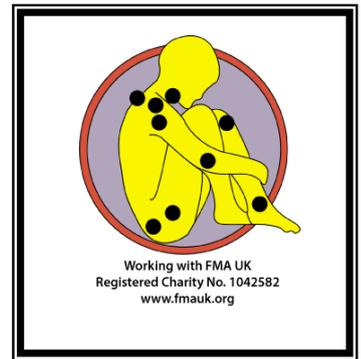


Welcome to Our January 2015 Newsletter.

Note from the Editor Maxine: Hope you all had a manageable holiday season. It was mad at our house as I had my daughter and the grandchildren. Early notice about the AGM on 19th March as Caroline is now collecting raffle prizes.



Monthly focus.

Please think about going paperless and having your newsletter sent by email.

Equipment to Borrow: We have a wheelchair and an electric mobility scooter (small enough to fit in car boot for days out or holidays). If you wish to borrow these, please phone Pam on 01204 793 846. Caroline has 2 pairs of SmartCrutches, phone her on 01204 525 955 to borrow them.

Dates For Your Diary:

Bolton Main Meetings at Wildlife Trust Centre, Bury Rd:

Our main meetings, often with guest speakers, are now held at The Wildlife Trust Centre, 499/511 Bury Rd, Bolton, BL2 6DH.

They occur on the third Thursday of each month from 7.30pm until 9pm (except in April, August and December). It is not far from Brightmet Health Centre. The building is on Bury Rd, between Morrisons/Home Bargains and the junction to turn onto Crompton Way, on the way into Bolton town centre.

Entrance is £1, carers are free. Tea, decaf coffee, water, biscuits, orange squash, etc provided. Gluten/dairy free also catered for. Any questions, please call Caroline on 01204 525955, or email caroline@mesupportgroup.co.uk.

Thursday January 15th, 7:30pm: Michelle Cardno, from Fightback4Justice. Non profit group offering welfare benefit advice/appeals and disability benefit applications completed. They have an office based in Bury and have given well received talks to other M.E groups. Michelle is a law graduate, working previously for the Citizens Advice Bureau.

Thursday February 19th 7:30pm: Rebecca Richmond, Author. She has overcome cancer and Fibromyalgia, and written several self-help books. She has come recommended by another FM group.

Thursday March 19th 7:30pm: Annual General Meeting. Please come and show your support for this very important meeting, or vote by post/email.

Yoga Classes: Are 3:15pm-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. **Our yoga classes are currently being funded by Comic Relief and The Co-operative Membership Community Fund.**

Bolton Socials: Are now at **Pizza Me** (www.wannapizzame.com), which is on Brightmet Fold Lane, BL2 6PP, just next to Brightmet health centre. We meet the **first Wednesday** of the month at 2pm, the next ones will be on **7th January and 4th February 2015**. There will put a newsletter on the table so that you can recognise us.

Prestwich Socials: Our Prestwich socials are now at **The Church Inn, 40 Church Lane, Prestwich, M25 1AJ**. This has level access and free parking outside. We meet on the **second Wednesday** of the month at 2pm, the next meetings are: **Wednesday 14th January and 11th February at 2pm**. **Please check on Facebook first to check it is still going ahead, as that's the quickest and easiest way, or call Maria on 07867 862 341 if you are not on Facebook**. Apologies to those not online, but it is either this, or stop them altogether.

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.



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.

Appeal to go paperless:

A large portion of outgoings is photocopying costs – awareness leaflets, welcome packs, monthly newsletters and several lengthy BenefitsAndWork.co.uk guides. It would help cut printing and postage costs (as well as our volunteer's energy, electricity and time) if you would get the email versions of the benefit guides and newsletters if you are able to please. (If you do not have access to email/a printer, does a friend or relative?) Could you also return the guides where possible so we can pass them onto other members to re-use, and also save some trees). Only around 40% of our newsletters go out by email. Of course we know not everyone has email, but if you can get the newsletter this way, please would you consider it to save us funds. A huge, unseen amount of work by people with ME/CFS/FM goes into them, producing these and getting them to you. Please contact caroline@mesupportgroup.co.uk / 01204 525 955 to switch to email newsletters. Thank you.

