



Serving ME/CFS patients, carers and interested parties in Glamorgan

## Chairs Report April 2010 – April 2011

Hello everyone, it has been another busy and eventful twelve months. On the 14<sup>th</sup> May 2010 our **Annual General Meeting & Therapies day** took place in conjunction with the National M.E. Awareness week. Two new committee members were voted in; Dee Penny and Gina Fisher.

11<sup>th</sup> August; our annual **'Tea in The Park'** event took place in the Roath Park café and was enjoyed by those who attended.

On the 28<sup>th</sup> September, I attended the **Action for M.E. conference** on behalf of MESiG, accompanied by Membership Secretary; Chris Davies.

On the 23<sup>rd</sup> October several MESiG committee and general members attended the **M.E. 'Question Time'** event at the County Hall in Cardiff which was organised by WAMES and the ME Association.

MESiG obtained **funding** from the **Big Lottery** to run a **course** teaching useful techniques to help people cope with symptoms of M.E. Marilyn Godfrey facilitated the course which ran from October 2010-February 2011.

We held our yearly **Christmas party** on the

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29<sup>th</sup> November. There was a buffet, raffle and bran tub. The festivities were thoroughly enjoyed by all.

During our committee meeting in November, Gemma Phillips and Martha Thompson were voted in as **new committee members**.

A **Zumba Christmas Party fundraising event** took place on the 27<sup>th</sup> December at the Park Conservative club on City Road, Cardiff. Christalla's daughter Irene; organised the occasion which featured a host of dancers and singers. The event was headlined by the famous Sian of 'Kosheen'.

In January the **venue** of the Monday Support Group meetings was **moved** from 'Thornhill Centre' to the 'Ararat Centre for the Community' in Whitchurch, Cardiff.

January 26<sup>th</sup> 2011, Gemma and Chris attended a **Cardiff Health and Social Care Network and Health Alliance event**, this was part of 'What Matters'-Cardiff's Integrated Partnership Strategy Consultation on Health, Social Care and Wellbeing Operation Plan 2011-2014.

MESiG applied for a **grant** through the **Voluntary Action Cardiff (VAC) Impact Plus Grant Scheme**, in order to upgrade our **IT systems**. We were successful in our application and on 28<sup>th</sup> February we were awarded £1389.23.

On March 1<sup>st</sup> I attended a **health watchdog meeting** with Chris, organised by Cardiff Health Council. The Chairman Steve Allen expressed an interest in our quest for services.

On the 7<sup>th</sup> March another **Fundraising performance evening** was again facilitated by Irene Davies. This event was an even bigger success than the one held in December, raising much needed funds for our support group.

**Speaker** Dave attended meeting March 7<sup>th</sup> in Ararat to demonstrate Balancers.

Also in March, committee member **Athena Harris resigned** her position due to other commitments. Many thanks, Athena, for your

support and contribution to MESiG during your tenure as a committee member. Although Athena has stepped down she continues to support our support group in a non-official role.

An important milestone for our support group took place during the month of March with the official **launch of the MESiG website**. A special thank you, to our Secretary, co-editor & Website facilitator; Gemma Phillips.

MESiG received a **donation of £400** from Arlene, in memory of her son Huw, an M.E sufferer who sadly passed away after contracting Swine flu.

The Mackintosh Tuesday evening **meetings ceased in April** due to a lack of attendance. I would like to commend member; Linda Shakespeare for her hard work and commitment in hosting these meetings for several years, and her continuing support.

Also this April a **survey** form was circulated to all MESiG members.

Sadly Martha Thompson was **unable to continue** as a committee member due to her University studies. Although Martha spent a few short months with MESiG we valued her contribution.

I would like to take this opportunity to thank each and every committee member for their hard work, commitment and support towards me during the past twelve months. Linda Tatham (Treasurer), Christalla Davies (Membership Secretary & Co-Newsletter Editor), Gemma Phillips (Secretary, Website Facilitator & Co-Newsletter Editor), Gareth Price, Dee Penny, Gina Fisher and Linda Shakespeare.

Best wishes and what I trust will be a healthier year ahead from your Chairman, **Ken Bailey**.



## Welcome to the 21<sup>st</sup> Century

Members we hope will be thrilled to learn that we are now online! Our new MESiG website was launched on March 26<sup>th</sup> and now anyone can access our services. Members can view up to date news and events with just the simple click of a button, share their story with the world in an effort to raise awareness of M.E/CFS and Fibromyalgia and emphasise the struggles we all face, obtain information with regards to permitted work schemes and benefits and much more. Some of the new features also include a shop facility where members have the opportunity to legally advertise the skills they offer and the items they produce. We have also launched a Penpals scheme for those of you who would like to extend your social outreach.

Members are urged to login in at [www.mesupportinglamorgan.co.uk](http://www.mesupportinglamorgan.co.uk) and browse at leisure. If anyone has any queries with regards to the website or would like to add appropriate information they can contact Gemma directly at [gemmaphillip47@yahoo.co.uk](mailto:gemmaphillip47@yahoo.co.uk). For those of you who don't have access to the internet or simply prefer not to use it, fear not, we shall still be sending you any important updates via post and the twice annual Newsletter.

## Bag a bargain

For all you shopaholics we're pleased to tell you that being launched along with the new website is a new and unique shopping experience. Committee members wanted to be able to offer our members a chance to promote the skills they have and the private work they are able to do, without jeopardising their benefits. The members' online shop does just that under the rules of permitted work schemes, which by law allow individuals claiming various benefits to undertake various types of work. The shop is

dedicated to those individuals who want to share their talents with a wider audience. The aim, as well as advertising, is to bring in some much needed additional income for these brave members, who have the will to try. We all have a talent, it's just a matter of finding it and doing something with it that can prove profitable.

If you have a talent you'd like to share or crafted items you'd like to offer please contact Gemma Phillips, who can work with you to set your own advertisement up on the new website and help you to get your feet off the ground. All members are advised to read through the permitted work scheme rules, which are displayed on the website and speak to their benefits advisor to be sure of which rule applies to them and their particular benefits setup before making a decision.



## Funding success

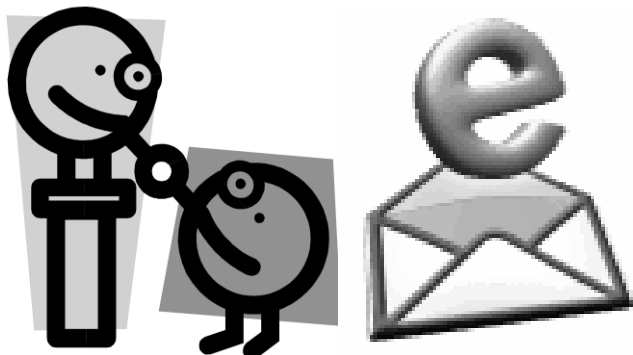
We hope members will be delighted to learn that we have been awarded a grant to purchase IT equipment. VAC (Voluntary Action Cardiff) presented us with a cheque for £1389.23 to supply our committee members with up to date software and equipment that will allow us to provide continuing and improved services to our members.

We therefore like to say a big thank you to VAC for making this possible!



## The penpals scheme – extend your social outreach.

MESiG is now able to offer its members a new and innovative scheme designed to branch social gaps and encourage communication, thereby preventing isolation. The penpals scheme relies on the pairing of members with similar interests and circumstances, unless otherwise requested. These members are then urged to continue independent relationships via email, letter or text to in effect become a buddy. Someone you can freely and confidently confide in, chat with and exchange advice with. Someone who can share and appreciate your experiences and generally be there in times of need. Just someone to talk through the everyday dramas with. We don't need to be in the same room, or even the same country as someone in order to socialise with them. Long distance relationships can work well and be a tremendous form of support. If anyone would like to join the scheme simply email Gemma Phillips at [gemmaphillips47@yahoo.co.uk](mailto:gemmaphillips47@yahoo.co.uk) and provide her with a few simple details that will be requested.



## Pain Relief Foundation - Fibromyalgia Syndrome

As most of us will be aware, Fibromyalgia is the name given to a particular group of symptoms the main distinguishing feature of which is chronic pain. There is no cure for Fibromyalgia and the current treatment regime is aimed at relieving symptoms and managing the condition. Everyday painkillers have been found to help, but the most useful treatment is a programme of exercise and relaxation to recondition the body. These exercises are used in pain management classes and are included in a relaxation CD currently being offered by the Pain Relief Foundation.

Responding to the need for a better understanding of this condition the Foundation has also recruited a new researcher, Nick Fallon, who has commenced a new study and began looking at Fibromyalgia. The study will monitor a large number of Fibromyalgia Syndrome patients based in the North West. The tests will look at the central nervous system, skin conductance, respiration, heart rate and the response to pain. A control group of healthy individuals will also be tested so that the results can be compared to identify the differences between the two groups.

