

UK Charities Helping Children with M.E.

On September 7th, 2010, there was national UK news coverage of research showing evidence of ongoing infection and increased oxidative stress in children with M.E.

BBC News, Scotland reported:

"Professor Jill Belch, an expert in vascular medicine at Ninewells hospital in Dundee who led the latest research project, said: "What we've found are blood changes that suggest chronic inflammation. "This is important because it's showing an abnormality that we might be able to devise a treatment for, but it's also important because some people do suggest that ME is a disease of the mind and here we are showing that it is a disease of the body."

Published in *Archives of Pediatrics & Adolescent Medicine*, the research was sponsored by a consortium of organisations, with ME Research UK (MERUK) and The Young ME Sufferers Trust (Tymes Trust) providing the bulk of the funding. This is another example of the many achievements of these two popular UK charities.

ME Research UK

MERUK explain they are: "a registered charity (sc036942) funding biomedical research into ME/CFS and related illnesses. Our principal aim is to commission and fund high-quality scientific (biomedical) investigation into the causes, consequences and treatment of the illness, but we also have a mission to "Energise ME Research""

MERUK's extensive list of completed projects includes investigations into blood and vascular abnormalities, oxidative stress, autonomic dysfunction, and pain in people with M.E.

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The Young ME Sufferers Trust

The Young ME Sufferers Trust (charity number 1080985) is the longest-established UK service for children and young people with ME and their families and was recently given The Queen's Award for Voluntary Service: the MBE for volunteer groups. As well as providing an Advice Line and an all-age magazine for families and professionals, it actively campaigns for the interests of children and young people with ME. Its Executive Director co-wrote the BBC questionnaire for the groundbreaking Panorama programme on ME and has given presentations to the Westminster All Party Parliamentary Group and the Scottish Cross Party Group. The Trust also played a major role in the children's chapter of the Chief Medical Officer's Report (DoH 2002).

Donations of any amount can help these charities to continue their good work, standing-up for the rights of children and promoting the research needed to understand M.E.

To support MERUK:

1. Telephone with your debit or credit card to 01738 451234 between 9.00 am and 4.30 pm, Monday to Friday.
2. Donate online at: <http://www.mereseach.org.uk/donation/donation.html>
3. Donate by post to: ME Research UK, The Gateway, North Methven Street, Perth, PH1 5PP.

Please make cheques payable to "ME Research UK" or "ME Research UK - Research Account". If 'Research Account' is specified the donation is only used to fund specific research projects; though please remember that charities also have running costs to meet in order to be effective.

To support Tymes Trust:

1. Donations can be made securely online with a credit/debit card or Paypal account at: <http://www.tymestrust.org/donations.htm>
2. By Cheque made payable to 'Tymes Trust' sent to: Tymes Trust, PO Box 4347, Stock, Ingatestone, CM4 9TE.

Thank You.

MEshare

TYMES TRUST

The Young ME Sufferers Trust

Tymes Trust is the longest established national UK service for children and young people with ME and their families. It is a respected national charity whose entire professional team give their time free of charge. They work constantly with doctors, teachers and other specialists, and played a major role in producing the children's section of the Dept of Health Report on CFS/ME (2002).

Registration costs £10

Tel: 0845 003 9002

Registration provides:

- **Full access to our support services by phone, post and email**
- **Welcome Pack** *This includes a copy of Vision.*
- **Subscription to Vision.**
- **Advice Line Service** *11.00am-1.00pm and 5.00pm-7.00pm weekdays.*
- **Professionals Referral Service** *Our expert panel can explain ME to your doctors, teachers or social workers.*

Personally signed Birthday and Christmas cards
Let us know if you prefer not to receive cards for religious or other reasons.

THE YOUNG ME SUFFERERS TRUST WINS THE QUEEN'S AWARD FOR VOLUNTARY SERVICE - THE MBE FOR VOLUNTEER GROUPS

The Young ME Sufferers Trust (Tymes Trust) has won the The Queen's Award for Voluntary Service, the MBE for volunteer groups.

