

Chairs Report April 2009 – April 2010

It has been a busy and eventful year. The first event took place at the Thornhill centre on 6th April. We invited Kay Jenkins, from the Cardiff and Vale Coalition for Disabled People to give a talk on Direct Payments, how to get them and who is entitled etc.

11th May; an event was held in conjunction with ME Awareness week. The event entailed an excellent and informative talk by a GP on food allergy and intolerance, followed by a recorded interview between M.E sufferer Andreas Constantinou and Able Radio, the new internet radio station for people with illness or disability. Dr Esther Crawley, who is a children's M.E specialist, was also interviewed about the condition.

1st June; Louise Tindal, a former M.E sufferer and member attended a support group meeting and offered free taster sessions in holistic therapies. Lots of people had an Indian Head massage. It was lovely to see people floating out afterwards, stress free. Louise has gone into business with her daughter, working from home and offering beauty and holistic treatment between them.

3rd June; a function was laid on in Cardiff Castle to celebrate people who donate their services as volunteers. There was food and entertainment which was absolutely fabulous. Denise, Ken and Chris were chosen to attend on behalf of ME-SiG. (M.E Support in Glamorgan). It was a good opportunity to talk to other voluntary organisations and to spread the word about our particular group.

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19th August; our annual 'Tea In The Park' event took place in the Roath Park café.

2nd September; a meeting took place between VAC (Voluntary Action Cardiff) and VCVS (Vale Centre for Voluntary Services) and NHS (National Health Service). The purpose and suggested aims of the meeting was developing integrated community care, involvement of the voluntary sector in collaborative joining together, planning delivery services across the board supporting the management of long term chronic conditions and aspiring to the delivery of a world class integrated coherent patient focused system.

M.E.S.I.G were fortunate to be one of the groups of voluntary organisations involved. Linda Tatham and Athena Harris attended the meeting where there was an opportunity to briefly explain some of the needs of people with M.E.

21st September, 5th & 12th October; 'Laughter Sessions for Health'. Carol Young attended our support group meetings in Thornhill on three occasions, providing us with stress relief techniques. These included laughter, relaxation and breathing exercises. Carol now runs these sessions on a regular basis in Heath.

7th December; M.E.S.I.G held a Xmas party in Thornhill centre. There was a buffet, Xmas crackers, a raffle and a bran tub. Fun was had by all.

4th January 2010; Elyssa, an alternative therapist came to our support group meeting and offered taster sessions in Reiki, Reflexology and Indian Head Massage. It was great to see people so relaxed after sessions. Many thanks to Elyssa.

1st February 2010; Amir Norris, who facilitates the 'Energy Excellence' course, gave a talk on his ground breaking work with people who suffer with M.E. and similar conditions at the Lisvane Memorial Hall. The event which was well attended.

Special thanks to committee members; Linda Tatham (Treasurer), Gareth Price (Temporary Secretary), Denise Thompson (Newsletter Editor), Christalla Davies (Membership Secretary & Co-Newsletter Editor), Athena Harris and Linda Shakespeare.

Best wishes and a healthier year ahead from your Chair.

Ken Bailey

AGM AND THERAPIES DAY

Saturday 15th May

2.30-5pm



Mackintosh Institute, Keppoch st, off
City Rd,
CF24 3JW



Hi all,

This year we are combining our annual general meeting with M.E awareness week and in order to inject some fun and relaxation into an otherwise serious condition, we have been fortunate enough to have the services of several alternative therapists. They have very kindly offered to donate their time for us free of charge. (If people wish, donations can be given to the therapist, no obligation).

As a group we really need more people to come on board in order to continue. At present we have been functioning without a vice chair and secretary. So we urge you to come forward in any capacity, it doesn't have to be a role, simply a committee member, which means you do as much or as little as you wish. The commitment would be to attend if/when able, meetings which are held approximately every 2 months.

On the day, we hope to get the official stuff out of the way, so we will be starting AGM promptly at 2.30pm. Then people can take advantage of treatments, chat and enjoy tea and cake. On offer as tasters will be reflexology, Indian head massage, reiki and Bowen to name but a few.

This invitation for AGM and treatment is open to all; members, carers, family, friends and any interested parties.

We are combining the AGM this year with M.E Awareness week, so we urge you to support us to support you.

If anyone needs a lift or would like to put themselves forward for committee, please let Ken Bailey know 07825702171.

Your newsletter editor Chris Davies

MEMBERSHIP MONEY IS NOW DUE

Membership of £6 is now due, this covers you from May 2010-May 2011.