Pain Relief Foundation does not receive any government funding, or support from the health service or any other public body. Their funds are provided entirely by donations from generous people, trusts and companies. To carry out this vital research the Foundation is asking for your help. They ask that you support their work to ease the suffering of those in chronic pain by making a donation.

If you'd like to do so or if you'd like to purchase their relaxation CD or other CD's, Tapes or Leaflets please write to:

Pain Relief Foundation  
Clinical Sciences Centre  
University Hospital Anitree  
Lower Lane  
Liverpool  
L9 7AL

**Tel: 0151 529 5820**

email: [secretary@painreliefoundation.org.uk](mailto:secretary@painreliefoundation.org.uk)

or check out the website at:

[www.painreliefoundation.org.uk](http://www.painreliefoundation.org.uk)

**Sourced from: [www.painreliefoundation.co.uk](http://www.painreliefoundation.co.uk)**

## Social Services

Did you know that your local social services can help you to adapt your home to accommodate your needs and that in most cases this is free of charge? If you struggle to remain independent as a result of your ME/CFS or fibromyalgia then give your local department a call. They can help with things as simple as taking a bath, getting out of bed, getting up the stairs and basic mobility around your home. Basically they help you to retain your independence. Don't delay, call your local branch today and see how they can assist you.



## Medical Aids

## Laughter Corner

Q. What's the definition of mixed emotions?

A. When you see your mother-in-law backing off a cliff in your new car.

You should always give 100% at work...

12% Monday; 23% Tuesday; 40% Wednesday;  
20% Thursday; 5% Friday

Q. Did you hear about the man who was tap dancing?

A. He broke his ankle when he fell into the sink.

*If you've got any jokes to share send them in to Chris or Gemma and we'll publish as many of them as we can in the next edition.*



## Our Chris is a Winner – But we all knew that!

Recently Action for M.E ran a competition asking people to suggest advice for people newly diagnosed with M.E.

Our membership secretary Chris Davies decided to enter and her advice was shortlisted and in the final 3. All 3 articles then went to public vote and Christalla's article won!

As her prize she received high street vouchers of her choice to a value of £25.

All three options will appear on the new Action for M.E website and can be viewed at [www.actionforme.org.uk](http://www.actionforme.org.uk)

Here is Christalla's advice:

“STOP and listen. Your body is trying to fix itself and needs complete cooperation.

Practice relaxation techniques, to help tune in to what your body needs to assist the healing process.

Be prepared to make change, eliminate stress, ask for help, seek a supportive GP, clean diet, keep hydrated, tackle sleep problems, be kind to yourself.

Take note of people close to you and how you feel, distance energy drainers, love and forgive, most importantly yourself.

Pay attention to what you can do and rejoice in that. Never lose hope, this illness is a lesson in discovery, embrace the journey.”

**Congratulations Chris – we're all so proud of you!**

## **Esther's Editorial - a black day for ME/CFS Sufferers!**

**Earlier this year Esther Rantzen; dedicated supporter of M.E causes, shocked the M.E community by stating that she has finally discovered the reason for her daughters '14 lost years'.**

Esther's eldest daughter Emily was struck down with M.E at the age of 14 after contracting glandular fever and ever since then Esther has campaigned for the rights of M.E sufferers in an effort to raise awareness of the condition and find suitable and effective treatments. Now she declares the condition could actually be as a result of an intolerance to gluten!

Coeliac disease is the common name given to the condition where gluten cannot be tolerated by the body and has a number of symptoms in common with M.E. Diagnosis of the condition can be confirmed by a simple blood test and a biopsy of the small bowel. Esther is now urging all M.E sufferers to get tested for Coeliac disease, believing that it may now be the major undiagnosed cause and states that 'if it is, giving up wheat, rye and barley is a simple way sufferers can have their lives back'.

Some feel that Esther has done the M.E community a great disservice with her recent comments others take an opposite view. Early indications do seem to be that Emily Rantzen's condition has improved since she excluded gluten from her diet but that it is still early days and there is no indication, despite the improvement that she is in fact cured and completely free of symptoms. Research indicates that food intolerance is a symptom commonly identified amongst M.E sufferers and even though changing your diet does usually have some positive effect

many sufferers find that the majority of symptoms often persist.

We leave you to draw your own conclusions and make your own decision as to whether or not a change of diet is the answer you've been searching for.....if it is we wish you every success.

**Sourced from: Daily Mail 12<sup>th</sup> February 2011**  
[www.dailymail.co.uk](http://www.dailymail.co.uk)



### **Disabilities Wales – here to help!**

Members may be interested in a new manifesto for independent living being put forward by Disability Wales. DW is the National association of disabled people's organisations, striving to achieve equality, rights and independence for all disabled people, regardless of physical, sensory or neurological impairment, learning difficulty or mental health conditions. It was established in 1972 as an independent, not for profit membership organisation of disabled people, disability groups and allies from across Wales. All board members and most staff members identify themselves as disabled people. Their core policy is to reflect the views of disabled people's organisations to government with the aim of informing and influencing policy.

Currently their focus is on the ESA benefits system and like us they are eager to hear from anyone who has experienced benefit or service cuts. Disability Wales are seeking case studies to support a campaign aimed at raising MP's awareness of the impact of welfare and service cuts on disabled people in Wales.

The squeeze on public sector finances is resulting in cuts to services across the country. This combination of welfare and service cuts is having



a “double whammy” effect, increasing the likelihood that growing numbers of disabled people will experience poverty and social exclusion.

Having identified a number of MPs from each of the main parties who they wish to hold discussions with, they are particularly keen to hear from disabled people and disabled people’s organisations in the following constituencies:

**Bridgend, Neath, Cardiff Central, Cardiff North, Brecon & Radnorshire, Preseli Pembrokeshire, Vale of Glamorgan, Carmarthen East and Dinefwr, and Arfon.**

They want to take individual cases to meetings with the MPs in these areas, in the hope that hearing their constituents’ concerns will prompt them to take action within their range of influence. They guarantee not to reveal individual identities without having express permission.

Our new secretary, Gemma Phillips has been working with Paul Swann; Policy officer for Disability Wales in an effort to demonstrate to MP’s just how poor the flawed system is and the devastating affect it is having on the disabled community. Gemma has recently completed a video interview detailing her experience of the system, which will soon be available to view on the Disability Wales website. Members may be encouraged to know that following a lengthy process Gemma was successful in securing her ESA benefits and an apology from the Tribunal services for the months of stress and anxiety it had resulted in. Paul Swann urges other individuals to come forward and take a stand.

If you’d like to offer your story as a case study to Disabilities Wales please contact:

**Paul Swann**

Policy Officer (Independent Living)

tel: 02920 887325, email:

[paul.swann@disabilitywales.org](mailto:paul.swann@disabilitywales.org)

or check out the website at: [disabilitywales.org](http://disabilitywales.org)

**Paul will be attending our monthly meeting on 5<sup>th</sup> September 2011 to give a talk and answer any questions. We hope to see you there.**



## **ESA – How are you managing?**

**New ESA benefit assessments are causing a number of problems for genuine claimants who suffer from chronic conditions such as M.E.**

In an effort to assist our members and offer as much support as we can during this time you will find attached to this special edition of the newsletter an information leaflet concerning the new benefits scheme, which offers advice regarding what to expect throughout the ESA process in an effort to prepare members for what is to come.

For those of you who have already commenced the new ESA process MESIG would be grateful for you to share this experience with us, regardless of the outcome. Our committee members are currently working with other organizations in an effort to improve this system but we simply can’t do that unless we can demonstrate the systems flaws and the effect it is having on individuals with genuine chronic illnesses.

If you’d like to share your experience please contact Chris Davies or Gemma Phillips. Contact details as always can be located on the final page of the newsletter.

## Balancers Demonstration – 7<sup>th</sup> March Ararat Centre

A man called Dave Bendall attended our support group meeting and demonstrated balancers.

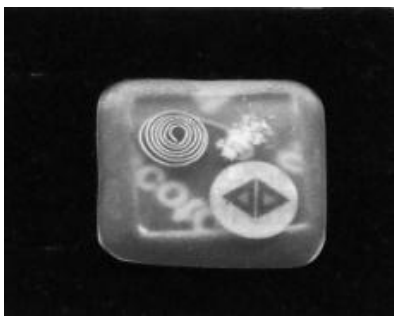
With the increased use of modern technology, the human body receives a large amount of electromagnetic waves travelling through them. These large electromagnetic waves are created by electrical and electronic devices, such as the emissions from mobile phones, cell phone towers, satellite navigation systems, fluorescent lighting, computers, monitors, cordless phones, WiFi and other electronic systems.

