April 2013, no. 2

me voice

The WAMES Magazine

WAMES

Welsh Association of ME and CFS Support

contents

King Cups at Frongôg

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

Contact tony@wames.org.uk

WAMES Subscriptions
The Coach House Frongôg
Aberystwyth SY23 3HN

the wames enformation 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):

- newsblog 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 Coach House Frongôg

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 and decrease size of page. In Adobe Acrobat press "control" and "L" together.

Copy dates for the magazine:

15 June, 1 Oct., and 1 Dec. 2013

about wames

Thank you to all who have sent their compliments and good wishes about *me voice*. Keep your comments and suggestions coming!

Thank you too to those who have sent donations. We rely on donations as we don't receive regular funding from any other source. We regret that an acknowledgement won't be sent by post unless requested, due to the cost of postage.

If you pay income tax, please request a Gift Aid form (or download it from the website) so we can claim an extra 25p in the £.

wames volunteering opportunities

- Secretary
- Awareness raising
- Welsh language
- Publicity
- Online
- Young people
- Communication
- Awareness raising
- Volunteer coordinator

AGM

Our AGM had to be postponed in March so will now be held on the 17th April. We'll include a report of that meeting in the summer issue.

Health Services Campaign Update

Hywel Dda

The Action plan devised by the Hywel Dda ME Working Group (consisting of Health Board staff, patients and carers) has run into a brick wall at the moment. We are working on having ME moved from the Musculoskeletal Health category to the Neurological Health category of the Service development plan!

Jan has been making contacts with health professionals with the help of the West Wales Neurological Alliance. Awareness displays were available in hospitals during Brain Awareness Week and she will be running training sessions for some health professionals in the coming months.

Powys

Reduction in staff numbers and budget has made it near impossible for meaningful engagement with Health Board staff responsible for ME & CFS service development.

Jan is exploring other avenues with the Health & Social Care Facilitator and Community Health Council for Powys. WAMES is also working with the local neurological alliance (MANGO) raising awareness amongst health professionals.

Betsi Cadwalladr

THE North Wales LHB has also not committed enough staff time and resources to pathway implementation and service development although talks are ongoing.

Cardiff & Vale

The consultation began well with a very positive response and understanding of the need to improve services, but it has lost impetus and needs to be jump started again.

Cwm Taf

After the GPs decided they were providing a good service (!) no progress has been made. There appears to be little willingness to consult with patients in this Health Board.

Aneurin Bevan

This Health Board still hasn't appointed anyone to be responsible for ME.

Abertawe Bro Morgannwg

The pathway implementation team has begun work on other neurological conditions and I am hoping to hear soon when they will begin to tackle ME.

The ME Brain

WAMES has published a booklet gathering together key research showing dysfunction in the brains of people with ME and CFS.

We hope it will be a useful way of showing health professionals the neurological nature of ME. You can read it online, download it from the website site or request a paper copy from Tony tony@wames.org.uk 01970 6365515

or Sharon (ME Awareness Week Contact) sharon@wames.org.uk 07855128647. One copy costs £2.45 + P&P of 55p.

help us campaign

Complete our survey and / or tell us your story so we can provide health boards and social services with 'evidence' that improvements are desperately needed – the deadline has been extended.

Complete online or request it in paper or electronic file.

news from wales

ME Group events round Wales

Clwyd ME Support Group
Benefits & Benefits Reform Workshop May

Book signing at the Grosvenor Garden Centre, just outside Chester on Fri 24 May. Clwyd ME Support member and best selling author of historical and romantic fiction, Katie Flynn, has had ME for 17 years. She dedicated her latest book to Barbara Turnbull and 100% of the proceeds of the book signing will be donated to the group.
www.katieflynn.com

Swansea valley
Kayleigh Jones hasn't been able to arrange a venue yet for a get together in the Swansea valley area (Ystradgynlais, Ystalyfera, Pontardawe, Clydach) Contact her for more information.
kmejones73@hotmail.co.uk
07429617002

Carmarthenshire ME Group
Meets Cae Maen Day Centre, Coleshill Terrace, Llanelli SA15 3BT at 2pm Sat 8th June. Please ring John James pm 01267 233793 for further details. If you have not been to a get-together before, please ring as it is sometimes necessary to cancel a meeting or change the venue.

North Ceredigion Group
meets Tuesday, June 11th 2-4pm at 11 Nant Seilo, Penrhyncoch. Please contact Dr Derryan Paul 01970 828896
edpaul@phonecoop.coop for a lift or directions.

North Ceredigion Yoga Class
11 Nant Seilo, Penrhyncoch on Thursdays 2-30-4.00pm. Contact Derryan 01970 828896
edpaul@phonecoop.coop for more information.

For other yoga classes in Ceredigion contact Cathy on 01570 421144 or 07748 031614
cathycrick@hotmail.co.uk

ME Support in Glamorgan (MESiG)
meets May 6th & June 3rd, 11am - 12.30pm at The Community Shop, Llangranog Road, Llanishen, Cardiff CF14 5BL Contact: Christalla Bailey, 029 2076 2347
christallaconstantinou@talktalk.net

New Pembrokeshire Group
Wed 20th May 11am to 1pm.
You are invited to the first Get together (bring lunch optional) at 65, Tudor Gardens, Merlin's Bridge Haverfordwest SA 61 1LB
Contact Tina Norman
01437 454359, tretiul@talktalk.net

Pick up from Haverfordwest train or bus station can be arranged.

MESiG awareness & fundraising

MESiG raised £1,000+ at their Zumba event in February to send a severely affected member to Burrswood hospital in Kent. In March they raised £124 and gave out information at Sainsbury's in Thornhill.

Wales e-library

If your local library service is a member of the e-books service you can download e-books online with only your library card number and a pin, which you can obtain from your library. You have to download an Adobe DRM enabled eReader or an Adobe DRM supported eBook app to view the books - they won't work on kindle.

