BBME

Support Group

"Breaking the Isolation"

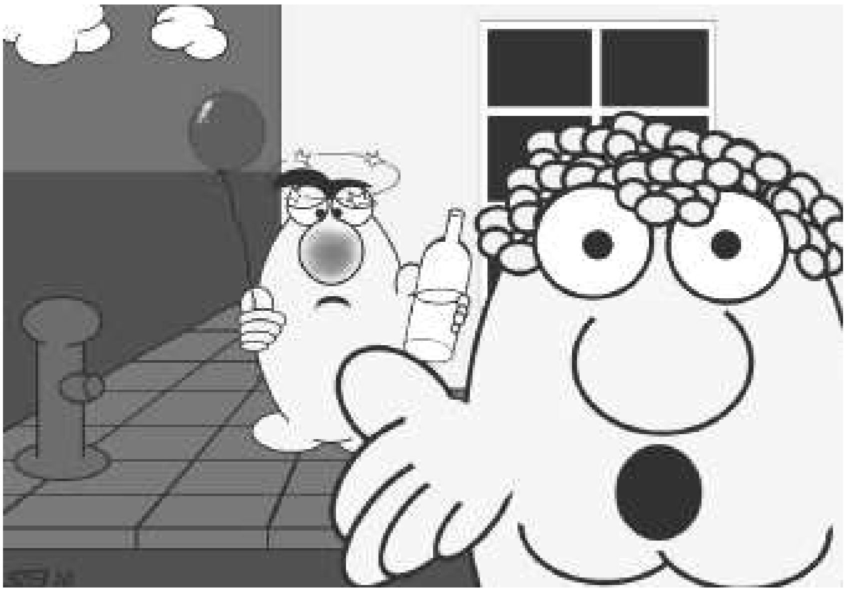
Welcome to Our July 2013 Newsletter

A Note from Alex: It's with great sadness, that this is my last newsletter, for more information about the newsletter please go to page 4.

We have some lovely photos of our very own Woman of the Year Yvonne Leech along with an article written about the event.

Also we have some interesting tips from one of our members on dealing with ESA, DLA or AA tribunals which is well worth referring to if you have to go to a tribunal.

There is an interesting article from the Benefit and Works website about PIP on page 10 which asks for our help.



Lucky him! Everyone knows exactly what makes Him feel horribly sick and dizzy and have a pounding headache.

With thanks to Invest in ME (www.investinme.org) for their kind permission to reprint this cartoon from the calendar available to download from their website.

Contents of July's Newsletter

DISCLAIMER: Anything expressed within this newsletter may not necessarily represent the views of the editor, the Committee, nor the Bury/Bolton ME/CFS Support Group. Any products, treatments, or therapies featured are for information only and their inclusion should not be considered an endorsement.

Issue: 85 **July 2013**

Dates For Your Diary

Longsight Meetings: Our main meetings, often with guest speakers, are held at Longsight Methodist Church, Longsight Lane. Harwood, Bolton, BL2 3HX, on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). Entrance is £1, tea, coffee, water, biscuits, etc provided.

Thursday 18th July: Social Bring and share supper….for the first time, we are going to hold a bring and share supper in the Summer! We always have one in November, except this time there won't be a mince pie in sight! We always have a lovely time, so please join us and bring food to share. Feel free to bring your carers or friends!

Please note that there will be no meeting in August.

Thursday 19th September: Bolton Mountain Rescue Team will be talking to us!

Radcliffe Socials: We meet informally on the first Wednesday of each month, our next will be on **Wednesday 7th August** at **2pm,** at **The Sparking Clog, Radcliffe Moor Road, Radcliffe, M26 3WY**. It has plenty of parking, good accessibility, comfortable seating and is relatively quiet. They serve very tempting chips that we just can't resist! For anyone who does fancy a snack, these start at just £1.50, with main courses from £3.50. We usually meet at the oval table next to the bar.

Prestwich Socials: We meet informally on the second Wednesday of each month, our next will be on **Wednesday 14th August** at **2pm,** at **The Orange Tree, Fairfax Road, Prestwich, M25 1AS**. Everyone and their carers are welcome and we'll put a newsletter on the table so you can find us.

Yoga Classes: Are **3:00pm-4:15pm on Tuesdays** at the **Jubilee Centre, Darley Street (off Eskrick St), Bolton, BL1 3DX**. Designed to cater for the average ME sufferer, classes are free and yoga mats are provided. Please wear loose, comfortable clothing. Contact Olivia on 07746 197511, or olivia@oliviayoga.co.uk for more information. **Our yoga classes are currently being funded by the Comic Relief/Community Fund.**

Neuro Support Groups: These groups, run by Greater Manchester Neurological Alliance, provide information, advice and support for people with any type of neurological condition and/or their carers. Call 0161 743 3701 or visit www.gmneuro.org.uk for information about meeting times and locations.