Due to large quantities of these emissions, surges of energy are created which in turn cause a fractional amount of chaotic disorganised energy, which irritates the body and particularly the subconscious, causing an inner stress subconsciously, which in turn can influence some of the body functions.

The natural frequencies of the Sosatec Balancer, enable the chaotic disorganised energy to be expelled from the body easier, and so reducing this subconscious irritation and stress, thus can reduce stress, improve mental agility, improved balance, and increased overall sense of well-being.

Balancers can be worn as necklace or attached to mobile phone.

For more info/demo or purchase contact: Dave  
02920362437



## Christmas Party

Thanks to all of you who managed to attend the christmas party in late November. There were quite a few of the regular faces and amongst the new included Dee's partner Peter, which was nice to see. Linda took charge of the catering for the event and bought a number of delicious things from Sainsbury's to create a really good buffet with an excellent selection, which was enjoyed by all. We extend our thanks to Linda for organising this.

The afternoon gave everyone an opportunity to exchange Christmas cards and chat to people they don't often get a chance to see. We all brought a contribution for the bran tub, which everyone wrestled with in turn to choose a gift. Amongst the gifts was a beautiful wooden angel figure, selected by Sylvia from Steve, which he had personally crafted. Chris organised a raffle and amongst the 10 or so prizes were a Piano lesson and an Aromatherapy treatment.

If you are feeling well enough do join us at any of the events or monthly meetings. We will be very happy to see you there, especially as the meetings can break up some of the isolation and frustrations that coping with M.E can create and it's also a wonderful opportunity to share useful information. We extend thanks to all who made the event a success. Be well all and enjoy the summer.

*By Gina Fisher*



## **Michael Crawford's success story**

**Michael Crawford, star of West End blockbusters Barnum, The Phantom Of The Opera and The Woman In White, is back on stage for the first time in seven years.**

He's playing the Wizard of Oz in Andrew Lloyd Webber's lavish new production at the London Palladium, and although voice problems caused him to miss some preview performances before the official first night, he insists he's fully fit – something he never thought he'd hear himself say; until recently.

For what Michael has rarely spoken about until now is that for the past seven years he has been battling the debilitating illness Myalgic Encephalopathy, more commonly known as M.E or Chronic Fatigue Syndrome.

He declared 'If anyone had told me when I was struggling with ME that one day I'd be back in London's West End, I wouldn't have thought it possible. I thought my career had come to an end because I no longer had the energy, or even the inclination, to work again'.

As he pushed himself to work before a diagnosis of M.E was confirmed Michael recalls feeling exhausted by mid-afternoon. He could barely climb the stairs at home. He found this particularly alarming because all his life he'd enjoyed doing all his own stunts in shows, taking on every physical challenge. Yet suddenly, He'd become like a very old man. He knew something was wrong, but had no idea what.'

Eventually he was diagnosed with ME, the chronic fatigue syndrome that can be triggered by a viral infection. The next step was to find out what had brought it on, and once the cause was pinpointed beyond doubt, he realised he had no one to blame but himself. It was his overactive life style!

What he thought had been flu turned into a physical meltdown. He went for all sorts of brain and body scans until ME was finally diagnosed. He had pushed his body to its' limits. Nothing seemed to cure him, so he prescribed himself constant sunshine and moved to New Zealand, living in a small house near Auckland.

For two years, he didn't feel well at all. Then he changed his entire regime, putting himself on a diet of healthy food and taking each day at a time, rather than worrying about the future. He went sailing and fishing every day and discovered the joys of gardening

After four years of ill health, Crawford was fit to work again. He got lots of tempting offers to return to performing, but was enjoying his stress-free life too much to get back on stage. During an inspirational speech he declared 'I'd always pushed myself to the limit, and look what good it had done me. Obviously, quitting did cross my mind but I thought, no, I still love what I've been doing all my life. There's nothing else I would want to do.' Eventually Michael was offered a role he simply couldn't turn down and returned to his acting career.

It just goes to show that there is hope.

**Well done Michael, we wish you continuing success!**

**Sourced from: Daily Mail 4<sup>th</sup> March 2011**  
**[www.dailymail.co.uk](http://www.dailymail.co.uk)**



**Michael Crawford**

# Treatment Centre for Chronic Fatigue Syndrome (USA)

**Dr A. Martin Lerner, M.D., M.A.C.P**

Welcome to the Treatment Center for Chronic Fatigue Syndrome (CFS), also known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). We provide comprehensive treatment for this life-altering illness.

We have, along with a team of investigators at this Center, accumulated strong evidence that CFS is caused by persistent herpes virus infection (Epstein-Barr virus, Cytomegalovirus and Herpes virus 6), singly or in combination. This infection is treated by specific antiviral medicines.

Our clinic has treated hundreds of patients who are now living normal lives.

## BACKGROUND QUESTIONS

In 1988 the United States Centers for Disease Control in Atlanta, Georgia sponsored a meeting of academic physicians who defined a syndrome called the Chronic Fatigue Syndrome (CFS). The physician-scientists described a syndrome – that is, a group of symptoms not understood by doctors – in which previously healthy young adults in their late 30's to 40's (typically) became ill with an unexplained, ongoing fatigue which ultimately was so severe that it disrupted the ordinary life of the affected patients. Exercise worsened the fatigue. A non-rotational lightheadedness was common. Multiple aches were common, and ultimately, the patients with the newly named Chronic Fatigue Syndrome could not work, shop or engage in ordinary activities of everyday life. There was no understanding as to cause, and some physicians thought this was really a psychiatric illness. But anyone experiencing such a drastic change in her/his life would become depressed.

I was unaware of their work at this time. However, the doctors assembled in Atlanta concluded that CFS was a physical illness of unknown cause. CFS offered a great challenge to physicians, because understanding the cause of an illness determines its treatment. There was no understanding of the cause of the overwhelming, incapacitating fatigue of CFS.

After a satisfying professional career of over 20 years, I left academic life in 1982. I looked

forward to practicing Internal Medicine and Infectious Diseases. My background was Infectious Diseases, particularly viral diseases. I was aware of virus induced heart disease, having studied this in my university research. This research resulted in articles as well as textbook chapters regarding cardiomyopathy.

Ultimately I became aware that the symptoms of CFS resembled a prolonged infectious mononucleosis. Infectious mononucleosis is an illness usually occurring in adolescence. Infectious mononucleosis may be caused by one of two herpesviruses: the Epstein-Barr virus (EBV) or the Human Cytomegalovirus (HCMV). These two mononucleosis syndromes are self-limited; that is, patients recover.

Fairly soon, I asked myself - *Could Chronic Fatigue Syndrome be a prolonged mononucleosis syndrome?* There isn't anyone who has any kind of a heart condition who isn't fatigued. *Could Chronic Fatigue Syndrome also involve the heart?*

## EVIDENCE

I began to look at patients with CFS for evidence of involvement of the heart, and experience (by tests of blood for antibodies) with the two mononucleosis viruses, EBV and HCMV. The findings have been remarkable!

## Abnormal Holter Monitoring

Abnormal T-wave flattenings and inversions are found in patients with the US Centers for Disease Control defined CFS. This finding has been tested statistically, and we can now say that 90% of patients with CFS have abnormal 24-hour monitoring. This is a biomarker. The absence of abnormal Holter monitoring leads us to believe that CFS as the cause of fatigue is less likely. The T-wave of the electrocardiogram records repolarization (electrical recovery) of the left ventricle after every heartbeat in preparation for the next heartbeat. The normal T-wave is upright. With increased heart rates the abnormal T-waves occur. Abnormal oscillating T-waves occur with exercise. The symptoms of CFS are worsened by exercise, a striking coincidence.

## Abnormal Contraction of the Heart

Patients with CFS who have been ill for months may have abnormal cardiac dynamics. This means that the rhythmic, symmetrical, wonderful symphonic-like harmonious closure of the left ventricle is now asymmetric. This indicates that there is some weakening of the left ventricular

muscle. (Patients with coronary artery disease may also have abnormal left ventricular dynamics.) We have found that approximately 1 in 4 patients with CFS who has been ill for one year or more has abnormal asymmetric abnormal cardiac dynamics. It is indeed frightening to hear of weakening of the heart muscle. Therefore, at this time and out of context, I report that the treatment with anti-viral medicines, which we use, may reverse this heart muscle weakness, and return it toward normal!