Please fill in enclosed subscription renewal forms and return.

Please also note that if anyone is experiencing financial difficulties, this fee can be waived. Just let your membership secretary know.

Many thanks for your support and a special thank you to those of you who also donate.

Best wishes from your membership secretary

Chris Davies

tel: 02920762347



TEA IN THE PARK

Wednesday 11th August

2.30pm

Roath Park Cafe

This seems to have become a group tradition.

We meet up in August in Roath Park café terrace, for a cuppa and chat.

All are welcome.

Christmas Party 7th December 2009 Report

We had an excellent turnout for our annual Xmas party. We held it at the Thornhill centre on the afternoon that would normally have been our meeting day for December. The lounge is always so comfortable and the centre provided our drinks. Food was provided by M.E.S.I.G via Sainsburys.

There were many familiar faces there but also new members, who we hope benefit from meeting and chatting to others. The bran tub is always quite exciting and Christmassy and we normally hold our breath to see what the men will end up with. I think they were relatively safe this year. But the main purpose of our group is that we can enjoy each others company, whether it is having a laugh or a cry with each other. It is always wonderful to hear from those whose health has improved over the year, but even better from those who are back to leading a full life again.

Linda Tatham

HELPING HANDS



A voluntary organisation “here to help”

Household chores/ Meal preparation

Hospital visits/companionship

Transport for shopping, errands, clothing and personal items

tel: 0845 095 0091

www.helping-hands.yolasite.com

Free, depending on circumstances



Book List

ME, CHRONIC FATIGUE SYNDROME & FIBROMYALGIA-The Reverse Therapy Approach by
John Eaton

CHRONIC FATIGUE SYNDROME-There Is A Cure by *Patricia Jane Taylor*

CHRONIC FATIGUE SYNDROME –A Natural Way To Treat M.E by *Professor Basant K Puri*

THE CHRONIC FATIGUE HEALING DIET by *Christine Craggs-Hinton*

FROM FATIGUED TO FANTASTIC by *Jacob Teitlebaum*

SECRETS TO RECOVERY

RECOVERY FROM CFS by *Alexandra Barton*

Available to borrow for free, just ring Chris 02920762347

£164,000 grant for study into the Lightning Process and children with M.E

£164,000 awarded for new research into the treatment of a chronic childhood condition

A research study looking into interventions and treatment options for a chronic childhood condition has been awarded funding of £164,000 by the Linbury Trust and the Ashden Trust.

The funding has been awarded to a research team led by Dr Esther Crawley, Consultant Paediatrician at the Royal National Hospital for Rheumatic Diseases NHS Foundation Trust, also known as the Min, and Senior Lecturer at the University of Bristol.

Esther and her team will carry out a pilot project to investigate whether it is possible to look at two different approaches to the intervention and treatment of Chronic Fatigue Syndrome/ME (CFS/ME) in Children.

CFS/ME in children is a relatively common and potentially serious condition affecting over one per cent of children across the UK. Over 50 per cent of affected children are bed bound at some stage of their illness and have an average time off school of one academic year. Despite this there is a limited evidence-base for treatment for children with CFS/ME. This research also incorporates the first study on health economic cost of this condition in children.

Dr Esther Crawley said: "We are delighted to have been awarded this research grant. CFS/ME can have a profound impact on a child's life. We hope that our research will enable us to understand more about this condition and how we can help those children who suffer with it."

The team will carry out a pilot project to investigate how to recruit to a randomised controlled trial looking at the Phil Parker Lightning Process® and specialist medical care. This will be the first study of its kind in this area, and the team hopes to establish a basis for a larger scale multicentre research project.

The specialist Paediatric CFS/ME service at the Min is the largest regional paediatric CFS/ME clinical

service in the UK, and also provides services nationally. The team currently provides assessment and treatment for over 200 children from across the UK and Western Europe each year. Approximately ten per cent of the children referred into the service are housebound and are assessed at home.

The Phil Parker Lightning Process® is an intervention that is used for a variety of conditions including CFS/ME and has been developed from osteopathy, coaching and neuro-linguistic programming. It is a three-day training programme run by registered practitioners and designed to teach individuals a new set of techniques for improving life and health.

Phil Parker, designer of the Lightning Process said: "We are thrilled to have the opportunity to collaborate on this exciting and groundbreaking research with Dr Crawley and her team. It is vitally important that all interventions that could assist children with CFS/ME to return to school and improve their health are explored. We hope that this study is successful and leads to further research collaborations between the Lightning Process and specialist teams like Esther's."

