



Jan making the ME case
at a recent conference

October 2013, no. 4

me voice

The WAMES Magazine

WAMES
Welsh Association of ME and 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

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

Copy dates for the magazine:

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wames news

Let's talk ME!

The focus of WAMES' work over the next 6 months will be to get patients and carers talking with health professionals in their local area.

This has already started with an awareness event in west Wales. Professionals in the Hywel Dda Health Board (HB) area met with patients and carers for an exchange of information. It was an opportunity to dispel some myths about ME, talk about what patients want from the NHS and hear what health care health professionals would like to provide.

The talking will continue in Hywel Dda (see p6 for details) but has yet to start in other areas. Some HBs have talked to me about talking (!) but so far nothing has materialised. Others still haven't appointed someone to be responsible for developing services for ME.

In November I will be meeting with the Major Health Conditions Policy Team in the Department of Health & Social Services prior to reconvening the CFS/ME Task & Finish Group. I hope this will lead to government support for action in ALL the HBs.

WAMES' long term goal is to have a biomedical clinic with specialist care and outreach clinics round the country, backed up by ME nurses. In the short term, we have to be realistic about what can be achieved without funding and clinical champions.

It is government policy that service users are involved in the development of services so that they truly meet the needs of patients. WAMES believes the first step to achieving such services is to raise awareness of the complex nature of ME and the debility and suffering it can cause.

So let's get talking!

If you would like to get involved in talking to health professionals in your area please let me know and I will keep you up to date with the campaign to get professionals, patients and carers round the table.

*Jan Russell, WAMES Secretary
(See Jan at work on the cover)*

Have your say!

Take part in the WAMES poll at www.wames.org.uk

news from wales

ME Group events round Wales

Clwyd ME Support Group

For info about meetings contact Margaret Dyas on 01952 271430 and leave a message.

Swansea valley

Contact Kayleigh Jones for more information about a get together in the Swansea valley area (Ystradgynlais, Ystalyfera, Pontardawe, Clydach) kmejones73@hotmail.co.uk 07429617002

Carmarthenshire ME Group

Meets on 30 November at Caemaen Day Centre, Coleshill Terrace, Llanelli SA15 3BT. Please ring John James [pm] for further details.

North Ceredigion Group

Mince pie party, Tuesday, 10th December, 2-4pm, at 11 Nant Seilo, Penrhyncoch. Mince pies, biscuits, sherry, tea, coffee and soft drinks. Gluten free pies and biscuits included

Contact Derryan Paul on 01970 828896 or email edpaul@phoncoop.coop

North Ceredigion Yoga Class

Meets at 11 Nant Seilo, Penrhyncoch on Thursdays 2.30-4.00pm. Contact Derryan [above] for more information.

ME Support in Glamorgan (MESiG)

4th November, at Llanishen Community Shop, Llangranog road (off Templeton Ave), Llanishen CF14 5BL.

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

Pembrokeshire

4th Monday in month - 11am until 1pm at 65, Tudor Gardens, Merlins Bridge, Haverfordwest SA61 1LB, 28th October, 25th November.

Transport can be arranged from the bus or train stations, or parking is available at the house.

Meetings are informal, for anyone with ME/CFS or FM and their carers.

Contact Tina Norman for more information. 01437 454359, tretiul@talktalk.net

news from wales

Sponsor Jessica for ME research

I have suffered with M.E for 11 years and live in Tregaron, Ceredigion. My daughter Jessica is taking part in the Great South Run on 27th October 2013 in order to raise money for research. It is a 10 mile run and she is looking for sponsors to help her reach her target of £250 for the ME Association's research fund.

Please can you take two minutes to check out her fundraising page at www.justgiving.com/Jessica-Guellich or get in touch with myself, Garry Guellich on 01974 831697, to arrange another method of giving for this worthy cause.

Aged 75 or older?

Contact the Elderly is a national charity that offers a lifeline of friendship to people over 75. Are you living alone, isolated from family and friends and too frail to leave the house by yourself? Then regular afternoons of conversation and laughter could be just what you need.

One Sunday afternoon a month a small group of volunteer drivers use their cars and a 'helping hand' to collect isolated, elderly people

from their homes and take them to a volunteer host's home to spend the afternoon together, where they talk, laugh, share stories in a small group.

If you'd like to join a Contact the Elderly group, or you know someone who might, call 0800 716 543 for information about groups in your area e.g. Denbighshire, Conwy, Flintshire, Wrexham, Monmouthshire, Powys.

North Wales officer 01766 522136
jane.carey-evans@contact-the-elderly.org.uk
Contact the Elderly, 15 Henrietta Street, London WC2E 8QG
info@contact-the-elderly.org.uk

Have mental health services improved?

Last year a law to improve local primary mental health support services came into force across Wales. Prior to implementation mental health charity Gofal conducted a survey about people's experiences of these services and published a report on the findings.

It is now one year since the law was implemented and they are repeating the survey to see if

people are noticing improvements in their experiences. They will use the resulting data to highlight good practice and to inform health boards and local authorities where they need to do more.

This national survey is open to any person in Wales who has visited their local GP surgery to seek advice, treatment or support for mental health problems during the last 12 months.

<http://tiny.cc/pbhs4w>
www.gofal.org.uk

From the older people's commissioner

Publishing her 'Dignified Care: Two Years On' progress report, the Older People's Commissioner for Wales, Sarah Rochira, has said that despite a number of improvements in hospital care, significant progress must be made in a range of key areas to ensure that all older people within Welsh hospitals are treated with dignity and respect.
www.olderpeoplewales.com/en/news/news/13-09-23/Dignified_Care_Two_Years_On.aspx

We provide direct bilingual support to older people across Wales on a wide range of issues and in a number of ways so please contact us if you need a little help:



- We can help to put you in touch with organisations best placed to resolve your issue
- We can intervene directly if you have been experiencing difficulties with a public service provider that you cannot resolve locally
- We can support you to make a formal complaint and monitor how your complaint is dealt with We also want to hear about any issues that are important to you as our work is driven by what matters to older people.

Cambrian Buildings, Mount Stuart Square, Butetown, Cardiff, CF10 5FL.

08442 640670 (standard rate) or 02920 445030 (local no.) - we can return your call if preferred.
ask@olderpeoplewales.com
www.olderpeoplewales.com

NORTH WALES

Good health event Dolgellau

18th October at the Leisure Centre
- An event for everybody!
Drop in at any time between 10 am
and 2 pm.

