



SUPPORTING PATIENTS, FAMILIES AND INTERESTED PARTIES
WITH MYALGIC ENCEPHALOMYELITIS, CHRONIC FATIGUE SYNDROME
AND FIBROMYALGIA

EVENT



**Monday 5th December
2 - 4.30pm**

Bethel Church
Llangrannog Road,
Llanishen,
Cardiff, CF14 5BJ

All welcome!

**Members • Friends • Family • Carers • Partners
• Food will be provided •**

Bran Tub *Please bring a gift up to £5 wrapped which goes in a box and we exchange gifts.

Please contact us to let us know you are coming or if you need a lift:

Email: mesigwales@gmail.com Tel: 029 20762 347

Text: 07825 641 970

Please join us at our monthly meetings which are currently held at:
Bethel Church Community Centre, Llangrannog Road, Llanishen, Cardiff CF14 5BJ

CONTACT:

<http://www.mesupportinglamorgan.co.uk> • <https://www.facebook.com/MESiGWales/> • Twitter: @MESIGWales

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MESiG WEBSITE UPDATED!

By Linda Tatham (Website Facilitator)

21st October 2016

I hope you have all noticed the new website, launched 21st October 2016. The updated look has been completely transformed, so please take a look at it if you haven't already done so.

Our appreciation goes to Jad of Cotswold Web Design who had the job of editing and shaping it. Also to Awards For All for the funding. We are really pleased with the finished look and it is much more fluid and fun to get around.

Those who will benefit most from the changes are yourselves and any new members or interested parties. Each page has been overhauled with the much needed updated information. The logo and shade of green vary only slightly from the original version by Janet Price in 2008.

Any upcoming Event is now easily seen on the front page and if you want further updates go to the Events page at the top, even the Christmas Party on 5th December has been added!

In the top right hand corner there is Twitter and Facebook

which we are all familiar with, but added to this is G+ which shows you the latest You Tube clip from Made In Cardiff for the Millions Missing Day.

When you click on 'About' the drop-down menu takes you to various titles i.e. Symptoms of ME/CFS which even if you have been unwell for a while might give you a fresh look into managing the illness. Also the 'MESIG Library' has been updated to bring it in line with 2016 information.

Click on any green writing and you're taken directly to those websites. Even old archive newsletters can be seen and they date back to May/June 2010 edition.

It may also interest you to view The Cardiff & Vale Health Board plans for 2015-18, all the latest news at your fingertip.

After perusing the website, to return to the front page, click on the logo in the left hand corner.

Add us to your favorites:

www.mesupportinglamorgan.co.uk

DATE FOR DIARY

MESiG Support Group Meeting - 6th February 2017

2-3.30pm

Stephen Allen with guests from the Community Health Council attending.

MESiG Support Group Meeting - 9th January 2017

Julie Skelton from Carers UK will be coming to our Support Group meeting 9th January 2017 2-3.30pm.

Come and find out what help and advice is available with regards to care for yourself and/or your carer.



Lottery Funding

MESiG are very grateful to 'Awards For All' lottery funding which has paid for this newsletter and our website among other things.

AGM MEETING.

MESIG AGM / AWARENESS DAY

14th May 2016, 2 - 5pm

By Ken Bailey



The Annual General Meeting and Awareness Day event took place in the Bethel Church Community Centre, Llangranog Road, Llanishen on Saturday 14th May 2016.

The event commenced with the AGM. The meeting was led by Chair-Chris Bailey, who read out the Chair's report. She summarised the year events between 2nd June 2015 and 12th April 2016.

Chris also highlighted the following meetings:

- Neurological Conditions
- Wales Neurological Alliance
- Rare Diseases
- Capita (assessors for PIP benefits) Policy Forum, with Darren Miller-Shadow Minister of Health for Wales

Chris also commended Nick Tatham for raising money by running in the Cardiff Marathon.

The voting for committee posts came next. Chris announced that she would not be seeking re-election as Chair but was willing to stay in post until the position is filled. Rob Goodman and Peter Baxter decided to no longer be on the committee. We are very grateful for their service with MESiG and wish them all the best.

Your elected committee members are:

- Chris Bailey
- Dee Penny
- Miriam Wood
- Mary Jones
- Mark Morgan

We welcome Mark as a new member.

The following positions are vacant:

- Chair
- Vice-Chair
- Secretary
- Newsletter Editor

The last item on the AGM agenda was the presentation of the Treasurers' report by Dee Penny.

We were pleasantly surprised by Assembly Member Julie Morgan who attended the meeting.

Julie gave a brief address to those present and commended MESiG for the work we do in the community and the professionalism of the presentation made at the Welsh Assembly in 2014.

Julie answered several questions posed by MESiG members. Julie Morgan invited MESiG to present in the Welsh Assembly again.

Our invited guest, Member of Parliament - Craig Williams gave an impassioned speech about the lack of services for specific disorders such as M.E. in Wales. He said that he would do all he could to raise awareness.

Chris told her story of recovery, highlighting key lessons that eventually led to full recovery. A member of MESiG displayed her wonderful work in the form of jewellery she made.

Many thanks to all who attended and showed their support.



WAMES AGM

25th June 2016

By Dee Penny

ST MARGARETS CHURCH HALL DINAS POWIS

It was many years since I had been to that corner of the village where the church is, a really pretty setting among the trees and greenery. I had lived in Dinas Powis in the 1970's - That dates me? Mark had already arrived and when I entered the Hall behind the church, everyone was seated around a large table with Jan Russell at the head. The others attending were: Tony Thompson, Sylvia Penny and her son, also secretary Kishli Laister-Scott and of course Mark Morgan and myself representing MESIG.

Introductions were made and drinks handed out, the AGM opened and after apologies for absence, discussions on different matters began. Their finances and balance sheet gone over, together with the various positions on the committee that inevitably stayed the same. Jan talked about the difficulties of recruiting help for the WAMES Committee despite distributing info on the benefits of volunteering - even paid help was mentioned, but of course, would be a bit difficult with their limited funds.

Then after the AGM came general discussion on what had happened over the year and what they hoped to achieve in the next one. It started with the subject of possible Bilingual Advice and Benefits info, Independent Living fund and Social Care. The controversial CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise) were mentioned. Also the concern that Welsh Government has no jurisdiction over Welsh Health Boards, and the lack of consistent Delivery Plans across Welsh Health Boards in regard to ME / CFS. The Canada Guide lines for the treatment of ME / CFS were talked over as a good example of what could be achieved for patients, and so it was decided to lobby the Welsh Health minister once more.

We stopped for a quick lunch and felt refreshed, then listened to more discussion on various subjects, including the need for help to set up support groups in certain areas, and more.

Jan spoke of her dissatisfaction that she had not achieved as much as she had wanted over the year, but Tony and the others were quick to reassure her that it was not for the want of trying; she and they had done as much as possible, given the problems of health and government - and by the amount of subjects and paperwork involved, she had obviously worked very hard indeed for WAMES. Then all of a sudden our time was up and it was time to finish. We said our goodbye's and went on our way. Jan and Tony had much farther to travel to their homes in Aberystwyth, so we wished them a safe journey.

We at MESIG thank WAMES for all they do.

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Chair: Jan Russell

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Secretary: Kishli Laister-Scott

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**Cymdeithas Cefnogi
ME a CFS Cymru**

**Welsh Association of
ME & CFS Support**

ACTION FOR ME CONFERENCE/AGM

By Ken Bailey

18th November 2016

Report on the Action for M.E. day conference which took place in the Allen and Overy building, One Bishops Square, London on the 18th November 2016.

The meeting was attended by MESiG Chair Christalla Bailey and her husband Ken Bailey.

Upon arrival we were given a warm welcome by Sonya Chowdhury (Chief Executive) and Clare Ogden (Head of Communications & Policy) and Christalla was seated at the top table alongside the other speakers for the morning session.

Alan Cook (Chair) commenced the meeting and introduced Sonya Chowdhury who presented the Action for M.E. five-year strategy entitled 'Improve, Inspire and Invest'. Sonya talked about the Action for M.E. commitment to ending the ignorance, injustice and neglect experienced by people with M.E. She said that these aims would be achieved through collaboration with others who share this vision. Sonya closed by saying that Action for M.E. 'will only consider undertaking an activity if it improves the lives of people with M.E., inspires action at all levels, or supports investment in change.'