The study will involve in-depth interviews with the patients and their parents, and the primary outcome measure will be school attendance after six-months. It is hoped that over 90 children aged between eight and 18 and their families will be involved in the study. They will be recruited after assessment by the specialist team at the Min.

The study will begin in September 2010.

www.meassociation.org.uk

M.E.S.I.G contacted Dr Esther Crawley and asked if she was looking for children to participate. Dr Crawleys response was that they weren't recruiting as yet.

Recovery Story

1st January 2010

The year of 2009 has seen some big changes in my health. I was diagnosed with ME in August 2003, although I managed to keep working until July 2004. My illness really started in the autumn of 1990 when I started to get ill with a virus. By 1991, I was unable to work for three months with a severe and prolonged episode of glandular fever. I was left with a permanent sleep disorder and frequent periods of exhaustion.

Throughout my time of illness since July 2004, I have found hope, comfort and encouragement in a practical Christian faith helped in no small amount by prayer and counselling from the Cardiff Christian Healing Ministry. I found this an invaluable help in dealing with the emotional side of the past twenty years. It has also deepened my prayer life and allowed me to experience a great sense of calm.

I had been slowly improving since stopping work in 2004, but it has been agonisingly slow and any small recovery would be so fragile.

In 2009, I was given word at the Christian Healing Ministry that I was healed. This occurred on three separate occasions whilst I was being prayed over. Throughout 2009 I have been steadily getting stronger and able to do things I wouldn't have tried before.

In November 2010 my health received a huge boost after attending the Energy Excellence Course run by R. Amir Norris. His course is similar to the Lightning Process and works on changing the neural pathways in the brain by using various techniques which are taught to the individual.

Since then I have felt confident and strong enough to start some voluntary work each week and also start a prescription of fitness training from my GP. I have a new lease of life and continue to be able to increase my activities. I have been able to use my bicycle for the first time in eight years

Getting better has been a long time coming and I still have a way to go. For me there has been no quick fix, easy answers or one-step solutions. Rather it has meant steady perseverance with a simple faith together with a neurological treatment that has gradually started to produce some wonderful results.

(Details of both The Cardiff Christian Healing Ministry and The Energy Excellence Course can be found on the internet.)

Chickpea, Potato and Kale Curry

Serves six



Ingredients:

340g dried chickpeas (or 2 400g tins, drained and rinsed)

1 tsp cumin seeds, plus a little extra to garnish

1tsp coriander seeds

1/2 tsp mustard seeds

1 hot, dried red chilli, crumbled

1 tsp ground turmeric

2.5cm piece of fresh ginger, peeled and grated

1 tbsp groundnut or sunflower oil

1 large onion, peeled, halved and finely sliced

2 cloves garlic, peeled and finely chopped

700l chicken or vegetable stock

250g potatoes, peeled and cut into 3cm dice

150g kale (or cabbage) finely shredded

Yoghurt to serve

2 tbsp coriander leaves, chopped

Soak the chickpeas overnight in plenty of cold water. Next day, drain, rinse and simmer them for about an hour and a half in fresh water, until tender, then drain. (If using tinned, just drain and rinse.)

Put a dry frying pan over a medium heat and, when hot, toast the cumin, coriander and mustard seeds and the chilli for a couple of minutes until they smell really fragrant and the mustard starts to pop. Grind to a powder in a coffee grinder, spice mill or with a pestle and mortar, and mix in the turmeric and ginger.

Heat the oil in a large pan over a medium heat, and fry the onion, stirring regularly, until soft and golden brown. Stir in the garlic and spices, leave to cook for a minute or two, and add the stock. Simmer for five minutes, then add the chickpeas and potatoes. Cook until the spuds are tender, then add the kale. Cook for a few minutes, until the greens are tender, then serve with a dollop of thick yoghurt on top, along with a sprinkling of toasted cumin seeds and some coriander leaves.

Submitted by Gareth Price



Weather

This is the weather that the cuckoo likes,
And so do I;
When showers betumble the chestnut spikes,
And nestlings fly;
And the little brown nightingale bills his best,
And they sit outside at "The Traveller's Rest",
And maids come forth sprig-muslin drest,
And citizens dream of south and west,
And so do I.

This is the weather the shepherd shuns,
And so do I;
When beaches drip in browns and duns,
And thresh and ply;
And hill-hid tides throb, throe on throe,
And meadow rivulets overflow,
And drops on gate bars hang in a row,
And rooks in families homeward go,
And so do I.

by Thomas Hardy

UNDERSTANDING SEVERE M.E. INFORMATION PACK

Essential reading for Family & Friends of Severe M.E. Patients

Are you a Patient or Carer living with Severe M.E. and need something that explains to people the hell you are going through? .

