't cost you a penny!**
www.easyfundraising.org.uk

Chepstow get-together?

If you live in or near Chepstow and have ME, FM or are unsure exactly what condition you have, and would like to meet up with others or chat on the phone, get in touch with Jan. There could be an opportunity to organise a local get-together.



ME services action plan for wales

“Clinical leads to be appointed by April 2015”

ME services Action Plan for Wales!

On 16 September 2014 the Health Minister, Mark Drakeford, wrote to Local Health Boards drawing their attention to the Action Plan for improving services for people with ME, CFS and Fibromyalgia in Wales.

“Health Minister writes to Health Boards about ME”

The Action Plan was devised by the ME/CFS and FM Task & Finish Group (which included WAMES), which met between December 2013 and May 2014, and looked at how to overcome the barriers that Health Boards face when providing services for patients, and is published as a Report and Recommendations. It is available on the [WAMES website](#) and will also become available on the Welsh Government website.

The 11 recommendations focus on strengthening pathway and service implementation arrangements and improving the patient voice in the process, not on discussing or defining the nature of ME, CFS and FM and the implications of that for treatments and management. Those discussions will inevitably take place at Health Board level between all the stakeholders.

“ME not to be placed in mental health”

The 9 main recommendations state that each Health Board should:

1. Identify an Executive Board member with responsibility for overseeing implementation of the recommendations below.
 2. Identify, by April 2015, an appropriate clinical lead or leads for ME/CFS and Fibromyalgia to take forward the recommendations and to identify a “home” for services for ME/CFS and Fibromyalgia. (not in mental health).
 3. Identify relevant specialists and those with expertise or interest in developing services to establish a stakeholder group or groups (including patient representation) to support the clinical lead or leads in ensuring the effective delivery of recommendations 4-8.
 4. Develop effective local pathways for children and adults with ME/CFS and Fibromyalgia, by drawing on Map of Medicine pathways, Scottish Good Practice Guide, Neurological
- Delivery Plan and emerging guidance [& FM sources].
5. Undertake work to raise awareness of ME/CFS and Fibromyalgia in primary care, to support timely diagnosis and effective management of both children and adults
 6. Identify the means by which they will provide support to people with ME/CFS and Fibromyalgia who need to attend hospital, or receive palliative care, as well as ensuring the delivery of care as close to home as possible, including the provision of telemedicine/home visits to severely affected patients unable to attend appointments via other means.
 7. Produce a practical, realistic and timed action plan to improve patient experience of services by people with ME/CFS and Fibromyalgia during 2015-2018, and report annually on progress.
 8. Release a representative (or representatives) to form an All Wales Implementation Group (which will also include third sector patient representatives)

“Pathway to use existing interest and professional expertise”

and Fibromyalgia in implementing recommendations 1-8.

The report then goes on to highlight main problem areas that Health Boards need to address:

- Improving GP understanding and timely diagnosis
 - Coordinating a range of health care specialists under clinical leads, not in mental health but not ignoring mental health needs of patients
 - A clear pathway to be developed based on patient needs and utilising and developing existing professional interest and expertise
- Children’s services to include support from education and social care services and help transitioning to adult services. The practice of inappropriate pressure to attend school when ill and misdiagnosis of ‘Fabricated illness’ leading to child protection proceedings to be avoided.
- The lack of in-patient hospital services and home visits)

Myalgic Encephalopathy/Chronic Fatigue Syndrome (ME/CFS) & Fibromyalgia (FM) Task & Finish Group Report and Recommendations Aug 2014 <http://tinyurl.com/mazococ>

Enseffalopathi Myalgig/Syndrom Blinder Cronig (ME/CFS) a FFibromyalgia (FM) Adroddiadac Argymhellion Grŵp Gorchwyl a Gorffen, Awst 2014 <http://tinyurl.com/m5atyov>
Health Minister’s letter to Health Boards <http://tinyurl.com/k9g65mc>

WAMES comments:

We are aware that everybody is very frustrated by the length of time this is taking and that no additional money has been allocated to this task. There is still a long way to go and it could be next year before patients and carers can get involved in local stakeholder groups to discuss patient needs with health professionals in their Health Board area.

On the plus side work is well underway on the development of a pathway in Hywel Dda. Hopefully this work will be of benefit to the other Health Boards and speed up the process there.

There are a number of things that we are particularly pleased have been included in the Report:

- A timetable and monitoring of progress at a national level.
- The importance given to the patient voice when developing a pathway and services.
- The use of the term ME/CFS, though we would have preferred the term used by the WHO: 'encephalomyelitis'.
- Highlighting the Scottish Good Practice guide (which promotes the Canadian guidelines) and the need to heed emerging guidance.
- Highlighting the relevance of the Neurological Delivery plan to ME and CFS.
- Highlighting the key problem areas of timely diagnosis, misdiagnosis

as a mental health condition or 'fabricated illness', attitudes to children and education, services for the severely affected.

WAMES will continue to be involved at a national and local level and push for speedy progress and will be hoping patients and carers all over Wales will be able to join in, when the time comes.

We intend to join Health Boards in looking for constructive solutions to service provision in less than ideal circumstances. It is hoped that as health professionals learn more about the nature of ME and patient needs, they will become as keen as us to see services improve.

Dr Sarah Myhill

Following the recent launch of her book *Diagnosing & Treating Chronic Fatigue Syndrome: it's mitochondria not hypochondria*, Dr Myhill recorded a webinar in May, focusing on the practical application of her successful and comprehensive treatment approach. She has treated over 5000 patients with CFS since 1982 and worked in NHS and private practice. You can watch the webinar here: http://www.youtube.com/watch?v=BG_v6-U1a8g

Dr Myhill is currently experiencing a very heavy work load and an exceptionally high number of referrals from other doctors, self-referrals, other requests for advice

and interpretation of test results. She has had to suspend all advice, appointments and test orders to "new patients". She will review the situation in January 2015 and perhaps then will be able to accept new patients.

Keep an eye on her website <http://www.drmyhill.co.uk> She will continue to see and treat all current patients i.e. those who have had previous contact me and have already received advice from her.

Cross border healthcare inquiry

The Welsh Affairs Committee has launched an inquiry focusing on cross-border arrangements between the English and Welsh healthcare systems and the experience of patients who rely on services on the other side of the border.

The date for registering for the Nov 24th meeting has passed but there is a web forum where you can submit your views online will be available from 16 October 2014.

Further information about the inquiry is also available at <http://www.parliament.uk/crossborder-healthcare>

More information on Outreach events is available on <http://www.parliament.uk/outreach>

More information about the Welsh Affairs Committee <http://tinyurl.com/6m4pnxs>

Prescribing powers extended in Wales

On September 24, 2014, new laws came into force, which will allow physiotherapists, chiropractors and podiatrists in Wales, who have successfully completed additional training to prescribe medicines, such as anti-inflammatory agents and painkillers, for their patients.

The new regulations mean they will no longer always have to refer their patients back to a GP if medication is needed.