Christalla was the next person to speak. She shared information about who MESiG are and how the organisation operates. She also talked about presentations made to the Welsh Assembly, meetings with Assembly Members/MP's and primary healthcare professionals. A film clip of the 'Missing Millions' event which took place in Cardiff on the 27 September 2016, was shown during her presentation. Christalla spoke about the importance of M.E. organisations/charities working together in unity. She remarked that, "a house divided cannot stand." She closed her presentation by thanking the Action for M.E. team, past and present, for all their hard work and commitment over many years, which had improved the lives of people suffering with M.E.

Clare Ogden was the next speaker. She talked about inspiring action at all levels. Clare also pledged support to MESiG on behalf of Action for M.E.

Tom Owen (Director of Services and Development for Action for M.E.) was introduced. He presented some

startling statistic statistics. Here are a few:

- Suicide is 6 times more likely in people with M.E. and CFS compared to general population
- More than 80% of people with M.E. are primarily cared for by a family member, but almost none receive a care assessment.
- M.E. is in the top three most challenging illnesses for GP's and has been for more than 10 years.

Dr Warwick Dunn (School of Biosciences of Birmingham) shared information regarding new technologies for M.E. research. Action for M.E. has made the commitment that 20% of their activities will be focused on bringing more research, more money and more people into the field to invest in change.

The next talk was by Kate McMahon (Policy Officer) on the subject of collaboration for change. The challenges facing Action for M.E. in trying to effect change were highlighted. She also commented on the impact of their work so far including a web seminar that involved 150 GP's. Kate outlined Action for M.E.'s promises for the future:

- They will develop a focussed programme of UK policy work
- They will increase the knowledge and understanding of primary healthcare professionals
- They will work at an international level to influence action in the UK to improve the lives of people with M.E.
- They will work more effectively at a local level

Supporting people with M.S. and M.E. was the next subject presented by Bernard Elwen (Honorary Secretary, MS National Therapy Centres). Bernard told us that his organisation have 50 MS therapy centres throughout the UK. The largest centre is in Chiltern, Buckinghamshire, which has a hydrotherapy pool. Individuals don't need to consult a GP, they can self refer. The centres offer oxygen therapy, alternative therapies, physiotherapy, welfare and benefit counselling. Bernard said that the treatment relieves fatigue and helps the body to become more

efficient and recommended this resource to people suffering with M.E.

Sonya Chowdhury spoke again on the global movement of Action for M.E. She told us that she had visited the United Nations in Geneva. Sonya continued to say that this is where decisions are made on health issues, globally. She informed us that 18 months ago she was involved in setting up an International Alliance with other nations to raise awareness and make decisions regarding affirmative action and research. Sonya said that the emphasis needs to be on collaboration despite disagreement within the M.E./CFS community and that the goal was not to lose sight of the sufferers. She also told us that Action for M.E. are going to employ someone to be based in Geneva.

After an excellent lunch we resumed with 'around the table' discussions. The topic on our table was "How can we collaborate more effectively to better meet the needs of people with M.E. at a national and International level. Two suggestions were that (a) there was a national need for training for GP's and other healthcare professionals and (b) that Missing Millions could become an event that national/ International M.E. charities/organisations could collaborate on annually.

The meeting closed following the AGM at 4:30.

This was an excellent conference. I was impressed by the high standard of speakers/ presenters who conveyed a real sense of optimism and hope to the delegates.



ALTERED GUT MICROBIOME IN ME / CFS

In 2007 as a doctor specialized in treating patients with Myalgic Encephalomyelitis (ME)/ Chronic Fatigue Syndrome (CFS), I was curious to see if there was a relationship of the patients' irritable bowel symptoms and their degree of fatigue and pain. Clinically I had noticed that when parasites were found in a patient's stool and treated, that afterwards, often in addition their fatigue going up a notch, sometimes their headache pain and general pain symptoms improved. I was intrigued. Dr. Alan Logan was able to secure private funding to look at a small group of my patients with ME/CFS and irritable bowel symptoms. We had 20 patients as controls and 20 patients that we treated with billions of probiotic bacteria: *Lactobacillus casei* strain Shirota for two months. We were hoping to see improvements in fatigue and pain in the patients. There was a rise in *Lactobacillus* levels as expected with the supplementation given to the patients. We were surprised to see an increase in the *Bifidobacterium* levels. We do not see improvement in their fatigue or pain levels. With experience, looking back, a two-month protocol for supplementation with a probiotic was far too short a time.

What did surprise us was that the patients who were treated with a probiotic had significant improvement in their anxiety scores. It was possible that the decreased anxiety was a direct result of improved bowel function. We postulated that perhaps this was an example of enteric neuroscience with the bowel communicating directly with the brain through the vagal nerve. Perhaps, we wondered, if by changing the microbiota in the bowel, it helped to restore normal intestinal health, decrease intestinal permeability, reduce inflammation and cytokines and indirectly reduce anxiety. We knew that there was lots of room for further studies in this area.

A Venket Rao, Alison Bested, Tracey Beaulne, Martin Katzman, Christina Lorio, John Berardi, Alan Logan. A

randomized, double-blind, placebo-controlled pilot study of a probiotic in emotional symptoms of chronic fatigue syndrome. *Gut Pathogens*, 2009, 1:6.

DOI: 10.1186/1757-4749-1-6

I was thrilled with this new article about gastrointestinal disturbances or irritable bowel syndrome and altered microbiota in patients with ME/CFS. Gastrointestinal disturbances are present in many patients with ME/CFS. According to the article by Giloteaux et al. dysbiosis or altered gut microbiome (types and numbers of bacteria present in the gut) is present in patients with ME/CFS. Dysbiosis of the gut microflora may contribute to ongoing symptoms of inflammation in patients with ME/CFS. Potentially, in the future, this could lead to better investigation and treatment for symptoms of dysbiosis or IBS in patients with ME/CFS.

Ludovic Giloteaux, Julia K. Goodrich, William A. Walters, Susan M. Levine, Ruth E. Ley and Maureen R. Hanson. Reduced diversity and altered composition of the gut microbiome in individuals with myalgic encephalomyelitis/chronic fatigue syndrome. *Microbiome* (2016) 4:30 DOI 10.1186/s40168-016-0171-4

<https://microbiomejournal.biomedcentral.com/articles/10.1186/s40168-016-0171-4>

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MEDICAL TESTS FOR BENEFIT CLAIMANTS TO BE SCRAPPED

Francis Elliott, Rachel Sylvester, Alice Thomson
October 1 2016, 12:01am, The Times

Damian Green, the new work and pensions secretary, admits that the current regime of repeatedly testing many of those on disability benefits is pointless and even harmful.

Controversial medical assessments for up to 100,000 of the most vulnerable benefit claimants, including those suffering from dementia, Parkinson's and MS, are to be abolished as Theresa May promises a more caring welfare state.

Damian Green, the new work and pensions secretary, admits that the current regime of repeatedly testing many of those on disability benefits is pointless and even harmful, in an interview with The Times.

In the latest break from previous Tory governments, Mr Green also refuses to repeat George Osborne's contrast between "strivers" and "skivers" and says that reality TV shows such as Benefits Street are distorted.

"It's Theresa doing what she thinks we should do, which is that the Tory party is not the nasty party it's a compassionate party," Mr Green says.

Some two million people claim employment support allowance, the benefit for being unable to work through illness or disability, worth up to £109.30 a week. Until now even those with progressive conditions were subject to tests, as frequently as every six months, to prove they were not capable of work.

"What we will be doing is stopping reassessing benefits for those who have long-term sickness, those who have severe health conditions that require help and that are not going to get any better," Mr Green says.

"If they are at the stage where they can no longer work it is pointless reassessing them and only adds to their anxiety and difficulties.

"It is important that we should take seriously the caring responsibilities of the welfare state and that people with



severe conditions which are degenerative don't constantly feel they have to prove themselves with repeated tests to prove they are still entitled to benefits."

The exact definition will be worked out after a green paper on welfare reform is published this year. However, officials said the expectation was that "very, very high tens of thousands" of claimants could be spared the repeat tests. "People with Huntington's, MS, severe autism and Parkinson's" will be among those spared repeated definition, says Mr Green, although he stresses that decisions will depend on the individual case.