Or perhaps you are a concerned relative/friend who is finding it hard to understand what is happening and just do not know what to do or say? Either way, this Information Pack is for you.

M.E. (Myalgic Encephalomyelitis) is a cruel and disabling illness which wrecks thousands of lives, none more so than those who suffer the most extreme version of the illness, Severe M.E.

Few people understand or appreciate the true impact of this illness, and for the millions of relatives and friends of patients, it can be a terrifying time. In 'Understanding Severe M.E.', 44 year old, Catherine Saunders draws upon her own inspirational recovery from Severe M.E. to explain the physically disabling realities of the illness:

'Before I became very severely affected back in 1998/99, I used to think, like many others, that Severe M.E. was just about being tired. How blissfully ignorant I was. Severe M.E. may not be a terminal illness, but it takes people's lives; I know, because it took mine for several years.

For the best part of 2 years I was little more than a breathing corpse. All I could do was lay in a blacked out room in constant pain, unable to talk, walk or tolerate a glimmer of light. I had to be spoon-fed, watered, washed, dressed and nursed by my husband and family, just like a baby.

And one of my promises to myself was to do all I could, once recovered, to help family and friends understand what it is that their loved one is going through, what Patients and their Carers have to battle against every day, and how their understanding, support and compassion can make such a dramatic difference to the speed of recovery.

Severely affected M.E. Patients can recover, BUT only if we are given the right advice and, the right support, at the right time, and I firmly believe that the understanding of friends and family can make the difference between recovering and not recovering'.

In this immensely positive, hopeful and easily accessible Information Pack, Catherine addresses the many questions, worries and fears that family and friends have about what is happening to the Patient, signposts the way to expert sources of information and treatments, and most importantly suggests hundreds of ways in which they can ease the burden for the Patient and their Carer, both practically and emotionally.

To find out how to order copies of this Information Pack priced at £10 + £1.95 Post/Packing

email [**understandingsevereme@hotmail.co.uk**](mailto:understandingsevereme@hotmail.co.uk)

visit [**www.understandingsevereme.blogspot.com**](http://www.understandingsevereme.blogspot.com)

call **07771 827 913**

25% of net profits will be donated to M.E. Charities

Private doctor is given drugs ban

A doctor has been banned from prescribing drugs and told to take down part of her website after appearing before the General Medical Council.

Dr Sarah Myhill will have to comply with the order for 18 months after two complaints were made against her.

She has a private practice near Knighton, Powys, where she specialises in treating chronic fatigue syndrome.

Her supporters were outside the hearing in London and claimed she was the victim of a witch-hunt.

There have been complaints against her on seven occasions since 2001, but this is the first time Dr Myhill has appeared before a General Medical Council (GMC) panel.

Before the hearing, she said that she could not understand why complaints against her were being heard.

But the chair of the GMC panel said there were serious concerns about the potential risk to patients and her fitness to practice would continued to be reviewed.

One of the complaints was on the content of Dr Myhill's website, which warned patients against oral contraceptives, the MMR triple vaccine as well as mammogram tests and biopsies for cancer.

But Dr Myhill says she tries to find the causes of a disease, rather than treating the symptoms with drugs.

The GMC considered whether there might be "impairment of Dr Myhill's fitness to practise which poses a real risk to members of the public or may adversely affect the public interests or Dr Myhill's own interests".

But her supporters say no patient has ever complained about her.

Dr Myhill runs a website which gives information on allergies and hormones, and advocates what she calls a "stone age diet" for people suffering from myalgic encephalomyelitis (ME) and other complaints including chemical sensitivity.

She treats people from across the UK.

However it is the website which has prompted the latest complaints against Dr Myhill.

She said in a statement on her website that a group of doctors have complained about her recommending a B12 vitamin injection to a patient.

A second complainant said the information on her website was "very worrying" and was concerned "patients are being seriously misled".

Six previous complaints have been made by other doctors against Dr Myhill since 2001.

She told BBC Wales: "I think there's a small group of doctors who perceive me as a threat to their professional integrity in some way and that is certainly not my desire to in any way threaten them.

"My motive is purely to help the patient to get well in as safe a way as is possible."

Patricia Chell has been travelling back and forth from Shropshire for three years to receive treatment, and says her health has improved dramatically since being prescribed magnesium by Dr Myhill.