- 40+ organisations to give Advice and Information
- Blood pressure taking opportunity.
- Local Pharmacy on hand to give advice
- Complementary therapies
- Taster sessions
- Memory & Friendship Café
- Light Refreshments
- Entertainment

If you could man a display / stall for WAMES please contact Jan

'Barbara bus' for loan

Specially adapted vehicles can be hired in South Gwynedd – from Aberdyfi, Criccieth and Dolgellau. For wheelchair users unable to use normal transport. Donations accepted
www.barbarabusgwynedd.com
01766 522 756

Stress is...

When you wake up screaming and then you realise that you haven't fallen asleep yet!

Support, therapy & information

The MS Support Centre has been helping people with neurological conditions for more than 27 years.

A pilot project is offering support, therapy or information from experienced healthcare professionals. If you simply want to meet other people who understand the challenges of living with a long-term condition such as MS, Parkinson's or ME visit the centre or contact:

MS Support Centre
Unit C4, Brymau Estate 1,
River Lane, Saltney, Flintshire
Nr. Chester, CH4 8RG

01244 678619
www.mssupport.co.uk

The following services are free:
IT Support; Choir; Wii Fit; Counselling Service; Benefits Advice.
Booking is essential.

Complementary Therapies can be purchased, including Indian Head Massage, Reflexology, Aromatherapy, Reiki, Hypnotism Therapy, Seated Acupressure Massage and beauty treatments.

wales regional news

Parabl talking therapies service

This new service provides short term therapeutic interventions as well as individual counselling, for those with common mental health difficulties or challenging life events which may be impacting on their emotional well being.

Guided Self Help - The Serenity Computerised Cognitive Behavioural Therapy (CCBT) programme is an interactive self help programme which allows you to work through a series of self help modules in your own time. Modules cover topics such as managing your anxiety and depression and relaxation techniques. After an introductory meeting with a CCBT worker, regular follow up sessions by telephone/e-mail are provided.

Therapeutic Groups - The following group based therapy is provided over 7 – 8 weekly sessions: Coping with Life; Stress Management; Mindfulness. These are educational based courses, which will be focused on your recovery. Through these courses you will gain the skills needed to manage your mental health and emotional well being more effectively. Examples of courses include Assertive-

ness Skills, Managing Anxiety and Dealing with Depression. Mindfulness also includes techniques such as meditation, gentle yoga and mind-body exercises.

The service is for any adult aged 18 and over who is living in Wrexham, Flintshire, Denbighshire, Conwy, Gwynedd or Anglesey.

You may refer yourself in confidence for an assessment by phoning or by visiting the website and completing the online referral form. You can also ask to be referred by your healthcare worker or GP.
www.parabl.org ask@parabl.org
0300 777 2257 (Mon - Fri 8.30-5.00)

NB These therapies are for psychological problems not ME.

Grwp cymorth i awduron yn y Gymraeg

Grwp newydd Celfyddyfau Anabledd Cymru yn ardal Caernarfon ar gyfer ysgrifennwyr sy'n ysgrifennu yn y Gymraeg (nofelau, straeon byrion, pethau ffeithiol, neu gerddi), ac yn hunan-nodi fel person anabl neu sydd â chyflyrau iechyd corfforol neu feddyliol hirdymor.

wales regional news

Am fwy o wybodaeth, cysylltwch â post@dacymru.com neu denni@dacymru.com

Ffrindia – befriending service for people over 50

Co-ordinators' contact detail:

Meirionnydd – Gwenlli

01341 422575

Arfon – Alan

01286 672626

Dwyfor – Dawn

01286 672626

Or you can contact Carys

01286 672626 or

ffrinida@mantellgwynedd.com or

log onto www.mantellgwynedd.com

Anxiety management

If you feel anxiety is stopping you enjoying day-to-day life you may find this free course helpful.

COURSE LENGTH: 7 weeks

WHERE: 3 Trinity Sq Llandudno

TIME: 2 ½ hours

The *Coping with Life* programme is designed to help people make positive changes and develop skills to manage life's challenges and be healthy. The courses use cognitive

behavioural approaches and are run by skilled facilitators. They are not therapy groups.

For initial enquiries please contact Heather/Amy on: 01492 879907 or email: info@aberconwymind.org.uk

Make friends with a book - north wales

If the article on p10 doesn't inspire you to become a creative writer, maybe the Reader Organisation can inspire you to read what others write. It is a charitable social enterprise working to connect people with great literature through shared reading.

Get Into Reading North Wales is a bilingual project, with reading groups in both English and Welsh.

Make Friends With A Book Project began in Sep 2013 with shared running groups running in libraries for adults and after-school groups for children, using English and Welsh reading material. The very first group for children aged 11-13 is underway at Bangor Library now!

More info:

jeanettewooden@thereader.org.uk

0781 223 8411

leahedge@thereader.org.uk



0781 223 8413

www.thereader.org.uk/reading-with-us.aspx

The Reader Organisation
The Friary Centre, Bute Str,
Liverpool L5 3LA

MID WALES

Your experiences of services in Montgomeryshire needed

The Neuro Voice Project Powys is a Community Voice Project run by MANGO, the neurological alliance in Montgomeryshire. Project coordinator Gayle Pearson would like to talk to people with ME in Montgomeryshire to find out your experi-

ences of services. If you have problems getting help or need information she will endeavour to help. She will then use your experiences, along with those of others (with your permission) to improve the quality of services in Powys.

Her normal working days are Thursday and Friday but she is happy to meet or phone you at any other time. Contact Gayle at gayle@mangomontgomeryshire.org.uk 07918 077 721. She is based at PAVO Plas Dolerw so you can also write to her there or leave a message for her at 01597 822191.

Hywel Dda services for ME & CFS

Hywel Dda LHB (Local Health Board) held an awareness event on Sep 12th when professionals, patients and carers from Ceredigion, Carmarthenshire and Pembrokeshire joined to share experiences of living with ME and offering services. It was a very useful event where professionals learned a lot they didn't know about ME, and patients were pleasantly surprised to find some interested and caring professionals wishing to tailor their services for people with ME.

A follow up meeting to discuss developing a local care pathway for West Wales is planned for Nov 8th in Carmarthen. Contact Jan for more information if you would like to go.

SOUTH WEST WALES

Neurological Alliance

SWWNA (the South West Wales Neurological Alliance) will meet on Wednesday 20th November 2013 - 2pm - 4pm at Ysbrid Y Mor, Tir Morfa Road, Port Talbot. SA12 7PB (along the Aberavon Beach front).