If you are thinking of attending any of our socials, whether you are a new member or a member who hasn't been able to attend for a while, please remember that you can bring along your carer or a friend. We don't bite, but we understand that meeting new people or if you have been house bound for a while, it can be quite daunting going out by yourself and we look forward to seeing you.

PLEASE DO NOT WEAR STRONGLY SCENTED TOILETRIES WHEN YOU ATTEND OUR MEETINGS, AS SOME MEMBERS ARE VERY SENSITIVE TO THESE PRODUCTS, THANK-YOU.

Tesco Charity Trust

COMIC RELIEF

Supported by Bolton Council

The BIG Bolton Fund...

Bury/Bolton ME/CFS Support Group Meeting June 2013

Before our June meeting, we were fortune to have our very own celebrity, Yvonne Leech, show us her Woman of the Year 2013 award and certificate. Yvonne was featured in the Bury Times and continues to use the award to promote awareness of ME/CFS.

For those of you with internet access, you can access Yvonne's Bury Times Article and watch her interview at the Fusion Awards by going to our website: www.mesupportgroup.co.uk and follow the link or alternately you can use this link below just to watch Yvonne being interviewed after receiving her Fusion Award: http://www.youtube.com/watch?v=jEQxnYWiMLw

Yvonne has been involved in spreading awareness of ME and helping families affected by it for thirty years, so it is wonderful she has received recognition for all her efforts. Many congratulations Yvonne!

Guest Speaker

Our speakers for our June meeting were Paul and Ed from the Bolton branch of Millercare, to tell us about some aids and adaptations we can use to make life easier for ourselves and give us more independence.

They told us how Millercare started 60 years ago, servicing Bubblecars! They are still a family run business and have nine stores in the Northwest. They sell all kinds of adaptations and home care aids, including stair lifts, hoists, wheelchairs and scooters. They have dealerships with every major supplier of mobility products and also are suppliers to the NHS.

They brought a few products to demonstrate, as well as some catalogues, but they said they could source over 600 items.

Paul and Ed showed us some rehabilitation equipment, including a pedal exerciser, which is good for improving cardiovascular fitness, stimulating circulation and improving leg and arm muscle strength.

Therapy balls (which look like large beach balls!) can be used for core strength and posture. These are useful for sitting on when watching TV or using a computer.

Balance boards can be used to improve core strength and stability, balance, ankle flexibility and range of motion. They are quite difficult to start on at first and you may need to hang onto something (or someone!), but you will get better the more you use it.

Thera-band's are large cuts of elastic ribbon which you can use as physiotherapy aids. There are many different exercises to do with these, which all work different muscles in your arms and legs. They have different strengths, depending on your ability and the resistance you want, but you would always start on the soft one, and build up.

They said that with everything, home care aids are a very personal thing, and what is fantastic for one person may be unsuitable for another.

Scooters have solid tyres, so you need a good seat cushion, as you feel every single bump as you go along! There are several wheelchair cushions you can buy, and the GoGo scooter now has a shock absorber in the seat. Wheelchair cushions tend to be gel-filled and not springs, so that you don't get pressure sores, but Millercare can also make you a bespoke cushion if you ask.

To make life easier (and save you a lot of back-ache!), you can get a hoist to lift your wheelchair or hoist into your car boot, or into a roof-rack box. They said that technology is moving on and they are making scooters that you are better able to dismantle and fit into cars.

There are hundreds of gadgets to make our life easier: grabbers, shower seats, kettle tippers, jar openers, foam handled-cutlery, bed levers, etc. Paul and Ed showed us a Handybar, which helps people get out of cars. It is small bar with a hook that you attach to a loop found in any vehicle door frame, which you can use as leverage to help you get up. In the event of an emergency, it also has a concealed blade to act as a seat-beat cutter, and it can also be used to break the windows. A few of our members already have one and would recommend it.

For any problem, Millercare say they can normally find an answer, so if you have a care or mobility need, they might be able to find a bespoke solution for you.

The Bolton branch of Millercare have kindly agreed to give group members a **10% discount** on their products.

They have also reduced the price of the Handybar (http://www.millercare.co.uk/Handybar.html) from £24.99 to only £20, valid until 30th July (you can't be greedy and get the 10% discount on top of this, and these offers only apply to the Bolton branch).

There is also an inflatable wash basin which is good for washing hair when you are bed-bound. A sock puller-on may also be useful for those who are unable to bend down very well.