The move is part of efforts to improve the patient experience and free-up time for GPs. Currently nurses, pharmacists and optometrists are among those who can prescribe medicines and other items, such as dressings and appliances, from the Drug Tariff.

news from wales

New Prudent Healthcare website

Health and Social Services Minister Mark Drakeford has launched the new website Making Prudent Healthcare Happen, which aims to ensure Wales remains at the forefront of this emerging global movement.

The interactive website sets out the principles of prudent healthcare, with 15 chapters designed to stimulate debate about the impact they can have on the provision of health and social care across Wales.

The website, which features videos with each of the authors, allows users to post comments about each of the chapters, also includes four case studies of services which embody prudent healthcare principles. It will be updated with more chapters in the coming months.

www.prudenthealthcare.org.uk

Press release:
<http://tinyurl.com/pxatxi7>

GP crisis in Wales

Patients could be getting sicker and need more expensive treatment due to GP appointment difficulties, it has been claimed. The Royal College of General Practitioners (RCGP) Wales

said surgeries were "buckling under the strain of rising workloads".

It estimates 650,000 people in Wales found it difficult to get an appointment last year. The Welsh government said the number of GPs and spending on them has increased.

RCGP chair Dr Myres said retention and recruitment of GPs was a major issue in north Wales, while across Wales 23% of GPs were over 55 years old. In the Cwm Taf health board area in the south east Wales valleys it was as high as 31%, he said.

He added: "When these doctors retire we have no-one to replace them. Who is going to care for our population?"

A Welsh government has described the RCGP's figures, extrapolated from year-on-year surveys, as "flawed". It stressed that investment in general practice had increased by almost £150m over the last decade - to £469m. A spokesperson said GP numbers were up over the same period by 11%.

More info:
<http://www.bbc.co.uk/news/uk-wales-29147315>

<http://tinyurl.com/m7yc4wc>



Council & Health Board consultations

Both County Councils and Health Boards all over Wales have to make significant budget savings over the next few years so are trying to decide where to make cuts. Councils are responsible for social services, leisure services, education, housing etc. Look out for public meetings where you can comment on their proposals.

NORTH WALES

Parabl - Dealing with Depression

Parable provides short-term therapeutic support for individuals facing common mental health problems or challenging life events in a non-stigmatising environment. Services include:

- Self help
- Online Workbooks and Support
- Therapeutic Groups
- Mindfulness
- Counselling

During these six evening interactive sessions between 12th Nov to 17th Dec, you will get to explore and understand more about what is causing your depression and gain tools to help deal with it.

3 Belmont Road, Wrexham, LL13 7PW 0300 777 2257
<http://www.parabl.org.uk>
ask@parabl.org

Care North Wales name change

Local Charity Crossroads Care North Wales officially changed its name to 'Carers Trust North Wales, Crossroads Care Services' on 4 August 2014. The Charity has been providing desperately needed respite breaks to carers in North Wales for over 35 years.

More information: 01492 516435
www.nwcrossroads.org.uk

'Ffrindia' befriending service

For people over 50 in Gwynedd.

Coordinators' contact details:
Meirionnydd Mirain 01341 422575
Arfon Alan 01286 672626
Dwyfor Dawn 01286 672626

ffrindia@mantellgwynedd.com
Or contact Carys 01286 672626 or
<http://www.mantellgwynedd.com/english/ffrindia.html>

Disability info at Bodelwyddan

The Disability Resource Centre now offers an information service to members of the public. project from their offices at Glan Clwyd Hospital Bodelwyddan. The DRC champions the needs and rights of people with disabilities and aims to maximise independent living.

For any advice on physical wellbeing, daily activities, social wellbeing, financial advice or advice for carers please get in touch with Emmy at the centre. 01745 448288
disability.resourcecentre@wales.nhs.uk

iWantGreatCare at Wrexham Maelor Hospital

Betsi Cadwaladr University Health Board will work with iWantGreatCare project to test a new and robust way of collecting feedback from patients

who use the hospital's services. iWantGreatCare is an independent company which collects reviews and ratings from patients, carers and families about NHS hospitals, GP surgeries, doctors, dentists, physiotherapists and clinics.

During the pilot, when patients are discharged from medical and surgical wards, antenatal, labour and postnatal services at Wrexham Maelor Hospital, they will be asked about their experience. This feedback will be reported in real-time so issues can be acted on immediately.

<http://tinyurl.com/kupvjhc>

Video link hospital consultations

Elderly patients in rural north Wales could be offered online consultations with hospital doctors saving them from having to travel long distances.

Under the trial, patients will be able to go to the GP surgery and have an internet video link appointment with their hospital consultant.

The Betsi Cadwaladr University Health Board in north Wales is one of four UK areas piloting the scheme. *The Future Hospital Programme* is run by the Royal College of Physicians. If successful, the scheme could be extended into peoples' homes.

<https://www.rcplondon.ac.uk/projects/future-hospital-programme>

<http://www.bbc.co.uk/news/uk-wales-29317465>

regional news

Llyfergell Caernarfon

Ydych chi'n hoffi llyfrau, straeon, cymdeithasu?
Ymunwch yn ein grwp darllen—Llais a Llyfr bob dydd Gwener 2.00-3.00

Cyfle i wrando ar amrywiaeth o straeon byrion a cherddi gan awduron da yn cael eu darllen yn uchel - dim ond eistedd nôl ac gwrando sydd raid. A does dim rhaid darllen dim ymlaen llaw.

Cewch gyfle i sgwrsio a thrafod—ac mae paned ar gael! 01286 679465

Red Cross Gofal Project

Gofal offers a weekly telephone befriending service for people over 50 years of age in North Wales who would benefit from companionship, support and a listening ear on the other end of the phone.

Perhaps you know a neighbour, someone in the community or family member who would benefit from the service?

Or how about volunteering?

More info: 01745 828360
GofalNorthWales@redcross.org.uk

MID WALES

Access Powys Children's Social Services

From October 30, the council will be operating a single point of access for all enquiries relating to children living in Powys and their families.

It could be to raise an issue or concern around the welfare of a child or young person, or if you would like advice and guidance on how to get extra support, or to find out more about services and activities for children and families locally.

For now, the service will only be available for children, young people and families, with Adult Services joining Powys People Direct in early 2015.

So from October 30, remember to dial 01597 827 666 to access Powys People Direct.
<http://tinyurl.com/n4on5ay>

I like long walks...

...especially when taken
by people who really annoy me.

regional news

SOUTH WALES

The Cardiff Debate

This will take place over the next 3 years and will involve local people and communities in conversations that will shape the future of public service in Cardiff.

The public and third sectors face significant pressures both in terms of reduced budgets and growing demand for services. That means we need to all work together and find ways of doing things differently.

Conversations will be held in local areas to discuss priorities for the city, as well as encouraging these conversations to happen online via social media.

<http://www.cardiffdebate.co.uk>

Long Term Conditions Alliance

This project in Cardiff and the Vale is creating an alliance of organisations which support people with long term conditions, and also service users who live with long term conditions.

The Alliance shares information, raises awareness of long term conditions and engages in consultation processes.

The next meeting is on December 18th 2-4pm. If you would like to join WAMES in representing ME please contact Jan

ME petition

The MESiG petition for a clinic was presented to the Welsh Government on Tues 16th Sep with a demonstration on the steps of the Senedd building. It was considered by the Petitions Committee on Tues 23rd Sep and referred to the health Minister for comment.