You can select up to 4 eBooks to download at any one time for a maximum of 21 days. You choose how long to borrow for and as soon the title expires you can 'borrow' another title. If a title is in use you can reserve it. There is a wide range of subjects available but many publications aren't available as e-books, so the stock will be limited. There currently appears to be only 2 books aimed at people with ME & CFS.
Contact your local library service to see if it is participating or check
http://wales.libraryebooks.co.uk

Introduction to Self Management

ISM is a half day taster session that gives an introduction to the 6 weeks course run by EPP Cymru (Education Programmes for Patients). It is open to individuals with a health condition or who care for someone with a health condition. The prime objective is to provide the individual with some "tools" and information to improve their ability to self manage.

About the course:
http://tiny.cc/dn3ivw

About EPP Cymru
www.wales.nhs.uk/expertpatient

See regional pages for details of the course in your area p 6 & 7.

Only order what you need!

Wasted medication is costing the NHS millions every year. A campaign aimed at reducing unnecessary waste was launched in January throughout Abertawe Bro Morgannwg University, Hywel Dda, Aneurin Bevan and Cardiff and Vale Health Boards.

One of the main concerns is repeat prescriptions, which are ordered and collected by patients but then not used. It is estimated that £90 million worth of unused prescription medicines are retained in individual's homes, across the UK, at any one time. Around half of all do not take or use their medicines as prescribed.

The potential money wasted on used or partially used medicines could pay for

- 141 more nurses;
- OR 3,600 more drug treatment courses for Alzheimers;
- OR 238 more drug treatment courses for breast cancer;
- OR 971 more hip replacements;
- OR 3,746 more cataract operations.

The campaign asks patients to only order what they need, return their unwanted medicines to their pharmacy for safe disposal and take their medicines with them when they go into hospital.

Find out about the campaign in your area at www.medicinewaste.com/campaign/index

My Health Online

Patients can take a greater involvement in their own healthcare via the internet, in a similar way to shopping or banking online.

My Health Online gives patients the opportunity: to book GP appointments order repeat prescriptions update their general details such as change of address all from the convenience of their home computer.

Advantages of online services include:

- No hanging on the phone, waiting to get through to the GP surgery
- Convenient access to GP services from home or work — or anywhere with internet access
- Reduced administration for the GP practice

How do I get it?

You need to call into your GP practice and sign up. Your GP will issue you with a registration letter, you will need to have proof of identity on you to enable them to do this.

Please be aware not all GP practices can offer this at present, as and when their IT system is upgraded it will become available. For a current list of practices please contact NHS Health Informatics Service by phone 029 20 500500 or online http://tiny.cc/2v3ivw

It will be available to all patients across Wales by the end of 2013.

Funnies

From Thomas Cook Holidays, listing some of their UK clientele's genuine complaints.

1. "Topless sunbathing on the beach should be banned. The holiday was ruined as my husband spent all day looking at other women."

2. "It's lazy of the local shopkeepers to close in the afternoons. I often needed to buy things during 'siesta' time — this should be banned."

3. "On my holiday to Goa in India, I was disgusted to find that almost every restaurant served curry. I don't like spicy food at all."

4. "We booked an excursion to a water park but no-one told us we had to bring our swimming costumes and towels."

7. "The beach was too sandy."

8. "We found the sand was not like the sand in the brochure. Your brochure shows the sand as yellow but it was white."

9. "No-one told us there would be fish in the sea. The children were startled."

wales regional news

NORTH WALES

Businesses offer mentors

Businesses in North Wales are offering to mentor both groups and individuals, so that they are able to achieve identified goals. Every community group or individual provides a project brief with support from their local Project Officer, and is then carefully matched to a mentor, though there is no pressure on either side.

Whether your needs are practical, financial, creative, digital or something else entirely, find out more from: www.b2cwales.co.uk

B2C(Business supporting communities) aims to create mutually beneficial relationships between business and communities.

Through bringing business and community groups together the Business Supporting Communities Project aims to:

- Increase the capacity and/or capability of at least 1700 local community and voluntary groups throughout North Wales
- Increase the skills and/or capacity of over 1000 individuals
- Improve community environments

Businesses will do this by offering volunteers, expertise, professional advice, equipment, training and sharing of facilities to community groups.

Conwy and Denbighshire
Project Officer: Lucy Kew
Lucykew@b2cwales.co.uk
Denbighshire: 01745 353110
Conwy: 01492 523847

Gwynedd and Anglesey
Project Officer: Emily Williamson
Emily@b2cwales.co.uk
Anglesey: 01248 724944
Gwynedd: 01286 672626

Wrexham and Flintshire
Project Officer: Alison Roberts
Alison@b2cwales.co.uk
Wrexham: 01978 317097
Flintshire: 01352 744018

Introduction to Self Management

Half day taster session run by EPP Cymru:
Wrexham -Capel y Groes, Bodhyfryd, Mon 13 May 2013 11:00-14:00
Caernarfon - Eryldon, Campbell Road, Mon 3 June 2013 10:00 - 13:00
Llangefni Hospital, Mon 10 June 2013 10:30 - 13:30
Chirk Community Hospital Mon 17 June 2013 11:30 - 14:30

More information:
Denbighshire, Flintshire and Wrexham 01286 674236
elois.davis@wales.nhs.uk

Gwynedd, Anglesey and Conwy
01286 674236
Del.Rawlins@wales.nhs.uk

http://tiny.cc/4o8ivw

MID WALES

Help needed in Montgomeryshire

Trustees are needed to save an important project designed to help people with ME and other neurological conditions in Powys. It will be run by MANGO (Montgomeryshire Alliance of Neurological Groups and Organisations) with the help of PAVO .

Community Voice funding has been promised for MANGO to employ a project worker for 4 years, whose job would be to help people with neurological conditions get their voice heard and influence service provision, first in Montgomeryshire, and then in the rest of Powys.

An added feature of this funding is that the Big Lottery required service providers to commit to engaging with service users, increasing the chance that we will actually be able to make a difference.

That project is now in jeopardy since officers had to retire due to poor health.