The prestigious National Honour recognises outstanding contributions made to communities by groups voluntarily devoting their time for the benefit of others. It sets the national benchmark for excellence in volunteering, with the work of those awarded being judged of the highest standard.

The Young ME Sufferers Trust has received the Award for pursuing the educational rights and advancing the care of children with ME.

Winners of this year's Award were selected from 341 groups nominated by members of the public who have been helped personally or witnessed the benefits of a group's work in their community. Tymes Trust will receive a certificate signed by the Queen and an exclusive commemorative crystal, presented by Her Majesty's representative in Essex, Lord Petre, at a special ceremony. The group has also received an invitation for representatives to attend a Royal Garden Party at Buckingham Palace in the summer.

Speaking of their success, former head teacher Jane Colby, Executive Director of The Young ME Sufferers Trust said: "It is a wonderful honour to have our work recognised by the Queen. ME devastates children's lives. It is potentially severe and chronic and is the biggest cause of long term sickness absence from schools."

The Queen's Award for Voluntary Service Main Award Committee Chair and former broadcast journalist Martyn Lewis CBE said, "Outstanding volunteer groups across the UK all too often go without recognition for the truly amazing work they do, despite the vital part they play in helping bind our communities together. It's a great pleasure to celebrate the efforts of The Young ME Sufferers Trust with The Queen's Award for Voluntary Service and help raise awareness of all they do for the benefit of others."

Well done to them.

GROUP NEWS

TEA IN THE PARK EVENT IN ROATH PARK 11th August 2010



'Tea in the Park' took us to new heights this year! On arriving at the lakeside cafe we found our usual outdoor venue almost unrecognisable. Gone were the chairs and tables, and in their place, rising above the rubble was a tall steel girder framework. A two storey shelter we were told, would eventually stand there, providing a lakeside viewing area for people to sit and enjoy the views undercover.

So we were directed to the terrace above the boat store area. Some of us braved the steep cast iron steps while others made for the gradual ascent via the ramp. We found a table to comfortably accommodate the six of us, who became seven, as Christalla's sister later joined us.

The sun came out - and stayed out, and so welcome, in the middle of a cloudy week! We sipped our drinks and nibbled our snacks while the conversation flowed. We exchanged news, but there was less talk of ME and more about putting the world to rights!

Altogether it turned out to be a lovely summer afternoon tea, savouring our elevated views of the park and across the lake. Just one little cloud....we were so sorry that more of our ME friends were unable to come to share in the pleasure of it all....but hopefully, next year.

Best wishes
Janet

AGM AND THERAPIES DAY REPORT 15th MAY

The AGM was held on Saturday 15th May in the Mackintosh Institute, Keppoch Street and the committee were grateful to those who came along to support us and listen to the annual report and accounts. We were also fortunate to have the services of two excellent therapists who were able to set themselves up in the adjacent room. They were Andrea Planchant giving Bowen treatment and Tracy King offering Indian Head massage.

The meeting was opened by your Chairperson, Ken Bailey who welcomed everyone and gave a brief overview of the past year. The election of the committee was voted upon and we are pleased to announce 2 new committee members, Gina Fisher and Dee Penny.

It is with regret that Denise Thompson is stepping down as one of your Newsletter Editors due to poor health, but expressed her gratitude for the support given to her by other members. We are all very sorry to lose her expertise in producing such excellent newsletters over the years, so her I.T. skills will be missed but her friendship with us continues and we wish her good health and strength in the battle against ME and fibromyalgia.

The accounts were presented and correct, subscriptions and donations for 2009-10 were our main source of income and the 'Bring & Buy' was a great success. We still need to boost the income level this year so have arranged a fundraiser again to maintain a healthy bank balance. See page 14 for details.

We finished the afternoon with teas and cakes and I think just about everyone tried out the treatments to end the day in a relaxed state.