Contact Jan if you would like to find out more about how working with other organisations in the Swansea, Bridgend and Neath Port Talbot areas can improve all types of services for people with ME. www.swwna.com

Community Voice Patient and Carer Open Day

Are you a Patient or Carer?

Registered with Ty'r Felin Surgery, Pen Y Bryn Surgery, Tal Y Bont Surgery, Gowerton Medical Centre, Penclawdd Surgery or Princess Street Surgery? (Llŵchwr Community Network)

Help evaluate patient and carer services in your area on Friday 11th October 2013, 1.00 – 7.00pm, Canolfan Gorseinon, Millers Drive, Gorseinon, Swansea, SA4 4QN.

Get your voice heard by local service providers such as health, social services and the voluntary sector and learn about what services are available locally. Contribute to the work of the Healthy City Programme.

Help is available with respite/child care; travel expenses; interpretation or personal assistance costs if you would like to attend meetings.

If you would like more information about the 4 year project or to attend the day, please confirm with: Cara Spowart, Community Voice Patient and Carer Development Officer, SCVS on 01792 544013 or email: cara_spowart@scvs.org.uk

Need help with house or garden in Bridgend county?

Save time and energy with Crossroads Timesavers Ltd

Are you living on your own, caring for others or working and juggling a busy family life? Would you love a helping hand to give you support and save you precious time?

Crossroads Timesavers Ltd, part of the Crossroads Care Bridgend charity, can provide a range of domestic services throughout Bridgend County Borough including: Cleaning; Ironing; Gardening;

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Shopping; meal preparation; Escorting to appointments; Dog walking.

Fees for the above services are £11.50 per hour (£12.50 per hour for gardening). All staff are Police (CRB) checked. Contact 01656 789348 emma@crossroadstimesavers.org.uk www.crossroadstimesavers.org.uk/

SOUTH WALES

Introduction to Self Management

One 3-hour workshop for carers and people with health problems. 10 to 1pm
25 Oct Barry Library
13 Nov Cardiff Central Library

Email Carol.Stingl@wales.nhs.uk or Carol.Young@wales.nhs.uk or call (029) 2055 6028 for more details and to book.

Forest Arts in Monmouthshire

At Bargain Wood, Whitestone, Monmouthshire (between Llandogo and Trellech at grid ref SO 525030)

Adults who would like to explore their creative side outdoors, particularly those who have difficulties in accessing creative groups and who would appreciate a calm, informal approach. Join in with a range of creative activities or simply come along to enjoy the surroundings. There will be hot drinks, crumpets and a camp fire. Thursday mornings 10am – 12pm until 14th Nov.

Families are invited to join in creative play or simply come along to enjoy the surroundings. There will be hot drinks, crumpets and a camp fire. Thursday afternoons 1pm – 3pm until 14th Nov.

For more information and to register for the projects contact David Rogers: david@geopath.co.uk 07592 732295 or Justine Wheatley at Arts Alive Wales 01873 811579 justine@artsalivewales.org.uk Location <http://tiny.cc/xfns4w>

I like long walks...

especially when
taken by people who really
annoy me.

wales regional news

Follow-up appointments: request for patient experiences

Aneurin Bevan Community Health Council (CHC) regularly receives reports of delays to “follow-up” appointments which are often vital to the monitoring and management of a range of conditions. As well as putting the health of patients potentially at risk, such delays cause great distress to patients when they are told that regular checks are important to their continued well-being. The CHC is seeking the experiences of patients in order to identify the extent of the problem and which specialities are affected. Contact the CHC or complete the questionnaire at <http://tiny.cc/4hns4w>

Survey on GP out-of-hours service

The ABM CHC are seeking the recent experiences of patients contacting the GP out-of-hours service locally. Please complete an on-line survey at <http://tiny.cc/7kns4w> as to whether the service is helpful in offering

timely, accessible and effective advice or treatment.

Aneurin Bevan Community Health Council 01633 838516
abchc@abchc.org.uk
www.communityhealthcouncils.org.uk/aneurinbevan/

Notices

Spotted in a safari park: elephants please stay in your car.

On a repair-shop door: we can repair anything. (please knock hard on the door - the bell doesn't work.)

Notice in a farmer's field: the farmer allows walkers to cross the field for free but the bull charges.

Outside a second hand shop: we exchange anything - bicycles, washing machines, etc. why not bring your wife along and get a wonderful bargain?

In health food shop window: closed due to illness.

Pace your way to Christmas

The anticipation of Christmas can be more fun than the event itself. Too many of us spend the festive season recovering from the preparations!

What can we do to plan ahead and avoid a relapse?



- make a family plan so everybody knows who is visiting who & when the key events are
- add events to your calendar as you find out about them and make sure you block off quiet times
- buy Christmas cards & wrapping paper – many charities are beginning to publish their Christmas catalogues e.g. ME Research UK, ME Association, Invest in ME.
- update your card list – consider sending e-cards
- start baking and cooking things you can freeze
- start researching ideas for presents and collect suitable catalogues or email addresses – find out if your family and friends have a ‘wish list’ e.g. on Amazon (if you’re not online, get a computer savvy friend to show you)
- buy non-perishables in advance to save time and spread the cost
- if you write an annual family letter, start gathering photos and planning the content & design
- if you wrap presents in advance, keep a record of exactly what they are so you don’t have to unwrap them when you forget what you’ve bought!
- Did you write a memo to yourself last year about how to make Christmas easier this year? Now, where did you put it...

Do you have any tips for an ME friendly Christmas? Send them to Tony or Jan for inclusion in the December issue of the magazine

Dental hygiene Q&A

Q. Sometimes I feel too ill to get out of bed. What can I do to clean my teeth?

If you are having a difficult day and feel unable to get out of bed, please don't neglect your teeth. It may be possible to ask a member of your family or your carer to help or failing that, to use a chlorhexidine mouthwash (0.2 - 0.12%) twice a day. It is important to follow any instructions given to you by your dentist or hygienist. This would be sufficient for a short period of time.

Q. I thought that mouthwashes were used to freshen breath, How can they help my teeth?

Mouthwashes can be used to freshen the breath. However, more importantly, they are useful in a role to prevent cavities, e.g. by containing fluoride, and to prevent gum disease e.g. by containing antibacterials.

Gum disease and dental decay are the most common causes of bad breath (halitosis). There are also mouth-washes designed specifically to deal with halitosis. As with any unexplained symptoms, it is best to seek professional advice if they persist for longer than a couple of weeks.



(from *Perspectives* 'All in the drill by Dr. Richard Cantillon BDS.