"I think it's dreadful, and in fact if she's suspended, my life's at stake - literally.

"Without this magnesium, I should eventually get heart failure again."

Story from BBC NEWS :
<http://news.bbc.co.uk/go/pr/fr/-/1/hi/wales/mid/8650048.stm>

Published: 2010/04/29 15:10:51 GMT

© BBC MMX

Benefits and Work

About the Benefits and Work web site:

Benefitsandwork.co.uk, was launched in 2002 by advice worker turned barrister Holiday Whitehead and benefits writer and trainer Steve Donnison, to provide such information as benefits news, and detailed step-by-step guides to DLA claims, medicals and appeals which members can download from the website.

It is unique amongst benefit information providers in that it asks for no funding or support from the government, local authorities, grant making trusts or large companies. Every penny of Benefits and Work's revenue comes from its subscribing members.

This complete independence means that Benefits and Work is free to publish information that makes it deeply unpopular with the Department for Work and Pensions etc.

On a personal note, it's on my heart to tell everyone I can that the information on the web site benefitsandwork.co.uk is soOOO useful. It's so important, I feel, for sufferers to get to grips with the information BEFORE it is really needed, and before we have any further dealings with DWP- before filling in any claim form or attending any medicals.

You see, I can only take in such a small amount of information. And right now, I am struggling with being ill, doing countless things for the DWP, and trying to learn the information from this site.

If I had known about the information before my benefits and rent rebate were cut off, I may not have ended up in this predicament.

So, that's why I'm keen to urge everyone in the group to make full use of the site, before really needing to.

By the way, although to get best use of the site you need to dispense some money, there is a lot of free information, including daily tips sent via e-mail in bite sized chunks.

Cheryl Adams



Support group Meetings

Keppoch Street meetings are held every 2nd Tuesday of the month at Mackintosh Institute, Keppoch Street, off City Rd, Cardiff, CF24 3JW (except February, August and December) 7.30-9pm

Thornhill meetings are held every first Monday of the month (unless this falls on a bank holiday and then it will be the following week) at the Thornhill community centre (by Sainsbury's), off Excalibur Dr, Thornhill, Cardiff, CF14 9GA, 2.30-4pm.

CAPITAL CHANGE Pension credit will have risen with a new savings threshold

More than half a million people who get a pension credit should have seen their income go up from the first week in November 2009.

The people affected will all have savings above £6,000. Prior to this, any savings above that amount reduce the pension credit you get.

But from November 2nd 09 that threshold will have risen to £10,000 and that will raise pension credit by up to £8 a week, though most of those affected will get an extra £3.20 and some will get less. You do not have to claim the extra-it should just appear with the first payment this month.

The new limit also applies to money off your council tax and, for tenants, to a reduction in rent. All these allowances should rise if they were previously reduced because savings were above £6,000.

The higher savings limit will also mean that 70,000 people excluded from pension credit because of their savings will now be able to get it.

Many more will be able to get council tax benefit or housing benefit for the first time. However, the Government has decided not to seek out or encourage those who are entitled them to claim.

Anyone who has been refused these benefits in the past should find out if they can claim now.

For more information;

Pension Credit helpline 0800 99 1234

Or put your details into the calculator at entitledto.com

SAGA magazine

‘Your Mind Over M.E. For A Change’ Course

M.E.S.I.G has applied to ‘Awards for All’ for funding to run a course. The course would be lead by Dr Marilyn Godfrey PhD MA DSH.

The course would consist of 5 sessions, one a month over 5 months, hoping to start in September.

It would include a) Introduction

b) Pain Relief - In the form of acupressure and practical ways for individuals to use this.

c) Cognitive Behaviour Therapy - This has been shown to help with many different types of problems including physical health problems, like pain or fatigue.

d) Mindfulness Meditation - As a practical way of refocusing the mind and the body on the healing and pain relief process.

e) Emotional Freedom Technique - Uses stimulation of acupuncture points combined with techniques to change the way we process information and pain. This approach can sometimes ease symptoms for a while.

The course has been put together with a view to give people tools to cope with this challenging condition.

Will keep you posted. If anyone is interested in attending, please let Chris Davies know 02920762347

'ENERGY EXCELLENCE' talk by Amir Norris

Amir Norris from the 'Energy Excellence' course attended the Lisvane Memorial Hall on the 1st February 2010.

