Guildford M.E. Support Group
(& West Surrey)

Newsletter

Spring 2009

Naturopathic nutrition lecture

Thursday 4th June – 7pm to 9.30pm

Guildford Institute, Ward Street, GU1 4LH

Free lecture. Sufferers and carers welcome. Capacity 60. There is a refreshments room where drinks and small snacks can be purchased during the break.

Judith Reid (Dip NNP, N.H.F. Clin. Dip) works as a Naturopathic Nutritional Practitioner in the Dorking, Surrey area. Judith has had CFS/ME in the past but has now recovered using Naturopathic Nutrition.

Naturopathic Nutrition is a form of nutritional therapy which looks at the individual as a whole, helping to improve and maintain good health. It takes into consideration diet and lifestyle, and uses the therapeutic qualities of food, supplementation where necessary, and techniques to support the individual during the healing process.

Poor health can impact our lives to a greater or lesser degree. Basically, our health affects our ability to enjoy life and live our lives to the full. Whether you suffer from a minor ailment or a major health issue, a problem which is physical, mental or emotional, Naturopathic Nutritional therapy could be the answer. It is very effective for a wide range of conditions.

Judith gave some insight into some of the content of the lecture…"I think there is so much conflicting info out there that I like to explain the basics of a healthy diet and the reasons why - such as why water is so important, how stress (including the stress we give our bodies through what we eat and think) affects our bodies/cells, what is the importance of pH, candida, weight loss, food intolerances/allergies etc… I think when people understand the basics, they can take more responsibility for their own health/diet. Even people who have a good grasp of healthy eating have said that they have learnt something from my talk".

Directions:
The Guildford Institute is located in Guildford town centre. A shuttle bus leaves from the forecourt of Guildford Station regularly. The stop outside the Public Library in North Street is opposite the Institute. Parking is available on North Street or in the nearby Leapale car park. Although free, please help our organisation of the event by indicating your intention to attend

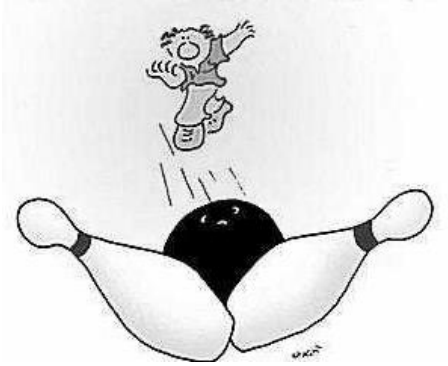
Future events

Please note that both sufferers and carers are welcome at the following group events. If possible could those attending try to avoid using perfume/aftershaves because some members react badly to them.

Afternoon meet – Tuesday 19th May – 1pm
The Bridge Barn Pub, Bridge Barn Lane, Woking, Surrey, GU21 1NL

Bridge Barn is an attractive pub located beside the canal, easily accessed from Junction 11 of the M25 close to Thorpe Arch. Pub Meals served from various extensive menus. Bar snacks, range of wines. Tea and range of Costa Coffee.

Bowling evening – Friday 29th May – 7pm
Guildford Spectrum, Parkway, Guildford, Surrey, GU1 1UP



At time of printing there have been eight members that are intending to attend the bowling evening. If you would like to join in please call Cathy on 01483 277790 so that the appropriate number of lanes can be booked in advance.

Prices Bowling: £4.50 Shoe Hire: £1.20

Nutritionist meeting – Thursday 4th June - 7 to 9.30pm

Full details are on the previous page

Morning meet - Monday 29th June - 10.30am
Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ

The hotel, which has plenty of parking, is near the Royal Surrey County Hospital. At the roundabout before the hospital, turn left into the hotel car park. They have a large foyer area with plenty of comfortable sofas and large coffee tables.

From M25: take junction 10 and follow A3 to Guildford and exit at exit sign for Research Park & Onslow Village. At 1st roundabout take 3rd exit. At 2nd roundabout take 2nd exit. From south: A3 to Guildford and exit signposted for Research Park and Onslow Village. At roundabout take 1st exit.

Potential new yoga class for CFS/ME

We have been approached by a yoga teacher called Nicky Whent who is interested in starting up a yoga class specifically for ME sufferers. She is based in the Farnham area and would consider hiring a hall in either Guildford or Woking for a group session and/or offering one to one sessions in the clients own home providing they live in the local area.

A group session would cost £7.00 per person, an individual session £25.00, for an hour long practice.

Nicky would structure the class to begin with 10 minutes of relaxation, followed by gentle stretches, a few sitting postures, gentle shoulder raises, yoga breathing techniques and ending with a 15 minute relaxation/meditation.

If anyone is interested or would like further information, then please email or call Cathy Gould (group secretary) and she will put you in touch with Nicky.

Email: catherineg_9@hotmail.com Tel: 01483 277790

Inquiry into NHS services for CFS/ME

The All Party Parliamentary Group (APPG) on ME is undertaking an inquiry. They are looking at NHS service provision for ME and they are asking for input from individuals and organisations.

Questionnaires will be created as part of the evidence being collated, and Dr Des Turner MP, Chair of the All Party Parliamentary Group (APPG) on M.E., has asked the following: "People with M.E., carers and professionals are invited to submit suggestions for specific questions which should be asked in these surveys".

M.E. is classified as a neurological illness under the World Health Organisation classification (ICD G93.3). However the NHS largely uses the term Chronic Fatigue Syndrome instead of M.E. or else adopts the hybrid CFS/M/E. in diagnosing and treating patients. Terminology is a contentious matter. It has some bearing on this inquiry because to use only the precise WHO classification of M.E. above will impede access to information from the NHS that is crucial to the success of this inquiry.

A central 'ring fenced' budget of £8.5 million was announced in 2003 with the specific aim of developing new secondary referral services for people with ME in England. The Department of Health funding was released in two phases in 2004/05 and 2005/06. This resulted in the establishment of 13 Clinical Network Co-ordinating Centres and some 50 Local Multidisciplinary Teams.

Subsequent changes in NHS organisation and budget setting arrangements have since made it far more difficult to establish the level of investment into the care of these patients. It has also become apparent that some of these newly established secondary services are having to cope with significant reductions in funding. As a result, some have either closed or are under threat of closure - an issue that was discussed by the APPG at its meeting on 12 July 2007.

Patient group surveys continue to identify high levels of patient concern about the services which are being provided and further concerns about the way in which the recommendations contained in the 2007 guideline on ME/CFS from NICE could result in an inflexible approach to management.

Aim

The inquiry will evaluate the extent to which the NHS is providing care for people with M.E. (Myalgic Encephalomyelitis) in England, particularly in primary and secondary care, and in specialist centres/teams.