Millercare Bolton: 661 Bury Road, Bolton, BL2 6HR. Tel: 0800 023 7447
Web: http://www.millercare.co.uk/Millercare-Bolton.html

Alex Stepping Down

As I said in my note from Alex, it's with great sadness that I am stepping down from editing our newsletter. As I have to be realistic about my health, over the last 6 months my physical and mental health have be getting worse and if I don't step down now I know that my health will get worse and it'll take even longer to recover, as we all know ME seems to work that way.

This will also mean that until someone steps forward to take my place as editor, from next month the newsletter will be a dramatically reduced version. There is nobody on our committee that can take over this job, as our committee members already have too many jobs to do, and can not take on any extra work.

We have a volunteer that prints out and distributes our newsletter and I will still email out the newsletter to our members who receive the newsletter via email. If you are worried about formatting the newsletter I can help whoever takes over with that. I have set up templates of the newsletter to the end of the year so it is a case of inserting articles and checking for mistakes etc.

If you want to find out more about editing the newsletter or you think you can help in some way please contact me email: alex@mesupportgroup.co.uk or Tel: 0161 761 5493.

I urgently request for members to step up and help us, we also need someone to write up the notes for our guest speakers at the Longsight social. We have a tape recorder so you don't have to worry about taking notes on the night, if you aren't very good with computers or at typing we have volunteers who can type up your handwritten article. If there are 2 or 3 people interested in helping, with this you could take it in turns. If you are interested please contact Caroline email: caroline@mesupportgroup.co.uk or Tel: 01204 525 955.

I hope some volunteers can help us as it would be such a shame for us to lose our newsletter and our support group due to the lack of help as I said before the committee is already snowed under.

Thanks Alex

BREATHWORKS

The group is wondering about obtaining funding to run a Breathworks course at Longsight in Harwood. Due to scheduling and funding issues, this will most likely be March next year.

Living Well With Pain and Illness: a mindfulness-based approach is an 8 week course to help people deal with the stress and uncertainty that chronic illness brings.

Mindfulness is a form of meditation derived from Buddhist philosophy. It is also used as a strategy for coping with a range of health conditions. Mindfulness is a skill, so can be learned and benefits from regular practice…it is about paying attention and will also address the "boom and bust" cycle.

The course requires home practice and reading, amounting to a commitment of around 25-45 minutes per day, or as much as you can, but the more you put into the course, the more you will get out of it. If there is anyone who would like to do the course but might struggle with the home practice for any reason, you and the trainer may be able to arrange something.

The course is usually £50, and that is heavily subsidised and that includes course materials, like books and CDs which cost £35, so they're not making any money. We would look to get even more funding so we could provide it a bit cheaper for you.

Can I please get an idea of how many may be interested? Those who have been, please can you tell me if you found it helpful and why, and if you think it may benefit others? I need to show there is proof of need and that it helps people, so need anonymous testimonials please. Please email caroline@mesupportgroup.co.uk or phone 01204 525 955.

Coping with a Tribunal for ESA DLA or AA

It can seem daunting for a person to be turned down for a benefit after review and to be told that the next step in the appeal process is a tribunal. I thought it may help to share some of the ways that I have coped with the 5 or 6 tribunals I have been to over the years.

1. Often the first emotion is panic and a fear that we will be turned down, instead why not try being positive? At least 49% of appeals are successful at tribunal stage. If you prepare for your tribunal the chances are you will be successful.
2. I would suggest you obtain a copy of the Benefits and Work guide to the benefit you are trying to resolve. Read this and highlight points that involve your claim. E.g. if you need a doctors letter (sorry if telling Granny how to suck eggs). You can also try obtaining the Disability Rights Guide from Disability Alliance, cost £15 for those on benefits, again it explains the process and how to make a successful claim.
3. If not already done, obtain any evidence you can, such as from GP, consultant, physio or occupational therapist, there are other professionals who may be able to provide evidence, such as employer or, occupational health. You need reports that explain the effects on you as well as the diagnosis; you should also enclose something from your carer as they are the people most probably aware of your condition. These reports may have to be paid for, and for some money is short. A professional well written report that explains your condition and how it affects you is valuable evidence for the tribunal and will increase your chances of success.
4. It is also worth contacting the local authority and telling them you want a Community Care assessment of your needs and a Carers assessment for anybody who cares for you. Don’t be fobbed off, you want a proper assessment at your home in which you have the time to explain your needs and also the issues relating to your carer. This may help you obtain resources from your local authority. The support plan and assessment details can be used as evidence at the tribunal.
5. Give yourself time to prepare, then the preparation can be worked over a longer period and this should help with fatigue and memory issues. Often people run out of time and then have to rush on preparation as the day gets nearer. Spending a little time over a period gives a better chance of a positive outcome.
6. The various guides will explain the process and who will be in the room for the tribunal, it is well worth taking someone with you, I have tried both on my own and with a professional representative, for me I found that I was better on my own and the last time I did not have a carer with me. I think it is partly a confidence issue.
7. It can be useful having someone with you will help whilst waiting and if you are struggling or tired so they can support you. They can also help explain what your needs are and why you meet the criteria. I have heard stories of poor behaviour by the panel; don’t forget you have the right to say this if you think the questions by the panel are unfair or intimidating in anyway. If you feel you are being treated inappropriately ask that it is recorded, you can at the end make a formal complaint. It’s worth taking notes that you feel are important. This is something that either you or your supporter could do. Do be aware that some of the questions are intended to catch you out, if you are unsure what they mean ask them to put the question again.
8. If you have any special needs then state them in advance, do be aware that you will most probably be watched when you arrive, e.g. in reception or will be questioned about how you arrived, if you are uncomfortable or in pain whilst in the meeting say so and ask for a break or to stand up etc.