Help required.

We are looking for volunteers who can help with all activities of running the group, if you have a particular skill (or just a pair of hands!) you think you can contribute, or are up for a certain task, please contact Caroline. **We are really struggling to keep the group going**; we are just a small number of sufferers, so we need all the help we can get please. Please contact Caroline on caroline@mesupportgroup.co.uk or 01204 525 955 for more information.

Support Group Posts & Contact Information:

The Bury/Bolton ME/CFS Support Group was founded in September 1990 and is managed by a committee of now five: Caroline Higson, Carole Senior, Jeff Glasser, Lynda Marney, Maria Sale.

Group leader, web site, and membership queries: Caroline Higson, 01204 525955
Caroline@mesupportgroup.co.uk

Treasurer: Lynda Marney, lynda@mesupportgroup.co.uk

Meetings Secretary: Maria Sale, 01204 575613

Minutes Secretary and Librarian: Carole Senior, 01942 810320 caroles4@virginmedia.com

Benefit & Work guides: Ruth Fryman, 0161 766 4559 ruth@mesupportgroup.co.uk

Newsletter: Maxine Fairhurst, 01204888758 maxine@mesupportgroup.co.uk

Roving Reporter: Andrew Levy, 0161 7986183 andmk1@googlemail.co.uk

Newsletter Distribution: Sara

Door at Meetings: Sue Critchley, 01204 883506

Parents' Contact: Vacant

Bury Medical Sub-Group Representative: Vacant

Carers' Contact: Vacant

Fundraising: Vacant

PR/Out reach: Vacant

Writing the speaker reports at meetings: Vacant

Benefit and Work Guides:

We also have the Benefit & Work guides available from Ruth 0161 766 4559
ruth@mesupportgroup.co.uk

Claiming Personal Independence Payments (PIP) (70)
Example PIP Diary Extracts for CFS (3), FM (2), arthritis (3), mobility (3),
anxiety & depression (2), blank template (2)
PIP Appeal Submissions (33)
Ways to Challenge a PIP Medical Report: Over 50 Grounds of Appeal (24)
I've Been Awarded PIP, What Else Can I Claim? (12)
DLA claims for adults physical grounds (61) / mental health grounds (53)
DLA adult renewal claims on physical (58) and/or mental health grounds (50)
Changes of circumstances for people claiming DLA (8)
Transferring from Incapacity Benefit to ESA (22)
ESA claims for mental health difficulties (86)
ESA claims on physical health grounds (84)
ESA appeals (39)

Caution, may not count as voluntary work (6)
If I do any work can I continue to claim? (4)
Work and benefits for people with long term health conditions (7)
Getting better treatment from the DWP (12)
Getting help with your benefits (12)
Am I covered by the Disability Discrimination Act? (9)
Reasonable adjustments: Employers and Jobseekers (9)
Bedroom Tax Case-Law Round-Up (7)

ME/CFS Steering Group Meeting

Caroline and Joanne joined the team for the now annual steering group meeting at their Brightmet Health Centre base.

We were introduced to Michelle, who is the new strategic therapy lead who will provide specialist input and help develop the team, and Simon, the principal service lead. We also met Tamzyn who is the new Occupational Therapist for the team.

There is also a new therapy assistant role in the team, to be piloted in a bid to provide a follow up appointment in the home. This could be for equipment, hoists, a wheelchair or a cognitive follow up. This is aimed at releasing more time for the other therapists to spend time in clinic.

Currently, patients can self-refer themselves back into the clinic within 12 months of discharge. The team are going to pilot how self referrals within these 12 months are seen. This would involve a therapy assistant going to the self referrers home to complete information / outcome measures and feed back information to the team, to allow the

patient to access the pathway at the most appropriate point. The trial will be for approximately 12 months.

Waiting times are variable at the moment, but do vary throughout the year anyway. As staff changes have taken place, recruitment and training was needed so the waiting list went up, but was managed as best as possible.

The amount of pre-appointment paperwork patient needs to fill out was brought up, e.g. the content, time taken to fill out, how relevant it was, etc. We had a long discussion about it and possible solutions.