Specific areas of enquiry

The inquiry will focus on collecting data from each Strategic Health Authority (SHA) and Primary Care Trust (PCT). It will also collect data from specialist treatment centres, directors of Public Health, patients and patient groups. Questions will inquire about:

- Their service framework for caring for people with M.E., including children with M.E. and those severely affected by M.E.
- The funding they had available in 2007-2008 for caring for people with M.E., what they will have in the budget to provide services for people with M.E. in 2008-2009.
- Their estimate of the number of people with M.E. living in their area of responsibility; of these how many are severely affected and how many are children; what is their estimate of the annual funding needed to provide adequate health care services for these patients.
- Their plans for the establishment of new clinical services where no such service currently exists.
- What currently happens to people with ME where a secondary referral is required but no local service currently exists.
- The ways in which patient outcomes are measured and seeing how this compares with how patients measure outcomes.

It will also consider:

- The extent to which the National Service Framework for Long Term Neurological Conditions addresses the generic issues affecting the management of the illness, sets standards for treatment and care and supports health and social care professionals to deliver high quality services.
- What diagnostic criteria are being used.
- How well the reality and impact of the condition and its symptoms are acknowledged in primary and secondary care and in specialist centres/teams.
- How well health professionals in primary care, secondary care and in specialist centres/teams provide information about the range of interventions and symptom management strategies available, including benefits, risks and likely side effects
- The extent to which health professionals in primary care, secondary care and in specialist centres/teams receive appropriate professional training in the range of interventions and symptom management strategies available, including benefits, risks and likely side effects.
- Whether health professionals in primary care, secondary care and in specialist centres/teams provide adequate information on the possible causes, nature and course of M.E.
- The extent to which health professionals in primary care, secondary care and in specialist centres/teams take account of the:
    - age of the person with M.E., particularly for children younger than 12 years
    - the severity of the patient's M.E.
    - patients' preferences and experiences and the outcome of previous treatments
    - the stage of the illness
- Provide diagnostic and therapeutic options to people with M.E. in ways that are suitable for the individual, including providing domiciliary services (including specialist assessment), or using methods such as telephone or e-mail.
- The extent to which health professionals in primary care, secondary care and in specialist centres/teams share decision-making with the person with M.E., establish a supportive and collaborative relationship with that patient and their carer(s) and recognise their right to refuse or withdraw from any component of their care plan without affecting other aspects of their care or future choices about care.

Evidence

Organisations and individuals are invited to submit written evidence. The strong preference is for written evidence to be in Word format - not PDF format - and sent by e-mail to turnerd@parliament.uk.

However it recognised that many people with M.E. will not have the use of computers or internet facilities and so typewritten scripts and legible hand written scripts will also be accepted.

The body of the e-mail or covering letter must include a contact name, telephone number and postal address. The e-mail/covering letter should also make clear if the submission is from an individual or on behalf of an organisation. The deadline is 9 June 2009.

Submissions must address the terms of reference. They should be in the format of a self-contained memorandum and should be no more than 3,000 words. Paragraphs should be numbered for ease of reference, and the document must include an executive summary. Submissions should be original work, not previously published or circulated elsewhere, though previously published work can be referred to in a submission and submitted as supplementary material. Once submitted, your submission becomes the property of the APPG. The APPG will expect to publish the written evidence it receives. Evidence sessions are likely to commence 14 July 2009 and a later notice will give details of these.

New ‘active callers’ service

For some time now the Guildford ME Group has provided a ‘listening ears’ service – which involves volunteers receiving calls from our members who want a friendly chat. Details of the service are included on the last page of this newsletter.

We are now introducing an additional service for group members called ‘active callers’. A few members of the group have offered to call our members and ask how things are going and if there is anything that the group could research and put as content into our newsletters.

Due to the number of members we have, the service may only achieve 1 or 2 calls per member each year. We hope that this new service will allow us to have closer contact with our members and enable us to create newsletters that better meet member requirements.

Ampligen for CFS/ME ?

February 19, 2009

An FDA ruling was expected this month on the investigational “antiviral/immune modulatory” drug Ampligen® - potentially the first to be approved for treatment of ‘chronic fatigue syndrome’ (ME/CFS).

As of Feb 18, however, Ampligen’s maker (Hemispherx Biopharma) revealed that the FDA has delayed the decision date to May 25. At the same time, Hemispherx also announced that its Medical Director, Dr. David Strayer, will be presenting “new Ampligen clinical data” at the IACFS/ME Science Conference in Reno, NV, March 12-15.

Strayer’s presentation, scheduled in Session 1 of the Professional Meeting:

“Will include new data from the ongoing treatment IND/compassionate study (AMP 511) as well as the completed well-controlled pivotal Phase III study (AMP 516).

“Individuals suffering with CFS are known to be at greater risk than age-matched healthy populations with respect to certain catastrophic events including cancer, sudden cardio-vascular death and suicidal ideation. The new data will evaluate the potential of Ampligen… to mitigate certain of these events. Data utilized will integrate serially performed immunologic lab panels and EKGs, as well as physical performance scores and medical records (including concomitant medications used to alleviate certain symptoms of CFS).

“Ampligen®, an experimental product, may modulate nature’s primary gateway to immune response, mediated by receptors termed “toll-like receptors” (TLRs). Many other immuno-modulators may work downstream from the TLRs immune “gateways” at so-called “checkpoints.” Since “checkpoints” are not normally part of nature’s own immune-defense surveillance apparatus, these alternative “checkpoint” strategies may be associated with unintended consequences including significant toxicities.”

What is Ampligen?

Ampligen (AMPLIfied GENetic activity) - an “orphan drug” under development & testing for 30 years and still allowed only in specific clinical trial settings conducted under U.S. governmental authorization - is termed “a nucleic acid drug,” designed to “modulate” the body’s immune system. Its mechanism of action in ME/CFS “is not entirely clear,” but it is thought to act on two enzyme systems so as to help the immune system destroy viral RNA and speed the death of virus-affected cells. In particular it may “downregulate” an anti-viral pathway which research suggests has become “upregulated” in certain ME/CFS patients (the 2-5 Synthetase/RNase L anti-viral pathway). A "Who's-Who" of the world’s leading ME/CFS specialists have participated in Ampligen trials over the years.

Just four quid

Raising £1 million for biomedical research into CFS/ME
Source: www.meresearch.org.uk/donation/fourquid.html

ME Awareness Day 2009 saw the launch of a £1 million appeal for much-needed biomedical research into ME/CFS, specially designed for the recession! The appeal will run for a calendar year to May 2010, and invites people with ME and their friends and family to join in a year of cleverly saving money so that they can donate a bit of their saving to research. The appeal is called 'Just Four Quid' to reflect how achievable the £1,000,000 target is; if each of the estimated 250,000 people in the UK with ME/CFS donated £4, the target would be achieved!

The idea is simple. Each week, the Just Four Quid dedicated daily blog will give you a new tip for saving cash and if, for example, that tip saves you £10, you might consider donating £5. By the end of the year, you will be better off AND you will have donated to the campaign. The key idea is that lots of people donating little and often will add up to a huge amount over the year — and they may even be better off at the end of it.