Perspectives is the magazine of the ME Association and is available to members. More info: www.meassociation.org.uk 01280 818 968)

Guide

to choosing portable access ramps <http://www.independentliving.co.uk/ramps-faq.html>

Keep warm this winter

Health through warmth
National Energy Action Cymru (NEAC) has teamed up with

living with me

npower, one of the BIG 6 energy companies in the UK, to showcase their community initiative, npower *Health Through Warmth*, which helps eligible vulnerable people experiencing ill health to access assistance to fund and install heating and insulation in their homes to improve their comfort and wellbeing.

Clients don't have to be or become npower customers. More information: http://www.npower.com/health_through_warmth/ info <http://www.nea.org.uk/nea-wales/home>

NEST

Nest is the Welsh Government's fuel poverty scheme. If you're worried about the cost of heating your home, you can call 0808 808 2244 free from a landline or a mobile phone. The advisors can give advice on:

- Saving energy
- Money management
- Making sure you're on the best fuel tariff for you;
- And whether you are entitled to any benefits to boost your income

You may also be eligible to receive home improvements at no cost to you, to help make your home warmer and reduce the cost of your energy bills. Nest support is avail-

able to everyone in Wales.
More info: <http://nestwales.org.uk>

Tackling fuel poverty in Pembro

The project is aimed at the most vulnerable people living in Pembrokeshire who are struggling with their energy use and those who are suffering with cold and damp related illnesses due to not having adequate heating and insulation.

The Cosy Homes Advisor will be available to look at options, solutions, grants and funding that can be accessed to help finance the measures required, and will support the client throughout the whole process to ensure that the vulnerable and the infirm are able to heat their homes adequately and at reasonable cost.

There is a small crisis fund available for those clients who can not afford to pay for all the measures. The advisor will assess each case and identify the work needed to improve their levels of warmth, comfort and quality of life.

For further information contact Tina Shevlin (Cosy Homes Advisor) Project Manager 01239 821905 or 01239 820235, email tina@ecocentre.org.uk

that's a good story

Have you ever felt that you have a novel inside you?

Many people's dreams of writing are dashed when they develop ME, but some have found it is possible to be creative in spite of ME and some have even been inspired by their experiences of illness. Here are 3 very different stories of how people with ME have unlocked the creativity within them.

Helena Mallet

In 2008 after many years of a multitude of complex and baffling symptoms I became bedbound and diagnosed with severe ME.



I was devastated.

I could no longer walk in my beloved Preseli Hills, continue my

counselling work or socialise with healthy friends. Life as I knew it was over.

As I lay on my bed day after day looking out at the beautiful countryside around me I started to write. I wrote short pieces of prose as the brain fog of ME made it impossible for me to follow or retain anything more than a few hundred words. It was only later that I discovered that what I was writing was in fact Flash Fiction.

Flash Fiction is a genre of writing where stories are told in anything from one sentence to a thousand or so words. The stories are short, sharp snapshots and I quickly realized that this was something I could create alongside living with ME and I loved it.

I submitted a few stories to Paragraph Planet, a website which publishes a different 75 word story each day and when these were accepted, that was it, I was hooked.

After I'd written twenty or so I had the idea for a book of 75 x 75 word stories. I committed to the chal-



lenge and my book was published first as an e-book in May 2012 and then in print in September 2012. There are of course still many days when I'm too ill to write but on better days it feels empowering to salvage something back from all that ME has taken.

I've had terrific support from the ME community particularly in Facebook groups. As my stories are so short, each one can be read in a minute or so, which makes easy reading for those with compromised concentration.

I hope that by sharing my story with you it might inspire those who lie in dark rooms feeling that their lives are over, to dig down deep and find perhaps a small spark of creativity

that can bring some respite and sense of fulfilment into their lives.

75 x 75 = Flash Fraction

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<http://tiny.cc/6rau4w>

More info: www.helenamallett.com

<https://twitter.com/lenaland>

Facebook [https://](https://www.facebook.com/pages/Helena-Mallett-75-Word-Storyteller/186205968168296?ref=hl)

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[186205968168296?ref=hl](https://www.facebook.com/pages/Helena-Mallett-75-Word-Storyteller/186205968168296?ref=hl)

The Knock, by Helena Mallet

She sees there's snow falling as she draws curtains over white ghost-like impressions on the darkening windows. Christmas Eve, and there's always a certain poignancy. It's a family time, a time to think of those not with us. Or those we've never known.

She remembers his tiny newborn body. The condemning cries as she places him in another's waiting arms, as if already angry, blaming.

There's a sudden knock at the old cottage door.

'Mum?'

Brian Jarman

When I worked on BBC Radio Wales' breakfast programme many years ago, we used to have a 'doc spot' on a Monday morning. A local doctor would discuss the health issues of the day.

I vividly remember him talking about a flu-like illness which could last for years. He mentioned one woman in Gwent who had had it for twenty. How can you live with something like that for so long, I wondered.

A few years later I was to find out. I was working for BBC World Service in London. It was a stressful time: I was making programmes during the first Gulf War, my father died and I went down with glandular fever. I was signed off for four months.

Gradually the symptoms got better, but did not go away. I went back to work but had to learn to pace myself. Eventually I was diagnosed with Chronic Fatigue Syndrome or ME.

Over the years I tried a whole range of remedies – pills, supplements, steroids, acupuncture, reflexology, Cognitive Behaviour Therapy. I managed to return to a normal life in the main, but every couple of months or so it would



flare up and I'd be in bed for a few days.

During these episodes one of my great comforts was reading when I could manage it, the radio when I couldn't. When it was very bad, the words on a page would do weird things like curl up and the end of the lines. When there were a lot of straight strokes next to next in a word, eg communication, it could start resembling the Russian Cyrillic alphabet.

The illness remained a mystery to me, and it could be a dark lonely place. So when I started writing novels, I decided to write one with

an ME sufferer as the narrator. I knew the challenge would be to describe the symptoms and experience without boring the reader to death.

I hit upon the idea of interweaving other mysteries into the novel. It started with a puzzle of my childhood – the room-sized space on the first floor of the farmhouse where I grew up in Mid-Wales, Lower Gwestydd, near Newtown. I called it *The Missing Room*.

What the narrator Lloyd discovers in the room with the help of his nephew, and the subsequent events, are pure fiction.



THE MISSING ROOM

BRIAN JARMAN



But my ambition was to bring some comfort to fellow-sufferers. That was what I was most nervous about when the book came out.

To my relief many people have said it's a moving account of the illness. A friend of mine who'd had ME five years previously said it described vividly the cacophony of symptoms, but it also made him realise how much better he was, and how lucky he was to have recovered.