From a medical professional point of view, the more information the better to help assess the patient and place them with the right therapist etc. Maureen the counsellor said she finds it crucial to know a patient's history before she sees them as it will help her and the patient, and would mean that she would have to take longer with them gathering information if it hadn't been filled out.

It was agreed that the information would stay in the current form, but the cover letter would be amended to say why the information was needed, and state it was optional.

The pre-assessment forms ask you to state your difficulties as mild, moderate or severe. If you would like to know what these categories mean so you can tick the appropriate boxes, you can find the definition of these in the NICE Guidelines for ME/CFS (a quick internet search will find them).

The library at Brightmet Health Centre has a Citizen's Advice Centre clinic on a Thursday by appointment, 10-12. The CAB are aware of the ME/CFS clinic and they are encouraged to provide updates to the clinic re benefits etc to help.

The team stressed it is important to keep in contact with your GP if receiving benefits or under medical treatment, so they are updated and in a position to help.

Discharge letters will now include any equipment that may be required as follow up.

In some circumstances housebound patients may receive a home visit.

We asked about funding (with fingers crossed). Hopefully the service will continue as it is, but reviews are always ongoing. We have every confidence in Simon and the team.

We were shown audits of the service. It is important patients provide feedback to ensure the running of the clinic and to obtain funding.

A member asked us to query if they could ever offer services like reiki or acupuncture? They cannot offer this unfortunately, as they were set up to deliver a very specific service.

They are unable to discuss individual patients with us due to confidentiality.

It was a positive meeting and lovely to meet some of the new team members.

Energy Saving Tip* Many clinics and consultants, as well as some benefit forms, ask you for a current list of medical conditions and medications.

Save yourself some time and type these up on your computer, and update when necessary (or handwrite and photocopy). Also include the start of symptoms and date of

diagnosis if possible. Then you can just print them out when needed, and take to your appointments or attach to forms. The consultant will also appreciate this, as it saves about 10 minutes of appointment time.

You can keep a copy of your prescription list in your wallet or purse, to show at appointments. This is also handy for when you need over-the-counter medication and need to tell the pharmacist what you are already taking.

Vitamin D and Vascular Function

Republished with kind permission from ME Research UK.

First seen in BREAKTHROUGH magazine Autumn 2014.

When people think of vitamin D deficiency, they think of rickets and its devastating effects on human populations. Yet, rickets is now recognised to be merely the extreme end of a spectrum of possible disorders; in effect, the tip of the vitamin D-deficiency iceberg. Recent scientific work – centring on the discovery that ‘vitamin D receptors’ are widely distributed in the body and can be found in most cells and tissues – has thrown new light on this vitamin and its role in a variety of key functions. In particular, there is great interest in the part played by vitamin D (or its deficiency) on the risk of chronic illnesses, including autoimmune and infectious diseases, common malignancies, and cardiovascular disease.

Why might this be important in ME/CFS? Well, as a chronic illness with immune, infectious and cardiovascular aspects, there is at least a possibility that vitamin D deficiency/insufficiency could somehow be involved. Also, vitamin D inadequacy has been linked with impaired neuromuscular functioning and chronic pain, two important facets of the day-to-day experience of ME/CFS patients. Given the possibility of links between vitamin D and ME/CFS, ME Research UK awarded funding to Dr Faisal Khan of the Institute of Cardiovascular Research in Dundee – who has worked for many years on cardiovascular factors in a number of diseases – to test vitamin D levels in already-collected samples from two studies previously funded by our charity.

The results of these preliminary studies were published in the International Journal of Cardiology in 2014. In the 41 patients for whom full data were available (their mean length of illness was 9.7 years, and all were of white European descent), levels of the main circulating form of serum vitamin D ranged from 7 to 108 nmol/L. Circulating vitamin D levels correlated significantly with age but not with sex or body mass index. Most importantly, the researchers found significant correlations between circulating serum vitamin D levels and markers of inflammation, oxidative stress, endothelial function and arterial stiffness.