You can donate to either or both the charities taking part — ME Research UK and the Ramsay Research Fund of the ME Association — which will provide regular information about the appeal in their literature and on their websites, and of course the Just Four Quid blog itself will also provide updates.

You can start helping immediately! Take a look at the Just Four Quid website (www.justfourquid.com) which gives more detail about the campaign and has a campaign poster that you can download and ask to be displayed in your local library or GP surgery. And you can tell other people about the campaign so they can join in.

How to give

However you choose to donate, it's important that you identify your donation as part of the Just Four Quid campaign so that your money goes into the charities' research accounts and so that we can feed back to you how much we're making as we go along. Both charities draw on separate funds for administration, so all of your money is going to research. Also, both are happy to handle small amounts so there's no need to wait to donate. Little and often!

When asking you to donate, I will always direct you to the charities' own websites for their donation forms, contact details and so on, or to Justgiving.com pages that you can see are linked to the charities' official accounts, so that you can be confident about where your money is going.

One of the easiest ways to give is via the Justgiving.com website. You can either donate to the Just Four Quid campaign pages (see the JFQ MERUK page and JFQ RRF page)

As you can see, each page has a photo, some blurb, and a table to show individual donations and the total raised so far. The money goes straight into each charity's bank account so they're not waiting until the end of the year for your cash, and it's easy to track progress. The site is funded by taking a small percentage of the donation.

Giving by mail

If you or any of your supporters prefer not to donate online, you can mail cheques, postal orders or details for credit/debit card payments to the charities. If you do this, please write "JFQ" prominently at the top of the form so that the charities can track the funds. Payments to MERUK should be sent with the MERUK donation form (included overleaf)

Giving by phone

You can also give by credit or debit card over the telephone, both to MERUK (on 01738 451234, 9.00 a.m. to 4.30 p.m. on weekdays) and the RRF (on 01280 818964, 10.00 a.m. to 4:00 p.m. on weekdays). Again, don't forget to say it's for JFQ (just four quid).

Myalgic Encephalomyelitis Research Group for Education and Support (Charity number: SC036942)

Donation Form

ME RESEARCH UK

1 Name

Address

Postcode

Telephone

E-mail

2 I wish to donate £10 ☐ or my preferred amount of £

3 I enclose my cheque/postal order payable to ME Research UK

OR Please debit my Switch/MasterCard/Visa/Diners Club/American Express
(please delete as appropriate)

Card number: *(Switch only)*

Three-digit security number: *(Please note that we will be unable to process your donation without this number)*

Expiry date: / Issue no: *(Switch only)*

4 If you are a UK taxpayer, under the Government's Gift Aid scheme we can reclaim the tax you have already paid on your gift. This means that your donation can increase in value by nearly a third at no extra cost to you. It doesn't matter what rate of tax you pay as long as you pay an amount of income or capital gains tax equal to the tax we reclaim on your donations in that financial year. Please inform us of any changes in your tax status.

Please tick the box below if you would like ME Research UK to reclaim the tax on your gift.

☐ Please treat this and any future donations I make to ME Research UK, and all payments I have made to ME Research UK since 6th April 2000, as Gift Aid donations.

5 Signature(s) _____ Date _____

6 **Please return this form to:**

The Administrator, ME Research UK, The Gateway, North Methven Street, Perth PH1 5PP, UK

Tel: 01738 451234, **Email:** meruk@pkavs.org.uk, **Web:** www.meresearch.org.uk

7 Please tick this box if you require an acknowledgement ☐

Thank you for your support

ME Research UK will use your personal information to provide you with the services, products or information you have requested, and for administration purposes. We would like to keep you informed of our important work.

☐ Please tick this box if you would like to receive email communication about the future activities of ME Research UK, via the e-mail address you have provided.

☐ Please tick this box if you would prefer not to receive other forms of communication about the future activities of ME Research UK.

By providing us with any personal data, you consent to the collection and use of any information you provide in accordance with the above purposes and our privacy statement.

Cheney seminar to include stem-cell therapy results on two patients

The following information is about an American seminar at which Dr. Cheney will be providing information about his 4 stage treatment of CFS/ME which includes stem-cell therapy. The information below is organised in to two sections – Clarification and Original announcement. The Original announcement is notification of the seminar and provides some insight into the content of the seminar. Although here it is in front of the Original announcement, the Clarification reveals that part of Dr. Cheney's 4 stage treatment includes stem-cell research.

Clarification

The following announcement was made in December, but I wanted to update it with an exciting clarification. Dr. Cheney will be presenting an up-to-date broad overview of CFS with a special focus on two key topics as outlined below, and will also present detailed information on his four-part treatment protocol. As someone disabled for over 20 years who is getting her life back, I can personally say this is the most comprehensive, effective protocol I've ever experienced.

Dr. Cheney has now given me permission to share that step four of his protocol is stem cell therapy. (Not every patient will need stem cell therapy. Many younger patients, or those ill for a shorter period, have returned to full functionality with just the first three steps.)

The first two CFS patients received a series of umbilical cord stem cell transfusions over the first ten days of February, and the pre and post testing done before and after the stem cell transfusions shows significant, dramatic improvement. The stem cells are known to circulate and continue the healing process for up to six months. It's too soon to know the full effect and final outcome of the stem cell transfusions, but the initial results are very good and very exciting.

One note: the stem cells transfusion is step four, and is likely not to be effective without the earlier steps in the protocol. Please don't jump into stem cell therapy without hearing what Dr. Cheney has to say about it.

The original announcement is below.

Original announcement

Paul Cheney, MD, PhD, will speak from 6 to 9 pm on Saturday, April 25th at the Fairfax Board Auditorium of the Government Center in Fairfax, VA (just outside Washington, DC, east of Dulles Airport).

Title: Chronic Fatigue Syndrome: is oxygen the problem and why? A four-part treatment protocol

In addition to presenting a broad overview of CFS (important principles, case definition, clinical findings, objective data, key medical literature), Dr. Cheney will present information on his latest four-part treatment protocol. His presentation will include in depth information on the following two topics:

Oxygen toxicity as a controlling factor in CFS

This section of the presentation will focus on the research finding of nearly 100% toxicity in CFS patients when oxygen is administered. (96% @ 4 lpm nasal cannula and 100% at 40% mask.) Dr. Cheney will present evidence that patients categorized according to increasingly powerful treatment protocols were transformed to an increasingly oxygen tolerant state. The most powerful treatment protocol was also associated with significant overall clinical improvement ($p<0.006$). The conclusion: CFS is an oxygen toxic state and oxygen toxicity status appears to determine outcome in therapeutic trials. Therefore, oxygen toxicity is a locus of control in this illness. These findings appear to force a narrowing of potential causes of CFS because whatever pathophysiology one puts forth must explain universal oxygen toxicity in CFS. Dr. Cheney will also present recent evidence of the likely cause of this oxygen toxicity.