Disability campaigners welcomed the change. Ed Owen, chief executive at the Cystic Fibrosis Trust, said: "Frequent reassessment for welfare support is stressful and inappropriate for a progressive condition."

Mr Green says he was heartened to hear that the number of claimants sanctioned for cheating the system has halved in a year and stresses he will not use terms such as scrounger. "If there are people who are playing the system our job is to stop them playing the system. I don't think using language changes people's behaviour," he adds.

BOOK REVIEW.

DEAR STRANGER *by Anastasia Palmer*

By Miriam Wood

I am currently reading this very interesting and different book. It is written by a girl who was hit by M.E. when she was aged about 14. It is fascinating, sad and heartwarming at the same time.

Anastasia began writing pages entitled 'Dear Stranger' and this is how the book was born, out of her thoughts put on paper to an invisible, unknown person:

"What shall I write? There is a lot on my mind of course but I don't know if I really want to put any of it on paper. I feel like I might be cheating a bit. I have just come home from the hospital and this is my reaction...
...One year and two months ago I got glandular fever and a severe form of tonsillitis called quinsy, and up until now I have been "recovering" ...Since then I have been in bed with a brain that refuses anything that wants to enter...

I have developed an illness called Myalgic Encephalomyelitis – M.E...." To close this first tentative attempt to make sense of her life Anastasia says:

"What does it mean to have M.E.? Does it mean that I failed in a task (to recover from those viruses) and am I to blame? What is expected of me now that I have an official name to put to a vague illness? Will people understand me better? Will I be like this forever? Where did I go wrong?

The doctor said ten years to life. Stranger I am numb and somewhere in there, I am afraid."

I'm sure that a lot of people of any age can relate to this when they have received a diagnosis which they are trying to take in and they don't know where to go from there.

Although I am finding this such a gem of a book, I don't know how easy it will be to read by someone who has M.E. The reason I say this is that it is writing without chapters or page numbers, sometimes a brief thought, a poem, or at other times a deep discussion, but each section begins with 'Dear Stranger' so there is no map to guide one through its pages. On the other hand, it is a good book to dip into for a short read, as long as you have a bookmark on hand to reserve the page for a return visit.

Anastasia, despite her young age, deals with the problem of having and sustaining a relationship when ill. At times she pushes her boyfriend away as she is too ill to see him but cannot tell him and explain why. She yearns for his

support and friendship, as she has lost so much of her life, but she argues with herself about the effect she is having on him and maybe his family too.

The way in which her soliloquies become a book is so interesting and might easily not have happened. As I read, I am going through each phase of her life with her as she grows up, a reluctantly sick person, exploring herself, her life and her illness and wondering whether she will ever be able to compile these random pages to form a book. Will she ever achieve any of her dreams? She also finds that she is more than one person and discovers Emmy (M.E.), the sick person and Anastasia the healthy person. I think her writing is delightful, insightful and touches on every aspect that people discover when they have M.E. and are trying to continue to live something resembling a 'normal life'.

One poem she wrote:

'Last night I gave my silent cry, I saw my life,
And felt it lost
Saw my shattered heart, And bones as dust
I gazed into this world of mine
Dropped my tears of sorrow inside
The wandered through
All of me
Showing things I can't stand to see, Stop I begged
Go another way
But the tears continued all the same
Tears I said, What did you find , An unknown ache,
Said tears
That is why we cry'

She struggles with the idea of if she can get better and how she could somehow force herself to get well.

"I wonder if this is how it is going to be for the rest of my life, having times that are just about bearable then do something too big for me and fall back to square one then build myself up to the just about bearable and around and around we go. I wonder if I really and truly rested, if I did NOTHING but resting, drinking juices, said no to everything and only had my tiny little baby projects that I could give fifteen minutes of my day to...would I then get better?"

This book is an amazing experience. Please take your own walk with Anastasia as her 'dear stranger' and let me know how meaningful this is for you.

TEA IN THE PARK

By Mary Jones

8th August 2016 2pm

When we arrived for our “Tea in the Park” in the Roath Park Tearooms, it had become sunny and warm and was therefore quite busy.

It was so pleasing to be able, once again, to see so many members, who were able to join in a pleasant gathering of sufferers and carers. Twenty or more people came along, including at least two new members, which was so good to see. It is hoped that they will be able join us to meet at our Support Meetings held at “The Bethel Church Community Centre” on Llangranog Road, Thornhill, Cardiff. Dates of these meetings are published on our website:

www.mesupportinglamorgan.co.uk.

The meeting was joined by Sonya from Action for ME (Bristol) who, earlier, had addressed the Committee members regarding the need for all interested parties to work together, whilst exchanging ideas and putting pressure on authorities to take urgent action to deal with ME / CFS / FM.

The Roath Park Tearooms provide a wide selection of coffees and teas (including herbal and fruit), together with meals, cakes etc.

We were joined by one of our members who entered and went on to take 2nd place in the Miss enchanted rose 2016 beauty pageant, which was held in Cardiff to raise

money for Bullies out Charity! Emily wanted to be a face representing people with unseen illness. Well done Emily.

Sitting there, we were provided with beauty of a different kind, with good scenery. On the lake itself several rowing boats were to be seen, with the rowers enjoying healthy exercise under a blue sky.

We fully recognise the effort that many had to make to come along to the Tea, and hope that everyone enjoyed the occasion. It seemed so, since there was no rush to leave. It was unfortunate that some members found it too hot inside the tearoom, but were able to sit outside where it was cooler and quiet.

We hope that next year’s “Tea in the Park”, the date of which will be announced later (keep an eye on our website), will be at least as good in all respects.

See you then if not before.



INTERVIEW.

RADIO CARDIFF

MESIG and Samantha Shaw by Dee Penny



Samantha Shaw from Radio Cardiff, interviewed MESiG on 21st September 2pm and on several previous occasions showing her support to MESiG by offering us a platform to speak about our events.

Sam has been trained by the British Council in Active Citizenship and is a Community Journalist, who researches, produces the content and also presents her weekly shows.

She provides a platform for many Third Sector Agencies, organisations, charities and individuals to promote their causes and awareness / fundraising events.

Sam had expressed a great interest in our quest for better medical treatment for our members and the estimated 250,000 sufferers of ME / CFS / Fibro in the UK. She wanted to follow our story.

So, when MESiG decided to take part in the Worldwide Protest 'MISSING MILLIONS' we remembered Sam's kindness and asked her for another slot on her Wednesday programme, to help publicise the event, and she readily agreed.

Miriam and I (Dee), arrived on the day armed with relevant literature and posters we would be using at the Demonstration. Sam was her usual smart, enthusiastic self, she settled us in front of the microphones, and in between the 'cool' music, she introduced us to listeners and asked us to explain what 'MISSING MILLIONS' was all about.

Miriam said that the Demonstration was Worldwide, with 25 Cities taking part on Tuesday 27th September. Between 12 midday and 2pm, MESiG members and supporters would be gathered on the steps outside the Welsh Assembly with relevant posters and placards. We would be supported by Cardiff Rock Group Singers - 50 strong, dancers Irene Davies and her two pals, and later a vocalist called May.

Dozens of pairs of shoes would be put out to represent our missing / invisible members, many who are either

house or bedbound, together with cards explaining the length and severity of their illness. Julie Morgan AM, our staunch supporter, would be speaking at the event, of the need for our requests. After this I explained to listeners, that there was a need for Governments Worldwide to

take responsibility for sufferers of ME / CFS. They are badly neglected and at present there is no Government backed research in the UK, and in Wales, no Specialist, or Clinic and very little or no treatment for people.

MESiG are asking that ME / CFS be correctly recognised as a Neurological illness. It has been accepted as such by the BMA and the World Health Organisation, since the 1960's. So, why is it not treated as such, and why is there so much ignorance about the illness - even among the medical profession.

Sam encouraged us to tell her and her listeners more, and we explained that the NICE guidelines for Cognitive Behaviour Therapy (CBT) and Graded Exercise (GET) were thoroughly inadequate and very often damaging to patients. We also told listeners that there is more and more evidence that ME / CFS is a physical illness - not a psychological illness, from private research going on around the World.