I could most probably list much more but I do think that the way forward is as I have already stated, to proceed with the tribunal, be positive, collect your evidence, try not to get to stressed with the process and seek help from others within the group.

A Founder member named North West Woman of the Year 2013 by Richard Leech

A founder member of the Bury/Bolton M.E/C.F.S Support Group, Yvonne Leech, has been named as North West Woman of the Year 2013 at the prestigious Fusion Awards, for her on-going commitment to raising awareness of M.E and C.F.S in the region.

The awards, now in their seventh year, are a celebration and recognition of the achievements of individuals and groups who take part in community work. The whole thing came as a bit of a shock to Yvonne as she wasn't even aware that she had been nominated by the Support Group, until she was shortlisted as a finalist.

Joining over 350 people at the awards ceremony on 1st June at Blackburn Rovers FC, Yvonne attended the event with her younger son Richard not really knowing what to expect but looking forward to enjoying the evening. The night started with a cocktail reception for the finalists before everyone was taken through to the ceremony room where they were welcomed by a performance from the SonAash Dancers. The Awards Ceremony followed, hosted by Sam Ali Khan who is currently the main presenter on ITV Central Tonight in the Midlands after having worked as a television reporter and presenter for BBC Northwest Today.

In total there were 11 awards with finalist attending from as far afield as Lancaster, Fleetwood, Oldham and Salford. In the Woman of the Year category, Yvonne's fellow finalists were from Blackburn, Burnley and Fleetwood and in true Oscar style all the nominees were shown on the big screen before the sponsors of the award AMT Lawyers, revealed the winner by opening the golden envelope. A short silence was quickly followed by a big cheer from everyone on Table 24 as Yvonne's name was read out and she made her way to the stage to collect her award.

Not one to miss an opportunity to raise awareness of the activities of the Support Group, Yvonne gave a short acceptance speech and thanked the many friends she had made at the Group over the years, before being whisked back stage to be interviewed and videoed by the awards organisers. Speaking after receiving her award Yvonne said: "I am absolutely overwhelmed. It is lovely to feel that after all of these years that my support group nominated me for these awards and I knew nothing about it. It was a really big surprise just to be a finalist, never mind winning it."

The evening was concluded by more dancing entertainment and a wonderful awards dinner.

You can see a photograph of Yvonne and a report of the evening in an article in Thursday, June 6 Bury Times and on the website for the Fusion Awards www.thefusionawards.co.uk.

Well done Mum.

Richard

Pictures Below left to right: Yvonne accepting her award, Yvonne showing off her award at the Longsight Social and lastly Yvonne's Fusion Woman of the Year Certificate.

Fusion
awards 2013
Woman of the Year
Highly Commended
Yvonne Leech
Sponsored by
Fusion

Nom De Plume.

For those familiar with my column, you will be aware of how poorly I sleep. Such is my affliction that without religiously taking my meds, sleep completely eludes me; this is particularly awful because the situation means that I am continually in a state of exhaustion.

Insomnia breeds strange creatures with queer nocturnal behaviour, and to this, I am no exception. During the early hours of a typical morning, with no sign of sleep, I can often be found walking about the place desperately trying to distract myself, in the vain attempt of lightening my weary frustrated load.

On such occasions I could do worse than pursue one of my top pastimes, which is to visit my larder. A rifle in pursuit of inspiration rarely fails to deliver and it is amazing what lurks in the dark crevices of our cupboards and draws.

Jostling for space one comes upon numerous forgotten treasures. The bottles of Egyptian Pomegranate syrup, tins of rose petal jam from Iran, and numerous cellophane packets of Italian crackers, all sit amicably alongside the tiny glass vessels of Saki, which no doubt, has been meticulously prepared in China.