Cell associated therapy for CFS: is this the next frontier?
Dr. Cheney will discuss the use of low molecular weight (LMW), mammalian tissue derived peptides as therapeutic agents when applied to the skin using novel transdermal gels. These LMW peptides are known to control gene expression and can shift organ function toward normal. Data will be presented from a one-year prospective trial in CFS using these LMW peptides which produced significant improvement in function (KPS>10, p<0.006, N=18). Therapy with LMW peptides from cell associated, mammalian tissue homogenates appear to offer a significant benefit in CFS, especially where it counts the most, namely, the functioning of the patient.

This event is being co-sponsored by the Northern Virginia CFS/ME, FMS, OI Support Group and the CFS/FM Support Group of Dallas - Fort Worth.

A 2-disc DVD master will be produced by a firm in Washington, and orders will be taken, duplicated and mailed out by a DVD fulfillment company in New York. DVDs will be available in both NTSC and PAL formats, making them compatible with DVD players around the world. No pre-orders will be taken. Ordering information will be posted as soon as it is available, which will be some time after the seminar.

Carol Sieverling
CFS/FM Support Group of DFW

Our group website

We have recently updated our group website, which is at: www.rescue.f2s.com
It now includes a members area that provides:

- access to PDF versions of all of the past group newsletters since 2006;
- members messages (explained below); and
- in-depth details of the next group meeting – directions, location.

The members messages section is an area that members can use to communicate with all other members. For example, it might be an article about ME/CFS or something the member has for sale. To submit a message to put in the members messages section just email it to rescue@f2s.com.

Access to the members area of our website is password protected to prevent non-members accessing the information – which may include personal information such as email addresses or phone numbers. To access the members area use the following:

Username = letme
Password = in

Currently the area that requests the username and password is marked with “unregistered”. Please just ignore it and enter the username and password. Removal of the marking is being worked on.

In addition to the creation of the members area the following changes have been made to the public part of the website:

- moving the sleepydust video introduction on ME/CFS to the greeting page of the site;
- the addition of two action for ME articles into the recommended reading section…”ME 2008 what progress?” and “no-one written off problems and potential solutions for people affected with chronic fluctuating conditions”; and
- the addition of three new links to the recommended links section…”Prohealth” “Foggy Friends” and “DoctorMyhill.co.uk”.

Abel & Cole
organic veg to your door + more

Organic vegetables, fruit, meat & more. The best organic food delivered to your door.

Outstanding service
We want to make your life easier - our online ordering system means you can do your weekly shop in under 10 minutes! You can set up regular orders, exclude anything you don't like from your box and let us know your holiday dates so that we automatically skip deliveries. Everything we sell can be delivered on a regular basis, from weekly to eight-weekly.

We love to hear from you by phone or email. We have the UK's best customer service (it's official - we won the National Customer Service Award in 2006, 2007 and 2008).

We work with the seasons
It makes sense (and tastes better) to eat strawberries in June and wonderful root vegetables in the winter. We have some fantastic European and international farmers who help us fill the gaps when, due to our cooler climate, the UK fields are in between harvests. Buying some produce from overseas enables us to keep our boxes full of a nutritional range of foods whilst supporting growers elsewhere. In these circumstances we never air-freight and obviously, our first choice is always British.

We support British farmers
We work with over 120 British farmers, bakers and producers - as well as some further afield (for Fairtrade bananas, coffee and chocolate).

We are guided by our ethics
We give a fair deal to farmers, fundraise with local schools and insist on the highest levels of animal welfare. All things we've done for years.

Example prices
To provide you with example prices, Vegetables, salads and chicken have been detailed below. An example delivery price is £1.

Vegetables

Aubergines (600g, 2 pieces)	£2.80
Broccoli (500g)	£1.99
Cabbage - Green	£1.49
Cabbage - Red	£1.60
Cabbage - White	£1.35
Carrots (500g)	£0.66
Chard (head)	£2.19
Courgettes (500g)	£2.99
Globe artichoke (2 pieces)	£2.45
Kale (400g)	£2.09
Pepper - Green	£1.60
Pepper - Red	£0.99
Potatoes (2kg)	£1.99
Spinach (400g)	£2.00

Salads

Avocado (2 pieces)	£2.99
Celery	£2.47
Cucumber	£2.05
Fennel (1 head)	£1.30
Lettuce (1 head)	£1.99
Potatoes - Salad (1kg)	£1.75
Rocket (100g)	£1.99
Sprouts - Adzuki (227g)	£1.73
Sprouts - Alfalfa (100g)	£1.50
Sprouts - Mixed Bean (227g)	£1.73
Sprouts - Mung (250g)	£1.73
Sprouts - Sunflower (227g)	£1.73
Tomatoes (500g)	£2.49
Tomatoes - Cherry (250g)	£1.59

Organic free range portions

Chicken Breast Fillets, Boneless & Skinless (375g, pack of 2)	£7.75 (£20.67 per kg)
Chicken Breast Fillets, Boneless, Skin-on (350g avg, pack of 2)	£6.99 (£19.97 per kg)
Chicken Breast, Bone In (x 1, 350g avg)	£7.19 (£20.53 per kg)
Chicken Drumstick & Wings Pack, (2 x 840g avg)	£7.99 (£4.76 per kg)
Chicken Drumstick with BBQ Marinade (500g avg, pack of 4)	£5.94 (£11.88 per kg)
Chicken Drumsticks (600g avg, pack of 4)	£3.29 (£5.48 per kg)
Chicken Legs, Bone In (500g, pack of 2)	£3.29 (£6.58 per kg)
Chicken Livers (250g)	£3.49 (£13.96 per kg)
Chicken Stir Fry Strips (500g avg) Serves 2-3	£10.35 (£20.70 per kg)
Chicken Thighs (600g avg, pack of 4)	£4.99 (£8.32 per kg)
Chicken Thighs Boneless (600g avg, pack of 4)	£7.39 (£12.32 per kg)
Chicken Wings (800g avg, pack of 6)	£3.49 (£4.36 per kg)
Childrens Breaded Chicken Pieces (500g avg)	£6.65 (£13.29 per kg)
Hot Smoked Chicken Breast (200g)	£5.80

Fee range portions

Free Range Chicken Breast, Skin On (375g avg, pack of 2)	£5.62 (£14.99 per kg)
Free Range Chicken Legs (500g avg, pack of 2)	£2.25 (£4.49 per kg)

Organic free range whole birds

Chicken, Whole, with Giblets (1.4kg avg) Serves 2-3	£9.79 (£6.99 per kg)
Chicken, Whole, with Giblets (1.7kg avg) Serves 3-4	£11.49 (£6.76 per kg)
Chicken, Spatchcock (1.7kg avg)	£17.77 (£10.45 per kg)
Chicken, Whole, Premium, with Giblets (2.1kg avg) Serves 4-6	£17.85 (£8.50 per kg)
Chicken, Whole, with Giblets (2.1kg avg) Serves 4-6	£13.99 (£6.66 per kg)