A huge thank you to all who attended, our present and new committee members and the two therapists who kindly donated their time and energy on the day.

Linda Tatham (treasurer)

Details for Bowen Therapist: Andrea Planchant, 07791118538 or 02920752795

BOOK REVIEW

M.E and Me

A sufferer's triumphs

By G.A. Phillips



I never cease to be amazed by the strengths, talents and determination displayed by individuals despite their own battles. This beautiful lady is one of those individuals. Gemma is the author of M.E and Me and in this book she tells her story from the heart, plain and simple, just as it is. Gemma considerably com

pleted the book with sufferers in mind as it is written and set in a very easy to read manner. The book is particularly ideal for people recently diagnosed as you will find a useful list of symptoms, good advice and helpful literature titles.

Gemma has very kindly donated M.E.S.I.G a copy of her book.

Many thanks and well done

Reviewed by Chris

LAUGHTER CORNER - hee, hee, ha, ha



Blood Donor Ban for ME/CFS

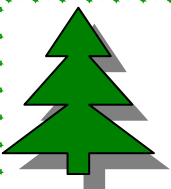
As of 1st November 2010, blood donors who report that they have had ME/CFS will be permanently excluded from giving blood in the UK. This change is being made on the grounds of donor safety, as ME/CFS is a relapsing condition. It brings practice for ME/CFS into line with other relapsing conditions or neurological conditions of unknown origin.

The change to donor selection criteria is being made following a recommendation by the UK Blood Services Standing Advisory Committee on the Care and Selection of Donors, and Joint Professional Advisory Committee (JPAC).

Clara Swinson Director of Health Protection Department of Health

Finally, you may not be aware that a number of other countries have followed the UK lead in banning blood donations from people with ME/CFS. These countries include Australia, Canada and New Zealand.

However, Dr Charles Shepherd, medical advisor for the M.E Association finds it surprising that no such precautionary action has been announced, at present, by those responsible for blood safety in America.



Xmas party

Monday 29th November

2.30-4pm

Thornhill Community Centre

Raffle

Bran Tub

Food

Please bring a gift, wrapped, no more than £5 for Bran Tub

All Welcome. Please let Chris know 02920762347.

Work, welfare benefits and M.E. – is anyone listening?

28 September 2010

More than 100 people attended Action for M.E.'s conference Work, welfare benefits and M.E. – is anyone listening? at the offices of Allen & Overy, London, on Saturday 25 September.

In addition to providing an opportunity for people with M.E. and their carers to present their experience of welfare benefits to a representative of the Department for Work and Pensions (DWP), the event presented the research findings of the National M.E./CFS Observatory, funded by the Big Lottery Fund.

Action for M.E.'s Chief Executive Sir Peter Spencer says: "I would like to sincerely thank everyone who attended the conference, particularly people with M.E. and their carers.

"I am especially grateful to Action for M.E. members Clare and Catriona, who spoke about living with M.E. and shared their first-hand experiences of the welfare benefits system."

Speakers' slides from the conference are now available in the following order:

Lucy O'Driscoll, University of East Anglia – The clinician's role in access to social welfare support for people with M.E./CFS

Dan Groves, Department for Work and Pensions – Employment and support allowance

Fiona Poland, University of East Anglia – Social support needs for equity in health and social care: study of experiences of people with M.E./CFS

Simon Horton, University of East Anglia – M.E./CFS in adults: perspectives from professional practice

Luis Nacul, London School of Hygiene and Tropical Medicine – Epidemiology and quality of life for people with M.E./CFS

Lee Hooper, University of East Anglia – Where can I find a service to help me manage by M.E./CFS?

Professor Derek Pheby, Observatory Project Co-ordinator – A disease register for M.E./CFS: pilot study.

You can watch the presentations <http://vimeo.com/album/1454336>



Ken and Chris (M.E.S.I.G. representatives) either side of Sir Peter Spencer (Action For M.E Chief Executive). Taken at the M.E. Conference in London.