As the authors point out, observational studies like this one cannot prove that vitamin D deficiency is causing impaired vascular function or the symptoms of ME/CFS, particularly as the interplay between the vitamin and physiological function is complicated. Nevertheless, the results are intriguing. In other illnesses, such as type 2 diabetes, high-dose vitamin D has been shown to improve endothelial vascular function. To see if this is also the case in ME/CFS, we have funded Dr Khan and colleagues to undertake a clinical trial of high-dose vitamin D supplementation, and the results of this larger study will be published shortly.

Vitamin D deficiency

The major cause of vitamin D deficiency is inadequate sunlight coupled with insufficient dietary intake, but medical conditions that limit its absorption or impair conversion of vitamin D into active metabolites (e.g. liver or kidney

disorders) can also be responsible. Deficiency/insufficiency can affect tissues or processes, such as:

Bone metabolism

Protein or mineral content of bone can be reduced (osteoporosis), or there can be a loss of bone (osteopenia), leading to osteomalacia and weakness.

Muscle function

Skeletal muscles have a vitamin D receptor and may require vitamin D to function optimally since a deficiency is associated with muscle weakness.

Immunity

Vitamin D deficiency tends to increase the risk of infections, such as tuberculosis and influenza.

Cancer risk

Vitamin D regulates the expression of genes associated with cancers, but whether its deficiency *per se* increases the risk of cancer remains unproven.

Cardiovascular dysfunction

Low levels of circulating vitamin D are associated with important cardiovascular risk factors, such as high blood pressure, increased vascular resistance, increased heart left ventricular mass, and increased calcification of the coronary vessels.

Personal Independence Payment (PIP) Tips

Here is some information I have condensed from my experience and the Benefit and Work guides we have distribute. Please be aware this information was compiled by a brain-fogged individual, and is not to be considered advice from the group itself. It is accurate to the authors knowledge at time of printing.

Please be aware that Earl Howe has acknowledged that ME is a disability, the group has a letter that states this. Please contact Caroline if you would like a copy.

There have been lots of delays till now, some people have had to wait up to a year for a decision, but they have now introduced more assessors to deal with claims.

PIP replaces Disability Living Allowance – in order to reduce cost of the benefit by 20%. How will this affect people's awards? The DWP estimate:

29% award increase
15% unchanged
29%decreased
26% no award at all

PIP is:

Not means tested. Not dependent on N.I contribution. Not taxable.

For people aged between 16 – 64 years old.

If you get awarded it before age 65, you stay on it.

Children and older people are not affected by PIP – this may change in future.

Can be awarded wither you are working or not.

Mobility and Daily living – each has standard and enhanced component

- Based on points system like Employment Support Allowance
- They have got rid of the lower care and night time element from DLA.

Like DLA – some claimants will be able to get blue badge and Motability car, depending on award.

To Qualify:

You need to have current level of needs for 3 months and likely for 9 more months. The 3 month test does not apply if moving from DLA to PIP. There are special rules for those with terminal illnesses.

You can go abroad for 13 weeks whilst on PIP – 26 week if for medical treatment, without effecting benefit.

Length of Awards:

Most awards will be fixed, except in exceptional circumstances.

Up to 2 years where DWP expects your condition to improve significantly.

5 – 10 years where changes are possible but less likely.

Ongoing/indefinite awards for a very small number of cases, where you are not expected to get better or worse.

Standard rate of daily living/mobility – limited ability to carry out these activities £21.55 care, £54.45 mobility

Enhanced rate of daily living/mobility – severely limited ability to carry out these activities. £56.75 mobility, £81.30 care

You need to score points on the following activities:

You must score 8 points for standard and 12 points for enhance awards.

Daily Living:

Preparing food, taking nutrition

Managing therapy or monitoring a health condition

Washing/bathing

Managing toilet needs/incontinence

Dressing/undressing

Communicating verbally

Reading/writing, understanding symbols and words

Engaging with other people face to face

Making budgeting decisions

Even if you have no one to help you with these activities, it does not matter, you still need the help.

You can only score one set of points from each activity. If two categories apply to you, only the highest will count.

MOBILITY ACTIVITIES

1. Planning And following journey 8 = standard
2. Moving around 12 = enhanced

12 points from this category will entitle you to the Mobility car scheme.

8 points from this category will result in automatic entitlement to blue badge.