### **Heart Biopsies Show Cardiomyopathy**

Biopsies of the heart from CFS patients indicate that there is cardiac involvement. I have been fortunate to attract a very talented group of physicians interested in studying CFS with me. They are Dr. Howard Dworkin, formerly Head of Nuclear Medicine at William Beaumont Hospital (WBH); Dr. William O'Neill, formerly Head of Cardiology, WBH, and presently Clinical Dean, University of Miami School of Medicine; Dr. James Goldstein, Academic Cardiologist, WBH, and Dr. Marcus Zervos, formerly Head of Infectious Diseases Research, WBH, now Chief, Infectious Diseases, Henry Ford Hospital, Detroit. Thomas Fitzgerald, Ph.D., Statistician on the faculty of the University of Michigan Hospital has been and is a continuing important collaborator. Sio Beqaj, Ph.D, molecular biologist, currently Director of Path Group Laboratory, Nashville, TN, has been and remains an active collaborator. He is also Director of the laboratory at the Treatment Center for CFS, Beverly Hills, MI. Robert G. Deeter, Ph.D., formerly of Anti-Infectives, GlaxoWellcome Co., now at AmGen Laboratory, California, was an active collaborator. In addition, Dr. C.H. Chang, Anatomic Pathology, WBH, has done special staining and electron microscopic studies of cardiac biopsies of CFS patients.

### **Viruses**

There is firm evidence in CFS patients that active Epstein-Barr virus (EBV), active cytomegalovirus (HCMV), active Human Herpesvirus 6 or a combination of these viruses, are common findings in patients with CFS. In 1997, Dr. Lerner hypothesized CFS is caused by 3 herpesviruses: EBV, HCMV and/or HHV6. These three viruses establish "latent" infection in B-lymphocytes, monocyte-macrophage precursors, or T-lymphocytes respectively. Virus reactivation, and both abortive and complete virus multiplication occur. Therefore CFS patients have been described with continuing primary or reactivated infections.

### **Treatment**

In a controlled pilot study (random and blinded) the antiviral drug valacyclovir (Valtrex) is shown effective in reducing the fatigue of single virus EBV CFS. A blinded trial of valacyclovir has been completed and confirms the original study. Initial studies involving subsets including HCMV and HHV6, utilizing the antiviral drug valgancyclovir (Valcyte), are also successful and exciting. When patients are treated with appropriate antiviral medicines after specific proof of EBV, HCMV and/or HHV6 virus active infection (subset classification), research has shown significant improvement in cardiac and CFS symptoms.

### **COMMENTS**

Any new infection (such as the common cold or bronchitis, or sinusitis, or a urinary tract infection) will worsen the symptoms of CFS. These common infections must be treated vigorously.

Exercise must be avoided, but living within the parameters of doing what you can do without ensuing exhaustion is encouraged. In other words, activities that increase your heart rate must be avoided.

Alcohol may be a cardiac toxin. I ask that CFS patients not drink alcohol.

Other conditions also may be chronic and may worsen or accompany CFS, for instance, chronic Lyme disease. Other co-existing conditions must be found and treated (e.g. high blood pressure, diabetes mellitus).

Of course, we want CFS patients to be well; we want CFS patients to live normally. We want CFS patients to be able to exercise, but I ask our patients not to exercise until her/his [Energy Index Point Score®](#) (EIPS®) improves to 8. A CFS patient has an EIPS® of zero if bedridden. An EIPS® of 5 allows a CFS patient to keep a sedentary job, but do little else. A CFS patient with an EIPS® point score 7 does not need to nap during the day.

[www.treatmentcenterforcfs.com](http://www.treatmentcenterforcfs.com)

# Breakspear Hospital

We have been made aware of Breakspear Medical Group, who specialise in the treatment of allergy and environmental illness.

This privately-owned and operated day clinic is located in Hemel Hempstead, Hertfordshire and offers many different clinical services to treat a variety of conditions with fully qualified, caring staff.

**How Breakspear Medical Group can help with chronic fatigue and myalgic encephalomyelitis**  
Breakspear has always had a policy of identifying causes and then offering treatment.

With chronic fatigue patients, they search for infectious agents such as Epstein-Barr virus, Parvovirus B19 and bacterial, rickettsial and parasitic organisms using a variety of tests and laboratories.

The treatments the clinic offers are anti-viral treatments, high-dose gamma globulin to treat Parvovirus and complex treatments for rickettsial and bacterial disease. They also use [hyperthermia treatment](#) to simulate the pyrexia of illness and support nutrition. Where people with CFS and/or ME have developed intolerances to foods, these are also recognised and treated using antigen-specific, low-dose immunotherapy.

They have found that the basis of prolonged ill health in CFS or ME involves "cytokine shift". In this condition the protein messengers between cells (cytokines) work together to cause allergy and increased reactivity by a mechanism involving antibodies instead of the normal activity against infectious agents, such as viruses. This is a cytokine shift from a "TH1" to a "TH2" pattern.

The situation is further complicated as these two patterns interact. In chronic fatigue or ME patients, allergies are perpetuated and the ability to wipe out viruses is compromised. However, they claim it is possible to reverse this

shift with a number of chronic fatigue treatment programmes that they offer. Treatment starts with a series of skin and blood tests for bacterial sensitivities, urine test for microbial organism products and peptides (indolyl-acryloylglycine), and we also use a stool test for lysozyme, a product of white cells called granulocytes, monocytes and macrophages. (This is a marker for damage to the gut lining by bacteria or by inflammatory bowel diseases, such as Crohn's disease and ulcerative colitis.)

Then they stabilise allergies by using low-dose immunotherapy that stops allergic reactions, giving respite to the chronic fatigue or myalgic encephalomyelitis sufferer. They also initiate a number of treatment programmes to stimulate the TH1 arm of the immune system that can deal with viruses. Amongst the other treatments they use are mushroom products, and Transfer Factor, which is an oral supplement, agents that can stimulate TH1 include some hormone products and bacterial agents such as Bacille Calmette Guérin (BCG), normally used in the protection against tuberculosis. They also now have available a bacterial product, known to help modulate the immune system. This is a high potency probiotic preparation that Escherichia coli, Bifidobacteria and others have a local effect, protecting against gut mucosal injury through both TH1 and TH2 responses.

Combination therapies for the treatment of chronic fatigue and myalgic encephalomyelitis are more effective than single agents

**Breakspear hospital are currently offering a test for the diagnosis and treatment of M.E/CFS known as the Quantitative Inotropic Fatigability Test (QIFT). Log on to the following websites to find out more.**

[www.medicalinsider.com/identification.html#qift](http://www.medicalinsider.com/identification.html#qift)

[www.breakspearmedical.com](http://www.breakspearmedical.com)

## SOS Talisman

People might be aware that medical alert jewellery is available to purchase from various locations; which is used to alert to paramedics and other medical professionals to a patients history in the event of an emergency but are you aware there are different types of jewellery that can be purchased, some of which may be more appropriate for you than others.

The most common type which we're sure members will be familiar with is the metal plate jewellery, which can be inscribed with brief information. The problem is the information is very brief and can't be altered and in most cases only the patients name and condition can be detailed. For this reason we feel it's important the everyone is aware of the alternative – SOS Talisman's. These come in the form of a pendant of bracelet and can be decorated with a variety of designs but all are still recognisable to medical professionals. The great thing about these is that instead of a few words of inscribed text they can hold many details on a folded piece of paper that is contained within the pedant or bracelet. Inserts can be purchased for the Talisman's for around £1 if preferred or alternatively patients can choose to type out or write out their details on a small piece of paper and fold it up to fit inside.

The most beneficial things about this is that you can amend the details to suit, for example as medication is changed. With M.E being such a complicated condition and widely misunderstood it's a good idea to provide as much information as possible in an emergency so that you get the best possible care and that's why feel everyone should be made aware of these great little items, which can be purchased as cheaply as £16.50 + £2.95 P&P on eBay. You can also go one step further and purchase an SOS pin badges to

display on your jacket to make sure your bracelet or pendant gets noticed. Why not take a look!



## M.E.S.I.G 2012 Calendars

Committee members are currently working on new ways to promote MESiG and raise awareness for M.E/CFS. In an effort to do this we are considering putting out a calendar for 2012 and as a contribution we are asking members to forward any photo's or images they have that they feel depict what it's like to live with M.E. The best ones will be selected for inclusion in the calendar.

You may also like to include a little anecdote, caption or phrase to go with it.

Please send your suggestions in by email or post to either Chris or Gemma.





# NHS Watchdog

## They want to listen to your patient stories!

The CHC is a statutory organisation – the independent voice of the public and consumers of health services. They monitor the quality of the NHS services provided in Cardiff and the Vale of Glamorgan. This is achieved by:

1. Representing the views of the public within the NHS, ensuring that local health care needs are recognised and raising public awareness of NHS issues.
2. Monitoring and evaluating from a patient's viewpoint the effectiveness of NHS services provided – for example, hospitals, GP Practices, dentists, pharmacies. This includes undertaking monitoring visits to those services.
3. Providing independent help and advice to individuals who have problems with or complaints about NHS services
4. Acting as a voice for the community on the standards and appropriateness of local health services – having consulted local people and gathered public views.
5. Ensuring that local views and needs influence the policies and plans of the Local Health Board (LHB) and NHS Trusts
6. Providing public opinion on consultation documents – from the Welsh Assembly Government, LHB, NHS Trusts and other organisations.