At Dundee University, they have found abnormalities in the blood cells of both adult and child patients, proving, they say, that that ME / CFS is Physical, NOT Psychological. Sam said she could see the need for our Support Group, and expressed her admiration for the work done by MESiG. To wind up the programme, she asked Miriam and I to give her listeners details of the MESiG website and the monthly support meetings at the Bethel community rooms. Sam then wished us luck in our venture - The MISSING MILLIONS. She also invited MESiG to come back with any MESiG news up-dates in the future.

You bet we will!!

Many thanks to Samantha Shaw from Radio Cardiff.



SUPPORT GROUP MEETING

with Guest Speakers by Chris Bailey

5th September 2016 2-3.30pm

Mr Stephen Allen the Chief Officer of the Cardiff and Vale of Glamorgan Community Health Council attended our support group meeting initially on 6th June with Jill Shelton the Chair of the Community Health Council CHC and Rebecca Meyrick, Advocacy Support Officer.

After listening to what people had to say about the difficulties faced, a number of actions and suggestions were made.

- 1) The CHC to contact the Cardiff and Vale UHB ME Champion lead and to arrange for the Champion to meet with us and give feedback about what they are doing.
- 2) The CHC to contact Chief Officers around Wales and highlight concerns from a national perspective about the pathway for diagnosis, treatment and living with the condition.
- 3) The Chair to raise awareness during upcoming Board of CHC meeting. The Chair of CHCs in Wales may also be able to raise concerns with the Cabinet Secretary for Health (previously known as Health Minister for Wales).
- 4) CHC to raise concerns about access to primary care services for patients who are house bound and have no carer support. The Chief Officer to invite discussions with the Bro Taf LMC to make them aware of local concerns and needs.
- 5) CHC to accept one or more patient stories to share with the University Health Board. Group members who are willing and able to provide a written account of their experience for the CHC to share at the next UHB board meeting.
- 6) Group members understand that a clinic is in the process of being set up between the UHW and Velindre. The CHC agreed to write to Velindre to find out further information about the clinic and ask for an update to be directed to MESiG and seek clarification about the UHB anaesthetist's (Sharmila Khot) involvement in setting up the clinic for ME patients.
- 7) The Chair of CAVOG CHC to raise on the agenda on the upcoming Clinical and Diagnostic Therapy group meeting imminently.
- 8) Any patients or representatives wishing to raise

individual concerns through the Putting Things Right process can contact the Complaints Advocacy Service on 02920 377407 and information packs were provided to members of the group.

On 5th September Stephen Allen returned with Jill Shepton. Consultant Clinical Psychologist: Dr Jo Hampson Velindre NHS Trust, and Executive lead: Fiona Jenkins physiotherapist, Director of Therapies. Maria Battle: Chair of Cardiff and Vale University Health Board gave her apologies as she was unable to attend.

This was a follow-up meeting to report on what services are being planned for ME/CFS/Fibro mainly in Cardiff and Vale but also throughout Wales. It was also an opportunity for members of the MESiG support group and committee to provide first-hand account of their experience of the current situation.

For more info look up: ME / CFS and Fibromyalgia Action Plan 2015-2018

Fiona Jenkins said that a national task force on ME/CFS/Fibro had been set up by the Cardiff and Vale Health Board. A request has come in to identify a clinical need and to identify an executive leader for this development. The request came into the Medical Director, Graham Shortland. Fiona and Graham have taken executive leadership. They are committed to plan for ME/CFS services. She advised that Dr Sharmila Khot, an anaesthetist working in pain management at Velindre hospital, has volunteered to take on the role of clinical lead for ME/CFS along with psychologist, Dr Jo Hampson, also based at Velindre.

Previously Prof Jonathan Richards Chair of the ME-CFS and FM Implementation Group attended a MESiG meeting. Prof Jonathan Richards no longer works for Cwm Taf Health Board, so has unfortunately had to resign as chair of the ME-CFS & FM Implementation Group. Claire Hurlin from Hywel Dda UHB has agreed to be the interim chair.

Many concerns and points were raised. We were assured that this team were keen to push things forward.

MESiG thank Stephen Allen for inviting the above relevant people. We look forward to the next meeting and meeting Maria Battle, Chair of Cardiff and Vale University Health Board.

MESIG PRESENT AT THE SENEDD

By Dee Penny

13th JULY 2016

Julie Morgan AM attended our AGM / Awareness event in May 2016 and kindly invited us to present on M.E. in the Welsh Assembly.

Everything was set up, and we took our places. Chris welcomed everyone with a special thank you to Julie Morgan, who invited us. She introduced herself and also the MESIG committee who all have personal experience of the illness and are all volunteers; and then explained that we are a charity supporting those with ME / CFS, Fibromyalgia, carers and family etc. with monthly support meetings, newsletters twice a year, Home visits to the housebound, we raise awareness and fundraise, arrange for speakers on various topics and help with form filling and lifts to appointments.' We are here to raise awareness and highlight the need for action.'

Next came the Sleepydust Video on screen all about ME / CFS and it explained some of the ways people are affected.

Then Dee told us how her daughter had contracted M.E. after a bad attack of glandular fever when she was only eleven, M was a bright girl who had to lose her place at Howell's school due to the illness. She had the wrong advice from a paediatrician, but was sent to psychiatrist and a psychologist! Some years later she went to the then M.E. clinic at UHW (Univeristy Hospital Wales) and was seen by the doctor, physio and yet another psychologist.

They prescribed exercise on a bike and rowing machine. M had difficulty just walking into the hospital, but I was assured it would not harm her. It did, and made her very ill and bedbound for many months after.

Dee questions why CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise) are the only NICE treatments recommended for M.E. sufferers when it can do so much harm. This is not a psychological illness - it is a neurological one, recognised by the World Health Organisation and BMA since 1969! She is calling on Governments to take responsibility and invest in suitable research soon, and a Specialist and appropriate clinic to alleviate the suffering of these forgotten people. Private research worldwide is proving that the illness IS PHYSICAL, and DEFINITELY NOT PSYCHOLOGICAL.

There followed a CLINICAL EXPLANATION BY MEDICAL ADVISORS-video by Action for M.E. MEAction is an International network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis. An event took place 25th May 2016 in 13 global cities, London

being one of them, raising awareness of the Missing Millions, forgotten and unable to fight for themselves. Round two 27th September!

Children are also affected by M.E. Isla aged 8 years old, has something to say: Miriam read out her poignant account and her perception of her M.E. - treated unkindly, as though she was to blame for being ill, and given the wrong advice.

Luckily her parents were kind and on her side. But it was so sad and unjust and put me in mind of my own daughter, when she was first ill and how she was pushed to do much more than she was capable. It made her so ill. There is so much ignorance among doctors! I'm sure we all felt very sad thinking of little Isla.

Carol is severely affected by M.E., bedbound / housebound and dependent upon carers, mostly her partner, struggling to cope himself. After two weeks at Burrswood Hospital, there was a great improvement, as her every need was catered for, both day and night, and hugely due also to the hydrotherapy pool, giving her some relief from pain. Despite the success, Burrswood no longer take in severely affected cases.

We hear about a patient who highlights the need for a change in attitude from some doctors, towards patients with M.E. Doctors can be great with most things, but very often patients with M.E. are not believed. She has had M.E. symptoms for 5 years and no diagnosis. Her doctor refused to send her anywhere, saying that M.E does not exist, even disputing the fact that it is recognised by The World Health Organisation (WHO), and that the Health Minister didn't know what he was talking about!

Mark came next and told us about Lyme disease, a vector borne infection caused by a bacteria called Borrelia. Depression and CFS were diagnosed over 20 years, but after much investigation he came to the conclusion that his symptoms were due to Lyme disease. Mark's doctor signed him off work in February 2015.

Mark contacted 10 doctors, both private and NHS, spent thousands of pounds, exchanged emails with specialists in America and finally one of his test results sent to Germany came back positive for Borrelia Burgdoferi. In November, he found a doctor in Yorkshire who diagnosed him with Lyme Disease, which is complex and controversial.

Doctors are taught that it is rare and easy to treat. It is neither. Doctors who do rarely treat chronic Lyme Disease, keep a low profile. Failure to follow NICE guidelines can jeopardise their license to practice medicine." Some doctors

have failed to diagnose Lyme Disease, yet are aggressively insistent I don't have it! Nonsensical!"