MESiG Petition:

We call upon the National Assembly for Wales to urge the Welsh Government to ensure that a dedicated Consultant/Clinic and medical support team for Myalgic Encephalomyelitis (M.E.), Chronic Fatigue Syndrome & Fibromyalgia sufferers is set up in South East Wales. I request that this petition be treated as an official voice of M.E. sufferers, their families, carers and interested parties.

Currently, sufferers of the above ailments are not being supported, with a few exceptions, by the medical profession. They are unable to work but the government bodies assessing them do not appear to understand their problems. This is the basis for this petition.



Petition raised by: M.E.S.I.G. (M.E Support in Glamorgan)

Number of signatures: 368 electronic signatures and 826 paper signatures. Total 1,196

Penarth Times news article: http://www.penarthtimes.co.uk/news/11502335.ME_support_group_petition_Assembly/

Monmouthshire Access

Monmouthshire's Access for All forum was launched in September with an attendance of over 70 people in Usk. The forum offers a chance for people with disabilities to influence services, policies and decisions that affect them.

More info:

Pennie Walker 07949 040538
pennie.walker@sewrec.org.uk

Cardiff & Vale patient consultation

Shaping Our Future Wellbeing – A Clinical Strategy Workshop for long term medical conditions will be held on Friday 14th November.

Discussions will place around the 5 themes:

- Empower the Person
- Home First
- Outcomes that matter to People
- Avoid harm, waste and variation
- Equity between the people who use and provide services

If you are a service user and would like to accompany a rep from WAMES to the workshop contact Jan.

Briefing paper:

<http://www.cardiffandvaleuhb.wales.nhs.uk/opendoc/249333>

WEST WALES Now's the Time to Get Online!

Communities 2.0 has launched their new National Digital Outreach Project, with IT support sessions starting in communities across Wales. The National Digital Outreach Project offers free ICT tuition for groups.

These could be sessions on basic IT, using tablets, using social media, using email, saving money online etc.

Swansea

IT drop in at Central Library
6 - 7.45pm on a Thursday.

IT for Work drop in at St Thomas
Library 1- 3pm on a Thursday.

Neath Port Talbot

IT drop in in Sandfields Library
Tues 10am-12pm & Fri 2-4pm

Pontardawe Library

Tuesdays 10am-12pm and Thursdays
2.30-4.30pm

More information:

Co-ordinator for South Wales and the
Valleys: Delyth Rees 07823342301
delyth.rees@walescooperative.org

Communities
Cymunedau 2.0



Values Into Action workshops

Following earlier workshops Abertawe Bro Morgannwg Health Board have summarised the shared experiences into prioritised key themes. This next stage involves a series of "Values Into Action" workshops to discuss the themes.

Port Talbot

Tues 4th November 10am-12.30pm
Aberavon Beach Hotel

regional news

Bridgend

Wed 5th November, 11am-1.30pm
Hernston Hotel

Swansea

Tues 4th Nov, 1.30-4pm Sinclair
Suite, 2nd Floor, Liberty Stadium

Fri 7th November, 10am-12.30pm
Sinclair Suite, Liberty Stadium

Anyone is welcome to attend – patients, families or carers – as long as they received care from ABMHB during 2014. There will be refreshments and transport costs will be reimbursed.

There will be a further workshop in the Liberty Stadium on Nov 12th to finalise the values underpinning what people can expect from the services.

Book electronically at <http://valuesintoaction.eventbrite.co.uk>

Or book via email
ABM.actionafterandrews@wales.nhs.uk
by text on 07507 319562 or by
voicemail on 01639 684468.

More info: <http://www.wales.nhs.uk/sitesplus/863/page/73970>

Top ten tongue in cheek reasons to volunteer !

1. When you stay home you get too many telemarketing calls.
2. Your family could use a break from you.
3. You might need help yourself some day.
4. It's hard to win a game of solitaire.
5. Soap operas all sound alike.
6. If you don't go out each day, you get old.
7. Why let your boss have all the fun in life?
8. The car needs a workout.
9. Your mom would be proud of you.
10. Who cares about money?

(Joy Pople, Baldwinsville Volunteer Center, New York)

the creative path... ...through ME

Whether you are a professional artist who lives to create, or you are exploring your creative side for fun, therapy or fundraising, you will face considerable challenges if you have ME.

Find out how some people with ME have developed their creative abilities:

Eleri Messenger from Carmarthenshire

"I became ill with M.E at the end of 2005. I had been getting lots of tonsillitis and chest infections for a few years and could never recover as quickly as my peers. I would be crashed out for two weeks instead of a few days. Then I had a chest infection in November 2005 and could not recover.

I tried going back to school, but I was getting worse and worse until eventually I was unable to walk. I was getting so many strange symptoms including intense pain, especially in my legs, spine and shoulders, intense dizziness and faintness, severe and sudden localized headaches, light, noise and movement sensitivity, cognitive dysfunction, skin

hypersensitivity, very disrupted sleep.

I was always very arty and creative. My dream was, and still is, to become a children's book illustrator. When I first got ill, I could manage to do a little art and crafts while lying on the sofa with cushions propping me up. I would do some painting by numbers, cross stitch or drawing for ten minutes and then I would have to have a long deep rest.

I got a little better at the end of 2007 and I painted a little watercolour Christmas card. My family liked it so much that I decided I would try and make more of them so I could send them out as that year's Christmas cards.

In January of 2008 I suffered a debilitating relapse which left me unable to talk or use my hands at



all. I couldn't even turn the page of a magazine and I could not look at a photo because of the neurological symptoms. I lived like that for a few years and then started to improve a little bit although still not enough to be able to paint and do crafts.

I was determined to do something to raise awareness and funds for biomedical research into M.E and so I came up with the idea of recreating my watercolour cards and selling them with 50% of the profits going to fund biomedical research.

With the help of my family and friends, we set up my little business "Eleri Haf Designs" and sold my cards and tags in the Christmas of 2011. I carried on doing this until June 2013 when I felt well enough to begin making things myself again. I

invested in a die-cutting machine and started making wedding stationery. This is when I set up my online shop.

I have been lucky to get some special equipment to help in some areas. I have a table that I roll under my tilt in space chair which I can put my art stuff on. I invested in an iPad so that I could easily access my online shop and manage the orders. I use cushions to support my arms as I work. My dad will tell you that I took over the entire house with my supplies! So, I bought a bookshelf from IKEA that has different compartments...I must admit, it's not the most organized of craft spaces!

My friend mentioned the website [Etsy](https://www.etsy.com/) to me and suggested that I sell my stuff there. I had never heard of Etsy but as soon as I went on it, I was addicted! I was so excited to start my shop. It was very easy to set it up. My products seemed so popular with my family and friends that it made me realise that I could sell many more if only I had the platform to do that.

I think you'd have to be quite well to make a living from art. I don't make a living from selling my arts and crafts and I have lots of help from my family and friends when making them. However, it brings in extra funds and



I'm able to do something I love, I'm learning new skills and it's something that gives me a sense of purpose and pride.