The Community Voice grant is only given to fully constituted groups, so in order to access the money and employ a project worker at least 2 more officers need to get involved in the committee ASAP.

This project could potentially make a big improvement to the quality of life and care of people with neurological conditions throughout Powys, and their carers so if you think you can help please contact Jan for more information
enquiries@wames.org.uk
01970 636515

Community Voice:
http://tiny.cc/cu8ivw

MANGO:
www.mangomontgomeryshire.org.uk

PAVO: http://tiny.cc/3w8ivw

wales regional news

Introduction to Self Management

Half day taster session run by EPP Cymru:

Aberystwyth - Thursday 12.30 - 3.30pm 4th July 2013
More info: 01554 779507
Caroline.Davies9@wales.nhs.uk
http://tiny.cc/118ivw

Broadband in Radnorshire

Many people with ME rely on the internet to keep in touch with people and avoid the isolation that the condition often brings.

If you live in Radnorshire and your Broadband is slow, or non-existent check out http://radnorbroadband.com

Mark Baylis (local resident and Senior Network Support Officer at Powys County Council) is rallying residents to get fast broadband in the area sooner rather than later. He is collecting details of Radnorshire residents and organisations that want to participate in a community application under the Welsh Government's scheme.

The scheme will allow residents to have up to £1000 applied to the (often high) cost of broadband installation that circumvents the weakness of the old copper network installed in the region. Already attracting significant interest, the first applications have already gone in to the Welsh Government.

The Radnor Broadband scheme seeks to reach a critical mass of 100+ residents participating, which would allow them to attract the interest of alternative providers of broadband using wireless and microwave technologies. Funding for this project is limited so an application will need to be made quickly. Go to http://radnorbroadband.com to register your interest.

SOUTH WEST WALES

Introduction to Self Management Half day taster session run by EPP Cymru:

Carmarthen - Thursday 10.00am - 1.00pm 27th June 2013
Pembroke Dock - Wednesday 10.30am - 1.30pm 26th June 2013

More info: 01554 779507
Caroline.Davies9@wales.nhs.uk
http://tiny.cc/k88ivw

Swansea Garden Wildlife Survey

Gardens, are miniature nature reserves, and can also help reduce pollution in our streams and rivers.

The Wildlife Trust of South and West Wales and the Nature Conservation Team of the City & County of Swansea want to discover (with your help!) more about the environment and hidden wildlife of Swansea's gardens.

Help them to protect the wildlife and environment for future generations by filling in the online survey at http://tiny.cc/la9ivw

SOUTH EAST WALES

Introduction to Self Management Half day taster session run by EPP Cymru:

Usk - Adult education Centre, Maryport Street, Usk Tuesday 4th June 2-5pm.
Blaina - ICC Old Blaina School Sat 27th april 1030am-1pm
Lys Glyn Coed Ebbw Vale - Thurs 13th June 1030am-1pm
Asda Stores Blackwood Wed 22 May 1030am-1pm
Llanishen Leisure Centre Mon 29th April 2.30pm -4pm
Western Leisure Centre, Ely Wed 8 May 1030am-1pm
Barry Leisure Centre Tuesday 21 May 2013 10am -1230pm

More info: http://tiny.cc/5n9ivw

Newport, Monmouthshire and Torfaen Localities
01291 67 19 03 ext 230
michelle.morgan@gavowales.org.uk

Cardiff & Vale 02920 350620
carol.stingl@wales.nhs.uk
carol.Young@wales.nhs.uk

For Sale

Sauna blanket for sale. A Firzone far infra red sauna blanket (No.FZ-200B), used only once because it needs too much space.

People use it for pain relief, fatigue, detox, general fitness, and relaxation. It cost £200, for sale £70 ono, to be collected from Machynlleth. Contact Fiona fifisugar12@gmail.com or telephone 01654 702778.

me awareness week

There seems to be some disagreement over the date of ME Awareness Week this year, but most UK groups will be celebrating it from the **12th – 18th May.** There is no reason to limit our awareness raising to one week however!

May 12th is International ME Awareness Day. This is a time when people round the world look for ways to highlight the long term and disabling effect that the condition can have on people, and the wide ranging disruption and distress it can cause to families and friends. The week (or month) around this date also serves as a focus for fundraising events.

The May 12th date was chosen because it is the birth date of Florence Nightingale, the nurse who inspired the founding of the International Red Cross. She is understood to have become ill in her mid 30s, with an unknown debilitating condition.

Despite her illness and being largely bedridden, she founded the first School of Nursing . Her example inspires people with ME to persevere and work for change.

How can I raise awareness?

Blue ribbons
a simple way to attract people's attention is to wear a blue ribbon. Be prepared to explain what it means, when asked. We can supply a small number for your friends or family or purchase them from BRAME. Or download (or make) a **twibbon** to add to your online presence. Find some at http://meaware.wordpress.com/badges

BRAME (Blue Ribbon for the awareness for ME) was set up 18 years ago by Tanya Harrison, who has severe ME, and her mother. As well as campaigning for a greater understanding of the nature and severity of ME, BRAME sells blue ribbons (5p each) and enamel badges (£1.50 each) plus P&P. www.brame.org

Pyjamas
Whether you're ill and normally wear your PJs most of the day or are well and just want to show your support in a fun way, you can join people all over the UK in wearing pyjamas from 9am – 9pm on 12th May.

Add an extra dimension and take part in ***National Sponsored Pyjama Day*** and raise money for WAMES and / or any other charity.

There is a £50 PRIZE for the person who raises the most money for charity! Find out more about at http://tiny.cc/bdghvw

If you go out it's OK to wear a jumper, coat, shoes, hat, scarf, gloves as needed over your PJs. If you don't or can't go out, invite others to join you, record the moment with your camera, and send it to the WAMES Facebook or web site, or to Sharon for the magazine.

Contact Sharon for a WAMES fundraising pack to help you make the most of the day.