Failure to diagnose and treat all chronic illnesses causes untold suffering. Many with M.E., MS, Dementia and Autism have been found to have Lyme infection by doctors who can diagnose. Lyme Disease is transmitted mainly from a tick bite, but doctors suggest it can be sexually transmitted and congenital. Prof Richard Wall is currently conducting the Big Tick Project, later to be published. So there is hope.

Clare Ogden, Head of Communications and Policy at Action for M.E., had come from Bristol to join us. She said that M.E. matters now, and that is why Action For M.E had embarked on an ambitious 5 year plan of investigation into M.E.

Chris stood to read out The Vision: "We dare to dream as Vision comes before Provision"

A Centre for people suffering with ME / CFS / Fibromyalgia, with a consultant / specialist and team.

An Occupational therapist, physiotherapist, psychologist, pain management, and nurses etc. All specially trained to manage the conditions.

An outreach team for those house/bedbound.

Specialist tests to include Lyme disease, and virus's, coeliac, mitochondria function, QIFT test, deficiencies in vitamins, particularly magnesium, B12, Vit D, Adrenal and thyroid function and hormones etc.

A patient centred approach offering holistic treatment and therapies alongside conventional e.g. acupuncture, desensitising for those with allergies and intolerances, sleep control etc., and an Inpatient facility for the severely affected or for those whose family need a break.

Mary told of her son's difficulty in getting his benefit renewed, and how upset they were that he had been misrepresented when interviewed and not believed. Mary said that basically, they were calling her son a liar. However, we are pleased to relate that on appeal later, after his wife complained of his treatment, he was awarded benefit.

There was general discussion with questions and answers about everything and especially from the visiting Fibromyalgia group from Aberdare, who promised to visit us again.

Then Gill Shelton, Chair of CAVOG who has done much to support MESIG this year, in trying to aid our cause with the Health Authority, spoke about contacting the person who is supposed to be M.E. patient's champion in Wales.

Julie Morgan AM, then spoke in reply to Gill, saying that she



knew the person and that she would get in touch with her. Julie then went on to say that our cause was so worthwhile and that she fully supported us and would continue to do so. For which we are truly grateful. Thus ended our second presentation in the Senedd - perhaps even more memorable as the same day of the new Prime minister, Theresa May's Inauguration.

MISSING MILLIONS.

#MEAction EXPLAINED

By Chris Bailey



#MEAction is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis.

#MEAction is not structured like a traditional advocacy organization. They are a platform designed to empower patients advocates and organizations, wherever they might be, with the technological tools and training to do what they are already doing – better.

The aim is to become a mass, grassroots organization by 2017.

ROUND 1: On 25th May 2016 Missing Millions took place as round 1. Boston, Dallas, San Francisco, Seattle, Washington D.C., Raleigh, and Atlanta; in London; in Melbourne; in a Canada-wide virtual protest; in Bergen, Norway; and in Belfast, Northern Ireland.

Impromptu shoe displays popped up in Ottawa and the Netherlands. Thousands of patients, caregivers, clinicians, and stakeholders raised their voices together to demand better funding, better medical education, and government oversight for this overlooked, underfunded illness.

There was unprecedented media coverage for the protest. Including meetings with government officials as part of a coordinated effort from multiple advocacy organizations, meeting with over 20 U.S. Congress members and numerous HHS officials to discuss the demands, and the way forward.

The protest was in the form of shoes being displayed, depicting the people missing from life due to ME / CFS / Fibro.

ROUND 2: This took place on the 27th September 2016. 25 cities in nine countries demanded change. ME Action presented protest demands asking for increased government

funding for research, clinical trials, medical education and public awareness.

MESiG GET INVOLVED

MESiG got involved in Round 2, by holding an event on the steps of the Welsh Assembly with the support of AM Julie Morgan. Shoes were collected and donated.

People sent their details which we printed and attached to the shoes. Others came along on the day.

A choir called Rock Choir, volunteered their services. They were amazing and lined the Assembly building singing out over the Bay with beautiful voices.

Irene Davies (Chris' daughter) came along with Auntie Anna and a friend to provide some great dancing. A singer called May also entertained us with a voice of an angel.

Even our very own Mark, gave us some tunes on his guitar. We knew he was talented but he had kept these talents hidden.

The entertainment drew attention while we displayed banners and posters highlighting the plights of ME patients. It was a very emotional day for all involved.

A man called Bo, filmed the whole thing for us and Made In Cardiff also filmed and put it out that very night on TV. <https://www.youtube.com/watch?v=ZI04eF8nlkI>

People came forward and spoke out about their experiences and what was needed.

We are grateful to everyone who made the day possible.

Many thanks to the Welsh Assembly for allowing us to raise awareness once again. Many thanks to all the helpers and committee for all their hard work.

GLOBAL EVENT • STEPS OF THE WELSH ASSEMBLY

27th September 2016
12 – 2pm

IT WAS A DAY TO REMEMBER

Remembering everyone affected by ME / CFS / FM who is MISSING a normal everyday life...

Remembering you, when your days are filled with pain, weakness, loneliness and frustration...

Remembering those who are no longer with us because illness ended their lives...

Remembering that if we support each other we are STRONGER than when alone...

Remembering that many other people around the world were PROTESTING simultaneously...

Remembering the people who stopped to listen and EMPTY SHOES...

Remembering CARDIFF ROCK CHOIR who sang so enthusiastically...

Remembering MAY's and MARK's singing too...

Remembering the SUPPORT from Julie Morgan AM and Jan Hutt AM on the Assembly steps...

Remembering the PEOPLE who bravely told their stories...

Remembering the poignant MESSAGES on the posters...

Remembering the need for better RESEARCH and TREATMENT...

THANK YOU TO EVERYONE WHO HELPED

Thank you for your SHOES...

Thank you for your good wishes and HELPING in whatever way...

Thank you for JOINING us on the steps of the Assembly...

Thank you to the ASSEMBLY for permission to occupy the steps and raise awareness of ME...

Thank you to AM Julie Morgan who sponsored MESiG...

Thank you to the 1,000s world-wide who supported the MISSINGMILLIONS EVENT...

The TV news report by MADE in CARDIFF and photos of the Global Event can be seen on MESiG Facebook and MESiG's website and on MILLIONSMISSING website.

<https://www.facebook.com/MESiGWales/>

<http://mesupportinglamorgan.co.uk/event/missing-millions/>

<https://meaction.smugmug.com/MillionsMissing-SeptOct-2016/United-Kingdom/Cardiff/i-GgbzsLM>

WALES NEUROLOGICAL ALLIANCE MEETING

By Miriam Wood

Tuesday 18th October 6.30pm

This meeting was held in Ty Hywel part of the Welsh Assembly in Cardiff Bay. Three of the MESiG Committee were pleased to attend the meeting. Dee and Miriam were there to represent M.E. and Mark represented Lyme Disease on this occasion.

The meeting was attended by an array of top people from the world of Health and Neurology, together with some people who have Neurological conditions. The Chair of these meetings is Mark Isherwood AM. There were two speakers at this meeting: Alison Shakeshaft, Head of Therapies in Aneurin Bevan Health Board and a young woman, Nina Burgonzi who has very severe Dystonia.

The layout of the room was somewhat difficult. In fact it was two rooms, one with a conference set-up around a square of tables with microphones and the other room with rows of chairs for the extra attendees. Also the North Wales Group were 'with us' via camera and screens at both locations. In all it was difficult to hear

what was being said but there was little that could be done to ameliorate the situation.

Interestingly for us Alison Shakeshaft is the person representing M.E. in Aneurin Bevan Health Board as no-one has been found to hold the position of Lead for M.E. During question time, Dee made a plea for help for people with M.E. as her daughter has had so little help. Following the meeting I spoke to Alison Shakeshaft about the situation in ABHB Aneurin Bevan Health Board, particularly from the aspect of one of our members in that Health Board who has Severe M.E. and is struggling to obtain understanding and good support. Alison assured me that there have been many attempts to find a Lead for M.E. without success. This is now the only Health Board without an M.E. Lead. This is very difficult for people with M.E. in that area of Wales as there is no-one to who they can turn.



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CULTURAL COMPETENCY TOOLKIT

By Miriam Wood

20th October 2016

I was invited to attend the launch of this Toolkit which is described as a practical guide for Mental Health professionals and front-line staff working within the Mental Health and Social Care sector in Wales. The manual is impressive and available in English and Welsh. It was written by Suzanne Duval, Director of Participation and Well-being.



and how things change over time following meeting between cultures.