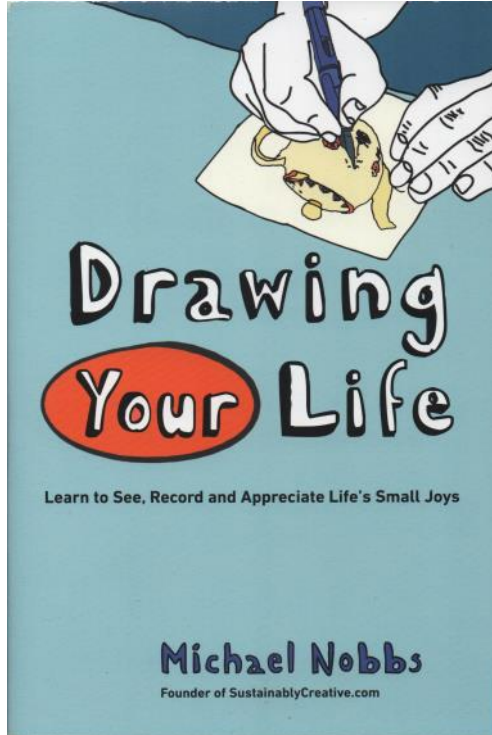
As I get better, I will be able to expand my business and hopefully then make a living from it. The internet has opened up so many opportunities and gives a platform for people to easily sell their work. Nowadays, handmade products are very sought after. People like the personal touch that it brings. Being able to sell online gives you more freedom to be flexible and pace yourself as you make things.

My message to others would be not to lose hope and to know how important you are. You are each individuals with your own talents, creativeness, qualities and dreams. ME does not define you. I've learned to use my bad experiences and try to squeeze some good out of them. Never give up and keep those dreams in sight!

<https://www.etsy.com/uk/people/elerimessenger>

Michael Nobbs from Ceredigion

Back at the end of the 1990s I was diagnosed with ME/CFS and was forced to stop what had turned into an increasingly frantic attempt at building a career as a writer and publisher. For a few years after the diagnosis I basically took to my bed, slowing my life right down, as I began to try to rebuild my health.



Before my life slowed to almost a halt I had been someone who loved the tools of the artist—their pens and their sketchbooks—buying enough over the years to be able to open my own stationers! However, since my early teens I'd never tried to draw in any of them.

Largely bedridden, that began to change. I was introduced to wonderful online artists like Danny Gregory [1] and Keri Smith [2], who made drawing part of their day.

I was encouraged by reading Julia Cameron's excellent book, *The Artist's Way*, [3] to make some tentative marks in my collection of blank sketchbooks. Unable to travel

the creative path... ...through ME

far, I began to make "bad" drawings of the everyday and ordinary things around me.

Slowly, ever so slowly, my confidence grew and it became second nature to reach for my sketchbook and make a quick drawing of my mug of tea, my breakfast or the book I was reading.

The everyday and ordinary things around me began to take on a new vibrancy.

These days I write and teach about building a creative life (and even a creative career) over on my website, *Sustainably Creative* [4].

I hope I can show people with limited energy that it is possible to be creative in very small ways and that those small steps can build over time into something quite substantial.

Over the years I've published numerous books and ebooks, making all of them one page and one day at a time. I record a daily micro-podcast in which I pick one small creative thing to do each day (often that is simply recording the podcast) and hope that I can encourage other people to do the same.

Whilst I still struggle with my health, making small daily creative steps has shown me that I don't need to be limited by my limits.

Bio: Michael Nobbs is an artist, blogger and tea drinker (not necessarily in that order). He was diagnosed with ME in the late 1990s and over the years has learnt a lot about sustaining a creative career with very limited energy.

The author and illustrator of numerous books and ebooks, his latest, *Drawing Your Life* was published by Perigee/Penguin in March 2013. He lives on the side of a hill near Aberystwyth.

1. <http://dannygregory.com/>
2. <http://www.kerismith.com>
3. <http://juliacameronlive.com>
4. <http://www.sustainablycreative.com>



the creative path...

...through ME

Kerry Mitchell

"I am an artist. First and foremost, I do art. It is in my soul to do art. I don't have a choice. When I got sick with CFS-FM-Lyme, I could no longer do art."

Textile artist Kelly rediscovered her ability to be creative when introduced to computer painting programs which she could use in bed. An example of her work is below.

<http://kerrycmitchell.com/2013/07/09/how-i-rediscovered-the-artist-in-me/>



Georgia from Gloucestershire

After 5 years of being ill and off school 14 year old Georgia went back to school, just for art classes!

This year she managed to scrape passes in 2 GCSEs to gain her a place at Gloucestershire college to study photography but she'd rather find a job or apprenticeship. She still has to work out how she can do that without causing a relapse!

<http://tinyurl.com/nneujyc>

Sarah Marie Lacey from Canada

"In a way, my illness and my art are interdependent – without getting sick, I think it would have been a long road to my art. Without my art, I don't know if I could have moved past being sick to building a better life."

<http://smlacyart.com/category/coping-with-chronic-illness/>

Melanie from Washington State USA

My favorite saying: "Some people complain that there are thorns on roses, others thank God for putting roses on thorns".



"Before I became ill in 2001, I taught creative dance for preschoolers, spoke at women's retreats and conferences and am a published author. Now, I am always looking for the roses on the thorns and I dance with a paintbrush."

<http://thecreatorspalette.com/category/art/>

<https://www.etsy.com/shop/thecreatorspalette>

Rachel Groves from Staffordshire

I do what I can towards my art – it's a welcome escape from the day to day ache, fog and let's face it – bore of a chronic illness.

My blog gives me a focus and impetus for that little artist within. Due to my illness I have certain limitations (which shift and change) so I focus on what I can do and then, umm, doing it.

<http://rachelcreative.wordpress.com>

Jeanette Orrell from Corwen

As a home based mother Jeanette has been inspired by domestic items to draw and make art works. She speaks about her approach to art in this video:

<https://www.youtube.com/watch?v=0FniylpSz3g>

<https://www.facebook.com/jeanette.orrell/photos>



Other artists with ME

Dan Becks <http://cfsrecoveryispossible.wordpress.com>

Birdie Fincham <http://smallofferings.wordpress.com>

Monet Clark <http://planetthrive.com/2010/09/monet-clark-interview/>

Jodie Bassett <http://www.ahummingbirdsguide.com>

Amanda Watson-Will <http://amandawatson-will.blogspot.co.uk>

Meeting and exhibiting online

Having an online presence has become increasingly important for artists, whether they are well or ill.

Rather than developing your own blog or website, a low energy way of being online is to join an existing community, whether you wish to meet people or sell your creations.

Etsy – an international online marketplace for unique goods

<https://www.etsy.com>

Folksy - a place to buy hand crafted gifts and handmade or commercial supplies from British designers

MEcuperate - A forum set up by Jennifer Barber for people "coping with chronic illness through creativity and healthy living"

<http://mecuperate.co.uk>

idrawandpaint – the community for artists of all abilities

www.idrawandpaint.com

Whole9 – community for creative people in the US and round the world

<http://www.thewhole9.com>

Bluecanvas - a place to display your art while connecting with other artists and art enthusiasts. [http://](http://www.bluecanvas.com)

www.bluecanvas.com

Are you a carer?