The Missing Room can also, of course, refer to the void that ME can leave in people's lives. I didn't want to hammer home the analogy too heavy-handedly, but I hope the book can help alleviate the sense of imprisonment that it entails.

The Missing Room is available in paperback or for download on Amazon, online from the Welsh Books Council at www.gwales.com or by order through your local bookshop.

The Missing Room
ISBN: 978-1480155534
2012, pp250

The pen is mightier than the sword... and considerably easier to write with.

Marty Feldman

that's a good story

Katie Flynn

'Katie Flynn' is the author of numerous historical and romantic fiction novels. Always a compulsive writer, she has lived for many years in north Wales. She began her career writing short stories and articles but has been writing family sagas and modern novels, since the 1970s, many of them set in Liverpool and north Wales. Her popularity has grown and she now has over 90 novels published under various pseudonyms, one of which is Judith Saxton.

After contracting shingles in 1995 she developed ME. She describes the effect on her ability to write:

For the first six months I lay on a bed in a darkened room listening to audio tapes when I felt able to concentrate - which wasn't often. On fine days Brian (my husband) took me out into the garden where I lay on a sunbed and watched the birds flying overhead

I think a turning point came when Brian persuaded me to dictate just a couple of lines a day on my current manuscript. It was hell and

caused many tears and much stress but then one day the story grabbed me by the throat and I tottered to the PC and did half a page, making many mistakes



because I could not read the screen. After that I wrote a little whenever the symptoms eased enough to let me sit up instead of lying down.

My lifestyle has changed totally. I work on the current book for about three and a half hours every morning (and am better for it!) but have to go to bed every afternoon and rest properly. I write two books a

year, both between 130,000 and 150,000 words long.

Brian is my carer and also my work colleague since I cannot read print and can no longer do my own research. He 'reads me in' to the current book each morning so I know what I said yesterday!

For the first four or five years of ME, once I was well enough I continued to type my books straight on to the computer. Then we had a road traffic accident and I got severe whiplash. I could not sit upright for long without a great deal of pain. I had a deadline coming up so I advertised for a secretary and since then I have dictated my books.

In my secret heart I believe that if I stopped work I would improve a lot (I am always very much better on holiday) but I am a compulsive writer and working makes me into a person again and not just another medical statistic.

Try one of 'Katie's' stories in a free sampler e-book
<http://tiny.cc/kkbu4w>

Her books can be borrowed from libraries, bought in bookshops or on Amazon as paperbacks, kindle books or audio downloads.

Clever Comments

The best vitamin for making friends..... B1.

Of all the things you wear, your expression is the most important.

The heaviest thing you can carry is a grudge..

Be kinder than necessary because everyone you meet is fighting some kind of battle.

A sharp tongue can cut your own throat.

One thing you can give and still keep...is your word.

Word search Birds

See puzzle on page 15

TURKEY
SEAGULL
PIGEON ROBIN
PEACOCK
PARROT
OSTRICH
NIGHTINGALE
MAGPIE
LARK MACAW
KOOKABURRA
EMU JACKDAW
CROW DUCK
CHICKEN
BUDGERIGAR
BLUETIT
ALBATROSS

NICE guidelines

NICE proposes placing the CFS/ME guidelines and 26 others on a 'static list'. This means that those guidelines would be reviewed to see if an update was necessary every 5 years rather than every 2 years. They would reconsider if major ongoing studies/research were identified as due to be published in the near future (that is within the next 3-5 years).

WAMES objected to the CFS/ME guidelines in 2007, especially the treatment recommendations of GET and CBT and would like to see them overhauled. NICE are asking their stakeholders to comment on the proposal by 5pm on 23 October. WAMES will be responding and would like to know what you think. Please let Sylvia know Sylvia@wamesorg.uk
029 2051 5061.

Severely affected on FB

There is a Facebook page for the severely affected called "A Bed in the Stars - dreaming of better days" at <http://on.fb.me/1dwMqtD>

New publications

ME – the new plague 2: Reclaiming the patient's voice, by Jane Colby
Jane is releasing an update to her

book *ME-the new plague* as a serial online
<http://www.methenewplague.net/>

Ramsay's Disease: Myalgic Encephalomyelitis (ME) and the Unfortunate Creation of 'CFS', by Leslie O. Simpson and Nancy Blake
Lifelight Publisher, 2013
£19.99 or £5.99 for Kindle version on Amazon.

Dr. Simpson describes his years of research (oddly-shaped red blood cells which can't deliver oxygen and the history of the re-naming, while Nancy Blake, who ascribes her virtual recovery from ME to ruthless laziness and taking the supplements Dr. Simpson recommends, puts a strong case for a reversal of current policies to do with ME and disability.

Lightning process

In March the Phil Parker group were found to have misled people by making medical claims on their website www.lightningprocess.com for the Lightning process.

In August the Advertising Standards Authority (ASA) rejected their appeal as their website misled about the efficacy and nature of LP and made unsubstantiated claims, and told them to alter their website.

More info:
<http://tiny.cc/gzyx4w>

news and research

The ME Association also made a complaint about a clinic in Essex which made similar claims about LP.

The ASA informally resolved the complaint and the practitioner agreed to alter her website.
More info: <http://tiny.cc/90yx4w>

liME's rituximab trial

Invest in ME have now raised over £260,000 for their UK rituximab trial from a variety of organisations and individuals, and can begin the first phase. The £350,000 trial is being funded through the 'Matrix project'. 100 people or organisations are invited to contribute by pledging to raise or donate £1,000 each.

The University College of London team is working on a study to confirm and expand Dr Bansal's B cell results in a different cohort of ME patients. liME's advisor, Professor Jonathan Edwards, will be consulting with Norwegian researchers Professor Olav Mella and Dr Oystein Fluge about their trial.

More information
<http://tiny.cc/hbcy4w>

Fundraising for liME

Jane Hurst & Geoff Allen have organised a quiz to raise money for Invest In ME's Biomedical Fund. The Picture Quiz is £2 to enter and the first prize is £50. Every pound raised will be MATCHED (by a very kind friend) and donated to Invest In ME's Rituximab Research Fund.

More details here:
www.justgiving.com/liME-Summer-Picture-Quiz-2013

If people would prefer not to/aren't well enough to enter the quiz but would still like to donate the £2 fee, you can do that too.