Firstly a huge apology from us (M.E. Support In Glamorgan) for the change of venue. The original venue was Thornhill Centre but due to a funeral taking place and us being cancelled last minute, we had to find an alternative. A big thank you for your support on the day and apologies again for any inconvenience caused. David Tucker from the Thornhill Centre also extends his apologies and has assured us that this would not happen again.

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Energy Excellence with R. Amir Norris B.Sc. ME/CFS Consultant Therapist

Few therapists have seen the range of ME/CFS cases and complex symptoms that Amir Norris has. From Wales to Nepal, Amir has personally trained over 1,000 people to get their lives back, with an exceptional success rate. In the field of Biobehavioral change-work and applied Neuro-linguistic Programming, Amir has earned a sterling reputation for training people to achieve fast effective relief from ME/CFS.

The success of his clients have been featured in various media reports including the Daily Mail and Radio 2.

Having had ME himself for 10 years and the extensive experience of helping over a thousand people recover, he has a unique perspective and understanding of the condition.

After you have been through the Energy Excellence Course, you will walk away with thousands of hours worth of effective strategies that you can put to immediate use.

For more information about Amir Norris and the course go to www.fatigueanswers.com or phone 0845 128 5228

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The talk in Lisvane was well attended and this is what one of our members had to say about it:

"I had spoken to Amir previously on the phone a couple of times, and had followed the progress of the Lightning Process over the last few years, so I was really looking forward to hearing about Amir's Energy Excellence program.

His talk was to be held at Lisvane Community Hall, and it turned out to be an ideal venue for the eager numbers that turned-up to listen.

A good crowd had arrived by the time I got there, and the atmosphere was warm and busy as I walked in, with many willing hands in the kitchen area ready to hand out refreshments to everyone.

When all had arrived, Amir began his talk with the aid of slides, in a very clear and relaxed way. It was very obvious to me that he was very enthusiastic and, of-course, knowledgeable about his work.

Having finished his talk, he patiently answered questions for quite a while, and when I spoke to him, he filled in a couple of 'gaps' for me in regard to the Energy Excellence program.

Amir 'came over' as a very genuine and caring person and his personal experience of M E must be invaluable to him and all of us. I understand he never stops investigating yet more things, in order to further his knowledge, and so improve his program yet further."



What is the Bowen Technique?

What is it?

The Bowen Technique is a holistic therapy involving a series of moves at precise points over the muscles, tendons, ligaments and surrounding soft tissue. After each series of moves the practitioner leaves the room for several minutes to enable the body to move and make fine adjustments in response. There is no manipulation of hard tissue and the treatment is not a form of massage.

It is non-intrusive, very gentle and very effective. Treatment can be carried out through light clothing.

The treatment usually lasts approximately 45 minutes. Often two or three treatments, at weekly intervals, are sufficient to achieve lasting relief from even long standing pain, although some further treatments may be required.

The Bowen Technique is often used as a means of preventing injury and illness by maintenance treatments carried out 2 - 4 times a year.

How does it work?

The Bowen Technique is based on the principle that the body has the ability to heal itself if it is given the opportunity and conditions to do so.

A treatment stimulates the central nervous system, helps release muscle spasm, relieves congested kidneys and stimulates the lymphatic system and circulatory systems. By doing so, it provides the body with the opportunity to rebalance on many levels.

History

The Bowen Technique originates from Australia and was developed in the 1930s by Tom Bowen.

After working as a labourer in his youth, Tom became interested in massage and body work and spent time watching football trainers and others involved in sport.

Although Tom had no medical training, he had an incredible eye which was able to spot structural imbalances and identify where these originated. With a few very simple and gentle moves, he would start the process of repair immediately, often without the client realising that anything had changed.

The results of his treatments spoke for themselves and Tom Bowen was no doubt the busiest therapist of his time. When interviewed for a parliamentary committee looking into complimentary medicine, he stated, under oath, that he treated around 280 clients a week with the help of an assistant and a receptionist. This makes a total per year of around 13,000 clients, 88% of whom only required two or three treatments. People would travel for hundreds of miles to see him, often in long term pain and would be corrected in a couple of sessions.

Tom also worked on racehorses and greyhounds having a remarkable result with one horse who came second in the Melbourne Cup.

Tom Bowen died in the early 1980s but there are a number of flourishing therapies based on his work.

Therapist

Andrea Planchant is a Bowen Therapist based in Cardiff, she is able to do home visits and can be contacted on; 02920752795 or 07791118538. Email; andrea.planchant@tiscali.co.uk. Website; www.welshbowentherapy.co.uk

Patient Statement

“Over the years I have been treated by Andrea Planchant for various ailments, I found that the Bowen treatment really agreed with me as having M.E, I was very sensitive and reactive to harsher treatments. Even though this technique is very gentle, the result is amazing. Andrea has been able to relieve me from the most excruciating pain, often when all else has failed”.