Ingredients informed by travel and my unflinching interest in the exotic flavours that define these foreign lands, have subsumed the equally treasured tinned salmon and peeled Mandarins my grandma would secret away. Hers, mine or yours, the best of our larders pay homage to the multicultural experience which we all can prosper from.

My chief pet indulgence, of which, I confess to having many, is book collecting. So having satisfied my curious fingers, my attention inevitably moves on to our library, which catalogues precious words that have been handled, as if they are themselves precious ingredients. Authors such as Claudia Roden, Nigella Lawson, Sam and Sam Clark, Marguritte Patten, Elizabeth David, Madhur Jaffrey, Anna Della Conta, Tessa Kiros, and Samuel Peeps all jostle for space and attention among many more of my favourite cookery writers.

This month's offering is an antidote to any of the involved recipes contained within my treasured books. This may surprise those of you who, perhaps, were expecting a long and involved recipe this time round. But let me explain my intention; all too often, we define ourselves by the confines of the borders we inhabit, rather than the things we universally share.

Indeed it has recently come to my intention that upon receiving a new cookery book, I almost always start by searching out the recipes I am already familiar with. Such clandestine idiosyncrasies highlight my point- that we share a great deal more than we many initially appreciate.

And so to highlight this, I have deliberately chosen a recipe of the simplest and best loved summer beverage I know. In doing so I hope we can raise our glasses, to toast the sky as we feel comfort in the universal rule that even stars need to sleep...

Homemade organic Lemonade Ingredients:

- 6 Un-waxed organic Lemons
- 6 Un-waxed organic Limes
- A choice of either 6 tablespoon of fair-trade caster sugar,organic rice syrup or Agave nectar
- A generous splash of rose water or an organic vanilla pod or tablespoon of Vanilla essence
- An organic sprig of Indian Mint

Like all my recipes, I encourage you to source the very best of in season and organic produce you can find. Often continental grocers and delicatessens sell the best and most economic citrus and bottles of rose water on the market. Being the aesthete I am, I typically gravitate towards the fruits which are enticingly wrapped in coloured tissue paper and the unusually shaped and decorated glass bottles which contain middle eastern Rose water. But you must follow your own persuasions.

Before I go on, a small confession, or tip, depending on your point of view. There are times that need, outshines conviction, ‘when the mind is willing but the flesh is not..' And so during these hard times, afford yourself some kindness. For me this comes via a small unassuming bottle of organic Lime juice, which spares one the only serious tax of labour this recipe demands.

Be it cloudy, clear, pink, pale, fizzy or still, Lemonade has been adopted by as many continents as there are variations of it. Mine goes like this...

Method:

1. By briefly warming the fruit in a moderately heated oven, or applying some pressure before cutting each citrus in half, both methods help release the juice when squeezed. Collect all the juice into a large glass jug, having discarded the pips and pulp.

2. To this, one can either add the granulated caster sugar and rose water, which when diluted with cold mineral water and vigorously stirred, may need a little tweaking to suit ones preference before serving; or for a more mellow flavour, I recommend boiling the sugar, essence of choice and citrus juice into a thick syrup, which when cooled and bottled should be treated like the cherished cordial it is.

Interview with the Foundation's Honorary Director, Anne Faulkner by the CFS Research Foundation

Anne Faulkner was recently interviewed for the on-line magazine ScienceOmega. For those of you who haven't yet seen it, here it is. If you want to see it on the ScienceOmega website, please follow this link:
http://www.scienceomega.com/article/1053/tackling-chronic-fatigue-syndrome-from-the-top-down

Tackling chronic fatigue syndrome from the top down. A top-down approach has helped to advance research within the field of chronic fatigue syndrome, explains the CFS Research Foundation's Anne Faulkner…

For more than a quarter of a century, chronic fatigue syndrome, or myalgic encephalomyelitis (CFS/ME), has stimulated vigorous debate amongst members of the medical research community. From the outset, however, those working to promote investigation into this illness have been involved in an uphill struggle. Surprisingly, one of the most significant obstacles originated from sections of the medical community that were reluctant to recognise CFS/ME as a genuine illness. Moreover, pejorative terms such as 'yuppie flu' did little to improve the condition's credibility within a broader societal context.

All the while, substantial numbers of people continued to suffer from the debilitating effects of CFS/ME. There is still no known cure for the illness, and attempts to learn more about its causes have been hampered by a widespread misconception that the associated symptoms are trivial.

In 1993, the CFS Research Foundation was established with the aim of improving our understanding of CFS/ME. The organisation's founders were committed to tackling what they saw as an illness that had been widely neglected by doctors and scientists alike. Two decades later, the fight against this illness is still being waged, but significant progress has resulted from the involvement of individuals at the very top of the scientific community.