Timetable from introduction of PIP

October 2013:

All new claims must be for PIP. Children turning 16 must apply when fixed DLA fixed term awards that end, must now apply for PIP. People on DLA who report a change of circumstances, must now re-apply for PIP (not things like moving or going into hospital, such things as an improvement/decline in your condition). People with fixed term award which expires after Feb 2014 will be asked to apply under PIP. ****HOWEVER****, at the time of printing, those in the BL postcode (at least), are still being asked to renew as DLA and report change of circumstances as DLA, as there are so many delays for PIP. You can also choose to claim PIP if you are on fixed term/indefinite DLA.

From October 2015:

Everyone else, including indefinite awards will be randomly selected to apply for PIP.

Expected to finish March 2018.

Being Transferred From DLA to PIP

If you are currently on DLA, you will receive a letter inviting you to claim for PIP, according to the timetable/conditions previously listed. You have 28 days to initially phone them to complete a PIP1 form (they can extend it with a good reason, e.g. a hospital stay). If no claim is made, your DLA is suspended. If a PIP claim is then made, they will lift the suspension. If still no claim is made after 8 weeks, they will stop your DLA. If you do apply for PIP, your DLA will continue until they have made a decision.

What usually happens:

Complete PIP1 form by phone

Complete PIP2 form, on how your disability/illness affects you

Have face to face assessment (not always).

If you do not return your form, with no good cause for delay, the PIP claim is refused. They will take into account your health and the nature of your disability when deciding this though.

However, if you do not return the form, but through your questions, you have been identified as having "mental or cognitive impairment", they must still assess you, by telephone, getting more medical evidence, or asking you to attend a medical assessment.

Completing the Form:

Remember, when completing the form, after every question, think about whether you can do it **reliably, repeatedly, safely, without discomfort and to a reasonable standard**. They will also take into account motivation, nausea, breathlessness, pain and fatigue, so mention any of these you have. What is "reasonable standard" is subjective, so up to you to describe how your condition affects you, and send in as much evidence as you can.

Aids and Appliances

These are very important to PIP. You should mention every day items such as electric tin openers and food processors, not just items like electric scooters or perching stools.

Their use however, may lose you points also, by removing the need for help or another person, or when you say you can't do an activity, they may say you can if you used the aid/appliance. Even if you currently don't use an aid/appliance, they will include any they would "reasonably expect" you to use, taking into account availability, cost, etc. You must

state that you use them because you NEED them because of your illness/disability, not just because you prefer them.

When your condition varies

They assess your condition as it is likely to be over 12 months.

You are assessed as how you are over majority of time, e.g. how you are 4 or more of 7 days a week. However, you do not have to satisfy a descriptor for most of the day for it to apply (this was the case in DLA).

If you satisfy a descriptor at any point in the day, this is enough to score you the points for the descriptor.

With variable conditions it is very hard to work out how you are the majority of the time and provide evidence for this. Try and give percentages or figures so they can see how you are over time.

This is why you need to provide as much detail as possible about your day, your difficulties, etc. You could fill in a symptom diary for a week and send that. You could get your carer (or a friend, relative, past employer, religious adviser, etc, if you live alone) to write a letter about your care needs.

There does not seem to be much emphasis on supervision and risk, as there was in DLA. However, if you need someone to steady you, because you get dizzy and may lose your balance and fall and you have osteoporosis, etc, say so.

Evidence:

More evidence means more chance of success. The more relevant, the less likely you may be called for a medical.

Symptom diary

Letter off a carer/relative/CPN/social worker/GP, consultant, etc

They may call you via telephone to collect more evidence

A & E reports

Social Services Assessments

Tests/Scans/Xrays/Reports, appropriate to your illness/disability.

Culinary Corner.

Please can people send me their recipes to maxine@mesupportgroup.co.uk

Another for the slow cooker.

Campfire stew

1small gammon joint, all fat cut off.

1 onion diced

2 orange peppers diced

3 cloves of garlic crushed

1 tsp of smoked paprika

2 tins of baked beans

6 table spoons of tomato purée

1 red chilli chopped finely

Put everything into the slow cooker and cook for 6 hours on high. Separate gammon with forks before serving.