In Parliament

Early Day Motion 212:UK ME/CFS Research Collaborative
<http://www.parliament.uk/edm/2013-14/212>

34 MPs have signed up to this EDM started by Annette Brooke:

"That this House welcomes the UK Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Research Collaborative; notes that estimates of the prevalence of ME/CFS range from 240,000 to 600,000 patients"

Has your MP signed?

young people

Anti-bullying poll

Barnardos Cymru would like to know if you have experienced or seen young people (18 years or younger) being bullied because of disability, receiving learning support at school, being (or thought to be) gay or bisexual, skin colour, religion or country of birth. They want to show the Welsh Government how much bullying happens.

Take part online

English www.surveymonkey.com/s/barnardosantibullyingpoll
Welsh www.surveymonkey.com/s/arolwgwythnosgwrthfwliobarnardos

Or download the paper version & return by Nov 1st:

English <http://tiny.cc/p3ew4w>
Welsh <http://tiny.cc/o4ew4w>
Or contact Elaine Speyer, Research and policy assistant, 19-20 London Road, Neath SA11 1LF 01639 620771

Anti-bullying week 18-22 Nov 2013

More info: <http://tiny.cc/l6ew4w>

What to do if bullied

NEVER IGNORE BULLYING

...ignoring it won't make it go away and it could get worse.

Tell a friend

Your mates can support you, even if you're not ready to talk about it in detail.

Tell a parent or guardian

They should be there for you, even if you're not ready to take it to your teachers.

Tell a teacher

The teachers in your school have a duty to look after you. Ask about the anti-bullying policy at your school.

Contact ChildLine

You can contact ChildLine for free on 0800 1111, anytime. Our friendly counsellors are here to listen and support you and can advise you on how you can stop the bullying in your particular situation.

Find a way to stay safe at school

No-one should be too scared to go into school. You have a right to be there. Stay away from your bullies and stay in a group of friends when you don't feel safe.

Walk home with someone or get a lift

If bullying happens on the way home it can be hard to avoid. Walking with someone, varying your route or getting a lift can help.

Ask your mates to look out for you

Your friends can be there for you, even if you don't want to talk about the details to them. They can support you to tell someone who could help make it stop.

Don't fight back

You could get in trouble or get hurt if you fight back against bullies. There's no shame in not fighting back.

Don't reply to an abusive message

Replying to a message from a bully can encourage the bullies and end up upsetting you more.

Block the bully from contacting you

Some phones will allow you to block numbers, and you can block, delete or unfriend other users on many social networking sites. Stopping them from contacting you could help reduce the amount of stress you feel.

Don't go along with what they want

Going along with what bullies want will give them the message that bullying is working.

Find out about your school's anti-bullying policy

It's good to know what your school has promised to do in the event of bullying. There might be something in the policy that could help you.

Keep a record of the bullying

Saving texts, emails and messages or writing down when someone has bullied you in person can be a

useful way to keep track of what has happened and will help when you are ready to report the bullying. More info <http://tiny.cc/d24z4w>

Filmmaking course

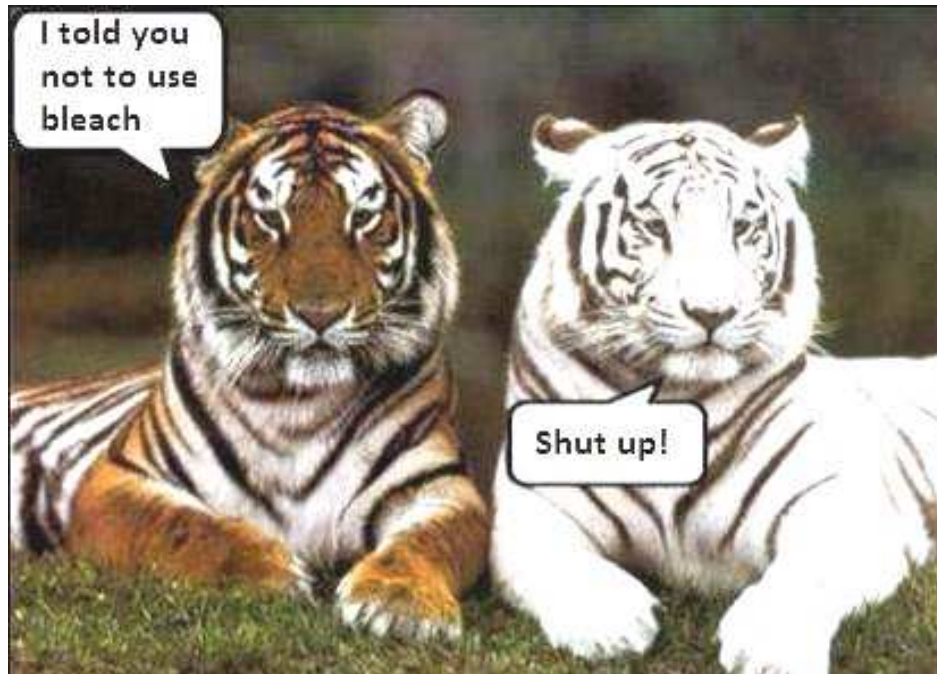
Are you between 16-19 years old?

Ready for the next stage in your development as a documentary filmmaker?

DAWN is part of the BFI Film Academy scheme, which provides opportunities for talented and committed young people to develop new skills and build careers in the film industry. The programme goes over 6 days (3 weekends) which can be attended either in North, Mid or South Wales.



young people



- Participants can choose from 3 courses in Bangor, Aberystwyth or Newport
- Each course lasts 3 weekends between Jan-March 2014
- Course fee is £25 – bursaries available

For more information and to apply: www.mediaacademywales.org/dawn

Zoom young filmmaker awards

Calling all young filmmakers 8 - 25.....Have you made a film? Then consider entering into the *Zoom Young Filmmaker Awards 2014!*

There are no strict rules about what your film should be like. What we're

looking for is originality and creativity. All we're asking for is that the majority of your film's crew, including the Director, and those who appear on screen are aged between 8 and 25.

The best films will have an interesting story or subject matter, filmed and cut to the best possible standard within their time and budget constraints. So if you have a good story you want to tell everyone and think you could tell it in an original way, send it to us and you may well be seeing your work on the big screen.

Download the entry form attached for guidelines on how to submit, you can also give us a call on 01443 888337 / 07717532723 or email lee@zoomcymru.com

DEADLINE: January 13th 2014

The Zoom Young Filmmaker Awards is part of the Zoom International Youth Film Festival 2014. Check out 2013's highlights <http://tiny.cc/c3gw4w>

Young Writers Award

Details for entry to the 2014 Terry Hetherington Award can be found at www.chevalwriters.org.uk The first prize is £1000.00. There is a second and third prize, and a chance to be published in the Cheval Anthology.