Andrea Planchant will be one of the therapists who will be attending and offering her services on 15th May at the Mackintosh Institute (refer to page 3 for details).

ME/CFS Information

How does ME/CFS start?

ME/CFS is often reported as having started with a virus or other infection, commonly involving the chest or stomach. However, it can also develop after an accident, operation, vaccination, exposure to crop sprays or sheep dip, or other shock to the system. Alternatively, it may creep on very gradually. The causes of ME/CFS are still unknown.

What distinguishes ME/CFS from other chronic illnesses?

By far the most widely reported characteristics of the illness, which distinguishes it from other chronic conditions, is exhaustion and malaise following physical or mental activity, the full extent of which becomes apparent only 24 to 48 hours after activity. Recovery from this flare-up of symptoms may be prolonged—days, weeks or even months. Rapid fluctuation of symptoms is a second key indicator.

What are the other main symptoms?

Abnormal muscle fatigue following activity. Muscle pain and muscle twitching. Sometimes with eyelid tic or twitch.

Failures in attention span, short term memory and concentration.

Other cognitive problems such as tendency to lose track of conversation in the middle of sentences, along with difficulty thinking of the correct word when speaking or writing and difficulty putting ideas into order.

Constantly feeling unwell, with 'flu-like' symptoms (e.g. sore throat, enlarged glands, joint pains) and problems with temperature control and night sweats.

Other symptoms may include:

Sleep disturbance, especially waking unrefreshed. The disturbance can include sleeping for long periods, perhaps 12 to 18 hours at a stretch, inability to get to sleep, sleeping during the day while staying awake at night, dreams (sometimes nightmares) particularly memorable by their vivid col-

our.

Pain in one or more joints, but with no signs of swelling, redness or joint deformity.

Feelings of unsteadiness, when walking or standing. Some people report feeling as though they are 'walking on rubber'.

Sudden, unexplained mood swings.

Headaches of a new type, pattern or severity.

Sensations of tingling or numbness, loss of sense of touch.

Over-sensitivity to noise and/or light.

Alcohol intolerance, particularly in the early stages of the illness, and onset of food intolerances.

Is there a diagnostic test or a cure for ME/CFS?

No, to both. The diagnosis has to be made from the typical pattern of symptoms, with the exclusion of other possible causes. Anyone suspected of having ME/CFS should have a number of routine blood tests to identify other possible illnesses, and have more specialized investigations if the diagnosis remains in doubt.

What are the chances of recovery?

People with ME tend to fall into one of three groups:

People who manage to return completely to normal health, but this may take considerable time. The percentage of people falling into this category is fairly small.

The majority tend to follow a fluctuating pattern with both good and bad periods of health. Relapses or flare-ups are often triggered by infections, operations, temperature extremes or stressful events.

A significant minority remain severely affected and will require a great deal of practical and social support.

Continued deterioration is unusual. When this occurs, a detailed medical assessment is advised to exclude other conditions.

How can recovery be helped?

It is important to remain positive about the prospect of recovery. The period of illness varies from person to person and improvements in health can occur, even in people who have been ill for a long time.

Anecdotal reports suggest two things which improve prospects for recovery. They are:

Taking control early on in the illness (in particular not trying to ignore the symptoms in the hope they'll go away). Youth-younger people seem to make a better recovery than adults.

Sudden improvement and sustained recovery

Fluctuation in symptoms may lull you into a false sense of security, so do not be tempted to do too much if you suddenly feel better for a short while. Sustained recovery is preferable to a roller-coaster ride of inappropriate activity and relapse.

If recovery slows or stops

Experience suggests a large proportion of people make a degree of recovery but then reach a point where the rate slows dramatically, becomes sporadic or even stops. We do not know the reason for this. Some doctors suggest this happens because the person develops an incorrect understanding of the illness and so rehabilitation therapy is offered.

Relapses

Relapses are a feature of ME/CFS and may occur through a variety of circumstances: exposure to other illness, sustained physical or mental activity unsuited to a person's capacity at the time, incompatible treatments and therapies, emotional stress, vaccinations, anaesthetics etc. So it may make sense to limit exposure to these situations, except where the consequences of doing so could make matters worse.