Chris and I (Ken) attended the Action for M.E. conference on behalf of M.E.S.i.G. expressly to gather information for our members in light of concerns regarding the proposed reassessment of IB (Incapacity Benefit) and ESA(Employment and Support Allowance) recipients by the DWP (Department of Work and Pensions).

Prior to the commencement of the conference registration took place and refreshments were served in the lobby which gave all the delegates an opportunity to meet with their counterparts from other organisations. Chris met a couple from London who were disillusioned by the lack of provision by the NHS for M.E. sufferers in London. Although it is well documented that generally there are better services for individuals with this condition in England.

The Chief Executive of Action for M.E. Peter Spencer introduced himself to me and expressed his thanks that representatives from M.E.S.i.G. were in attendance. Peter presented as a person who is passionate about his work and genuinely wanted to make a difference.

The conference commenced with an address to the conference by two women who both gave an account of their personal experiences of the DWP. The first woman to speak was Clare Collins who lives in Cardiff. With her opening gambit she commended Chris for her advice and support many years ago.

You can watch the whole line up of speakers by looking on 'presentations' site on page 8.

Dan Groves who is head of analysis at the Department for Work and Pensions deputised for the scheduled speaker; Cath Hemp who is Head of Employment and Support Allowance Division. Her absence was disappointing given that Employment and Support Allowance was not his specialism. Mr Groves gave his assurance that he would accept e-mails from anyone who wanted to enquire about issues that they were concerned about. He would then either reply personally or ask Cath Hemp to respond. Daniel.groves@hmps.gsi.gov.uk. Dan Groves happened to also be local from Canton in Cardiff.

The plenary session in the morning had a recurring theme; ‘better trained assessors’, ‘occupational therapists on assessment panels’, ‘doctors who assess for benefits must be properly trained in M.E.’ and ‘more focus on ensuring that research outcomes are put into practice by DWP’.

The group discussions on all the tables had many similarities;

- poster campaign in doctor’s surgeries by Action for M.E.
- better training for assessors
- more placements of M.E. consultants in NHS /DWP assessors
- more representation from CFS/MS clinicians in the media
- training for GP’s
- inclusion in research data of positive results from alternative therapies and in particular what the nature of the therapy was.

Advice to contact local MP’s for advice and support – delegates had found that letters and phone calls for MP’s were often effective when trying to access services.

An updated ME/CFS online services directory will have gone live in November 2010.

Website www.actionforme.org.uk. The new features are ;

- Services extended Uk wide
- Services for children included
- Up to date NHS specialist CFS/ME services
- Existing resources to information and support groups doubled
- Regional or postcode searchable through listing or map

Other e-mail addresses that you may find useful;

Disability Alliance-Neil Coyle-ncoyle@disabilityalliance.org

Ciaran Farrell (advocate) 28 Headcorn,25 Malden Road,London NW5 3HZ. tel : 0207 485 3404. e-mail -Ciaran@jfarrell58.freemove.co.uk

ARE YOU STRUGGLING FINANCIALLY? CAP UK might be able to help.

Christians Against Poverty is a national debt counselling charity with a network of centres across the UK.

First step is to go on their site www.capuk.org and find out if there is a CAP centre near you, after you call CAP, a Debt Coach and Support Worker from the local CAP Centre will visit you in your own home. A realistic budget is then worked out at CAP HQ by prioritising your essential bills, negotiating affordable payments with each creditor and stopping unfair interest and charges where possible. The local Debt Coach will then visit you again to explain the budget and the payments you will need to make.

Report of the Task and Finish Group on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)

INTRODUCTION

There is very limited evidence to support how CFS/ME should be assessed diagnosed and treated. The National Institute for Clinical Excellence (NICE) published Guidelines for the Management and Diagnosis of CFS/ME on 22 August 2007 which set out the general principles of care and diagnosis and initial management. These have been heavily contested by some patient groups and a Judicial Review was mounted. This was overturned in court.