The event ran from 12 to 1pm with a short welcome and talk by Suzanne Duval. Then VAUGHAN GETHING AM, Cabinet Secretary of Health, Well-being and Sport took the floor. Following his speech there was a pregnant pause. Dr Annie Proctor, Director of Mental Health Services, Cardiff and the Vale UHB was expected to be the next speaker but had not arrived. Suddenly the door opened and the doctor walked in, to applause from the waiting group. Without missing a beat she took the floor, while Vaughan Gething had the honour of holding her large red handbag, much to everyone's amusement.

I had gone to the event in order to meet Vaughan Gething, as we had not seen him when MESiG occupied the steps of the Welsh Assembly on September 27th. Of course the manual may also be useful for MESiG as it has very good advice about meeting people from different backgrounds and raising awareness of different customs

I took the opportunity to speak to Vaughan Gething and introduce myself as a representative from MESiG and told him how we relate to and assist people of all races and creeds and gave him our leaflet. Then I chose to speak to Dr Proctor. She and the person with her from Diverse Cymru agreed that ME is not a Mental Health condition but can be mistaken as such, especially if the person has had mental health problems or depression in the past, so it could mistakenly be viewed as an extension of depression. That seemed to be a good result in just a few minutes. I gave the doctor a leaflet and retreated to my corner to eat items from the delicious buffet that had been provided.

No-one seemed to have expected more than a drink but the table was groaning with delicious food that included chicken in various forms, cheesy items, vegetable tasties and gluten-free food. Then there were plates of fruit too. After we'd all had our fill there was still sufficient left for the office staff and probably plenty for an afternoon tea as well.

Thank you Diverse Cymru for a very happy and useful event.

MESIG FEATURE IN ACTION FOR ME INTERACTION ISSUE 93 AUTUMN 2016

ME Support In Glamorgan were in the InterAction newsletter under the spotlight. Chris had this to say: "The most rewarding aspect is seeing people filled with hope, and finding themselves again and gain confidence. It's a privilege to be working with such an amazing and dedicated group on the committee. We are just ordinary people, being driven to do extraordinary things, just because we are willing and want to see change. We shed a few tears over some of the dire situations but have many a laugh too".

THE FUTURE OF HEALTHCARE SERVICES IN WALES

Regulations, changing structures and ensuring quality

By Miriam Wood

Park Inn Hotel 19th October 2016

Another day in the City of Cardiff and another Policy for Wales meeting. One person from MESiG is allowed to attend these sessions free of charge, as we are a small Charity. This time when I arrived I was amazed to find my name on a chair reserving it for me near the front. I must be becoming a 'regular attendee'. It is good to be there and to listen to what is being discussed regarding the future of healthcare in Wales.

The Chairperson for the first half of the morning was Huw Irranca-Davies AM, Member, Cross Party Group on Cancer, and for the second half Dr Dai Lloyd AM, Chair, Health, Social Care and Sport Committee, filled this role. Altogether there were twelve other speakers during the morning who each had 10 minutes to speak. Then following each section the speakers formed a panel to which questions from the floor could be addressed.

The first speaker was professor Siobhan McClelland who is visiting Professor at Swansea University and Chair of the Emergency Ambulance Service Committee. She spoke about the current trends in healthcare in Wales. She mentioned the challenges including an ageing population, increasing expectations and chronic conditions. She suggested that there would be a massive gap of funds in three year's time.

Dr Rebecca Payne spoke about the regulation and standards within General Practice in Wales. She reminded us that GP practices are privately set up and that each GP must join the General Medical Council in order to practice in Wales and retain this membership. There is a performers list and if there are very severe problems the GP's membership may be suspended. During question time later I addressed a question to her:

"How does a patient make contact with the 'performer's list', what is the process? For example: a patient is refused diagnosis and treatment for M.E. by a GP and by all of the GPs in a practice 'because M.E. does not exist' according to them, despite NICE guidelines, the World Health Organisation and the Welsh Assembly's acceptance of M.E. as a serious neurological condition."

I knew the answer would most likely be 'through the normal

complaint procedure – putting things right', however several people came to speak to me later commenting briefly on my question and on M.E. In addition, having been aware of a recent complaint, regarding the care of a different person with M.E., I had been concerned about this line of action, as that complaint merely landed back on the desk of the person about whom the complaint had been made. It was then 'not really considered to be a complaint'. I was unable to discuss this aspect at the time, however we know that the Community Health Council will assist people with making a complaint, in order to obtain a useful result.

A little later in the morning one of the speakers was Alyx Peters, Managing Director MPS Healthcare. She spoke about the recruitment of GPs and nurses in Wales and stated that the problem of recruitment is the similar in the USA where more than a millions nurses are needed. She felt that there is a need for retention of nurses once they are trained. She and two other speakers were addressing the future structure, organisation and configuration of NHS Wales.

Another speaker was Dr Kate Chamberlain, Chief Executive, Healthcare Inspectorate who encouraged us to read their website to fully understand what their role involves. They are independent of the NHS and address the concerns discovered during inspections. Patient experience is very important in this process. She mentioned that some issues are reported year after year but these must be dealt with. She spoke about systems being under pressure but that for the future the importance is getting the basics right, that feed back is helpful to staff and that staff are unhappy if standards slip.

Dr Paul Myres, Chair, Health, Academy of Medical Royal Colleges Wales and Quality Lead, RCGP Wales was again a speaker. He commented that most of our resources are aimed at the end, in treatment. He sees the need for early intervention in life, for health improvement. It is difficult for me to cover all that he spoke about in his 10 minutes as he packed so much into this short space.

A reason for attending these meetings is to network with

NEXT STEPS FOR SOCIAL CARE IN WALES

By Miriam Wood

Park Inn Hotel, Mary Ann Street, 12th July 2016

I attended this morning on behalf of MESiG as many people who have M.E are reliant on Care in the Community and express difficulty in obtaining Care in the first place and then problems with the Service once it set up.

The event was held in a hotel in the centre of Cardiff and ran from the 8:30 registration until 1pm. These meetings are not for the faint-hearted. So much information is packed into the morning that it can be difficult to retain it. There are usually two Chair persons during the morning and on this occasion the first Chair was Professor the Baroness Findlay of Llandaff who is Professor of Palliative Medicine, Cardiff University. She stated that she is the Chair of the National Mental Capacity Forum and illustrated a method for remembering the five principles of the Mental Capacity Act, with audience participation. An unexpected and interesting exercise.

Each speaker is given a limited time and then there is a period for questions from the floor. Imelda Richardson, Chief Inspector, Care and Social Services Inspectorate, was the initial speaker. She spoke about domiciliary care in Wales and that there are 422 agencies with 14 million hours of care commissioned each year, at a cost of almost a quarter of a billion pounds. She said that whether this is working is the fundamental question. The best care, she said, is relationship centered with familiar consistent carers. I think we would all agree with this. One of the biggest problems that I have heard of regarding people with ME is that too many different carers come to see

Continued...

other people. One person there was a journalist, so I made a point of speaking to her during the coffee break. However she is more interested in the use of technology and health, not specific conditions.

A very good morning but all that information makes my head spin. I hope I have reflected some of what was said and that I heard the information correctly. I cannot begin to imagine how Assembly Members manage on a day-to-day basis as a myriad items are presented to them and we, the public, are demanding that our particular need for support is greater than anyone else's need.

them and they do not have the energy to keep explaining what they require to each new person.

The Domiciliary Care Review report was due to be published in September this year (2016).

The next speaker was Sarah Rochira, Older People's Commissioner for Wales. She described her experience of what people say about the care they receive. One of them was the shortness of care visits and how people describe that they feel rushed or cannot have all the care they need in the short time allocated. People also told her the way things work when care goes well but how distressing it is when it doesn't.

After question time the next section of the morning was regarding the challenges raised by the National Review and opportunities to redesign social care delivering in Wales.