Free range whole birds

Free Range Chicken, Whole, with Giblets (1.5kg avg)	£7.99 (£5.32 per kg)
Free Range Chicken, Whole, with Giblets (1.7kg avg)	£8.89 (£5.23 per kg)
Free Range Chicken, Whole, with Giblets (2.1kg avg)	£10.99 (£5.23 per kg)

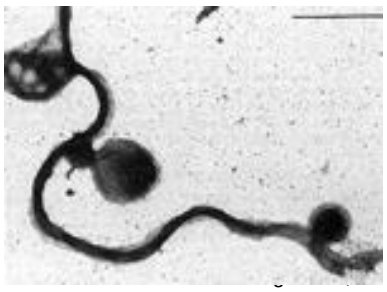
Internet screenshot

Optional idea

If you decide to join Abel and Cole they will put £10 into my account (Neil Perrett, newsletter editor). I will then use the amount gathered (e.g. £30 if 3 people join) to get things like chocolate cookies and brownie mini-bites to bring along to ME group meetings (or Cathy can bring them if I can't make the meeting). To make the £10 happen after joining, simply email Abel and Cole at organics@abelandcole.co.uk and say something like "My name is XXXX and I was sent to join by Neil Perrett whose account number is 310886"

Understanding L-form bacteria

Source: http://bacteriality.com/2007/08/15/l-forms
Author: Amy Proal


Kersten 1995

In a 2006 the Centers for Disease Control and Prevention (CDC) released a paper stating, “Infectious agents have emerged as notable determinants, not just complications, of chronic diseases. To capitalize on these opportunities, clinicians, public health practitioners, and policymakers must recognize that many chronic diseases may indeed have infectious origins.”

According to the CDC, infectious agents likely determine more cancers, immune-mediated syndromes, neurodevelopmental disorders, and other chronic conditions than currently appreciated. In fact, they argue that the potential to avoid or minimize chronic disease by preventing or treating infections may yet be substantially underestimated. Those of us familiar with the Marshall Protocol know that they are absolutely correct.[1]

The same can be said for Dave Relman, PhD, assistant professor of medicine and of microbiology and immunology at Stanford University in California who argues, “The list of chronic inflammatory diseases with possible microbial etiologies is extensive; it includes sarcoidosis, various forms of inflammatory bowel disease, rheumatoid arthritis, systemic lupus erythematosus, Wegener granulomatosis, diabetes mellitus, primary biliary cirrhosis, tropical sprue, and Kawasaki disease….. the concept of pathogenic mechanism should be viewed broadly.”[2]

Fortunately, the stealth pathogens responsible for causing the vast majority of chronic diseases have already been identified.

Almost all of us have suffered from a bacterial infection. Sometimes the forms of bacteria causing our symptoms can be killed by antibiotics that work by targeting their cell walls.

However, part of the life cycles of many bacteria include phases where they transform into small forms that lose their cell walls. This means that they can no longer be killed by many commonly used antibiotics. These bacteria are called cell wall deficient (CWD) or L-form bacteria.

Multiple studies have also shown that when one of the Beta-lactam antibiotics (a class of antibiotics that includes penicillin) are applied to wild-type bacteria in a Petri dish, small colonies of L-form bacteria form on the edges of the plate. “Treatment with penicillin does not merely select for L-forms (which are penicillin resistant) but actually induces L-form growth,” states researcher Josep Casadesus in a paper about L-form bacteria published last month in the medical journal BioEssays.[3]

L-form bacteria are pleomorphic, a term that refers to their ability to change in size and shape. During much of their lifetimes they are tiny, about 0.01 microns in diameter, and can be found clustered together inside the cells of the immune system.

Since they are smaller than viruses or fungal particles, they cannot be seen with a normal optical microscope. The small, individual forms of L-form bacteria are often referred to as coccoid bodies. Coccoid bodies sometimes group together, assuming the appearance of a string of pearls

Occasionally L-form bacteria break out of the cells. In the lab they can grow into long, thin biofilm filaments that can reach 60-70 microns in length. The biofilm filaments are composed of L-form bacteria and a protective protein sheath. For reasons still unknown, L-forms can also grow into large “giant” bodies.

L-form bacteria replicate in various ways, including budding, filamentous growth and binary fission. Some species of L-forms such as Proteus can form large bodies that replicate by division. In other instances, granules bud from the body of the bacterium and give rise to small L-form colonies.

L-form bacteria also lack flagella, long slender appendages that allow some forms of bacteria to propel themselves forward by using a whip-like motion. Instead they glide to their destinations in a snail-like fashion.

Groups of L-form bacteria are often encased inside tubules. They are also separated from the environment inside the cell by a membrane or exoskeleton that keeps them from being digested by the cell.

Researchers have currently identified over 50 different species of bacteria capable of transforming into the L-form and it is likely that more species will be found in the coming years. “Probably most bacterial species can be converted into L-forms if treated with the antibiotics that inhibit cell wall synthesis,” states Casadesus.

Although scientists have known about L-form bacteria for over a century, many of them have not detected them in tissue and blood samples because they are very difficult to culture. However an increasing body of research has shown that these bacteria are responsible for causing a wide array of chronic diseases including rheumatoid arthritis, Chronic Fatigue Syndrome, Lyme disease, sarcoidosis, and Crohn’s disease.

Some of the species of L-form bacteria that have been implicated in chronic disease include Bacillus anthracis, Treponema pallidum, Mycobacterium tuberculosis, Helicobacter pylori, Rickettsia prowazekii, and Borrelia burgdorgeri.

Survival mechanisms

Classical forms of most bacterial species can be found in the bloodstream. However L-form bacteria have figured out how to successfully infect and live inside the very cells of the immune system whose job is to kill bacteria. Once inside these cells, they can no longer be detected by the immune system and are able to persist in the body over long periods of time. L-form bacteria can infect many types of cells but prefer to infect white blood cells called macrophages.
The life cycle of Sprirochaeta gallinerum, Hindle 1912
The life cycle of Sprirochaeta gallinerum, Hindle 1912

Several very recent studies have confirmed the fact that bacteria can live inside the cells of the immune system. In a paper published in the Jounal of Immunology by a team at the University of Michigan Medical School, Gabreil Nunez, senior author of the paper, stated “In our study, the presence of bacterial microbes inside the cell is what triggers the immune response.”

Similarly, a team of researchers at the Bacterienne Institute in France released a paper detailing how the bacteria E.coli is able to live inside the cells of the immune system. The researchers state that E.coli are “true invasive pathogens, able to invade intestinal epithelial cells and replicate intracellularly. Strains also survive and replicate within the macrophages.”
Infection with L-form bacteria

People are exposed to L-form bacteria in many places. Not all species cause disease.
A granuloma

Because they cannot be killed by pasteurization or chlorination, L-form bacteria can be found in milk, food, and water. They can be transmitted via sperm, intimate contact, and can be passed from mother to child during childbirth. Since they are too small to be filtered during the purification processes used in pharmaceutical manufacturing procedures, they can be transmitted through injectable medicines. They have even been cultured from dry soil.