## To help them in their role, we would like to invite you to send in your patient stories.

To tell them about your experience of using any of the NHS services, including:

1. Primary Care Services – GP Practice, Dental Services, Pharmacy, Opticians, routine patient transport and volunteer drivers to take you to and from hospital outpatient and
2. Clinic appointments
3. Emergency ambulances
4. Hospital Services

## What are patient stories?

Patient stories are where patients and carers are able to discuss their experience, often relating to

chronic ill health or a traumatic event, to enable them to reflect on the experience. The stories are not just a sequence of events but include the emotional effect of the experience and the story-tellers expectations and needs. Patients can provide a valuable insight into the quality of the healthcare they have received and their opinion of the services provided. The therapeutic benefits of this have long been recognised but there can also be benefits for the service provider.

## What is the benefit to the CHC?

1. Patient stories will enable the CHC to be aware of the patient's experience of the NHS.
2. Allow patients and carers' voices to be heard
3. Encourage reflection by the storyteller and those who hear / read the story
4. Highlight any improvements that need to be made to the health services provided
5. Reveal situations which did not, but could have resulted in injury, damage or loss.
6. Put patients needs at the heart of service development and improvement
7. Taking the needs of the patient into account will lead to a better understanding of patients' needs, concerns and their priorities and result in more effective services.

**Please note that patient stories should not be used for making a complaint - please visit the [NHS Complaints: How We Can Help](#).**

## Confidentiality and consent

What you decide to tell NHS Watchdog will be used in the strictest confidence.

Stories that are published on the website will normally appear with the story teller's first name and age - but you can let them know if you would prefer for your story to remain anonymous.

Please remember that, if you decide to take part, you can change your mind at any time. You do not have to provide a reason for this decision and any information already provided by you will be destroyed.

## How you can tell them about your story?

If you would like to tell them about your experiences of the NHS, **in no more than 2500**



**characters**, you can do so by using the Patient Stories Submission Form. The Consent Form and Submission Form can be downloaded and completed from:

[www.wales.nhs.uk/sitesplus/documents/897/pages/45747](http://www.wales.nhs.uk/sitesplus/documents/897/pages/45747) and click on:

Patient Stories – Consent Form and Submission Form.

Please return the completed form to the CHC:

Cardiff & Vale of Glamorgan Community Health Council

Ground Floor

Park House

Greyfriars Road

CARDIFF CF10 3AF

Email: [chief.officer@cardiffchc.org.uk](mailto:chief.officer@cardiffchc.org.uk)  
[advocacy@cavogchc.org.uk](mailto:advocacy@cavogchc.org.uk)

Get involved on Facebook:

[www.facebook.co./cavog.chc](http://www.facebook.co./cavog.chc)

Or join our E-Consultation Group:

[e-group@cardiffchc.org.uk](mailto:e-group@cardiffchc.org.uk)

check out the website at:

[www.communityhealthcouncils.org.uk/cardiffandvale](http://www.communityhealthcouncils.org.uk/cardiffandvale)

Sourced from [www.wales.nhs.uk](http://www.wales.nhs.uk)

*On March 1<sup>st</sup> Chris and Ken attended a health watchdog meeting, organised by Cardiff Health Council. The Chairman Steve Allen expressed an interest in our quest for services. Due to poor health have not managed to arrange a meeting as yet, but is in the pipeline.*

## MEMBERSHIP REMINDERS

**Membership of £6 is now due for May 2011-12.**

**Many thanks to those you have renewed and for generous donations.**

**Cheques payable to M.E.S.I.G, 75 Llanon Rd, Llanishen, Cardiff, CF145AH.**

## Cardiff Health and Social Care Network CHSCN

January 26th 2011, Gemma and Chris attended a Cardiff Health and Social Care Network and Health Alliance event. This was part of 'What Matters'-Cardiff's Integrated Partnership Strategy Consultation on Health, Social Care and Wellbeing Operation Plan 2011-2014.

Chris and Gemma attended on behalf of M.E.S.I.G with the intention of highlighting the need for services for people with long term chronic conditions such as M.E.

Unfortunately Gemma collapsed and ended up in hospital before any verbal message got across. Chris joked that they were meant to tell them not demonstrate our needs.

P.S Gemma is ok, just got a little too ambitious with her energy levels and had a few obstacles put in our way that day.



*Some of our members at one of our monthly meetings*

## Support Group Meetings

Meetings are held every first Monday of the month from **2.30pm-4pm** at the **Ararat Centre for the Community, Plas Treoda, Whitchurch, CF141PT** (unless this falls on a bank holiday, in which case the meeting will be held the second week of that particular month). Please note: no meeting in AUGUST.

**Meetings will no longer be held at Keppoch Street from April 2011.**

# Fundraising Events

Irene Davies (Chris' daughter) arranged 2 fundraising events for MESiG, Irene was inspired to help after her mum mentioned trying out something called a BIOMAT at one of the course meetings. A member had very kindly brought it along for people to try, mum had been feeling particularly awful that day had been given a boost just from lying on it for 10 minutes.

We hope to purchase one for the group. There was one on loan available to try at the AGM/Awareness Event on Saturday 14<sup>th</sup> May.

Both events were held in The Park Conservative Club on City Rd in Cardiff on 27<sup>th</sup> December and 7<sup>th</sup> March. The events involved having lots of fun and being entertained. There were a host of professional performers who gave their time freely to support people with M.E. These included singers, dancers and DJ comedian John Patrick. There was such a variety in styles, something to suit everyone, whether you liked opera or hip hop. We were also supported by celebrity Sian of Kosheen on both occasions. Kosheen was (and still is) breathtakingly awesome as I'm sure those who attended would agree. In between the acts people could join in with some Zumba line ups led by Irene and had an opportunity to show their own moves

There was a raffle and nibbles were provided and Chris gave a talk about M.E.

It was truly heartwarming that so many people were willing to do their bit to help us whether they performed, offered their services, attended or donated.

A special thanks firstly to Irene Davies for making it all possible, to John Scaccia for the use of venue, to top Dj John Patrick, to cameramen Hoosh and Dave, to members Ken, Julie, Dee for their exceptional support, to friends Alex and Liz, all the performers for their time and talents and

last but not least all who attended especially braving Decembers snowy/icy conditions. The sum of £663 was raised in total.

[www.ipdiscosouthwales.co.uk](http://www.ipdiscosouthwales.co.uk)

[www.kosheen.com](http://www.kosheen.com)

[www.iredance.co.uk](http://www.iredance.co.uk)



**Chris, Irene and Sian of Kosheen**



**Zumba line up led by Irene**



**Capoeira Dance Group**

## **'Herbalife' Sera's success!**

*It's always great to hear that someone has been successful and found something beneficial when it comes to treatment and here's hoping Sera Yorwerth's story will prove inspiring. Written in her own words we can think of no better way to share this with you.*

"3 years ago, I was diagnosed with M.E. I was pretty desperate back then and hoped there was a cure. I was glad to know I wasn't alone and there was support available. In the last year I found something that might be of help to others.....

During the past 3 years I've experienced so many of the extreme physical and cognitive lows this illness can deliver. There have been times when I've felt like the illness may have actually been verging on burning itself out. Too soon I found myself back in bed, in the dark with a belly full of pills to ease the symptoms.

Last Easter my sister got married. As her bridesmaid, I feared that I would struggle to maintain any strength during the wedding and also be laughed at for gaining so much weight, since I hadn't been able to exercise like I used to. A friend suggested I try a product that had been gaining popularity amongst his fitness instructor friends. It was called Herbalife. I used it the week before the wedding and found I'd lost 4 lbs, which was great. More interesting was that I had experienced a lift in my energy and memory. I wasn't totally convinced that this was only due to the products so when the two weeks supply ran out, I didn't buy anymore.

By mid-summer, my body seemed to be giving up again. I'd tried to eat as healthily as I could but it was getting more difficult as my energy levels depleted. The worse I got, the less time I could invest in cooking and taking care of myself. At my lowest, I experienced paralysis in my legs and feet. I was admitted to the Princess of Wales hospital in Bridgend for investigations to be carried out. When the Doctor's found nothing I was told to go home, stop fussing and do some exercise!