Bruce McLernon, Senior Special Advisor for Wales, HC-ONE was the speaker, followed by Peter Randall, Corporate Services Director, UK Homecare Association and then a Pharmacist, Suzanne Scott-Thomas, Clinical Director and Head of Medicines Management, Cwm Taf University Health Board and Chair of the Welsh Pharmacy Board, the Royal Pharmaceutical Society. Rhian Davies, Chief Executive, Disability Wales spoke about a project called Citizens Co-operatives Cymru which is about developing direct payments co-operatives in Wales. As you probably know, Direct Payments is a different way of care provision, where the person selects their own carer and becomes their employer. This is ideal if you know of someone who is willing to be your carer but less easy if you have to interview potential strangers a potential carers.

Lord German Chaired the second half of the morning with more eminent speakers each having ten minutes to present the topics one of which was: Preparing for 2020: professionalizing the workforce, enhancing skills and attracting talent. My most memorable quote of the day is this: There is an issue about better pay and I have been told several times that sometimes people think it better to stack shelves in Tesco's than work in the social care sector because it's not enough money and it is hard work.

MY STORY.

DEAR STRANGER

By Anastasia Palmer

I developed M.E after having glandular fever and quinsy when I was 14. During the first year it was undiagnosed and I tried continuously to get back to school, to be able for the active life I was used to but my health simply deteriorated.

Finally I was diagnosed and on that day I began to write this book, Dear Stranger. When I came home from the hospital I couldn't find the words to say to anyone about how it felt to be told that I no longer had a life, just an existence- a weak existence, just a broken body in a fast moving world. I turned instead to paper with my pen, writing Dear Stranger at the top of the page without knowing why or where that would take me. That night it came to me in a dream that I would write a book called Dear Stranger and I did. At first I was shy of the space, unsure what to say and confused about what I was doing especially because I was such a private person and I would never have wanted someone to read my words, but I continued all the same. Soon it became quite a deep relationship, a real sharing, like writing letters to someone I trusted most in the world. Throughout the letters a journey took place, towards an inner healing which I soon found to be more valuable than the healing of my body, yet amazingly, it too found its strength again and by 18 I was leading an almost normal life.

I remember when I was 21 and walking in a forest and suddenly out of nowhere I was hit with the incredibly painful realisation that when I had recovered from M.E not everyone else with it had recovered too. I saw in front of me the thousands of people who were still in bed, still unable to walk, still being tormented by the 60 symptoms of M.E and most probably not being understood or believed in. This realisation was like a punch in the stomach, my tears were streaming and I was gasping for breath feeling my heart breaking for all those I had left behind. It was in that moment that I realised that Dear Stranger was going to be my way of staying beside those who had not recovered with me.

I decided that it was time to publish but I didn't want to

go through a publisher, I wanted to be part of the process and create a book that would do justice to the raw voice of a teenager amongst illness. I thought about how I could do this and in that search I found out about letterpress

printing, the first form of movable type invented in the 15th century, an ancient craft which would allow me to create Dear Stranger by hand and be completely present to each part of the book making process. Though I had no idea about printing or book making I dove right in and found a studio where I could work and over the next three years I hand-set every letter and rolled each page through the printing press. It was an absolutely stunning journey, I got to be there while my private words got pressed deeply in black ink making them visible to the world, I used my physical strength to create a book where the words were all about the lack of strength and ability my body held. Through this way I created 230 books, all of them entirely handmade, and quite wonderful! I gave these books to people and places to share around and pass on

to others and the response has been very moving.

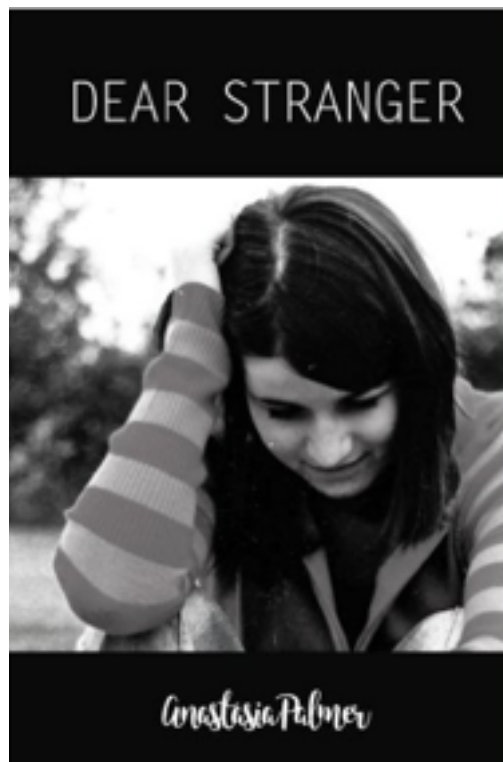
There was more interest in the Dear Stranger than copies of the book so I have now chosen a new approach and have self published my book which is now available on all amazon sites. I am delighted that there is so much interest, M.E is a topic that needs to be discussed, illness is something that needs to be understood and I very much hope that Dear Stranger will contribute to this.

My heart will always feel the pain of those with M.E and for parents who have to watch their children fall over and over, I give Dear Stranger into that space and I hope it can give it's love and strength to many on their journey.

https://www.amazon.co.uk/Dear-Stranger-Anastasia-Palmer/dp/1536862134/ref=sr_l_1?ie=UTF8&qid=1476963830&sr=8-l&keywords=dear+stranger

Anastasia has kindly donated her book to the MESIG library but can be purchased on Amazon.

Thank you Anastasia. MESIG wish you all the best.



UPDATE: CONTROVERSIAL 'PACE' TRIAL

By Deirdre Penny

The Medical Treatment and the lack of appropriate Research generally in the UK, concerning people with ME / CFS / Fibromyalgia, has for a long time been controversial. Although M.E was accepted as a NEUROLOGICAL illness by the World Health Organisation (WHO) and the BMA since the 1960's, it is never the less treated as a PSYCHOLOGICAL one.

When people become ill and finally get a diagnosis, they are often given the wrong advice, if any. But they are sent to a psychologist, and even a psychiatrist - as was our experience with my daughter when she was only eleven in 1992, and it is still the same procedure 24 years later.

Governments around the World are not spending on appropriate research for this Neurological illness as they should be. Pockets of research around the world, and even as close as Dundee University, who did a Trial with both Adults and Children found, abnormalities in the blood cells of M.E patients - proving, they say, that M.E is PHYSICAL NOT PSYCHOLOGICAL.

However, in 2011 £5 Million pounds was spent to set up the 'PACE' trial for people with M.E by scientists in the UK, to prove or otherwise, that COGNITIVE BEHAVIOUR THERAPY (CBT) and GRADED EXERCISE was a helpful treatment - and sometimes a cure for M.E Patients. Some sufferers with ME / CFS have long disputed the fact that GET is any help whatsoever to them, and felt really strongly. Very often GET proved to be damaging to health, as it was with my young daughter; it made her very ill for many months after.

The 'PACE' trial was deemed to be successful for M.E patients. The authors claiming a 60% improvement for M.E patients. However, a group of six scientists from Stanford Columbia, and many others, disputed the findings of this trial and demanded that the details be released for scrutiny, as they did not agree with the protocol of the trial which had been changed, and they suspected it to be seriously flawed.

After failing to get the release of this data for many months, and the inventors spending £250,000 in the

Courts trying to defend their right not to release the Trial Data - Finally in September 2016, the Courts demanded its release to be examined.

After scrutiny by the opposing six scientists, they found that the improvement measured by the original protocol which had been changed, had been only 20% or less, and not deemed to be very successful.

Psychologists still plan to go ahead with a similar trial for child sufferers with M.E., but there has been strong opposition from patients and some scientists to stop it. Let honesty and common sense rule so that ME / CFS / Fibro patients be listened to and treated with the respect and dignity they deserve, with appropriate research and treatment.

KARINA HANSEN, 'PRISONER OF DENMARK', IS HOME AT LAST

On Monday 17 October 2016, after three and a half years of incarceration, Karina (who has severe ME) finally returned home to her family.

The arrangement was on a trial basis but in the hope and expectation that she would be finally and permanently back where she belongs.





GIG
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WALES

Ymddiriedolaeth GIG
Gwasanaethau Ambiwylans Cymru
Welsh Ambulance Services
NHS Trust

Pre Hospital Communication Guide

Now Available as an App!



In 2013 we developed a bilingual Pre Hospital Communication Guide in the form of a small booklet.

We have now developed an App version of the guide, which is available for everyone to use, you can download it to your phone for free!