To find out more about how the landscape of CFS/ME research has shifted over the last 20 years, I spoke to Anne Faulkner, Honorary Director of the CFS Research Foundation. I began by asking her to outline some of the most common symptoms associated with the illness.

"CFS/ME can cause devastating exhaustion, both for muscles and for the mind," Faulkner explained. "Painful joints, painful muscles, migraines, a lack of sleep, gastrointestinal upsets, a loss of short-term memory and difficulty concentrating: all of these symptoms are associated with this illness."

Chronic Pain

Three quarters of individuals with CFS/ME endure chronic and widespread pain. This situation is worsened by the fact that conventional painkillers are often ineffective in relieving the illness's symptoms. When you take into account additional aggravating factors such as exhaustion and loss of concentration, it is easy to see how CFS/ME can result in suffering without the prospect of relief.

Unfortunately, little is known about why pain associated with this illness causes such a problem for those affected. There is some evidence to suggest the brains of CFS/ME patients handle pain differently from those of healthy individuals. Indeed, some experts believe that people with this illness have a hypersensitivity to pain. I asked Faulkner about the research currently being conducted to uncover more about the causes of CFS/ME.

"Gene research is always going to be one of our main priorities," she explained. "We have to drill down to the basics of this illness. However, we also have to acknowledge that advances in this area are not easily won: understanding the genetic mechanisms of CFS/ME is a long-term objective. In light of this, we are working to help the patients who are suffering now. To this end, we are about to undertake a three-year research project involving scientists from London teaching hospitals. We are going to address the problem of pain."

Faulkner went on to discuss some of the common misconceptions surrounding CFS/ME. Whilst progress has been made in combating erroneous views of the illness, she contends that public awareness still needs to be improved.

"This particular situation is getting better all the time, but I do think that significant numbers of people still think that CFS/ME is mere ‘tiredness’. When this view is allowed to prevail, people begin to say: ‘I get tired too, but I don’t make such a fuss about it’. Even so, society is slowly beginning to recognise that this is a painful, devastatingly crippling illness. A quarter of patients with CFS/ME are either housebound or bed bound: that is a huge number of people. I think that some sections of the public are beginning to wake up to the fact that this illness needs to be taken more seriously."

Social Consequences

Unfortunately, CFS/ME can have adverse consequences that extend beyond the arena of health. A lack of understanding can lead to the emergence of social difficulties, both for those suffering from the illness and for their families and friends.

"The extent of these problems will depend on your location and the people with whom you are mixing," explained Faulkner. "For example, patients frequently have difficulty getting their employers to understand exactly what they are going through. Unfortunately, similar problems can also emerge within family units. There have been cases in which women have had CFS/ME, and their husbands have been told that they need to ‘pull themselves together’. This has often been the advice of the family doctor. Naturally, this sort of medical advice can have a dreadful impact on a marriage. In turn, if a person’s children don’t really understand what their mother or father is going through, they are unlikely to help out as much as they should."

Faulkner contends that in order to overcome such challenges, we need to encourage a public discourse on CFS/ME. In addition to the funding of potentially beneficial studies, the CFS Research Foundation is committed to raising public awareness of the illness. So, how has the landscape of CFS/ME-related research shifted during the last 20 years?

"When we created the foundation in the early 1990s, CFS/ME was an illness which was misunderstood by almost everybody," Faulkner replied. "Doctors were – on the whole – hopeless. They simply told people that there was nothing wrong with them and to pull themselves together. Furthermore, scientists tended to shy away from the illness because unfortunately, some of the related patient support groups were fairly aggressive. The research community was wary of CFS/ME because it received so much angst from patients. During the course of the last two decades, we have done our best to turn this situation around. CFS/ME is now more widely recognised as a devastating and debilitating illness that can have tragic consequences for those affected."

Top-down approach

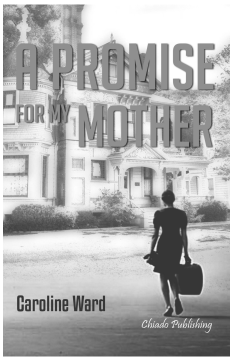
Faulkner concluded our conversation by explaining why a top-down approach to combating this illness has proven so successful in changing attitudes for the better.

"Two decades ago, the quality of most of the research conducted within the field of CFS/ME was poor," she said. "We knew that we needed to enlist the help of scientists who were pre-eminent in their fields – not necessarily within the field of CFS/ME, but in biology, neurology, and so on. Over the years, four Fellows of the Royal Society have sat on the Research Committee of the CFS Research Foundation. It doesn’t get much better than that. For example, when GPs suggest that CFS/ME is not a genuine illness, we point out that their opinions differ from those of Royal Society Fellows. Involvement at this level has trickled down through the scientific community and has helped CFS/ME to garner some of the attention that it deserves."