It was at this time that my husband, in desperation insisted I try the Herbalife products again. This time he wanted me to follow the plan strictly. The shakes helped provide all the basic protein, vitamins and minerals I needed.

It took 6 weeks before my body began to recover. My energy levels lifted to around 60%. Unfortunately, if I

caught a slight cough or cold I would still get ill fast. That said, I definitely recovered quicker.

When my husband saw this, he decided to invest some time researching the other products the manufacturer offered. He eventually began working for Herbalife as he'd seen first hand how well they work for athletes in training including decathlon competitors and footballers, for weight loss and for people like myself - experiencing poor health. I've used the Herbalife products continuously and strictly for 7 months now and have most certainly had a huge improvement in my life. There has been a launch of a new product by Herbalife that has most benefited me recently which is Quick Spark. It contains Co Enzyme 1 which, it says on the packet - 'has crucial role in many cellular processes including production of ATP....and is the primary enzyme in the production of cellular energy'.

I'm not trained in explaining how it works except to say that I know it helps the body at a cellular level and is not a stimulant drug. Also, there are 7 new products being developed and patented that specifically target muscle recovery after exercise. I will be trying these when they come out to see if I can walk further and finally do some regular exercise."

*We are thrilled for Sera and hope the relief she's experiencing will last indefinitely and that she continues to improve and is able to do all the things she and the rest of us would sometimes never think possible again.*

***If members are interested in learning more about Sera's story and Herbalife products then we urge you to attend our monthly meeting on July 4<sup>th</sup>, when Darren Yorwerth will be generously donating his time to talk to us about the products. Sera has also kindly offered to talk directly to members about her experience and has provided her contact number which is 01656 737658.***



## Mickel Therapy

This is considered by some, to be a ground-breaking and effective treatment for **Chronic Fatigue Syndrome (CFS)/ Myalgic Encephalomyelitis (ME)** and **Fibromyalgia (FMA)**.

Developed by UK-based medical doctor, Dr David Mickel, the treatment involves no medication, dietary change, supplements or psychotherapy of any sort - it is a truly unique approach in a genre all of its own. Treatment involves a series of 1 hour face to face sessions during which you will learn why your symptoms are there and, crucially, how to work with them to regain your health. Mickel Therapy is a process that involves identifying and rectifying the cause of symptoms rather than working directly on symptoms. It is not 'passive healthcare' and does require the involvement of patients in the process.

We know that the notion of a talking therapy allowing you to free yourself of a hugely debilitating physical condition might sound improbable but the reported success rate is very favourable. Statistics show that to date, over 2000 people have successfully applied the tools and techniques of Mickel Therapy.

For more information regarding Mickel therapy and who to contact members are advised to visit [www.mickletherapy.com](http://www.mickletherapy.com)



## 'TEA IN PARK' Invite

Thursday 11th August 2.30pm

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

All are welcome.

Do come join us.



## Mickel Therapy Recovery Story - Helena

August 2010

I wouldn't say I'm completely without ME yet, I'm not fully out of the woods, but I'm in the outskirts and there are plenty of clearings and blue sky. It no longer feels right to say "I have ME" but rather to say "I'm recovering from ME". I'm sharing the following with you as my story. I'm not suggesting this is what others with ME need to do. However if any of it is at all helpful for anyone, that's wonderful.

I lived with ME for over 40 years so the recent rapid recovery is a curious experience. For nearly 30 years I'd just very gradually got worse until for a few years I was unfit to look after myself and classed myself as disabled.

I'm seeing that the recovery is due to three things.

Firstly, Raja Yoga as taught by the Brahma Kumaris. [www.bkwsu.org/uk](http://www.bkwsu.org/uk) and tel 029 2034 3052.

Completely free of charge. All the teachers are unpaid and it just runs on donations. It is not the physical yoga of positions and breathing practices, it is a study and meditation practice which enables you to get to know yourself with exceptional clarity and depth. Also it gives a very helpful outlook on life. I've studied and practised this for 25 years and it has kept me firmly within the realm of sanity despite all the self-doubt which years of unrecognised ME generates (about 26 years in my case before anyone - the GP in fact - recognised it) and all the cruel misunderstanding people tend to have of those with ME. But much more than just sanity it gave me a deep sense of my own worth which is irrespective of the state of the body or one's role (or lack of !) in life. It also gave me many opportunities to share it with others. To be able to help others when you yourself are in such a needy state is a wonderful blessing. So raja yoga made me psychologically healthy, and that is very important. It didn't cure the ME but the self awareness it has given me is a great help in powering this recovery time forward and safeguarding against relapse (well, so far!).

Secondly, for the past fifteen months I've had great help from Emma Jones, a naturopathic nutritionist ([www.healthyjones.co.uk](http://www.healthyjones.co.uk)). She had ME, was cured by naturopathy, so trained in it herself. A very genuine person who I'd wholeheartedly recommend. I was

eating wholesome food anyway but had no idea how inadequate it was for me. I feel more nourished now than I think I've ever done in my life and have learnt lots about what food and drink is right for myself. I remember last winter when my brain state shifted and became more relaxed. Emma works with the Chinese five elements and the seasons of the year, teaching you how to benefit from each one. In all that cold weather last winter I was chuckling away because while everyone was complaining about it I was actually benefiting from the winter ! Yes really. The winter is a time for absorption, Emma taught me, for deep hydration and for rest. Use it wisely instead of fighting it and you are strengthened ready for new expansion in the spring. Another very helpful thing Emma has taught me is how to maintain a high-protein diet while vegetarian and even vegan. It works!

Then thirdly, in May, I contacted Mickel Therapy ([www.mickeltherapy.com](http://www.mickeltherapy.com)) and that provided the final numbers to open the combination lock. It worked so fast it seemed like magic, starting with a phone conversation which opened up my beliefs about ME. It gave me the belief that I could shift it with mental process. I started straightaway by applying raja yoga more carefully, tapping into the beautiful qualities and experiences which lie at the heart of each of us, deliberately going into lightness, contentment, joy, peace..... Two days after I first saw Kyle Davies (Mickel Therapy practitioner) I felt energetic in the early morning (WHAT ??) and my brain felt better than ever. "I'm better!" I thought, though a terribly sensible little voice inside me warned that this may be a rather premature idea. And yes, there were plenty more ME symptoms but the next week Kyle suggested I experiment with living as though I didn't have ME. "Play with it, as though it's a game", he said. So I did, and have never looked back.

I'd suspected for some years that somehow I myself was perpetuating the ME but just could not see how. I'd had a lot of help and thought I'd found someone who could cure me, but although I improved I still had ME. Once a friend (not one who had ME) had been told by a therapist that it was as though she was living with one foot on the accelerator and one foot on the brake. I think I've been doing something like that. As though I've been turning my energy against myself. Mickel Therapy enables you to see your blind spots which you just can't do on your own.

I no longer have the frazzled brain state of ME, even when I've had a non-stop really busy active day, though I have to take it very easy the next day. I get

naturally tired instead of agonisingly drained and "its just too much hell to go on".

I get naturally hungry, though I still have to be careful to eat regularly and well. I continue to have normal energy in the mornings. I don't feel I can fully earn my living yet but I'm working towards that, along with looking after myself entirely and living on my own.

January 2011

Time I sent you this, Dee. Perhaps its good that I left it a while so I can now give a longer-term picture. From the end of July to the beginning of November I averaged 16 hours paid work per week, which felt like quite an achievement. It was outdoor work, on my feet for 2, 3 or even 4 hours at a stretch, but work which I loved doing and enthusiasm and happiness definitely helps keep your energy up.

However by November I was really flagging and feeling it to be too much, and much as I'd loved doing it I was really glad to stop. I've not felt up to working since, though I managed to do a course of four full days in early December, much of it outside, in sub-zero temperatures ! I'd also had two long- haul flights together with ten days of pretty unsuitable diet, in October. I consider all those factors to be a large part of my needing recovery time. Also, November tends to be a low-stamina time of year for me. So I don't have lots of stamina at present but don't feel it is ME again. It is winter and I need to rest more than I do in the summer. I've committed myself to some voluntary work starting very soon now, outdoors, on my feet, and feel confident I shall be up to it, though not full time.

Nearly forgot to tell you an interesting bit. A couple of days after I stopped work in early November my stamina was really plummeting. The second day it definitely felt like ME again. Yikes. So I recalled what I'd taken from Mickel Therapy, applied it as well as I could, and it worked. Within a few hours I was out of the ME experience again and, as of writing this in January 2011, it hasn't returned. In fact to have experienced a relapse and to have got myself out of it quickly, is more reassuring and encouraging than if I'd not had the relapse, especially as I'd been pushing myself for some time by then. Well, there you are.