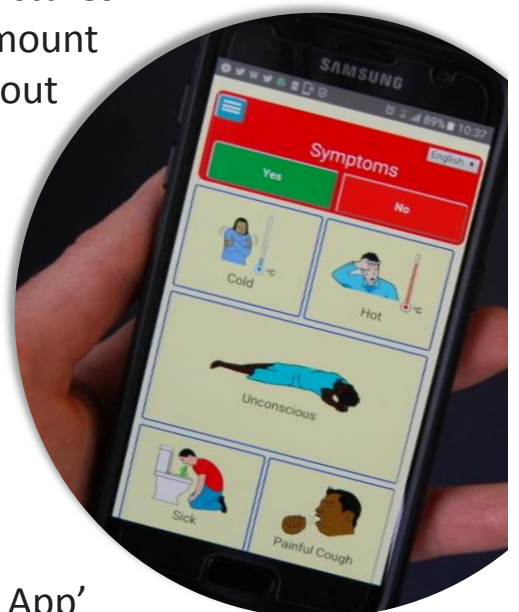
The App is a tool to help communicate with those who have additional communication needs including:

- ✓ People who are Deaf or hard of hearing
- ✓ People for whom English is not their first language
- ✓ People with learning disabilities
- ✓ People whose illness or injury affects their communication

A person may use a mixture of speech, gesture and pictures to communicate. The App uses images and a small amount of text to help you find out important information about someone or what has happened if they have had an accident. You can use the App to identify if the person uses a specific communication method or the language they speak.

Anyone can download and use the App for free!
Its available on iOS, Android and Blackberry.

- **iOS** - search for 'PreHospApp'
- **Blackberry** – search for 'pre hospital app'
- **Android** – search for 'Pre-Hospital Communication App'



CARING FOR A LOVED ONE, YOU ARE NOT ALONE

Carers are people with families and many other responsibilities, struggling to juggle their role as a carer alongside their everyday life.

Caring is now a common and important part of our lives. It's something that we are all likely to face, as people are living longer with illness and disability. It is carers, who are holding families together, enabling loved ones to get the most out of life. Caring requires huge and unexpected lifestyle changes, as carers take on responsibilities such as cooking, cleaning, healthcare and providing around the clock support.

Carers make an enormous contribution to society and save the economy billions of pounds, yet many carers are stretched to the limit – juggling care with work and family life, or even struggling with poor health themselves. It can be difficult to make ends meet especially if the carer reduces working hours to care

Caring can be complicated. The maze of rights and entitlements can be complicated. Filling in paperwork can be complicated. Getting a break can be complicated. Our feelings about caring can certainly be complicated.

Carers Wales is here to make sure that no matter how complicated the query or the experience, no one has to care alone

Across the UK today

*6.5 million people are carers,
supporting a loved one who is
older, disabled or seriously ill.*

*That's 1 in 8 adults who
provide unpaid care for their
family and friends.*



Carers Wales works as part of Carers UK. We aim to make life better for carers.

Our expert telephone service is here to provide information and advice.

Our website, leaflets, booklets and newsletters give accurate and up-to-date information so carers know exactly where they stand.

02920 811370

<http://www.carersuk.org/wales>

CONTACT AND SUPPORT.

ME Association

7 Apollo Office Court,
Radclive Road,
Gawcott,
Buckinghamshire MK18 4DF
Tel: 01280 818968 9.30am - 3pm
Email: admin@meassociation.org.uk
Website: www.meassociation.org.uk

Brame

30 Wimmer Avenue
Winterton-on-se
Great Yarmouth
Norfolk NR29 4BA
UK
Tel/Fax: 01493393717
Email: info@brame.org

ME Connect

DO YOU NEED HELP?

ME Connect is the telephone and email helpline service of The ME Association. It provides support for people with ME and those who live with or care for them. ME Connect provides a safe and understanding opportunity to people with ME so that they know they are being heard and understood.
Tel: 0844 576 5326 10am-12noon, 2-4pm and 7-9pm every day
Email: meconnect@meassociation.org.uk

National ME Centre

Long Term Conditions Centre via Kings Park Estate
Gubbins Lane
Harold Wood
Romford
Essex, RM3 0AR
Tel: 01708 576250
Email: nmecent@aol.com
Website: www.nmec.org.uk

Action for M.E.

42 Temple Street,
Keynsham,
Bristol BS311EH
Tel: 0845 123 2380 / 0117 9279551
Mon - Fri: 9am - 5pm
Email: admin@actionforme.org.uk
Website: www.actionforme.org.uk

MCS Matters

(Multiple Chemical Sensitivity)

Gordon D McHenry
UK Co-ordinator
Global Campaign for recognition of mcs
Website: www.mcs-international.org
Tel Helpline: 01446 794 700
Tues & Thurs 2-4pm and 6-7pm

25% ME Group

21 Church Street, Troon
Ayrshire KA10 6HT
Tel: 01292 318611 9.30am-5pm,
Monday- Friday
Email: enquiry@25megroup.org
Advocacy worker: 01415702938
11am-3pm Wednesday and Thursday
Website: www.25megroup.org

Association of Young People With ME (AYME)

Tickford House
Silver Street
Newport
Pagnell MK160EX
Email: helpline@ayme.org.uk
Helpline Tel: 03302211223 Mon-Fri 10-2pm
Website: www.ayme.org.uk
Main Office Tel: 01908379737

CONTACT AND SUPPORT.

Fibromyalgia Association

FMA UK
Studio 3007
MileEnd Mill
12 Seedhill Rd
Paisley PA11JS
Helpline Tel: 0844 887 2444 (10am - 4pm
Mon - Fri)
Email: charity@fmauk.org
Website: www.fmauk.org

Welsh Association of ME & CFS Support (WAMES)

Helpline Tel: 029 20515061 (Mon-Fri
before 7pm)
Email: enquiries@wames.org.uk
Website: www.wames.org.uk
WAMES Young People
Email: michelle@wames.org.uk

C.L.I.P- Coping and Living in Pain.

Tel: 02920693852
Email: pain.help@ntlworld.com

Benefits Advice and Support

If you are having problems with your benefits,
need some advice or your benefit entitlement
checked, you might like to get in touch with
one of the three listed below.

The Law Centre

41-42 Clifton Street, Adamsdown, Cardiff
TEL: 029 20498117
Drop in: Monday, Wednesday, Friday 10-12.30
Tuesday, Thursday 2-4.30
Phone advice: Monday and Thursday

Speakeasy Advice Centre

166 Richmond Road Cardiff, CF24 3BX
TEL: 029 20453111 Riverside Advice
41a Lower Cathedral Road. Cardiff
TEL: 029 20341577

Useful Contacts

Benefits: Citizens Advice Bureau
Website: www.citizensadvice.org.uk
Disability Advice: 08088003333
Website: www.scope.org.uk
Diverse Cymru: 02920368888
VEST: for help with local lifts and transport
for the disabled
Tel: 029 20490325 and ask for an information
pack.
Carers Line 08088087777
The Samaritans: 116123

The Young ME Sufferers Trust

PO Box 4347
Stock
Ingatstone CM4 9TE
Tel: 0845 003 9002
Website: www.tymestrust.org

Association for Myalgic Encephalomyelitis

Website: www.afme.org.uk

MESiG on SOCIAL MEDIA



Please 'Like' our Facebook Page:
**ME Support in Glamorgan
M.E.S.I.G**



Follow us on Twitter:
@MesigWales



Send us a message:
Mesigwales@gmail.com



Visit our Website:
www.mesupportinglamorgan.co.uk

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CF14 5AH

Telephone: 029 2076 2347

Online:

www.mesupportinglamorgan.co.uk

Email:

mesigwales@gmail.com

MESiG Newsletter

MESiG would like to thank Naomi Dunstan for editing this newsletter. Hasn't she done a great job!

Naomi came forward to volunteer and has had to work hard at short notice.

Many thanks Naomi.



Have something to contribute?

Please send us anything you wish us to submit in the next newsletter: poem, recipe, personal story, questions etc.

Send to: mesigwales@gmail.com

We'd love to hear from you!

DISCLAIMER:

The views expressed in this newsletter are not necessarily those of the editor or The Glamorgan Group. Individuals may express opinions. We do not recommend any particular treatments.