Benefit and Guides Request

We are pleased that so many members have been helped by the Benefit and Work guides. However, these are costing us a lot of money to print out, so if you no longer require your copies of these, please can you return them where possible, as they are very popular with all of our members! If you are able to return them you can bring them along to the Longsight social or contact Ruth who deals with the Benefit and Work Guides. Ruth email: ruth@mesupportgroup.co.uk Tel: 0161 7664559

Book Signing



Another one of our members, Caroline Ward, is having her first novel, "A Promise for My Mother" published!

The novel is based on a true life story. If you are interested in purchasing Caroline will be signing copies at our July meeting.

The official launch of her book is on 29th August at the Holiday Inn on Bridgeman Street in Bolton from 4pm - 8pm.

Well done Caroline.

PIP Mobility Consultation Begins. From Benefit & Works Website on 26 June 2013

The DWP has launched a six week consultation on personal independence payment, looking solely at the enhanced mobility component. The move comes after protestors launched a judicial review of the DWP's failure to consult on changing the qualifying distance from 50 metres down to 20 metres.

Benefits and Work is urging members to take part in the consultation, even though there is a strong likelihood the DWP will ignore its findings.

We believe it is important that the DWP are forced to admit that the changes to PIP have nothing to do with improving the methods of assessing disability and everything to do with cutting costs. In addition, we think it is vital that support is given to the brave campaigners who have forced the DWP to make this embarrassing concession. In addition, the judicial review is likely to be stayed whilst the consultation takes place, but may be restarted once it is over. The consultation document is available on the .gov.uk website. The consultation will run until 5th August.

It is extremely likely that the vast majority of individuals and organisations who respond will be against the change in the qualifying criteria. However, the DWP have made clear in the text of the document what their planned strategy for ignoring the results of the consultation is. They explain that: *"In reaching our decision we will consider how any potential changes might affect individuals and the numbers of people likely to receive the benefit. We will also consider the potential impact of any changes on PIP and overall welfare expenditure and whether this is affordable and sustainable. We will publish a report summarising the responses received and how we reached our conclusions, once we have completed the consultation."*

In other words, they are preparing for the possibility of arguing that in spite of the overwhelming rejection of the new criteria, keeping the current 50 metre limit is not *'affordable and sustainable'*. This will at least make the real reasons for the changes clear and give campaigners ammunition to fight for the 50 metre limit to be reinstated at a future date. And there's always the outside possibility that the government will actually accept the findings of the consultation. The consultation question is: *"What are your views on the Moving around activity within the current PIP assessment criteria?"*

The document adds that: *"We would like to know what people think about the current Moving around criteria, including the current thresholds of 20 and 50 metres; what they think the impact of the criteria will be; and whether they think we need to make any changes to them or assess physical mobility in a different way altogether.*

"We are not consulting on the Planning and following journeys activity or any other aspect of the assessment."

You can respond to the consultation by emailing your views to:
pip.assessment@dwp.gsi.gov.uk or writing to: PIP Assessment Development Team, Department for Work and Pensions, 2nd floor, Caxton House, Tothill Street, London SW1H 9NA

Remember, the closing date is 5th August.

Hydrotherapy Project at Bolton One

Bolton Neuro Voices have funding for 2 new courses, which consists of 5 weekly, 30 minute sessions. The 2 start dates are: Wednesday 14 August and Wednesday 25 September.

Priority will be given to new participants the cost is £5 per session which is preferably paid in advance.

If you're interested, please fill in the form on the website or phone for a form if you don't have internet access Tel: Marie Oxtoby on 01204 594004 or

Web: http://www.neurologicalphysio.co.uk/hydrotherapy/

There will be a self management programme for anyone who did the previous courses. Please let Maria know if you're interested, preferably by email: maria@mesupportgroup.co.uk

The closing date for the courses is the end of July so please contact the above people as soon as possible.

Biobank Gets £1 Million Funding Boost Acton for ME Website

28 June 2013

The UK ME/CFS Biobank project has announced that it has been awarded a grant totalling £1,029,411 ($1,588,225) over three years by the US National Institutes of Health (NIH).

A biobank is a large collection of biological samples including tissues such as blood, which provides a valuable database for scientific research. Patients with an illness, as well as healthy people (controls), volunteer their tissues for inclusion, and each sample can be linked with detailed clinical information about the donor.

The Biobank was launched in 2011 and has been funded by Action for M.E., the ME Association, ME Research UK and a private donor.