Dressing gowns
as an alternative to wearing PJs you could hold a dressing gown event one day during Awareness week. Join friends in a coffee shop or restaurant or arrange an 'own clothes day' at school or a 'dressing down day at work'. Get sponsorship in advance, pay to wear your dressing gown or invite donations on the day.

Share your story with local media - contact your local newspaper or radio with your experience of ME. Highlight the need for better services and more research or advertise your local awareness or fundraising event. Contact Sharon for guidelines on how to write your story.

Know a professional who is interested in finding out more about ME?

Ask them to get in touch with Jan to find out about the professionals' network. Tell them about the **IiME conference** in London on 31st May http://tiny.cc/fzwkvw Top experts will be speaking and important CPD (Continuing Professional Development) points are available for healthcare professionals. WAMES will 'sponsor' them to attend and they will receive a discount.

Give them a copy of the ***WAMES ME brain booklet*** (details on p3). Or give your medical surgery's name & address to the ME Association so they can send them a copy of Dr Shepherd's medical guidelines: ME/CFS/PVFS: an Exploration of the Key Clinical Issues (aka the **purple booklet**). A fully revised edition of the booklet is being prepared for the campaign. Email: tony_mea@btinternet.com or text: 07516 656 537.

All fall down for ME!
At 3pm on Sun 12 May opposite the Houses of Parliament in London, people will 'fall down', and lie silent and still for 2 minutes, to represent the brain/body collapse and pain people with ME are forced to endure, year in, year out, with no end in sight. *This is not a life, it is a living death*. Biomedical research is urgently needed. http://www.me-alivingdeath.org.uk

How can I fundraise?

Fundraise for WAMES in a way that matches your energy and free time. This can be done during awareness week or whenever is convenient.

Supermarket collection – organise a group of friends and ask your local supermarket if you can collect in their foyer. Ask us for collecting tins and posters. Choose a busy day and you could raise hundreds of pounds.

Buying and selling

Make money from your unwanted items by selling them locally or online. Sell on Ebay and donate some or all the proceeds to WAMES. Donate to WAMES while shopping, organise an online auction. Find out more about the Paypal giving fund at www.missionfish.org.uk.

Sponsored event

This could be for something active like a cycle run, marathon, or for something more low energy like silence, body shave (e.g., head, legs), sleep; pyjama wearing day – how many places can you visit in your PJs.

Last year El, our Facebook editor, shaved her head and raised £331 for WAMES – a great result!

Set up a fundraising page online through MyDonate or Charity Choice. View the WAMES pages at https://mydonate.bt.com/charities/wames or http://www.charitychoice.co.uk/wames.

Ask Sharon for a sponsorship form.

Raise money for WAMES online through Mydonate, Charity Choice or Mission Fish.

Other suggestions include:
car boot sale, concerts, coffee mornings, parties, pub quizzes or treasure hunts. Use your skills to design and sell your own cards, cakes, fudge, plants etc. Or auction your time for babysitting, gardening, teaching a skill etc.

Invite others to raise money at work or school, or name WAMES their charity of the month or year. Ask for a donation to WAMES instead of a birthday present.

Contact Sharon Price, our Awareness Week Contact (who wore blue hair last year) for any help with publicity and planning. She can provide posters, leaflets, gift aid forms, sponsorship forms.
sharon@wames.org.uk
07855128647

Money raised for WAMES during Awareness week will be used to support the health services campaign and will pay for publications, transport costs for meetings and training.

The poetry cure?

When did you last read or listen to poetry?

For many this would have been while they were in school. For some it might have been in church or when their children were performing at school or the local eisteddfod. A few might continue the tradition and watch the poetry classes at the national eisteddfod on TV. But how many of us sit down and read poetry regularly for enjoyment or feel the urge to write?

Why read poetry?

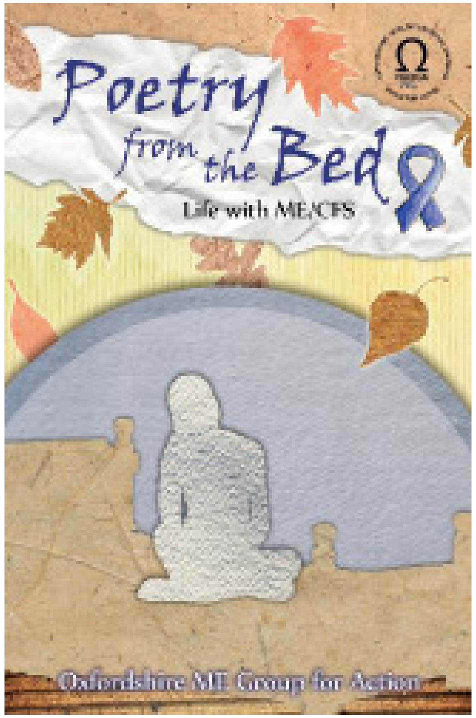
Poems can be written in such beautiful language they can take your breath away. Or they can express familiar emotions and concepts in a new and succinct way to make you stop and think. They can also be downright funny or have a captivating rhythm.

People with illnesses like ME have also discovered more practical reasons to read poetry. Poems are often short and can be therapeutic!

John Andrew Denny

When John Andrew Denny [1] struggled with the debilitating effects of full-blown ME, he was unable to concentrate for long and his memory was very poor. A friend sent him a postcard with a poem on it, which he read and reread, finding he was mesmerised by the music and rhythm of the language and as he slowly discovered other poems he often took comfort in the memories or images the words evoked.

He began a journey of exploration into poetry which eventually led to a discovery of clinical studies which show that when a person reads or writes poetry it stimulates a physical response that is of therapeutic benefit. The effect is akin to that of hypnosis or meditation, stimulating the body’s production of endorphins – technically, opioid neuropeptides, which resemble opiates in their analgesic and euphoric effects. At an unconscious level the mind does not distinguish between real and imagined experience. A strongly imagined experience can reproduce the emotional effect of a real experience. Not just words and thoughts but a kind of spell that sticks in the mind where it stays to make its magic.



Why write poetry?

Poets have described writing poetry as a way of thinking about difficult and uncomfortable things and taking greater control over their lives.