Competitors should be resident or studying in Wales and aged between 18 and 30 yrs on the 31st of January for the application year.

Submit the entry fee of £3 along with 1-3 poems or a piece of fiction up to a maximum of 3000 words on any subject. If you submit both poetry and fiction, the entry fee is £6.

All entries must be submitted by the 31st Jan. 2014, and must be the author's own work and previously unpublished.

Postal entries (entry and cheque payable to Cheval) to be sent to: Amanda Davies, 60 Lewis Road, Neath, SA11 1DX. <http://tiny.cc/ph7z4w>

Bird Wordsearch

Can you find the 20 birds hiding in here? Answers on p. 12.

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

Created by Puzzlemaker at DiscoveryEducation.com

welfare

GPs & Benefits appeals

GPs in South East Wales have been told by their local governing body to always refuse to provide letters for claimants in connection with benefits claims as it is 'an abuse of the national health service'. Only requests by the DWP will be met in future. Patients will still be able to request copies of their medical records for a fee of up to £50.

More info: <http://tiny.cc/c7cy4w>
<http://tiny.cc/c7cy4w>

Benefits & medical evidence

Action for ME has produced a factsheet to help GPs understand why their medical evidence is so important in supporting benefits claims and appeals. If your practice is reluctant to provide such information or makes a substantial charge for it, consider giving a copy to your GP and practice manager. If a GP is too busy to read the factsheet you may wish to tell her/him briefly the key points and check that your medical record is up to date.

Supporting medical evidence for people with M.E./CFS: a guide for healthcare professionals who are asked to provide reports for welfare benefit claims and appeals AfME, August 2013
<http://tiny.cc/wady4w>

Personal Independence Payment (PIP)

The roll out of PIP for existing claimants of Disability Living Allowance (DLA) is now scheduled from 28/10/2013. This should affect claimants of DLA who either reach 16, are due renewal of their award or have a change of circumstance after this date. This coincides with a consultation on the criteria for the enhanced rate of the Mobility Component and could be later if the decision on this criteria is delayed.

It can also affect those who are on Disability Living Allowance and want to change over to Personal Independence Payment (PIP) early. From the same date they will be able to request this. However, as awards could go down as well as up people should seek independent advice before doing this.

New claims for PIP of course have been rolled out nationally since June 2013. Very few have had decisions on these claims which could lead to the view that the Department for Work and Pensions (DWP) are postponing decisions until the rules have been set (the DWP deny this).

New appeal rules for DWP decisions

From 28th Oct people can no longer go straight to appeal but will have to ask for a revision from the DWP initially and then will be required to appeal directly to Her Majesty's Courts and Tribunals Service (HMCTS). Time limits for both requests are 1 month which can be extended for up to 13 months for special reasons. There will be time limits for the DWP to give appeal responses.

Clients challenging ESA decisions would have to claim Job Seekers Allowance, in most cases, before the revision is heard, and then ESA at the assessment phase rate, as normal, whilst appealing.

There are fears that as independent advice services have reduced provision due to funding cuts, clients will be put off appealing. Currently around 2/3 of all appeals relate to ESA.

Bedroom tax

As the first appeals against the bedroom tax go to tribunal, the news could scarcely be worse for the DWP. Not only did they lose four out of five appeals in Fife, but the reasons for the decisions are legally well-constructed and likely to be argued in other cases too.

For instance, in one appeal, the judge held that if under-occupation was to be prevented, then over-crowding must also be avoided. So, if a room was too small to legally be treated as a bedroom for an adult under the Housing Act 1985, then it could not lawfully be treated as a bedroom for benefits purposes, no matter what the local council or the DWP might think. More info <http://tiny.cc/fgdy4w>

First-tier tribunal decisions are not binding on other tribunals, but if the DWP appeal those decisions to the upper tribunal and lose again, then they will become binding. In the meantime, the same arguments can be used by any other claimants to whom they apply.

E-Petition:

Stop further harassment of ESA claimants

<http://tinyurl.com/qfcdmyv>

So far there are 7960+ signatures. Please ask family and friends to sign up, too

BackCare Awareness Week Oct 7-11

This years campaign was 'Caring for Carers'.

Carers provide invaluable help and assistance to their children, friends, relatives, and partners, but what happens when their work leads to back pain, compromising their ability to care?

Back pain is endemic among carers: a 2011 survey found that 70% of carers experienced back and shoulder pain. This issue seriously affects the quality of life of those who should be most valued in our society, as well as impacting on their caregiving work.

More information can be found from the Backcare Charity www.backcare.org.uk/

Care for your back

- 1 Exercise your back regularly. Walking, swimming (especially backstroke) and using exercise bikes are all excellent ways to strengthen your back muscles.
- 2 Always bend your knees and your hips, not your back.
- 3 Never twist and bend at the same time.

- 4 Always lift and carry objects close to your body.
- 5 Try to carry larger loads in a rucksack and avoid sling bags.
- 6 Maintain a good posture. Avoid slumping in your chair, hunching over a desk or walking with your shoulders hunched.
- 7 Use a chair with a backrest. Sit with your feet flat on the floor or on a footrest. Change how you sit every few minutes.
- 8 Quit smoking. It is thought that smoking reduces the blood supply to the discs between the vertebrae and this may lead to degeneration of these discs.
- 9 Lose any excess weight. Use our Healthy weight calculator to find out if you're a healthy weight for your height.
- 10 Choose a mattress suited to your height, weight, age and sleeping position.

Health weight calculator
<http://tiny.cc/f5bu4w>

Backpain
<http://tiny.cc/5acu4w>
<http://tiny.cc/kdcu4w>



Carers rights day Nov 29

This year Carers Rights Day is taking place on Friday 29th of November and the theme is '*rights, advice, support*' focusing on ensuring that carers understand their rights and get access to good quality advice that can support them to care.

Carers Rights Day aims to make carers aware of different kinds of practical support that could support them to care so this year the organiser's handbook has more information on how different kinds of technology can benefit carers by; monitoring things to provide the peace of mind that lets a carer get a good night's sleep or to juggle

carers

work and care, or enabling carers to connect with other carers and access support and information online.

Events around the country:
Pembs - 09.45 am to 3:00 pm at Johnston Institute, 4 Hayston Road, Johnston, Haverfordwest.

Activities include: info& advice, therapy taster sessions for carers. Help is available with travel and respite / replacement care costs.

Transport cost can be reimbursed or a combination of shared transport and Cars4Carers transport can be arranged.