Once macrophages and other cells have been infected with L-form bacteria, the bacteria circulate in the blood and tissues. In some cases they cluster together in clumps called granulomas. In other cases, they accumulate in regions such as the joints.

Once L-form bacteria have successfully invaded a cell, they begin to use the nutrients inside the cell to their own advantage, disturbing the cell’s delicate chemical balance. They are also able to take control of the host’s genetic material, which allows them to create proteins that enhance their ability to survive.

L-form bacteria cause inflammation and painful symptoms by taking control of a protein called Nuclear Factor Kappa B. They are able to activate proteins that increase the activity of Nuclear Factor Kappa B, which subsequently moves to the nucleus or center of the cell. Once there, it

turns on a variety of genes that cause the release of inflammatory cytokines, proteins that generate pain and/or fatigue. These cytokines include interferon gamma and TNF alpha.

Thus, an inflammatory response is correlated with diseases caused by L-form bacteria. “An inflammatory immune response—one of the body’s primary means to protect against infection—defines multiple established infectious causes of chronic diseases, including some cancers,” argues Relman. “Inflammation also drives many chronic conditions that are still classified as (noninfectious) autoimmune or immune-mediated (e.g., systemic lupus erythematosus, rheumatoid arthritis, Crohn’s disease). Both [the innate and adaptive immune systems] play critical roles in the pathogenesis of these inflammatory syndromes. Therefore, inflammation is a clear potential link between infectious agents and chronic diseases.

The CDC concurs, stating, “The epidemiologic, clinical, and pathologic features of many chronic inflammatory diseases are consistent with a microbial cause.”

Detecting L-form bacteria

Once bacteria have transformed into the L-form they can no longer be detected by many standard laboratory procedures.

Regular forms of bacteria can be easily grown outside the body (grown in-vitro). However L-form bacteria have great difficulty surviving in a foreign environment. In order to grow them successfully in the lab, conditions must be similar to those in the human body (grown in-vivo). Consequently they can be cultured on a medium called blood agar at very specific temperatures and at a certain pH.

The concept that some bacteria cannot grow in-vitro is not new. Scientists have known for decades that neither (Syphilis Treponema pallidum) nor leprosy (Mycobacterium leprae) cannot be easily cultivated outside the body.

L-form bacteria take several measures to ensure they can survive for as long as possible inside a cell. They are able to infect all types of white blood cells, but prefer to infect macrophages, the type of white blood cell with the longest life span (about 45 days.)

Several studies have shown that once inside a macrophage, L-form bacteria are able to delay the process of apoptosis, or programmed cell death, allowing them to thrive inside the cell for a period of time even longer than 45 days.

Classical bacterial forms can be detected by a lab test called Polymerase Chain Reaction (PCR). PCR identifies and amplifies the proteins and DNA of bacteria that have been killed. However since L-form bacteria are able to persist inside the macrophages for such extended periods of time, few of them die and only tiny amounts of L-form bacterial proteins and genetic material reach the bloodstream at any given time; an amount so small that the PCR test cannot pick them up.

Even if a few small fragments from L-forms that have been killed are identified by PCR testing, the remains are often not from the bacterial species causing the most harm to the patient. This is because the most well adapted, persistent bacterial species are the ones who have developed the most effective survival mechanisms and are consequently least likely to die.

L-forms can also not be detected with antibody testing. Antibodies are Y-shaped proteins that are found in blood. They are used by the immune system to identify and neutralize foreign objects including bacteria.

However antibodies only form in response to bacteria that have died. Since L-form bacteria are able to persist for such long periods of time inside the cells, very few antibodies are created in response to their presence.

Gaining acceptance

Scientists such as Lida Mattman at Wayne State University have worked extensively with the L-form and figured out new ways to grow and view the pathogens. These techniques include a variety of special staining techniques.

British clinician Andy Wright and Danish researcher Marie Kroun have used a Dark Field Bradford Microscope to view L-forms in the bloodstream.

Nevertheless, many doctors and researchers still question whether the L-forms actually exist.

Mattman and other researchers have spent decades figuring out how to correctly culture the L-form. Applying their techniques correctly requires rigorous adherence to specific guidelines. Mattman has said that, over and over again, researchers misinterpreted just one of the steps required to correctly grow the bacteria. They then report to the medical community that no L-forms appear in their samples.

As Gerald Domingue, a (retired) professor at the Tulane University School of Medicine stated, “Unfortunately, in the area of L-form or cell wall-defective bacteriology, too often there have been conclusions (anecdotal) drawn without supporting scientific data. In my opinion, many of these studies have hampered progress in the field and especially the role of these cryptic organisms in bacterial persistence and expression of disease.”

“Features of a number of important but poorly explained human clinical syndromes strongly indicate a microbial etiology,” states Relman. “In these syndromes, the failure of cultivation-dependent microbial detection methods reveals our ignorance of microbial growth requirements.”[2]

There is also little incentive for scientists to study the L-form. Since the bacteria can be killed by simple low-dose antibiotic therapy, drug companies have little interest in investing money into related research. Researchers studying the L-form often find themselves with very little grant money but must still work long, tedious hours in the lab.

As Domingue states, “It is generally agreed among scientists that L-form bacteria are extraordinarily intriguing, interesting tools for biological study, yet the most neglected area of research has been on the role of these organisms in disease, particularly in host-pathogen interactions.”

Another problem rests with the fact that many researchers rely on a series of rules called “Koch’s Postulates” when interpreting research data. The postulates state that only one pathogen can cause a given disease. But research has shown each chronic disease is the result of infection with multiple species of L-forms.

This means that separate teams of researchers often detect different L-forms in patients with the same disease. For example both Borrelia burgdorferi and Rickettsia helvetica have been detected in patients with sarcoidosis. These findings make little sense to researchers still bent on adhering to Koch’s Postulates.

Hopefully as the medical community begins to better understand the role of the L-form in chronic disease, more and more researchers will take the time to learn how to correctly culture and interpret these forms of bacteria.

Most importantly, now that L-form bacteria can be effectively killed by the Marshall Protocol, the opportunity to curb chronic disease is groundbreaking. According to the CDC, chronic diseases represent the major health burden of established economies (>90 million people in the United States) and are a rapidly growing burden in developing economies.

“If a mere 5% of chronic disease is attributable to infectious agents, in the United States alone 4.5 million of the 90 million people living with chronic disease might benefit from strategies designed to prevent or appropriately treat selected infections. Worldwide, the impact could be far greater,” states the 2006 CDC report.