Julia Darling

Julia Darling [2] is a cancer sufferer and Literature lecturer who is interested in the healing powers of poetry. She believes it should be part of every modern hospital, not just something to keep patients amused. It is a powerful force, which can help us through the darkest times. How?

- It uses **images and metaphors** to help us see things in a new way. She chose to imagine her body as a house and wrote many poems during her treatment using this analogy which helped her step outside her difficult situation. Once you have found a metaphor that works, she suggests exploring and adjusting it, creating new views and a feeling of being in control over the body.

- Poetry also gives a **structure** that can make a mess manageable. Initial scribbles, diaries or notes can be turned into a well-shaped object by using a simple poetic form like haiku or sonnet.

- **Language** can be used to express things in new ways, bringing a better understanding. Julia looked for a new vocabulary for pain which would communicate more effectively than using words like stabbing, throbbing, etc. e.g. My joints are rusty cranes. My hot flushes are like a thousand red ants marching up my body. She believes this can improve communication between doctors and patients.

- Poetry is all about **music and rhythm** and music comforts and lulls us. The process of writing can be described as a way of creating harmony, allowing us to relax. Using an important rhythm from our past can create poems that echo somewhere inside us.

Keryn Dawer

Keryn Dawer [3] hid her CFS from the world for 29 years until she crashed and became bedbound. Convinced her death was imminent, she began scribbling down words and phrases that she believed summed up her life –‘a life not just unfair, but unscrupulous, undeserved and unsparing’.

These fragmentary thoughts and reflections gradually evolved into poems. To begin with she simply wanted them to be read at her memorial service but she was persuaded to share them with others.

She realise that she wanted to communicate. She wanted the world to feel the ordeal of CFS and she wanted to convey the message to fellow sufferers that *You are not alone – We are one*. She also wanted to say thank you to carers and assure them they are desperately needed and appreciated.

> Poetry is a deal of joy and pain and wonder, with a dash of the dictionary. *Kahlil Gibran*

Eleanor Dent

Eleanor Dent from Cardiff began to write poetry when her second child was born nineteen years ago. She had given up work and missed adult company so she used poetry to express her frustration at being isolated:

“My poetry wasn’t very good until I began to read other contemporary poets in the small press and it improved with practice. I have had ME for nine years and found writing difficult at first. I still struggle but enjoy reading and writing poetry when I can. I self-published an anthology a few years ago and gave most of the small print-run away.

My poetry is not online but one of my poems is in the anthology ‘Heart Shoots’ [4] which is published in aid of Macmillan Cancer Research. Read Eleanor’s prizewinning poem on the next page.

Jan Russell

May 12th is not just ME Awareness Day, but also Limerick Day (the birthday of Edward Lear, the famous limerick writer).

The poetry cure?

Resources

1 ***Through corridors of light: poems of consolation,*** edited by John Andrew Denny, Lion Book, 2011 (£6.89 Amazon) A collection of poems by well known and lesser known poets which reflect the progression he followed through his illness: illness as part of being human; the need to change attitudes to find contentment; learning to be still and appreciate what we have; rebuilding courage and hope in the future; finding consolation in the cycle of the seasons; meditating on the certainty of death.

2 ***The poetry cure,*** edited by Julia Darling & Cynthia Fuller, Bloodaxe books, 2005 (£8.95 Amazon) A collection of modern poems for all who go through illness: admissions; poems to make you feel better; what it feels like; for those we love; the language of pain; healing rhythms; body parts; talking to the dead.

3 ***The limbo of lost dreams: poetry written on the runaway train of Chronic Fatigue Syndrome****,* by Keryn Dawer, Kindle, 2012 (£2.96 Kindle only)

4 ***Heart Shoots*****:** An anthology to aid the work of Macmillan Cancer Support. 2013 (£9.89 Amazon) Contains work by well known people (Bob Dylan, Benjamin Zephaniah, Seamus Heaney etc) as well as Cardiff based poet Eleanor Dent.

5 ***Poetry from the bed: life with ME/CFS.*** OMEGA, 2012 A collection of poems written by members of the Oxford ME Group for Action, for a competition to express their experience of ME: how my life changed; brain fog and other symptoms; getting through the day; imagine; judgements; endurance; looking out; hope; ME/CFS affects us all; thank you to all who care for us.

6 www.literaturewales.org covers writers, events, publishers, tips on how to write, national poet of Wales

7 Action for ME poetry corner http://tiny.cc/dprkvw

8 http://youngpeopleslaureate.org/ see more on Young people’s pages, p 14

M.E.

Do you know how it feels to be utterly and completely without hope
to watch the well through jaded windows passing by each day
while you are walled alive inside a home you would escape from
if you could, though you have not committed any crime,
incarcerated indefinitely, no parole, appeal or pardon?

Not one prison visitor ever calls, no social worker, education officer,
welfare woman, surly screw, committee member, doctor, nurse or shrink.
Do you know the helpless, heartless moment when the politicians
send polite replies to your appeals for help? ‘We know. We sympathise.
We’re sorry. We will do our best.’ The years go by. You write again.
‘We know. We sympathise. We’re sorry. We will do our best.’ They don’t.

The NHS will tell you: ‘We are wonderful. We help so many people. We’re improving.
We’ve improved. We’re winning. We have reached our targets.’ ‘We don’t care’
is what they should be saying. ‘Not for you. You are nothing much to us.
You are a bafflement, a nuisance, an embarrassment, a perplexing puzzle.
Failure is not good for our P.R. Your condition undermines our success rates.
We shall continue to ignore you, though you mushroom and envelope us.’

Beware complacence. Here we come, dragging wasted bodies to your threshold,
whimpering sotto voce through your letterbox, hauling heavy limbs
to immolate two hundred thousand corpses in a beacon blazing brightly
you cannot fail to see, you ministers, you medics, bureaucrats, despisers
of our frailty, you excuse-makers, you children with your clumsy, clammy,
hammy hands clasped tightly on your ears. Make a wish, oh M.E. people,
that every smarmy, slimy, scheming, selfish politician might suffer
as we do and have done, will do five, ten, fifteen, twenty years,
a lifetime, without hope, so we can smile and sigh and shrug our shoulders
and close the door, ignoring them in turn, until they’re dead.