More info <http://www.pavs.org.uk/carers/> or contact Julie Campbell, Carers Development Worker at Pembrokeshire Association of Voluntary Services on 01437 769422
julie.campbell@pavs.org.uk

RCT - 10am - 3pm Coleg Morgannwg, Nantgarw Campus For more information or to book a place please contact Claire Meredith on Freephone 0808 100 1801 or carerssupportproject@rctcbc.gov.uk

Caerphilly – to be held at

carers

Llancaiach Fawr, Nelson Contact carers@caerphilly.gov.uk or Hayley Smith on 01443 864604

For info about events in your area contact your local Carers' Service.

Carers Rights Workshop Cardiff

Mon 21st Oct 10.30-2pm

Find out about: Carers (Recognition & Services) Act; Carers & Disabled Children Act; Carers (Equal Opportunities) Act; Carers Measure; Work & Families Act; Other relevant legislation
Carers Wales, River House, Ynysbridge Court, Cardiff CF15 9SS
A light lunch will be provided.

More info: Pat McCarthy, Carers Participation Officer on 0786 653 9075
<http://tiny.cc/onlu4w>

Short term respite North Wales

The short term respite service is available to carers who are experiencing ill health or when there are identified short term health needs

or to enable them to attend clinical appointments.

Crossroads Care North Wales can provide high quality respite care for up to 12 weeks per annum, providing preventative and practical support to the carer to enable them to resume their caring role.

Referrals must be via BCU Health Board / NHS staff (Discharge Co-ordinator, Ward Mangers, District Nures, CPNs, School Nurses, Health Visitors etc). The bi-lingual service will be offered pan North Wales.

Upon referral, a carer's needs assessment will be taken and, once a health need has been identified, a short term respite service will be provided in the cared-for's home.

Times and dates for the planned delivery will be agreed, but will be provided between 0900-1700 hrs, Monday to Friday. Carers will be fully involved with the referral/assessment process.

Carers' voice project

This 4 year project will be working to ensure that the voices of carers, particularly those who are seldom

heard, are listened to by decision makers and acted upon, to improve the lives of carers and those they care for.

If you are a carer living in Powys or Pembrokeshire, or know someone who is, and would like to know more please contact Ingrid. She would like to hear from you about your experience whether it's about the access to information, emotional or financial support or any other issue you'd like to address and talk about. The project is designed to give you - the carer - a chance to share your ideas and views on how to improve the services you and the people you care for receive so that we can work together towards making positive changes.

Ingrid Bernathova, Project Development Officer on 01437 764639 or email ingrid.bernathova@crossroadsmww.org.uk

Flu Jabs

As a carer you may be worried about getting the flu because it would affect your ability to care for the person you're looking after. You may be able to get a flu jab because of this, or because of your age or your own health.

If you're not aged 65 or over, tell your GP if you receive a Carer's Allowance or are the main carer for

the person you are looking after. Explain your concerns for the welfare of the person you're looking after if you should fall ill, e.g. if there is no one else who would be able to step in. If you have health problems of your own, your GP should also check to see if you fall into one of the risk groups.

'The selfish pig's guide to caring'

"This book by Hugh Marriott is for those of us who have come reluctantly to caring for someone with a long-term disability and who secretly feel bad about our unwillingness."

In a highly entertaining manner the author, himself a carer of his partner who has Huntingdon's Disease, tackles the really difficult issues of "What if you didn't care?", and "Tips which the experts don't tell you".

£6.99 from Amazon
£9.99 from bookshops
£5.99 for kindle version (Amazon)
or for an e-book check www.waterstones.com/

To err is human, but to really foul things up you need to be a computer

Paul Ehrlich

And how!

Tony Thompson



Are you interested in forming a Men's Shed?

What is a Men's Shed?

- A Men's Shed is a dedicated, friendly and welcoming meeting place where men come together and undertake a variety of mutually agreed activities.
- Men's Sheds are open to all men regardless of age, background or ability. It is a place where you can share your skills and knowledge with others, learn new skills and develop your old skills.
- The men have ownership of their Shed and projects and decide their own program of events. A Shed is a not for profit concern, owned by all the members

- Shed can agree to undertake any project they wish for example, repair an old car, mend a boat, grow vegetables, IT project, recording studio... anything you wish.
- It's about men sharing a space and working on projects shoulder to shoulder.

To find out more contact Luke on 0790 8860061 or find interested people in your area at <http://menssheds.org.uk/index.php/programs>

The Association of Men's Sheds Cymru <https://www.facebook.com/menssheds.cymru>
UK Association
<http://menssheds.org.uk/>

Why register as a carer?

If you look after someone who can't get by on their own due to old age, frailty, illness, disability, mental ill health or addiction, your GP practice will want to make a note on your medical records that you're a carer. That's because:

- Being a carer can affect your health. You may injure yourself when lifting someone or sometimes feel anxious or depressed.

carers

- As a carer, you can request a free flu vaccination. This could help prevent you from becoming



too ill to look after the person you care for. Ask your GP practice for details.

- Your GP practice can also refer you to your local carers' centre. They will send you an information pack with details of benefits and services you may be entitled to because you look after someone.

1Stop Swansea

1Stop Swansea is a website that will provide a single information point for parent / carers of disabled children and young people in the Swansea area. Information will include:

- Things to do, places to go, events;
- Links to organisations;
- How to access support for an emerging diagnosis; local services;
- A jargon buster
www.1stopswansea.org.uk

Swansea Parent / Carers' Forum Coffee n' Chat

The Forum holds an informal coffee morning once a month. This provides an opportunity for any parent / carers to drop in and meet other parent / carers and find out more about the work of the Forum.

More information:
<http://tiny.cc/rmmu4w> or contact Sandra Spratt 01792 544019
sandra_spratt@scvs.org.uk

Health fair for carers Carmarthen

2nd November, Info, advice & fun activities at Carmarthen Leisure Centre 10am-3pm If you need transport or replacement care please phone Carmarthenshire Carers Service on 0300 0200 002.
carers@cavs.org.uk

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

Brecon area contact
Richard Jones
richardj5@virginmedia.com
01874 622310

Carmarthenshire ME Group
Meets Caemaen 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.

Pembrokeshire 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

Secretary and campaigns
Jan Russell 01970 636515
enquiries@wames.org.uk

Youth and Care officer / Media contact
Sylvia Penny 0292 051 5061
sylvia@wames.org.uk

Young People's contact
Michelle Penny
michelle@wames.org.uk

Publications officer
Tony Thompson
tony@wames.org.uk

wames on the web

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