Contact and Support:

<p>ME Association</p> <p>7 Apollo Office Court, Radcliffe Road, Gawcott, Buckinghamshire MK18 4DF</p> <p>Tel: 01280 827070 9.30am - 4.30pm</p> <p>Website : www.meassociation.org.uk</p>	<p>MCS Matters</p> <p><i>(Multiple Chemical Sensitivity)</i></p> <p>Gordon D McHenry UK Co-ordinator Global Campaign for recognition of MCS</p> <p>Tel Helpline: 01446 794 700 Tues & Thurs 2 –4 and 6—7pm (manned when able)</p> <p>Website: www.satori-5.co.uk</p>
<p>25% ME Group</p> <p>21 Church Street Troon Ayrshire KA10 6HT</p> <p>Tel: Office 01292 318611 Advocacy line: 01292 312369 Website: www.25megroup.org</p>	<p>National ME Centre</p> <p>Disablement Services Centre. Harold Wood Hospital Gubbins Lane Harold Wood Romford Essex RM3 0BE</p> <p>Tel: 01708 378050 Website : www.nmec.org.uk</p>
<p>Action for ME</p> <p>3rd Floor, Canningford House 38 Victoria Street Bristol BS1 6BY</p> <p>Website: www.afme.org.uk Tel: 0845 123 2380 or 0117 927 9551</p>	<p>STIFF (UK)</p> <p>PO Box 1484 Newcastle-under-Lyme Staffordshire ST5 7UZ</p> <p>Tel: 01782 562366 (between 11—4pm) Website: www.stiffuk.org</p>
<p>Fibromyalgia Association</p> <p>PO Box 206 Stourbridge West Midlands DY9 8YL</p> <p>Helpline: (Calls charged at national rate) Tel: 0870 220 1232 (Mon-Fri 10—4pm) Email: fmauk@hotmail.com</p>	<p>Welsh Association of ME & CFS Support (WAMES)</p> <p>Tel: 029 2051 4328 Email: enquiries@wames.org.uk Website: www.wames.org.uk</p>
<p>ME Support in Glamorgan</p> <p>Details on back page.</p> <p>BRAME</p> <p>Website: http://www.brame.org Tel/Fax: 01493 393717</p>	<p>C.L.I.P-</p> <p>Coping and Living in Pain, support group. Tel: Richard Goss, 01443 757378 Gloria Edmunds, 029 20530593 Steve Sweetman, 02920214339 Email: pain.help@ntlworld.com</p>

Contact and Support continued:

Association of Young People With ME (AYME) PO Box 576 Milton Keynes MK10 1AQ Tel: 08451 23 23 89 Website: www.ayme.org.uk	A 4 ME Tel: (See AfME) Website: http://www.a4me.org.uk
The Young ME Sufferers Trust PO Box 4347 Stock Ingatestone CM4 9TE Tel: 01245 401 080 (best between 11 –1 and 5—7pm weekdays) Website: www.tymestrust.org	Welsh Association of ME & CFS Support (WAMES Young People) Michelle Penny Tel: 029 20515061 Email: michelle@wames.org.uk Website: www.wames.org.uk (Carers— same as above but contact Sylvia Penny—same tel no. Email: Sylvia@wames.org.uk

Useful Telephone Numbers

A range of useful information leaflets can be obtained from any of the groups.

Benefits:

Citizens Advice Bureau

Tel: See telephone directory for nearest office#

Website: www.citizensadvice.org.uk

Dial UK

Tel: 01302 310 123

Website: www.dialuk.info/index.asp

Benefits Helpline

Tel: 0800 88 22 00

Social Care:

Assessment Centre

Will help with occupational therapy and evaluations

Tel: 029 2052 0984

Occupational Therapy:

Tel: 029 2076 7404

Carers Line

Tel: 0808 808 7777

The Samaritans

24 hour confidential and emotional support helpline and email service for anyone in crisis.

Tel: 0845 90 90 90

Email: Jo@samaritans.org

Travel:

National Rail Enquiries

Tel: 0845 748 4950

Disabled assistance

Advance notice is required by the train operator.

Bus and Coach:

National Express

Tel: 0870 580 8080

Travel Line

Tel : 0870 608 2608

VEST: for help with local lifts and transport for the disabled - Ring 029 20490325 and ask for an information pack.

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

4 Arabella Street

Cardiff

TEL: 029 20453111

Riverside Advice

41a Lower Cathedral Road.

Cardiff

TEL: 029 20341577

Useful Websites

www.meresearch.org.uk

www.butyoudontlooksick.com/the-spoon-theory

www.nice.org.uk

www.entitled.co.uk

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