© ***Eleanor Dent*** 2007

Eleanor’s poem, ‘ME’ won Third
prize in the Indigo Dreams Press
Awards 2007, and was first
published in Reach Poetry

Help Invest in ME win £2000

Direct Debit ‘Big Break’ competition is giving away £5,000 a month from March until June, and your votes will decide how the money is divided up.

The good cause with the most votes each month will receive £2,000, the runner up £1,000 and the remaining £2,000 will be divided equally amongst the runners up. At time of writing IiME was is in first place in the April competition, but competitors were closing on them.

Vote by clicking on the link, then click “Vote for this cause” and follow the instructions. http://tiny.cc/t2cqvw

It is free to enter and nothing to sign up to. Anyone can vote in the competition no matter where they are in the world. It is a one off vote, no daily voting. You need either a google account or facebook account to vote.

Alternatively vote on a postcard with your name and address & charity name to:
The Big Break,
131-151 Great Titchfield Street,
London W1W 5BB.

AfME research fund

Action for ME is launching a new research appeal to help fund cutting-edge research that could transform the lives of people with ME.

The research programme includes pilot studies in partnership with 3 universities, investigating the roles of fatigue, muscle dysfunction and sleep in ME.

Donate *online* http://tiny.cc/mkcqvw
Donate *by texting* SEEK13 and your donation amount (eg. SEEK13 £10) to 70070 (texts to this number are free) PO Box 2778, Bristol BS1 9DJ

Legal challenge to PIP

2 law firms say that the government’s consultation process on the Personal Independence Payment was flawed, because the reduction of the distance that can be travelled from 50 metres to 20 metres as a criterion for receiving the mobility component of the new benefit, was not introduced until after the consultation process had been completed.

50 metres is widely recognised as representing a minimum functional level of mobility; in guidance for town planners and architects, for example, as well as accessing other benefits.

PIP is currently being trialled in England. More info on PIP: http://wearespartacus.org.uk/pip/

Legal challenge to Bedroom tax

Solicitors claim that new housing benefit regulations, which came into force on 1 April 2013, are discriminatory to disabled people.

They are arguing that disabled people often need extra bedrooms for equipment storage or for partners to sleep in.

More info on bedroom tax http://wearespartacus.org.uk/bedroom-tax/

Regulations 29 & 35

A sample letter for GPs to complete in support of a patient’s ESA appeal can be found at: http://tiny.cc/8ocqvw

It cites exceptional circumstances Regulations 29 and 35:

- Because of your physical or mental health condition or disability, there would be a substantial risk to the mental or physical health of any person, including you, if you were found not to have limited capability for work. (Regulation 29)
- Because of your physical or mental health condition or disability there would be a substantial risk to the mental or physical health of any person, including you, if you were found not to have limited capability for work-related activity. (Regulation 35)

E petition

Provide every ESA PIP claimant with a short form for their GP/consultant asking if DWP rules 29 & 35 apply to safeguard vulnerable claimants http://tiny.cc/4wcqvw

Diclofenac

A painkiller should be banned because it raises the risk of heart attack and stroke by almost half, say British academics.

Safer alternatives exist. Diclofenac, like ibuprofen, is a non-steroidal anti-inflammatory drug or ‘NSAID’. It is often prescribed when ibuprofen is not strong enough.

Its over the counter name is Voltarol Pain-eze tablets.

young people

Is poetry cool?

The new Young people's poet laureate for Wales thinks it is!

Martin Daws is a former DJ who's built a reputation as a performance poet. He hopes to encourage future generations to embrace literature by adopting a range of disciplines – from sonnets to soundscapes and from beat-boxing to broadcasting.

He believes young people should be given the chance to discover the value of their voice and be given a forum to express themselves.

"It's my belief that there is a poem for everyone, and a poem in everyone, and as Young People's Laureate for Wales I'm excited to offer every young person in Wales an opportunity to find those poems."

www.martindaws.com/

Interactive twitter-poem

Martin will be tweeting daily via the Young People's Laureate Twitter account, @YPLWales, giving young people and adults alike the opportunity to converse with him and take part in an interactive twitter-poem which will grow in multiple directions each day.

Museum Wales

Performance poetry is specifically written to be spoken in front of an audience.

Martin talks about discovering performance poetry:

"It was a big moment in my life, an epiphany for me," he said. "Performance poetry didn't have generic restraints – it was almost like rapping. Sentences didn't have to rhyme. It's about people talking about their experiences of life in a creative way. I loved it and embraced it and have been doing it ever since. It combines music and literature – the two cultural forms I love the most."

Young people's Manifesto project

Martin invites you to contribute a word, line, verse or even a whole poem, written in any style and in the language of your choice, towards the creation of Wales' first Young People's Manifesto.

This innovative project gives young people aged 11-25 the opportunity to creatively explore crucial themes of citizenship, culture, language and landscape. It is an opportunity to ask questions, voice opinions and create a vision for a future Wales, and to develop skills in creative writing and self expression.

Once compiled, the Young People's Manifesto will be showcased and presented at a special event held at the Pierhead Building, Cardiff Bay, on Wednesday 19 June.

A film and recording of the manifesto will also be available online at www.youngpeopleslaureate.org following the showcase. This will be the beginning of many platforms for young people to present their views, hopes and dreams creatively as part of the Laureate initiative.

Manifesto worksheet

Need inspiration to write? Martin will be offering groups and schools a number of workshops in May but he has also devised a worksheet with suggestions for how to develop your ideas for your manifesto.

He calls his approach *'The meaning machine'*

Step 1. Please fill in the gaps.

Example:
Wales **means** ...... **means**............

It can be filled in as:
Wales **means** *Home*, and then
Home **means** *Heart*.
Wales **means** ..home.. **means** ..heart..