General video from the Carers Trust
<https://www.youtube.com/watch?v=TZQSo3OYKE&feature=youtu.be>



Young carer's videos

Young carer Jenny Louise has a video channel talking about her experience and answering questions about being a carer. <https://www.youtube.com/user/youngcarersupport>

Carers Rights Day event

Thurs 27 Nov 2014, 9.30am - 3.15pm, Liberty Stadium, Landore, Swansea, SA1 2FA

There will be: Guest speakers; Information; Question time; Health and Well-being sessions; Free buffet. All carers and those who work with carers are welcome.

For further information or to book your place, please contact Swansea Carers Centre 01792 653344
admin@swanseacarerscentre.org.uk

Carers rights day is Fri 28 Nov.

Find out more

<http://www.carersuk.org/news-and-campaigns/campaigns/carers-rights-day>

Access to learning for carers

The Open University in Wales offers flexible, part time distance learning so you can study from home around your caring and other commitments and work towards recognised qualifications.

- The OU in Wales is open access, there are no entry requirements
- There are courses to suit all levels and interests, from short taster courses to postgraduate study
- Financial support is available for those on low incomes or benefits Additional support is available for students with disabilities
- Special bursary funding is also available for carers in Wales

More info:

029 2047 1170 email

wales@open.ac.uk Please quote 'Carers Project'

carers

<http://www.open.ac.uk/choose/ou/carersproject>

Online course for carers

This course was developed with and for carers by the Open University Scotland. It will help you gain a clearer understanding of who you are, to identify your personal qualities and recognise the range of skills and abilities you've developed from your personal experiences and while caring.

It will also help you to look forward, to think about what you'd like to do now or in the future, and to make plans that will help you get where you hope to be. It is open to all carers.

Caring Counts: a self-reflection and planning course for carers <http://www.open.edu/openlearnworks/course/view.php?id=1688>

Carers event Powys

Crossroads Care Mid & West Wales invites Carers in Powys to a free half day event with refreshment which will include sessions on:

- How to say 'no' or put your point of view across without feeling guilty
- Dementia Friendly – awareness raising session on the effects of

carers

memory loss not only on those with the diagnosis but also their Carers and family members

- What support there is in your local area?
- Taster sessions (e.g. arm and hand massage; art therapy)
- Carers Voice – how to enable Carers to be more involved in their community

Tuesday 18 Nov 2014

Brecon 10.30am – 2.30pm

More info about respite care arrangements and to register for the event please call Ingrid: 01437 764639 or 07837188360 or e-mail ingrid.bernathova@crossroadsmww.org.uk

St John Wales' free first aid app

Knowing what to do in the first few minutes of an emergency is vital. The official St John Wales app contains simple step-by-step advice on dealing with injuries such as severe bleeding, burns and scalds and choking, while also giving advice on how to give CPR and other treatments. The first aid quiz helps you test your knowledge and lets you share your score on social media

<http://www.stjohnwales.co.uk/about/first-aid-app/>

Free flu vaccination for carers

People who provide care on a voluntary basis will be eligible to receive the seasonal flu vaccine free of charge this autumn by telling their GP they are a carer.

A carer who has flu could pass the infection to someone in their care, risking their welfare, as older people and those with existing health conditions are more susceptible to the complications of flu.

More information on flu: <http://www.wales.nhs.uk/sitesplus/888/page/43745>

Carer's Allowance Digital Service Survey

Since it was introduced in October 2013, over 70,000 users have made a claim or reported a change of circumstances using the Digital Service.

This remains the quickest and easiest way to submit a claim. The Carer's Allowance Digital Service is available 24 hours a day, 7 days a week. It is accessible through tablet or mobile phone and currently 32% of carers are choosing to use these devices to make their claims. The Carer's Allowance Digital Service is



accessible at <https://www.gov.uk/apply-carers-allowance>

Carer's Allowance Threshold

The government has announced that from April 2015, the earnings threshold for Carer's Allowance will be raised to £110 a week.

This is a rise of £8 on the current limit of £102. The change means that more people will have the opportunity to work part-time and still be eligible for the full £61.35 a week Carer's Allowance.

However, the minimum wage is increasing to £6.50 from Oct 2014 which means that in the meantime many carers again face the impossible situation of either cutting their working hours or losing thousands of pounds a year in financial support from Carer's Allowance.

Carer's Allowance is a non-contributory benefit available to people who have given up the opportunity of full-time paid employment in order to provide substantial care, of at least 35 hours a week, to a severely disabled person.

The net earnings figure is calculated net of income tax, National Insurance contributions, half of any contributions to an occupational or personal pension, plus a number of other allowable expenses.

In addition, half the net earnings figure calculated as above can be allowed towards the cost of alternative care for the disabled person, or for a child aged under 6, while the carer is at work.

SUDOKU

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

Employee absence levels increase

More than one in three employers report that absence levels have increased because their staff are struggling to cope with their caring responsibilities outside of work, according to a survey by the CIPD – the professional body for HR and people development.

But only one in six organisations have policies in place to help employees achieve a better balance between their home and working lives.

An estimated 2.4 million carers in the UK find themselves part of the 'sandwich generation' - juggling caring responsibilities for older loved ones, while looking after younger children and often holding down a job outside of the home.

The survey found that flexible working arrangements are by far the most common type of support supplied by employers (68%), followed by compassionate leave (53%) and (paid or unpaid) carers' leave (48%).

Two-fifths (42%) offer access to counselling services and three in ten offer career breaks and sabbaticals. One in six organisations offer access to financial services (17%) or options to purchase additional annual leave days (15%).

<http://www.cipd.co.uk/research/absence-management>



Managing sickness absence from school

A controversial booklet being distributed by South Wales Health Boards advises parents on when and how long to keep their children off school if they have the listed illnesses.

Two of these conditions are proven triggers for ME/CFS, slapped cheek (Parvo Virus B19) or Glandular Fever. Some of the conditions listed require safeguarding certain patient groups such as pregnant women and vulnerable children or adults. It also states that only the Head teacher can authorise sickness absence.

Illnesses & action:

<i>Hand Foot and Mouth</i>	- None
<i>Conjunctivitis</i>	- None
<i>Glandular fever</i>	- None
<i>Head lice</i>	- None

<i>Threadworm</i>	- None
<i>Tonsillitis</i>	- None
<i>Slapped cheek</i>	- None
<i>Flu</i>	- Until recovered
<i>Chickenpox</i>	- 5 days from onset of rash
<i>Impetigo</i>	- Until lesions are crusted & starting antibiotic treatment
<i>German Measles</i>	- 6 days from onset of rash
<i>Measles</i>	- 4 days from onset of rash
<i>Ringworm / Scabies</i>	- Not usually required child to return after first treatment.
<i>Scarlet Fever</i>	- Child can return to school 24 hours after commencing antibiotic treatment
<i>Shingles</i>	- Keep home only if rash is weeping and cannot be covered
<i>Diarrhoea and/or Vomiting</i>	- Keep home for 48 hours from or Vomiting the last episode of vomiting/diarrhoea
<i>Whooping cough</i>	- 5 days from commencing antibiotic treatment or 21 days from onset of illness if no antibiotic treatment
<i>Mumps</i>	- 5 days after onset of swelling

The booklet can be downloaded from <http://tinyurl.com/mu2zqjif>

carers

'Time to be Heard Wales' for young adult carers

Young adult carers (age 16-25) are often invisible in their communities. The important role that they play in caring for family members is often misunderstood – by schools, colleges and universities, by employers, or by those in Government.