Things to do

A lot of ME sufferers are unable to work but need activities, within their capability, to keep themselves occupied. It is with this in mind that this article has been created. Although not all ME sufferers will be capable of doing all activities listed I hope that the list is long enough for everyone to find some useful suggestions. Thanks go to those at www.foggyfriends.org who contributed suggestions. If when reading this article you think of other suggestions that could be listed in a future newsletter please email them to rescue@f2s.com

Suggestions

- Create lists of daily/monthly things to get done
- Learning to cook new things
- Researching ME on the internet
- Reading/making posts on foggy friends and using their chat room
- Yoga, Tai chi or pilates at home using a DVD
- Gentle stretches of your own
- Epsom salt bath
- Playstation 3 or xbox 360 games
- Using facebook to contact old friends
- Browse for new clothes on the internet
- Get some DVDs online from blockbusters or lovefilm
- Search for new music to download (e.g. on itunes or napster)
- Go through all your old photos – scan some favourites on to the computer
- In the summer do a barbecue
- In the summer go somewhere in nature locally and read or listen to music on headphones
- Look online for greeting cards to order for the next events
- Go for a local short drive just to get out of the house
- Ring an ME contact to catch up
- Consider new supplements to try for the ME – nadh, D-ribose
- Listen to an informative radio station
- Listening to awesome (but very chilled out) music
- Any kind of pampering that you can manage – e.g. get someone to rub your feet
- Meditation
- Part time correspondence study
- Join a cause you believe in and lobby (letters, email, etc) or volunteer on behalf (maybe an ME group, maybe a charity, local interest or political group).
- Try a new hobby or game (e.g. Sudokus)
- Go for a short walk
- Have a good sort out, clear out and organise your PC - it'll run a lot better and you'll find things you'd forgotten about.
- Put some of your unwanted items on Ebay, gives you such a buzz when they sell and gets you a bit of money.
- Shop for bargains on Ebay
- Look after pets and plants
- Swap unwanted household items/clothes with friends/family
- Look up old music videos, cartoons and TV programmes, that you used to love, on YouTube
- Make a compilation CD or MP3 list of your favourite music or relaxing or uplifting tunes
- Do some admin and design work from home for a charity. Volunteer: http://www.csv.org.uk/
- Write a diary so you can look back and see how you've improved, hopefully!
- Get crafty start making cards now you have the time...get things off ebay or craft suppliers
- Read
- Sewing
- Write letters - people love getting letters
- Enter competitions
- Feed the birds in the garden and watch them.
- Shop at online supermarkets and buy all the offers.

SID

Social Information on Disability

If you need information on living with a disability talk to us about...

- solving everyday problems
- what is available
- your local information service
- how to get services
- buying and selling equipment

Please get in touch:

0800 0439395

www.asksid.org.uk

email: info@asksid.org.uk

With thanks to Surrey Adults & Community Care Services and the Millennium Awards Trust Charity No. 1110708

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0800 0439395

www.asksid.org.uk

SID

Social Information on Disability

With thanks to Surrey Adults & Community Care Services and the Millennium Awards Trust Charity No. 1110708

Benefits and Tax Credits

What money can I get if I become unable to work?

The main benefits that you need to know about are Statutory Sick Pay, Employment and Support Allowance. Incapacity Benefit (for existing claimants), Income Support and Industrial Injuries Disablement Benefit.

● Statutory Sick Pay (SSP)

If you are unemployed and earn at least £95.00 a week, you usually get £123.06 a week SSP, which can last up to 28 weeks. It applies when you have been off sick for at least four days in a row.

Periods of illness with eight week or less at work between them count as one in order to qualify for SSP.

If you are still off sick after receiving SSP for 28 weeks, or your employer no longer has an obligation to pay you SSP because your contract has been ended, you may get Incapacity Benefit. Your employer should be able to give you a changeover claim form (DWP form SSP1).

Unemployed and self-employed people are not covered by SSP. If you cannot get SSP, claim Employment and Support Allowance instead.

Claiming SSP – you need to notify your employer that you're off sick and may be asked to provide evidence that you are not capable of work. But an employer cannot ask for a doctor's certificate for the first seven days. SSP will be paid in the same way as you receive your wages.

People with ME/CFS often ask The ME Association for information about benefits.

The first thing to remember is that you probably won't get benefits just because you have ME/CFS. In most cases, you will have to show how your illness has a disabling impact on the way you live your life.

● Employment and Support Allowance

What is it?

Employment and Support Allowance (ESA) is the name of a new benefit that was introduced on 27 October 2008. It replaces both Incapacity Benefit and Income Support for people who are incapable of work.

What are the main differences between ESA and current benefits?

The biggest difference is that claimants are divided into three groups: an Assessment Group; a Work-Related Activity Group and a Support Group.

Who will be in the Assessment Group?

All claimants who are eligible for ESA will be in the Assessment Group for the first 13 weeks of their claim. Eligibility for this group is based on sick notes and either having paid enough National Insurance contributions or passing a means test similar to the current test for Income Support.

Who will be in the Work-Related Activity Group?

After the 13-week assessment period, the vast majority of claimants who pass the assessment will be placed in the Work-Related Activity Group and receive an additional amount of ESA which should raise their income to above the current level of incapacity benefit.

Members of this group will have to attend work-focused interviews and draw up an action plan setting out the steps they are willing to take towards moving into work. Failure to do so will result in cuts in their benefits.

Although actually undertaking work-related activities and taking part in condition management programmes will not be compulsory initially under ESA, the government has indicated that it will consider making such activities compulsory in a few years' time.

Who will be in the Support Group?

A much smaller number of the most severely disabled claimants, perhaps 10%, will be put

in the Support Group. Claimants in the Support Group are paid at a higher rate than those in the Work-Related Activity Group and they will not have to do anything in return for their benefit.

Is that the only main difference?

No, one other major change under ESA is that the Personal Capability Assessment – the test of whether you are incapable of work – has been renamed the Work Capability Assessment and made much harder to pass.

The physical health test has been tightened up, with many fewer opportunities to score points. The mental health test has been rewritten completely and will also be very much harder to pass. There will be no exemptions from the test except for terminally-ill people, some pregnant women and people receiving chemotherapy.

Will existing incapacity benefit claimants have to go on to ESA?

The Department for Work and Pensions have said that they intend to move all existing claimants onto ESA. Claimants under 25 may be moved in 2009, with the majority of claimants being moved between 2010 and 2013.

The ME Association has had very limited feedback so far from people who have claimed ESA. We will be publishing more on the subject when we are able to offer more detailed analysis.

But, if you would like to find out more about this new benefit, we recommend a visit to the Benefits and Work website, a privately-run, online benefits advisory service where much more information is available.

www.benefitsandwork.co.uk

● Incapacity Benefit (IB)

IB is for existing claimants who have been unable to work because of illness or disability but do not qualify for SSP, or your SSP has ended.

(Since 27 October 2008, many people with ME/CFS who would previously have applied for IB are being required instead to apply for Employment and Support Allowance).