The NHS has made little progress in implementing the NICE guidelines, which may be partly because of the lack of consensus and patient numbers are considered to be very small.

The Minister for Health and Social Services, Edwina Hart, asked that a task and finish group be set up to support efforts to improve services for CFS/ME. To tackle the lack of consensus and to promote service development, the Minister was keen to secure agreement on a care pathway which could be implemented across Wales to ensure consistency and equity of access.

The Minister also wanted the task and finish group to comment on whether people with or suspected of having fibromyalgia should be referred and managed in a similar way to people with CFS/ME.

On 28 August 2009, the Chief Executive of the NHS, Paul Williams, wrote to the Chief Executives of the new Local Health Boards (LHBs) informing them of the Minister's decision to establish a task & finish group and asking each LHB to undertake a baseline assessment, based on the NICE guidelines, of the services provided to people with CFS/ME within both acute and community settings by 30 November 2009.

January 26th 2010, WAMES (Welsh Association of M.E & CFS Support), put forward a very good presentation to the ME/CFS Task and Finish group, highlighting what is lacking and what is needed.

Anyone wishing to read the letter from the Minister for Health and Social Services and the letter from the Chief Executive of the Nhs, the findings of the Task and Finish group and WAMES presentation, can do so on the following sites.

<http://wales.gov.uk/docs/dhss/publications/100621reportmecysen.pdf>

<http://wales.gov.uk/topics/health/publications/health/ministerial/ml02710/?lang=en>

M.E QUESTION TIME

County Hall, Saturday 23rd October 2010

Organised by WAMES and the ME Association

ON THE PANEL: Dr Charles Shepherd (ME Association), Jane Colby (Tymes Trust),
Dr Nigel Speight (Consultant Paediatrician), Sue Luscombe (Dietician),
and Jan Russell (WAMES).

Funding award

WAMES is delighted to have been awarded a £5000 *Awards for all Wales* grant from the Big Lottery Fund for their campaign which started in October entitled **Information for all**. The aim of the campaign is to improve the nature and availability of information for patients, carers and professionals about the neurological condition ME. Some of the information will be bilingual and be downloadable from their new website, which is under construction.

By including the results of biomedical research WAMES hope they can change many of the misconceptions about the illness that exist within the health service and general public, thus improving dialogue between professionals and those affected by ME and their carers, leading to an improvement in their quality of life.

CFS/ME care pathway

Work has begun on the national care pathway for professionals in NHS Wales. The purpose of a care or clinical pathway is to outline essential steps in the care of patients with a specific medical problem, in order to achieve a diagnosis and appropriate care. It should also provide information about good clinical practice and the services and support available. Jan Russell is the patient rep on the working group and is working alongside consultants, nurses and therapists with an interest in CFS/ME.

Due to the lack of diagnosis and care in Wales the care pathway will begin by outlining recommended steps and services and following its publication next year Local Health Boards will be expected to customise it and develop services. Although there is strong support in Wales for services based on CBT and GET, WAMES does not envisage a rush to set up clinics to serve all people with ME & CFS, as the Welsh Assembly Government has not given extra funding and all LHBs are anticipating financial cutbacks.

Working in partnership

WAMES is a member of both the Wales Neurological Alliance and the Long terms Conditions Alliance Cymru. Through these alliances they keep up to date with issues that affect ME, and make useful contacts and raise awareness of ME in the NHS, Social services, voluntary sector and Assembly Government.

Secretary	Jan Russell	enquiries@wames.org.uk	01970 636515
Youth and Care Officer	Sylvia Penny	sylvia@wames.org.uk	029 2051 5061
Website	www.wames.org.uk	Helpline	helpline@wames.org.uk 029 2051 5061
Patron	Lord Barry Jones	Adviser	Dr Betty Dowsett

On Saturday 23 October 2010 several MESiG committee and general members attended the 'M.E. Question Time' event at the County Hall in Cardiff.

Each panel member gave a précis of their backgrounds and the work they were currently involved in. Panel member Dr Speight apologised for the medical professions' poor record of provision for ME/sufferers a statement which drew applause from the audience.