To find out what comes next download the worksheet from the links at the bottom of the project page http://tiny.cc/qpdjvw or contact the WAMES helpline and we will email or post one to you.

young people

ME manifesto for Wales

A manifesto is a public declaration of what you are all about or aim to do i.e. your goals, motives, or views, written in a way that really communicates. The way the words are presented pictorially can also communicate some of your meaning.

We have made a start on a WAMES manifesto by publishing a vision for Wales.

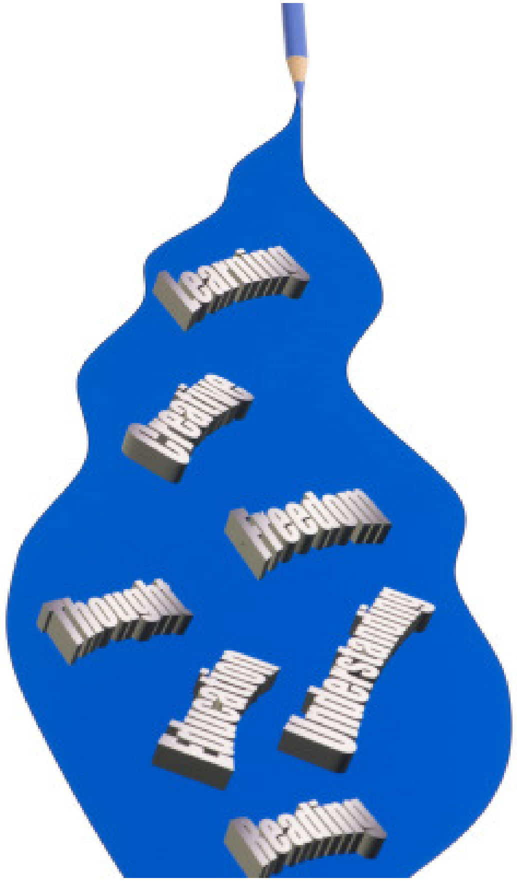
Can you help us develop an ME manifesto for Wales?

If you were in charge, what would you do to make Wales ME friendly? What matters most to you as a person with ME or a carer of one?

Send your ideas to us by email or on Facebook or to the address on page 2.

WAMES' Vision

is for a Wales where adults and children with ME and CFS and their carers are taken seriously and treated with respect, where diagnosis, treatment and services are accessible without a battle.



Example of a manifesto
Amina's young people's manifesto: www.youthspace.haringey.gov.uk/amina.pdf

Did you know?

ME is the biggest cause of long-term sickness absence in schools.

A study of 333,000 pupils discovered that 51% of those on long-term sick leave had ME. This is the biggest category of pupils with medical needs requiring home tuition or distance learning on a long-term basis.
http://tiny.cc/23djvw

Young People in Gwynedd

GISDA's aim is to offer vulnerable young people aged 16 - 25 years in Gwynedd the opportunity to improve their quality of life so they aren't disadvantaged because of poverty. Support and advice about housing, benefits, form filling, jobs etc.

Drop in for tea and a chat. Information Centre 40 High Street Caernarfon Mon- Fri 1030-4.30
01286 67115
www.gisda.org

Mind the abyss: film

Mind the Abyss: Part 1 - Prodrome" is a 15 minute film with a Sci-fi feel which tells the story of one person's experience of the first 6 months with ME.
http://tiny.cc/998kvw

Dog owner?

Have a look and a laugh at http://tiny.cc/6lalvw

me q&a

What causes a relapse?

Relapses, where you unexpectedly feel worse and/or your symptoms increase, appear to be caused by:

- too much mental and physical activity
- stress
- or an additional illness (usually an infection, possibly a minor one)

Manage it by:

- conserving energy
- reducing all types of stress
- simplifying your activities

carers

A young carer's story

About me

I'm female and 16 years old, from a small village in the South Wales valleys. I have a brother, much older than myself, who has moved out of the family home. At the moment my goals are to complete my A-levels, obtaining A's (hopefully) and to go to University to study to become a teacher. I enjoy dancing, drama and theatre, and music. My passion is playing piano and I aspire to one day be as good as my grandfather, who was a professional pianist.

Mam and ME

My Mam has suffered with ME for around 16 years, although she was not diagnosed until about 4 years after the onset of the illness. As a young child, I can remember her illness being quite severe, preventing her from working, and carrying out a normal life. But as time passed by, her condition seemed to improve. Currently, on good days, she can continue with normal daily life, as long as she does not over exert herself. However, during relapses she can be bed-ridden for days, maybe weeks; frequently contracting viruses which make recovery that much more difficult.

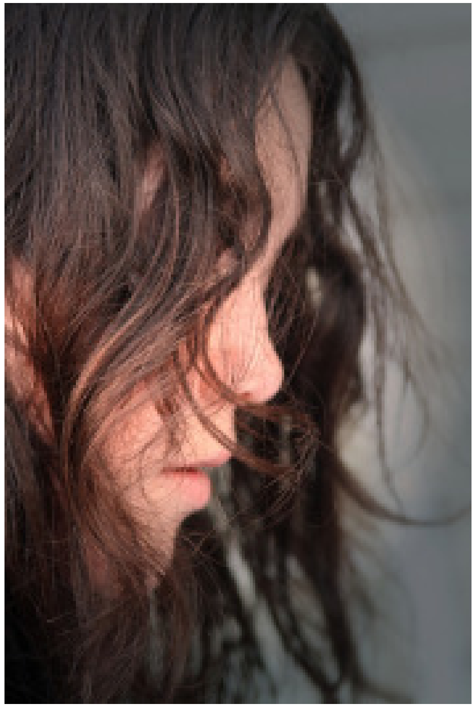
Growing up

My childhood was normal, but my Mam was too ill when I was very young and I stayed with my aunt most of the time. When I was little, I didn't really notice my life being any different to my friends (I suppose it wasn't really).