Sonya Chowdhury, Chief Executive of Action for M.E., said, "*This is fantastic news and another major step forward in an already exciting time for research into M.E. It is great to see that Action for M.E.'s investment in this research project has now attracted mainstream funding. It demonstrates the potential that collaboration and co-funding can achieve.*

"International recognition and support such as this emphasises the importance of the Biobank in providing an essential resource for those engaged in bio-medical research into M.E. throughout the world. It will enable the Biobank to expand and increase the chances of significant breakthroughs."

To read the full Biobank project media statement: http://www.actionforme.org.uk/get-informed/news/research-news/biobank-gets-1-million-funding-boost

'ME: medical or mystery?' Dr Charles Shepherd writes for 'Public Services Europe' journal | June 2013

by Tony Britton on 29 June 2013 from The ME Association Website

Dr Charles Shepherd, medical adviser to The ME Association, has contributed the first page in a two-page feature on this illness in the June edition of the public policy review journal, *Public Service Europe.* **The second page has been contributed by Dr Ingrid B Helland, Leader of the Norwegian National Competence Service for ME/CFS at Oslo University Hospital. The journal can now be read online HERE**.

Dr Charles Shepherd, Honorary Medical Adviser at the ME Association, reports on a disease that continues to divide medical opinion…

Back in 1955, London's Royal Free Hospital was forced to close for several months. Nearly 300 members of staff had been taken ill with a mysterious polio-like infection that involved their muscles and nervous system. The following year, the cases were written up in The Lancet, and a new disease – myalgic encephalomyelitis (ME) – entered the medical dictionary.

However, the precise infection was never identified – so many doctors viewed the discovery with growing scepticism. A paper in the *British Medical Journal* claimed the outbreak was 'mass hysteria' and I can still recall being taught at medical school that ME was a non-existent illness that doctors could forget about.

After catching chickenpox from one of my patients, I had to change my mind. The chickenpox went away but I was left with all the classic symptoms of ME: exercise-induced muscle fatigue, cognitive dysfunction and feeling as though I had a constant dose of flu. At the time, thanks to continuing scepticism about ME, it was impossible to get a diagnosis or proper advice on management. So instead of pacing my activities, I tried to exercise my way out of ME and ended up feeling worse rather than better.

Fortunately, the situation is now slowly improving. ME is recognised to be a serious and debilitating condition by the Department of Health, Department of Work and Pensions and NICE, and classified as a neurological disease by the World Health Organisation. The Medical Research Council set up an Expert Group who identified a list of biomedical research priorities and went on to provide £1.5m of ring-fenced funding to support this. And there are now NHS services where people can be referred for both diagnosis and management, although these services still operate on a ‘postcode lottery’ basis.

Symptoms: What is ME?

Most people pre-date the onset of their ME to an acute viral infection from which they ‘fail to recover’. From then on, they experience a characteristic range of muscle, brain and infective/immunological symptoms. Other key symptoms include pain (in muscles, nerves or joints), un-refreshing sleep, and problems with balance and temperature control. More serious neurological symptoms occur in a minority, especially those at the severe end of the spectrum.

Research findings

Research suggest, that ME is a three-stage process involving predisposing, precipitating/triggering and perpetuating factors. Firstly, there appears to be a genetic predisposition, making some people more likely to develop ME/CFS when they have an inappropriate immune system response to a precipitating event – commonly a viral infection. ME is then perpetuated/maintained by a mix of abnormalities involving the brain, muscle, endocrine and immune systems (where there appears to be an ongoing immune system activation).

Diagnosis

Diagnosis is made on the characteristic system complex and the use of blood of other tests to exclude other conditions that can cause an ME/CFS-like illness.

Management

The most important aspect is learning how to balance appropriate periods of rest with activity. This has to be done according to stage and severity of the illness – a process known as pacing. Drugs such as Rituximab, aimed at dealing with the underlying disease process, are now being assessed in clinical trials – but they are not yet available for routine use. The main use of drugs is for relief of symptoms such as pain and sleep disturbance.

SPOTLIGHT ON CHRONIC FATIGUE SYNDROME (CFS)

Epidemiological research suggests an estimated 250,000 people in the UK have ME/CFS. Onset commonly occurs during 20s to 40s in adults, and between 11 and 14 in children, of which there are around 25,000 sufferers, with ME a common cause of long-term school absence.

All social classes and ethnic groups are affected, and the annual cost to the economy has been estimated at £3.5bn. Prognosis is variable with 25% of people severely affected – house or bedbound – at some stage in the illness.

Reminders

Equipment Hire: We have a wheelchair and two electric mobility scooters (small enough to fit in car boot for days out or holidays). If you wish to borrow any of these, please phone Pam on 01204 793 846.

Amazon: The group gets 5% commission when you shop at www.amazon.co.uk, but only if you follow the link from our own website www.mesupportgroup.co.uk.