Carers Trust Wales will be working with young adult carers (YAC) across Wales over the next two years, helping them make their voice heard and carrying out a bespoke Wales-focused research project to better understand:

- their experiences
- the relevance of the recent findings of UK-wide research to young adult carers in Wales
- how to begin to formulate solutions to the challenges they face

An advisory group will help to steer the project; hold a residential in Nov 2014; host a professionals' conference in spring 2015 for politicians, employers, education providers to hear the views of YACs; launch a report with clear recommendations on tackling the challenges faced by YACs and ensuring their voices are not just heard but listened to and acted upon.

More info: Donna Jones Lucas.

DJLucas@carers.org
<http://www.carers.org/timetobeheard>

young people

The real conversation about skills & training

The government wants to find out what difficulties young people have encountered accessing the Apprenticeship Programmes. In particular they are interested in hearing from young people from black, ethnic groups and those with disabilities on their experience of the Apprenticeship Programme.

Follow the Real Conversation online and contribute via <https://www.facebook.com/realconversation> and twitter [@therealconvs](https://twitter.com/therealconvs)

You can also contact them with your views, questions and experiences via e-mail at RealConversation@wales.gsi.gov.uk

Musician with ME

Stuart Murdoch, the Scottish lead singer and songwriter for the indie pop band Belle & Sebastian, once bedridden with ME, is now able to live a near normal life.

In the late 1980s, while he was studying at the University of Glasgow, Stuart became ill and was unable to work for seven years. He is said to have been housebound for eight years. Murdoch said that it was

because of this isolation that he became a songwriter.

"That was a big desert at the time, a kind of vacuum in my life," he said. "From that, these songs started coming out, these melodies where I could express what I was feeling.

In 1995 he worked with a faith healer, whom he credits with his recovery. He said that she placed her hands above his body for an hour, and the recovery took several months.

He is not fully recovered and is still susceptible to bugs and stress but manages to live a full life. Being sick and spending a lot of time alone at home, Murdoch learned an incredibly precious lesson about life.

"The thing I learned when I was sick was to do things when they felt right," Murdoch told the Times. "Not hold on to things for a future time that may never come."

Belle and Sebastian's latest album is due out January 2015. The album opens with a track called "Nobody's Empire" that deals with his struggle with ME.

Recent interview
<http://thequietus.com/articles/16415-belle-and-sebastian-interview>
<http://www.belleandsebastian.com>
<http://www.funkydragon.org/en/>



Funky dragon demise

On 1st October 2014 Wales became the only country in Europe without a National Youth Assembly. Funky Dragon will be replaced by an as yet unknown mechanism. This decision was taken by government without any consultation with children and young people.

More info <http://www.funkydragon.org>

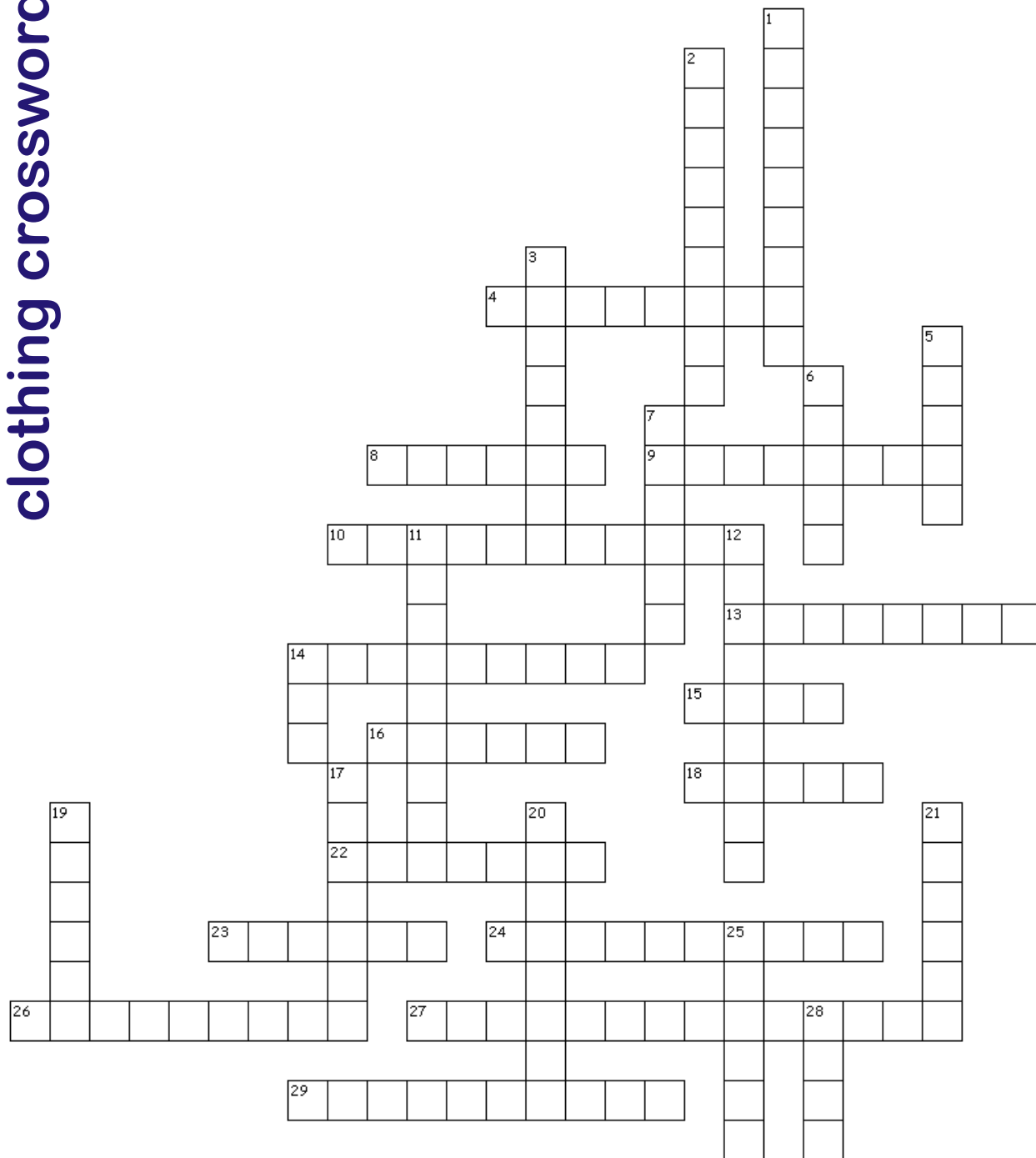
Fixers arrive in Wales!