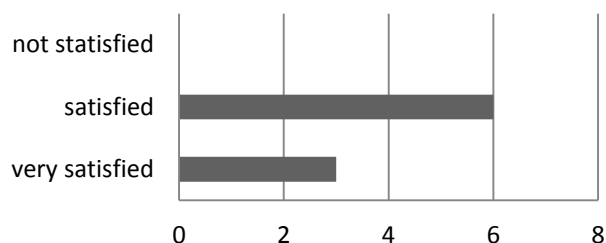
Hope this is useful. Helen.



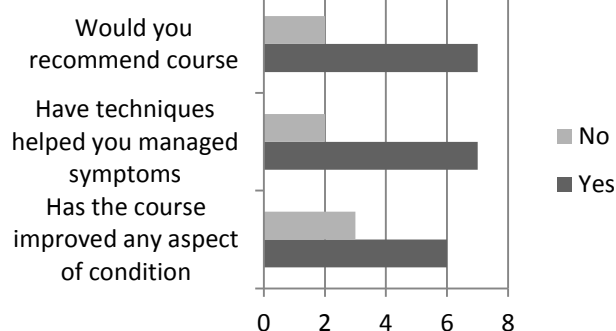
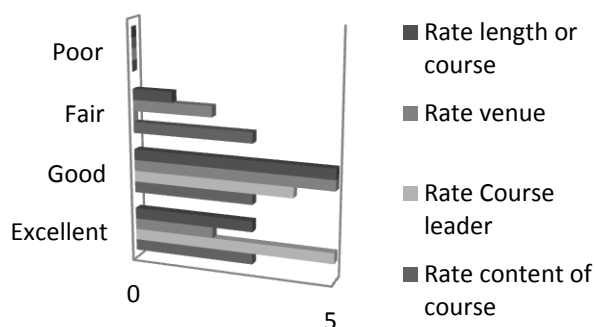
## M.E Course with Marilyn Godfrey (Oct 2010 – Feb 2011)

Between October 2010 and February 2011 some MESiG members took part in a course, led by Marilyn Godfrey, the aim of which was to learn how to manage their symptoms via a number of new and interesting techniques. Marilyn demonstrated a variety of techniques, which members were encouraged to try. Here's the feedback: -

### Satisfaction With Course Overall



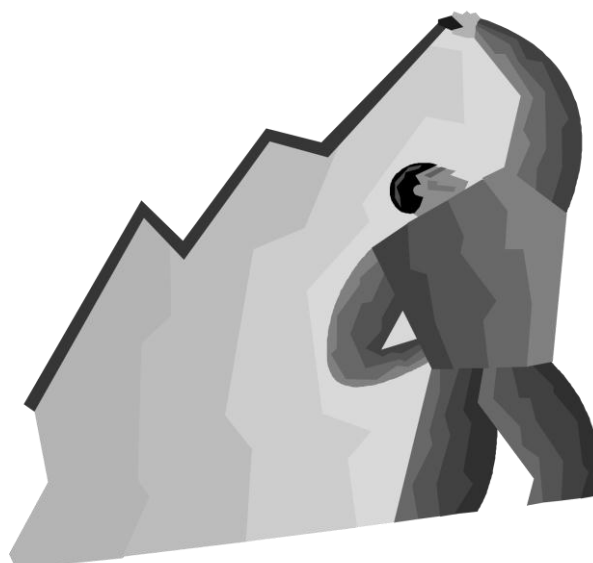
### Rate the following:



In general it seemed that all members were satisfied with the course and enjoyed it; 33% were very satisfied. Everyone agreed Marilyn was a great course leader with 56% rating her as excellent and the remaining 44% rating her as good. There was mixed feedback on the course content with equal scores being awarded for Fair, good and very good but encouragingly no-one suggested the content of the course was poor. The majority agreed the length of the course was good as was the venue, even though the venue changed during the course.

MESiG is pleased that a majority of members (78%) who attended the course noted that the techniques had helped them to manage their symptoms. 67% also stated that the course had improved some aspect of their condition and encouragingly 78% would recommend the course to someone else! The remaining 22%, even though they would not recommend the course still offered some positive feedback, stating that the course "gave me an awareness of how to relax" and "the physio aspect was very good and techniques have helped with pain management".

Based on this feedback it seems that we should be looking to provide similar courses of this nature in future. If anyone has any suggestions or has tried a course that they feel may be beneficial to others please contact us and let us know.





## Lighthouse of God Ministries

### – Sponsor A Child Appeal

We'd like to draw our members attention to a truly worthwhile cause and tell you a little about a very special individual called Pastor Michelle Warren.

***Michelle had M.E and we are hoping to publish her full and very interesting story in our next issue.***

Pastor Warren is an ordained minister and the representative for a charity called 'Lighthouse of God Ministries'. With the call of God she helps to support orphans and needy children in Kenya and Uganda. She also preaches, teaches, evangelises, presents a Tv ministry, supports various pastors and ministers and is a minister in healing and deliverance. She gave up a nursing career to live by faith serving God full-time in ministry.

The Ministry is currently running a number of projects to help children who are less fortunate but the main project is the £5 a month Education scheme, which provides each child sponsored with porridge, milk on school days, a new uniform and shoes for school and education.

If you would like to support this cause the easiest way to do this is to go to your bank and fill in a standing order form. You will need to fill in the following details:

Lighthouse of God Ministries

Nationwide Building Society

Account No: 333 333 34. Sort Code: 07-00-93

Ref Role No: 0453/703 768 393

Please contact Michelle to let her know if you will be sponsoring a child. You can contact her by email, text or letter. Please let her know the amount you will be sponsoring, the date the money will go out each month, and your name

and address. She will then send you details of a needy child who needs sponsoring. You will get a photo of the child and another one when they get their new school uniform and shoes.

For further details about this cause and other work done by the Lighthouse of God ministries you can contact Michelle by telephone or email or log into the website, where you will also find details of other ways you can support the cause.

Tel: 07961 361 363

Email: [lighthouseofgod@hotmail.com](mailto:lighthouseofgod@hotmail.com)

Website: [www.lighthouseofgodministries.org](http://www.lighthouseofgodministries.org)

**Sourced from Website**



## Tragedy and Kindness Of

### Recovering M.E Sufferer Huw And Mum Arlene

Huw was 38years old and had been suffering with M.E since November 2002 but in the last 2 years he had been feeling a lot better.

Tragically Huw died January 8<sup>th</sup> 2010 of Swine flu. Despite the pain of losing a son, mum Arlene Bryant got in touch with us (MESiG) and donated £400 from Huws funeral in lieu of flowers.

I'm sure you all join us in offering our sincere condolences to Arlene and her family, and in thanking Arlene for her kindness.

We are planning to use the money towards purchasing an item which would benefit M.E sufferers, in his memory.  
God bless him.

## **M.E Support Group Meeting changes and Speakers**

As of January 2011, we have changed from our Thornhill venue to Ararat Centre for the Community. We still meet the first Monday of the month at 2.30-4pm. Apologies for any inconvenience caused. The decision was out of our control. We have had to sacrifice the comfy sofas but are looking for a more suitable venue. We are ideally looking for somewhere with comfortable seating, a warm and pleasant environment, refreshment facilities (or at least somewhere we can make tea and coffee) and convenient parking. Places to consider may include churches, community halls, conference centres, local supermarkets which have large meeting rooms; there are a number of possibilities. If anyone has any suggestions please get in touch. Please note, meetings will continue in Ararat until further notice.

The Tuesday evening meetings which were held on the second Tuesday of the month in the Mackintosh Centre have been cancelled due to lack of attendance. We extend a huge thank you to Linda Shakespeare who religiously hosted the meetings and has been a blessing to the organisation. If the evening meetings are requested in the future we can provide them.

### **DATES FOR YOUR DIARY:**

#### **Speakers booked for Ararat Centre**

**July 4<sup>th</sup>** Herbalife representative Darren - Talking about the products which helped his wife with M.E.

**September 5<sup>th</sup>** Policy officer Paul from Disability Wales - Talking about Independent Living

## **M.E.S.I.G Committee**

Two new members joined the committee in November this year, Gemma Phillips and Martha Thompson.

Regrettably Martha decided to step down again as she had studies to contend with.

Gemma has taken the group by storm. Thanks to Gemma our organisation has come on in leaps and bounds. Gemma is responsible for setting up the website and everything that it entails. She is already a wonderful asset to the group with her ability and enthusiasm. Gemma is also now your co-editor for the newsletter

Sadly we have lost Athena, due to family commitments but she assures us she will still help if needed. Many thanks to both new and old committee members.

The recent re-election of committee members saw no change to the structure; other previous committee members have retained their roles.