Following the précis there was an open question and answer session. One of the topics discussed was that the DWP do recognise ME as a genuine neurological condition but the problem arises in the assessment process.

The recommendation was made that if anyone feels they haven't been treated fairly during an assessment that they a) write a letter of complaint and b) notify their MP. This advice was also given at the Action for ME conference in London and by the local Citizens Advice Bureau (CAB).

Anyone needing support with this can contact one of the three advice centres on the back of this newsletter. Information and support can also be obtained through the ME Association. ME Connect- tel: 0844 576 5326 -10am -12 noon: 2-4pm & 7-9pm daily.

Of concern was the statement that there is no ME consultant in Wales, and MESiG committee representatives couldn't understand why this issue is not being addressed. Chris asked the panel why there had been no developments in this area. The response was that sadly no one wants the job and if they were to become involved they would become inundated with; heavy work loads, long patients waiting lists.

In our view this would be better than nothing but WAMES believe that ME sufferers can be supported through NHS primary care.

M.E.S.I.G wish to thank the M.E Association and WAMES for organising the meeting and congratulate WAMES for their success in obtaining some funding from 'The Big Lottery Fund'.

Ken Bailey M.E.S.I.G

C.C.H.M. (Cardiff Christian Healing Ministry)

Cardiff Christian Healing Ministry are a team of very caring and qualified counsellors who have a passion to help those who are sick or in need of counselling.

Quite a few of us from the ME group have been greatly helped and strengthened through attending their healing sessions at Woodville Christian Centre once a fortnight on a Thursday 1-3pm.

They invite you to come in and lie down on a fleece with a pillow or if you prefer you can sit on a comfy chair. There is quiet background music and it's a place of calm and peace. The team of helpers gently move around the room asking for healing for those present and if you have specific prayer needs then they will pray for these too. It can be so deeply relaxing that its easy to fall asleep.

If you would like to find out for yourself what it is like, the next session is 18th Nov and 2nd Dec., recommencing in January.

If you are uncertain about going on your own or would like a lift please ask or ring Linda Tatham on 029 20627237 www.cardiffchristianhealing.org.uk

Library 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 *by Alex Howard*

RECOVERY FROM CFS *by Alexandra Barton*

WHEN YOU WANT TO SAY YES BUT YOUR BODY SAYS NO *by Liz Tucker*

SAY NO TO ARTHRITIS *by Patrick Holford*

LIVING WITH FIBROMYALGIA *by Christine Craggs-Hinton*

PAIN FREE - A Revolutionary Method For Stopping Chronic Pain *by Pete Egoscue*

PAIN FREE FOR WOMEN *by Pete Egoscue*

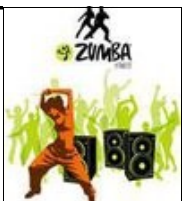
THE FIBROMYALGIA HEALING DIET *by Christine Craggs-Hinton*

CHRONIC FATIGUE SYNDROME, ME AND FIBROMYALGIA *by Dr David Mickel*

STOP THINKING START LIVING *by Richard Carlson*

M.E AND ME - A Sufferer's Triumphs *by G.A. Phillips*

Available to borrow for free, just ring Chris 02920762347



ZUMBA XMAS PARTY FUNDRAISING EVENT

Park Conservative Club, 217 City Rd, CF243JD

27th December 2010, 7.30-11.30pm. Tickets £10

(Nibbles, performances, fun follow along line ups, xmas crackers, raffle)

Irene Davies (Chris's daughter), has decided to hold a fundraising night for M.E.

Zumba is a new dance exercise craze which is sweeping the nation, it involves moving to Latin music in a variety of styles. No partner or experience is needed to participate, just the desire to have fun. Irene qualified in October after obtaining her degree in dance and has started 2 classes to date in Cardiff.

If you can't make the above event please tell your family, friends etc.