A unique project which will help thousands of young people to 'fix' the issues they feel strongly about was officially launched in Wales today. Fixers is a movement of 16 to 25-year-olds across the UK who are supported to take action and change things for the better, addressing any issue they want to tackle. With an aim to recruit more than 2,500 Fixers in Wales by the end of 2016, the organisation is already working with 132 young people in Wales on 19 projects.

How each Fixer tackles their chosen issue is up to them – as long as they benefit someone else. Each Fixer is supported to create the resources they need to make their chosen project a success, with creative help from media professionals. Many Fixers chose to make a film, music video, run workshops or hold an event to encourage change in their communities.

More info <http://www.fixers.org.uk>
01962 810970





Across

4. A sleeveless undergarment for women, normally extending to the waist
8. Single figure plus what you do with your eyes
9. Worn to protect clothing whilst doing dirt
10. Casual sporting peaked hat
13. Worn on the feet for sports
14. A warm suit worn by athletes
15. Tartan material pleated and worn by Scots
16. Two piece suit worn in the sunshine
18. A hooded sweatshirt, jacket, or other top
22. Looks like the letter T when laid out flat
23. Buttonless sleeved cardigan
24. A sash worn around the waist, especially as part of a man's evening suit
26. Shoes with heels
27. Outer garment worn in wet weather
29. Sometimes referred to as a dj and worn for formal occasions

Down

1. Trousers held up with a bib
2. A sleeveless waist length garment with buttons at the front, often worn under a suit jacket
3. A shawl made from fine-quality goat's wool
5. Decorate something in an artistic or attractive way
6. Made of denim and worn as casual lower garment
7. a garment of a type originally worn in South America, made of a thick piece of woollen cloth with a slit in the middle for the head
11. Worn on the legs, made of nylon
12. Lady's undergarment
14. Knot it around the neck
17. Fingerless and worn on the hands in winter
19. A dust cover of a book or record
20. Worn on the legs by both men and women
21. A short, wide strip of fabric worn by men round neck and tucked inside an open-necked shirt
25. A loosely fitting garment resembling a long shirt
28. An outer garment for use in winter

young people

Youth led grants

The aim of this scheme is to support a range of small volunteering projects and activities, led and carried out by people aged 14-25. Maximum grant £500.

Closing dates for applications:

- December 6th 2014
- January 30th 2015

WAMES is happy to support applications for suitable projects by young people with ME. Contact Jan.

More info: <http://www.gwirvol.org/en/organisations/funding/youth-led-grants/>



Crossword Solution (Page 17)

Across: 4 Camisole, 8 Onesie, 9 Overalls, 10 Baseball Cap, 13 Trainers, 14 Tracksuit, 15 Kilt, 16 Bikini, 18 Hoody, 22 T-Shirt, 23 Bolero, 24 Cumberbund, 26 Stilettos, 27 Waterproof Coat, 29 Dinner Suit

Down: 1 Dungarees, 2 Waistcoat, 3 Pashmina, 5 Dress, 6 Jeans, 7 Poncho, 11 Stockings, 12 Petticoat, 14. Tie 17 Mittens, 19 Jacket 20 Trousers, 21 Cravat, 25 Blouse, 28 Coat

Badger	Jerboa
Bat	Ladybird
Bear	Lizard
Bee	Mosquito
Blackfish	Moth
Butterfly	Mouse
Chipmunk	Nighthawk
Earth Worm	Prairie Dog
Echidna	Pupfish
Gila Monster	Racoon
Gopher	Skunk
Groundhog	Slow Worm
Ground Squirrel	Snail
Hamster	Snake
Hedgehog	Squirrel
Turtle	Woodchuck
Wasp	Yellow Jacket

Word Search: Animals that Hibernate



Created by [Puzzlemaker](#) at Discovery Education

Home lifts – a dream or a possibility?

Do you have mobility problems or low stamina made you long for a stair lift or even an elevator style lift? But you always thought it was 'pie in the sky'?

You might need an unexpected windfall, but maybe it is more within reach than you thought. Stannah makes lifts for the home market as well as their widely advertised stair lifts and they cost £16,000 plus:

- 4 x 3 foot lift, only requires an aperture in the ceiling of the same dimension
- can carry two people or a wheelchair
- can carry a weight of 250kg or 39 stone
- does not need to be attached to a wall
- no planning permission is required, only building control checks
- they have full battery back-up and manual overrides and the possibility of a phone
- you might hear the soft hydraulics on ascent but on the way down it is virtually noiseless

Find out more about indoor and outdoor lifts or stair lifts, with suppliers <http://www.independentliving.co.uk/?il-editorials=stairlifts>

Home lift suppliers:

Stannah: 0800 378386
Terry Lifts: 0845 365 5366
Power lift: 0115 926 9996
Bentley-Fielden: 0800 612 1140

Cooking when brainfogged

People on the forum MEChat know that brainfog can be a problem, especially when cooking.

MEChatters have come up with two ideas to help you avoid missing out vital ingredients.

- Assemble all the ingredients you need on a tray before you start and put them away when used (to avoid double-dosing!)
- Use fewer ingredients.

There is an Australian site at <http://www.4ingredients.com.au/> that specialises in recipes that use only four ingredients. They have published books available on Amazon and are on Facebook. Also useful is that they have special recipes for gluten-free, allergies and diabetes.

<http://www.mechat.co.uk>

Christmas is coming... again

Pace your way to Christmas with the help of the tips in last October's **me voice** (available online or from Tony).

Also check out the tips on the MEChat website: <http://www.mechat.co.uk/db/tips.htm#Coping>

living with me

FIREACTIV Thermal joint supports

Are a range of innovative joint and muscle supports that comprise of adjustable neoprene support braces with Velcro fastenings for compression and secure fit over specific body areas, and two removable interchangeable heat pads with bio-ceramic particles permanently fused to the fabric.

They utilise the heat generated from the body's own warmth – captured by bio-ceramic particles in the heat pads and amplified and subsequently reflected back to the surface of the skin as long wave infrared radiation heat. It penetrates up to 60mm deep to relieve pain, improve circulation, enhance healing and provide soothing warmth and lasting comfort.



Batteries, wires or external power sources are not required. There are supports available for back, neck, shoulder, elbow, wrist, knee and ankle.

Win Health Ltd, Brockhirst Oxnam Road, Jedburgh TD8 6QN
Tel: +44 (0)1835 864866
<https://www.win-health.com/fireactiv-support-thermal-pain-relief.html>

Dr Myhill's shop

Dr. Myhill has set up an online shop for supplements. For the newcomers amongst you, Dr. Myhill is a private specialist who is trained in ecological medicine and has years of experience of treating people with ME.

Her website has been described as a Tardis of information. e.g. She believes that modern Western diets are deficient in micronutrients. To address these deficiencies taking nutritional supplements should be an essential part of life for everyone. She provides them in her Basic package. www.salesatdrmyhill.co.uk

***"You don't stop laughing
because you grow old - you
grow old because you stop
laughing"***

welfare

New Universal credit fact sheet available

Action for ME's new fact sheet, *Universal Credit: an overview*, is available to read and/or download in the Publications section of the website. Universal Credit is the new single benefit that is will eventually replace a range of current means-tested benefits. <http://tinyurl.com/m3dvqtu>

Benefits sanctions overhaul

The government is to overhaul the way it treats benefit recipients threatened by sanctions, after an independent report it commissioned showed systematic failings in the process, including disproportionate burdens placed on the most vulnerable.