There are currently 3 vacant posts one of which is currently being shared by two of our committee members; who hold other positions in addition and therefore ideally we would like to see this position taken over by someone who can give it their full attention. The current vacant posts are:

Vice Chair

Political Liaison Officer

Newsletter Editor

If anyone would be interested in filling these positions please contact Ken, Chris or Gemma for details.

## Services for the disabled!

### City Centre mobility Assistance

Free mobility assistance - helping you around the city centre.

Do you need help to get around the city centre then look out for City Centre Mobility Assistance, a new electrical vehicle scheme offering an innovative travel solution to those who need help accessing the city centre. Our environmentally friendly vehicles can carry up to 3 passengers each and travel around the city on a flexible route. Drivers can be flagged down by pedestrians wishing to use the service, and passengers will then be taken to their chosen destination within the city centre. In addition if you wish to pre-book a vehicle in advance you can call 02920 873888. This number can also be called for general enquires.



### Cardiff Christian Healing Time

Woodville Christian Centre, Crwys Road on Thursdays 1.00pm - 3.00pm. 5th & 19th May, 9th & 23rd June, 7th July. This is a relaxing quiet time spent lying down or sitting in a chair with music and prayer if requested.

For further information please contact Linda Tatham on 02920 627237 or check out [www.cardiffchristianhealing.org.uk](http://www.cardiffchristianhealing.org.uk)



### Ellwood Cottages - take a well-earned break.

Named after Dorset writers Hardy, Barnes and Blyton, these cottages have been lovingly restored to provide superbly equipped, comfortable, tastefully furnished, year-round, single storey self catering holiday accommodation for the less-abled, their families, friends and carers. Outdoors are spacious landscaped gardens with tables and chairs for guests' use, providing stunning views across fields with farm animals and wildlife, to Bulbarrow Hill and Ibberton Hill.

Britain has awarded Ellwood Cottages a 4-star rating for quality of accommodation (excellent standard throughout) and an M3I rating (suitable for an independent wheelchair user) under the National Accessible Scheme.

For additional details please contact Ann and **John Heath**

Ellwood Cottages, Woolland, Blandford Forum, Dorset, DT11 0ES

Tel: 01258 818 196 email:

[admin@EllwoodCottages.co.uk](mailto:admin@EllwoodCottages.co.uk)

## 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 colour.

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

## **ME Association**

7 Apollo Office Court,  
Radclive Road,  
Gawcott,  
Buckinghamshire  
MK18 4DF

**Tel:** 01280 827070 10am - 3.30pm

**Email:** [meconnect@meassociation.org.uk](mailto:meconnect@meassociation.org.uk)

**Website :** [www.meassociation.org.uk](http://www.meassociation.org.uk)

## **ME Connect**

**Helpline** 08445765326

10am-12pm, 2pm-4pm, 7pm-9pm weekdays



## **25% ME Group**

21 Church Street  
Troon  
Ayrshire  
KA10 6HT

**Tel: Office** 01292 318611

**Advocacy line:** 01292 312369

**Website:** [www.25megroup.org](http://www.25megroup.org)

## **MCS Matters**

*(Multiple Chemical Sensitivity)*

Gordon D McHenry  
UK Co-ordinator  
Global Campaign for recognition of MCS

**Tel Helpline:** 01446 794 700

Tues & Thurs 2 –4 and 6 –7pm (manned when able)

## **STIFF (UK)**

PO Box 1484  
Newcastle-under-Lyme  
Staffordshire  
ST5 7UZ

**Tel:** 01782 562366

## **BRAME**

30 Winner Avenue  
Winterton-on-Sea  
Great Yarmouth  
Norfolk  
NR29 4BA

UK

**Tel/Fax:** 01493 393717 **E-Mail:** [info@brame.org](mailto:info@brame.org)

## **Action for M.E.**

PO Box 2778

Bristol

BS1 9DJ

**Membership/general:** 0845 123 2380 / 0117 9279551

Mon - Fri: 9.30am - 5pm

**Telephone support:** 0845 123 2314

Mon - Fri: 11am - 3pm

## **Welfare rights helpline: 0845 122**

**8648** (Membership only service)

Monday: 1pm - 5pm

Tuesday: 9.30am - 12.30pm & 3.15pm - 6.45pm

Wednesday: 1.30pm - 4.30pm

Thursday: 9.30am - 1pm

Friday: Closed

**Email:** [admin@afme.org.uk](mailto:admin@afme.org.uk) **Website:**

[www.afme.org.uk](http://www.afme.org.uk)



## **National ME Centre**

Disablement Services Centre.

Harold Wood Hospital

Gubbins Lane

Harold Wood

Romford

Essex

RM3 0BE

**Tel:** 01708 378050 **Website :** [www.nmec.org.uk](http://www.nmec.org.uk)

## Contact and Support continued

### **Fibromyalgia Association**

PO Box 206  
Stourbridge  
West Midlands  
DY9 8YL

#### **Helpline:**

**Tel:** 0844 887 2444 (10am - 4pm Mon - Fri)

**Email:** fmauk@hotmail.com



### **Welsh Association of ME & CFS Support (WAMES)**

**Tel:** 029 20515061

**Email:** enquiries@wames.org.uk

**Website:** www.wames.org.uk

### **C.L.I.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

### **Association of Young People With ME (AYME)**

10 Vermont Place  
Tongwell  
Milton Keynes  
MK15 8JA

**Email:** [info@ayme.org.uk](mailto:info@ayme.org.uk)

**Tel:** 08451 23 23 89

10am-2pm Mon-Fri

**Website:** www.ayme.org.uk

### **The Young ME Sufferers Trust**

PO Box 4347

Stock

Ingatstone

CM4 9TE

**Tel:** 0845 003 9002

(best between 11 –1 and 5—7pm weekdays)

**Website:** [www.tymestrust.org](http://www.tymestrust.org)

### **A 4 ME**

Third Floor

Canningford House

38 Victoria Street

Bristol

BS1 6BY

**Tel:** Lo-call 0845 123 2380 or 0117 927 9551

**Fax:** 0117 9279552

**Email:** [admin@afme.org.uk](mailto:admin@afme.org.uk)

**Website:** <http://www.a4me.org.uk>

### **Welsh Association of ME & CFS Support (WAMES Young People)**

Michelle Penny

**Tel:** 029 20515061

**Email:** [michelle@wames.org.uk](mailto:michelle@wames.org.uk)

**Website:** [www.wames.org.uk](http://www.wames.org.uk)

**(Carers—same as above but contact Sylvia Penny—same tel no.**

**Email:** [Sylvia@wames.org.uk](mailto:Sylvia@wames.org.uk))





## Contact and Support continued

### 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.

### **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

### Useful Websites

[www.mererearch.org.uk](http://www.mererearch.org.uk)

[www.butyoudontlooksick.com/the-spoon-theory](http://www.butyoudontlooksick.com/the-spoon-theory)

[www.nice.org.uk](http://www.nice.org.uk)

[www.entitled.co.uk](http://www.entitled.co.uk)

[www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)

## 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 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](http://www.citizensadvice.org.uk)

**Dial UK** (Disability Information and Advice Line services)

**Tel:** 01302 310 123

**Website:** [www.dialuk.info/index.asp](http://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

## M.E.S.I.G Committee Members

### Ken Bailey

(Chair)

**Tel:** 07825702171

**Email:** kenbailey@talktalk.net

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### Linda Tatham

(Treasurer)

**Tel:** 029 20627237

**Email:** lindatat@btinternet.com

.....

### Chris Davies

(Membership secretary,  
Newsletter Co-Editor )

75 Llanon Road

Llanishen

Cardiff

CF14 5AH

**Tel:** 029 20762347

**Email:** christallaconstantinou@talktalk.net

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### Gina Fisher

(Committee member)

**Tel:** 029 20901179

10.30-7pm

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### Gareth Price

(Committee member)

**Tel:** 029 20664559

**Email:** [garethv.price@yahoo.co.uk](mailto:garethv.price@yahoo.co.uk)

### Gemma Phillips

(Secretary, Newsletter Co-editor and  
Website Facilitator)

**Tel:** 07542 526831

**Email:** gemmaphillips47@yahoo.co.uk

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### Dee Penny

(Committee member)

**Tel:** 02920842499

**Email:** deirdrepenny@yahoo.co.uk

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*Please send us anything you wish us to  
submit in next newsletter: poem, recipe,  
personal story, question etc.  
or email*

[christallaconstantinou@talktalk.net](mailto:christallaconstantinou@talktalk.net)  
[gemmaphillips47@yahoo.co.uk](mailto:gemmaphillips47@yahoo.co.uk)

### M.E.S.I.G (M.E. Support In Glamorgan)

75 Llanon Rd

Llanishen

Cardiff

CF145AH

Tel :02920762347

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