Suitable for all ages and abilities

Irene Davies 07891712344, Email: irededavies01@hotmail.com, Website: www.irededance.co.uk



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.



The Oakhouse Foods winter range is now available, offering over 380 freshly frozen meals and desserts with FREE home delivery.

We offer a regular, reliable service and can deliver to you on a weekly basis or just when you fancy it - perfect if you find it hard to shop for yourself or you simply like the convenience of having a few meals in your freezer.

Our British-made meals start at just £1.65 and with no minimum order value you can be sure you're spending your money wisely with Oakhouse Foods. In fact, we've introduced a whole new Value Range of meals and desserts at lower prices and this season you'll find a whopping 131 meals under £3 in our range.

To make life even easier we offer hundreds of other home delivered products, including everyday groceries, stylish homeware and practical aids for independent living. We recommend you request a copy of our FREE full colour brochure to get a good look at all of our ready meals and desserts

Whether you order online or by phone, our locally-based drivers will bring your order to your door on a regular delivery day and normally at around the same time of day. We deliver in most areas of the country on a weekly basis.

The driver will also be very happy to put your order straight into your freezer if this helps - we do it for lots of people.

If you'd like more information about any of our products simply call us on **0845 643 2009** or drop us an email enquiries@oakhousefoods.co.uk – we are always happy to help.

Website www.oakhousefoods.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 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 7 Apollo Office Court, Radcliffe Road, Gawcott, Buckinghamshire MK18 4DF Tel: 01280 827070 10am - 3.30pm Email: meconnect@meassociation.org.uk Website : www.meassociation.org.uk</p> <p>ME Connect Helpline 08445765326 10am-12pm, 2pm-4pm, 7pm-9pm weekdays</p>	<p>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 Website: www.afme.org.uk</p>
<p>25% ME Group 21 Church Street Troon Ayrshire KA10 6HT Tel: Office 01292 318611 Advocacy line: 01292 312369 Website: www.25megroup.org</p>	<p>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</p>
<p>MCS Matters <i>(Multiple Chemical Sensitivity)</i> 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) Website: www.satori-5.co.uk</p>	<p>Fibromyalgia Association PO Box 206 Stourbridge West Midlands DY9 8YL Helpline: Tel: 0844 887 2444 (10am - 4pm Mon - Fri) Email: fmauk@hotmail.com</p>
<p>STIFF (UK) PO Box 1484 Newcastle-under-Lyme Staffordshire ST5 7UZ Tel: 01782 562366 (between 11—4pm) Website: www.stiffuk.org</p>	<p>Welsh Association of ME & CFS Support (WAMES) Tel: 029 20515061 Email: enquiries@wames.org.uk Website: www.wames.org.uk</p>
<p>BRAME 30 Winmer Avenue Winterton-on-Sea Great Yarmouth Norfolk NR29 4BA UK Tel/Fax: 01493 393717 E-Mail: info@brame.org</p>	<p>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</p>

Contact and Support continued:

Association of Young People With ME (AYME) 10 Vermont Place Tongwell Milton Keynes MK15 8JA Email: info@ayme.org.uk Tel: 08451 23 23 89 10am-2pm Mon-Fri Website: www.ayme.org.uk	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 Website: http://www.a4me.org.uk
The Young ME Sufferers Trust PO Box 4347 Stock Ingatestone CM4 9TE Tel: 0845 003 9002 (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 (Disability Information and Advice Line services)

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

www.benefitsandwork.co.uk

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

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Chris Davies (Membership secretary,
Newsletter Editor)

75 Llanon Road
Llanishen
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CF14 5AH

Tel: 029 20762347

Email: christallaconstantinou@talktalk.net

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Gina Fisher (Committee member)

Tel: 029 20901179

10.30-7pm

Gareth Price (Committee member)

Tel: 029 20664559

Email: garethv.price@yahoo.co.uk

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Athena Harris (Committee Member)

Tel: 029 20626696

Email: bagsofvalue@tiscali.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

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

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