Child and Family Poverty in Wales

A new report published by Children in Wales shows the detrimental impact that welfare reform is having on many children and families living in Wales.

<http://www.childreninwales.org.uk/resources/poverty/>

Bedroom tax update

A vote in parliament defeated government to force changes to bedroom tax
<http://www.independent.co.uk/news/uk/politics/coalition-rocked-by-bedroom-tax-revolt-9715640.html>

Campaign against pre-paid cards

38 Degrees member Llewelyn is demanding Conservatives scrap plans for benefits to be put onto prepaid cards, which could only be used to buy certain products in certain shops.
<http://tinyurl.com/m9sf9mh>

Mobility criteria for PIP

A judicial review case was brought on behalf of Steven Sumpter, who has ME and can walk a few metres with the aid of sticks, otherwise being dependent on a wheelchair to get about.

He was challenging the lack of proper consultation over the reduction of the eligible distance to qualify for the highest mobility rate of Personal Independence Payment to 20 metres, rather than the 50 metres which is applied in the case of



Steven Sumpter

Disability Living Allowance (DLA), the benefit which PIP is gradually replacing.

Unfortunately, the judgement went against Mr Sumpter, who fears that although he currently receives higher rate DLA, which he uses to lease a Motability car, under the new rules he would lose the entitlement – and with it, his independent mobility.

He won't be alone in this predicament: government figures suggest that by May 2018, some 400,000 people will lose a mobility benefit they would have received under the old rules.

Steven's blog:
<https://www.latentexistence.me.uk>

A Sunday school teacher was telling her class the story of the Good Samaritan. She asked the class, "If you saw a person lying on the roadside, all wounded and bleeding, what would you do?"

A thoughtful little girl broke the hushed silence: "I think I'd be sick."

7 day Waiting Period for ESA & JSA

From 27th Oct 2014, an extended waiting period at the start of a claim for ESA or JSA is being introduced. The new law will mean that no ESA or JSA would be paid for the first 7 'waiting days' instead of the present 3 days. Both types of ESA and also JSA are affected but not Housing Benefit. There is a fear that this extra cut will put further pressure on claimants.

A similar measure, predicted to save £200 million by 2016/17, may be introduced for Universal Credit.

PIP waiting times to fall?

The government has said that the lengthy wait to get a decision on PIP (often one year), should now be a thing of the past! By the autumn it should be no longer than 26 weeks and by the end of the year, no longer than 16 weeks. Also, online claims might be available in the future.

Disabled friendly houses needed

The *Hidden Housing Crisis* report is available from Leonard Cheshire organisation
<http://tinyurl.com/n5oe9no>

Child abuse allegations

Tymes Trust have published a booklet describing their experience of being involved in 121 cases of child abuse allegations because the child has ME and doesn't get better. All allegations have proved to be unfounded.

Download from their website :

False allegations of child abuse in cases of childhood myalgic encephalomyelitis

<http://www.tymestrust.org/pdfs/falseallegations.pdf>

NICE & ME

Tymes Trust discovered over the parliamentary recess that NICE had listed the CFS/ME Guideline under mental health.

They immediately alerted Patron the Countess of Mar who contacted NICE and the CFS/ME Guideline was removed from mental health. It is now under neurological conditions. This now agrees with the WHO classification ICD10 G93.3.

Videos about ME online

Hollie Ransley

Understanding ME – an allegorical tale

<http://www.fixers.org.uk/news/9682-11208/understanding-me.php>



Prof. Ian Lipkin

Prof Leonard Jason

<http://tinyurl.com/oetquwv>

Prof Ian Lipkin

<http://tinyurl.com/nmh3elm>

Broadcaster and US political commentator **Llewellyn King and Deborah Waroff**, a journalist who also has ME, have a Youtube channel ME/CFS Alert, where they post interviews about ME with influential people
<https://www.youtube.com/user/MECFSAlert/videos>

One million lovely letters

Jodi Ann Bickley, who has ME, offers to write you a letter, just to

make the day a bit better or to remind you of the amazing stuff about you that you've forgotten, because we all forget once in a while.

If you would like a letter you can email her at:
onemillionlovelyletters@gmail.com

More info:

<http://onemillionlovelyletters.com>

CMRC Conference report

September's UK CFS/ME Research Collaboration Conference Report is now available on the Action for ME's website.

Speakers included:

Dr Stuart Watson, Prof Wan-Fai Ng, Prof Carmine Pariante, Dr Sue Wilson

<http://tinyurl.com/qfmt4o2>

Health Apps - a Toolkit to Help You

An online guide helping people find and use tried-and-tested health apps. It walks the reader through each step of a journey towards getting started with health apps.

The Toolkit identifies the main pitfalls with health apps, and educates on how to overcome these problems.
<http://www.blastphotography.co.uk/patientview.html>

Call to legalise medicinal cannabis

A man with ME was interviewed on ITV news in September backing the campaign to legalise cannabis. He feels forced to trawl the back streets to buy the drug illegally because it is the most effective drug for his pain.

The ME patient, who struggles to walk much of the time says he has repeatedly tried - and failed - to get his local NHS trust to pay for Sativex, which is the government's first legal, licensed cannabis-based medication.

The government's Crime Prevention Minister, Norman Baker, has called for medicinal cannabis to be legalised as he believes it is wrong to deny people a product which could help.

A Home Office spokeswoman said there were "no plans" to review how cannabis is classified.

More on ITV website:
<http://tinyurl.com/mjrus3p>

me groups

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

Anglesey & Gwynedd Fibromyalgia / ME Group

Contact: Rhian Medi (secretary)
01248 722184

fmsmemonagwy@yahoo.com

Brecon Area Contact

Richard Jones
richardj5@virginmedia.com
01874 622310

Carmarthenshire ME Group

Meets Coleshill Social Centre,
Coleshill Terrace, Llanelli SA15
3BT. Please ring John James (pm)
01267 233793 for further details.

Clwyd ME Group

clwydme@gmail.com
01745 822953 www.clwydme.net
Contact Adrian Jenkins
adrianj15@hotmail.co.uk

ME Support in Glamorgan (MESiG)

Monthly meetings are held on the
first Monday of the month, 11am -
12.30pm at The Community Shop,
Llangranog Road, Llanishen,



Cardiff CF14 5BL
Contact: Christalla Bailey,
029 2076 2347
christallaconstantinou@talktalk.net
www.mesupportinglamorgan.co.uk

Montgomeryshire ME/CFS FM Group

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

North Ceredigion Yoga Class

tailored for people with ME and
other medical conditions.
Meets on Wednesdays, 2.30-4pm,
at Canolfan y Morlan, Aberystwyth.
For details contact Cathy Crick on
01570 421 144 or 07748 031614 or
cathycrick@hotmail.co.uk

Pembrokeshire

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

Live near the border?

**An English group may meet
closer to you:**

Shropshire

www.shropshiremegroup.org.uk
Maralyn Hepworth 07516 401097

Chester

www.chestermesh.org.uk

contacts

helpline@wames.org.uk
02920 051 5061

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