It wasn't until I was home full time that I realised, my friends would go on days out with their mothers - we didn't do any of that. I'd go to friends houses but my friends weren't allowed to stay here. Too be honest though, it didn't bother me, I didn't see it as such a big deal. "Ordinary" childhood? I've had a lot more than most people.

Life today

When my Mam has her good days, life is normal for me. Yes, there is the worrying, thinking "What if something has happened? What if she becomes ill again soon?" and sometimes concentrating in college can be a problem. However, I am able to go to college, see my friends etc. On her bad days it can be a bit more difficult. My responsibility doubles, from doing chores to caring for her, shopping to cooking. It can be difficult to juggle my time. My college work, hobbies and seeing my friends has to be put on hold. Not that I mind, I mean, she's my Mam.



When times got tough

Up until recently, I didn't receive any support, neither did my Mam. But, as my home life started to badly affect my college work, my lecturers started to become worried. I decided to confide in a very trustworthy lecturer, who helped and advised me as much as they could. They helped arrange for me to talk to the support officer for young carers employed by the college, which has really helped me cope. My school had something similar – a Child Welfare Officer.

The value of support

Now that I am receiving this support, I am much more happy and relaxed. My support officer acts as an intermediate, speaking with lecturers on my behalf, so that when there are problems, I can get some extra help. The support officer also helps me deal with home life and has directed us to different organisations which can help.

She has also arranged so if I need to leave college early, or miss lecturers due to my home life, I can just leave, no questions asked. Everything is completely confidential, so if I do not wish for lecturers to know what is going on at home, they don't have to know. My support officer also acts as an emotional support. Someone is there to talk to anytime of the day, even out of college hours. All this has taken a great deal of pressure off of me and has given me the ability to cope with college and home-life.

The future?

I hope that as time passes, my mother's illness will continue to improve, and her life will hopefully become normal. I hope that one day she will be able to work, and return to her old career as a carer.

For myself, I hope that I can achieve my goals, and become a teacher. I hope that I can use the skills I have gained through being a carer to improve the lives of other young people. I hope that one day I can help others in the ways that I have received help, help to improve their lives, and allow them to be children instead of growing up too quickly.

To be honest, when I leave to go to university, I have no idea what will happen. But that is something that my support officer is helping work out.

Any regrets?

If I were to change anything I wouldn't. I know you think I'd say "I wish my mother wasn't ill" but because of her illness we have such a close relationship. Of course I don't want her to suffer, but I think that it's made me more confident, outspoken - I'm not afraid to say my opinion, or ask for something (from the experience of stupid doctors!) however it has made me caring, considerate of people's feelings, more mature. My friends call me the Mami of the group, I'm always the one making sure people are ok, helping if they have a problem etc…

My tips for other young carers

Get help! You may think that you can cope, or maybe you're not coping but feel that asking for help makes you weak.

For me, personally, it was a mix of the two. I felt like a wimp for complaining, that because she's my Mam I should just get on with it but trust me, after speaking to others I can see that I was wrong. Just because they are your family, it does not mean that you have to do it all alone. You're not a superhero!

Admitting you need help, and asking for it, makes you a strong person. You'll be really surprised by the help that's out there, and all you have to do is ask. Don't be ashamed, or embarrassed of what you do. It's an amazing, wonderful thing and you should be applauded for what you do.

What helped me

- local carers centre – social services can give you contact details
- carers direct - a branch of NHS direct http://tiny.cc/gt9kvw
- NHS Wales Direct http://tiny.cc/dx9kvw
- YCNet. www.youngcarers.net a supportive, online community of young carers for discussion or for advice from qualified youth workers.
- Counsellors (accessed through college - and outside - through GP)

How can I thank you, how can I say
How simply your presence, day
after day
Stops me from falling into the
abyss.
Helps me to realise just what I
would miss?

From *To John* by Jo Porter, from *Poetry from the bed* (see p.11)

More info about young carers

Young Carers' network
consults with young carers to enable their voices to be heard by policy makers http://tiny.cc/ty9kvw

Video from Children in Wales
http://tiny.cc/8z9kvw

Story from Barnardos
http://tiny.cc/f19kvw

Did you know?

- 13,000 of the UK's young carers care for over 50 hours a week
- Following a survey in 2010, the BBC estimated that there are 700,000 young carers in the UK
- Young adult carers aged between 16 and 18 years are twice as likely to be not in education, employment, or training (NEET)
- In total there are 290,369 carers in the UK who are aged 16–24
- More than half of young carers live in one-parent families and almost a third care for someone with mental health problems

Carers Week UK

10th to 16th June
Carers Week is a UK-wide annual awareness campaign. Its aim is to improve the lives of carers and the people they care for.

This year the theme for Carers Week is *Prepared to Care?* Every day at least 6,000 people start caring. Becoming a carer can impact significantly on a person's life – it takes time, energy, can leave you isolated and can be costly.

Organisations throughout the UK are encouraged to take part and join in by organising events, running information sessions and recognising the carers they work with or support.

Check out www.carersweek.org/ or your local carers' web pages and newsletters to see what is happening in your area.

Carers count – count me in!

Don't forget to register as a carer. It will make it easier to access information or support when you need it and it gives a stronger 'voice' to your local carers forum.

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 assistance in setting up local meetings

Anglesey & Gwynedd Fibromyalgia / ME Group
Contact: Rhian Medi (secretary)
01248 722184
fmsmemonagwy@yahoo.com

Carmarthenshire ME Group
Meets Cae Maen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James pm 01267 233793 for further details.

Clwyd ME group
clwydme@googlemail.com
01745 822953
www.clwydme.net

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 Group meets in Penrhyncoch, Aberystwyth. Contact Dr Derryan Paul on 01970 828896 edpaul@phonecoop.coop

North Ceredigion Yoga Class 11 Nant Seilo, Penrhyncoch on Thursdays 2-30-4.00pm. Contact Derryan above for more information.

Pembrokeshirer Get togethers 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
Joan Crawford 01244 370988

contact us

helpline@wames.org.uk
0292 051 5061

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http://health.groups.yahoo.com/group/WAMES/

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