IB is paid at three different rates, depending on how long you have been unable to work and, in the case of long-term awards, upon your age.

Additions to IB for dependent children are in place for those claiming IB since before 5 April 2003. Other claimants are expected to claim Child Tax Credit instead *(see last page)*.

What else can I get?

You cannot get IB as well as State Pension or Jobseeker's Allowance.

But you may also be able to claim the following benefits, providing you meet the qualifying criteria: Disability Living Allowance, Attendance Allowance and Industrial Injuries Disablement Benefit. Working Tax Credit can be paid on top, but IB is taken into account when assessing this.

If your income is low, you might get Income Support to top up your IB. Ask your local Jobcentre Plus or Social Security office for a claim form. If you get long-term IB, you can also get disability premium with Income Support, Housing Benefit or Council Tax Benefit.

Cash benefit usually available:

Short-term Lower Rate..... £67.75pw

Short-term Higher Rate.....£80.15 pw

Long-term Basic Rate.....£89.80 pw

● Income Support (IS)

You can claim IS if you don't have to sign on for work, or if you are a carer or single parent.

You can't claim IS if you have savings or capital of more than £8,000 (£12,000 if you have a partner aged 60 or over, or £16,000 if you live permanently in a care home).

IS is a means-tested or income-related benefit that does not depend on National Insurance contributions. It is intended to provide for basic living expenses for you and your family.

It can be paid out on its own if you have no other income, or it can top up other benefits or earnings from part-time work to the basic amount that the law says you need to live on.

If you don't have much money coming in, it is always worth checking to see if you might qualify. IS has been replaced by pension credit for people aged 60 or over.

But you will not be able to claim IS if your partners works 24 hours or more a week.

IS can help towards mortgage interest payments and certain other houing costs. If you get IS, you may also get Housing Benefit and Council Tax Benefit to help with your rent and council tax. You won't have to go through a separate means test for these.

Getting IS may also entitle you to a range of other benefits including Free Prescriptions and Dental Treatment, Free School Meals and Help with Hospital Fares.

● Industrial Injuries Disablement Benefit

You may be able to claim this benefit if you have been employed (but not self-employed) and become disabled because of an accident at work or if your disablement/illness has been caused by work.

What support can I get if I'm still able to do some work?

This section covers Jobseeker's Allowance, Working Tax Credit and the Permitted Work rules.

● Jobseeker's Allowance (JSA)

JSA is for people who are unemployed or working less than 16 hours a week and who are actively looking for work.

There is contribution-based JSA, a personal flat-rate allowance based on your NI contributions record (payable for up to six months and taxable), and there's income-based JSA – means-tested and taxable, which is paid if you have no income or low income, not more than £8,000 savings (£12,000 if you or your partner are aged 60 or over, and your partner is working less than 24 hours a week).

● Working Tax Credit (WTC)

WTC is a means-tested or income-related payment for those in low paid work. It replaced Working Families Tax Credit and Disabled Persons Tax Credit in April 2003.

The level that you are entitled to will be higher if you are disabled or have children. You may be able to claim this if you or your partner are in work at least 16 hours a week, and if you have at least one child or if you are disabled.

You may also be able to claim if you are aged 50 and over and have started work for at least 26 hours or more a week (having been out of work or off sick), or if you are aged 25 or over without children or a disability and you work at least 30 hours a week.

Claim WRTC and Child Tax Credit (which we explain later) on rhe same form, TC600. This can be obtained by ringing the Tax Credit Helpline on 0845 300 3900, or from an Inland Revenue inquiry centre, social security office or from your nearest Jobcentre Plus office.

WTC will normally be paid by your employer into your wage packet, except if there is a child-care element which will be paid to the main child carer, or directly into a bank if you are self-employed.

● Permitted Work

If you are getting employment and support allowance (ESA) , Incapacity Benefit (IB), severe disablement allowance (SDA), National Insurance Credits or Income Support (IS) because of incapacity for work you are allowed to do some permitted work.

You do not need the permission of a doctor to do permitted work but you should tell the Department for Work and Pensions (DWP) if you are working.

Permitted work for those on ESA, Incapacity Benefit, Severe Disablement Allowance or National Insurance Credits

You have a choice of permitted work options depending on your circumstances:

1. Permitted Work Lower Limit – under this option you can earn up to £20 a week for an unlimited period.

2. Permitted Work Higher Limit – you can work for a 52-week period, if the work is for less than 16 hours a week and your earnings do not exceed £92 a week after deductions. After you have done 52 weeks work, there must be a gap of at least 52 weeks before you can work again, whereupon another 52 weeks work is permitted.

3. Supported permitted work – if you choose this work option you must be supervised by someone who is employed by a public or local authority or voluntary organisation which provides or finds work for people with disabilities. You cannot earn more than £92 a week.

4. Work done as part of a treatment programme done under medical supervision whilst someone is an in-patient or regularly attending as an out-patient of a hospital or similar institution. Again the limit is £92 per week.

5. If you are exempt from the IB/IS personal capability assessment – you can work for an unlimited period, if the work is for less than 16 hours a week and your earnings do not exceed £92 a week after deductions.

6. You are on ESA and you have limited capability for work related activity (you are in the support group) – you can work for an unlimited period, if the work is for less than 16 hours a week and your earnings do not exceed £92 a week after deductions.

What other benefits are available?

● Disability Living Allowance (DLA)

DLA is a cash beneft for adults and children aged under 65 who need help with looking after themselves and who have difficulty walking or getting around. You don't need to have someone looking after you to qualify.

DLA is tax-free, not means-tested and you don't need to have paid any National Insurance contributions. It is paid on top of any earnings or other income you may have. DLA acts as a gateway to several other types of benefit.

It is divided into two parts:

- **a care component** – for help with personal care needs, paid at three different levels;
- **a mobility component** – for help with walkig difficulties, paid at two levels.

Cash benefit available as follows:

Care component per week

Highest rate..... £70.35

Middle rate..... £47.10

Lowest rate..... £18.65

Mobility component per week

Higher rate..... £49.10

Lower rate..... £18.65

You can be paid either the care or the mobility components on its own, or both at the same time. DLA is paid to you for your own use, not paid to a carer or parent.

Remember that DLA is paid not because you have ME/CFS but because your illness has a disabling effect on your ability either to look after yourself or on your ability to get around – or both.

If the DWP decide that a medical assessment is necessary, arrangements will be made for you to see an Examining Medical Practitioner.

If you are in hospital, payment of DLA stops after 28 days in hospital (or 84 days for children under 16). Payment resumes on the first benefit pay day in the week after you leave hospital.

It is important, when filling in claims forms, not to minimise the effects of your disability.

Claiming DLA – phone the Benefit Enquiry Line free on 0800 88 22 00 and they will send you a claim pack. The claim can be backdated to the date of your call, but it is important to return your completed form within the time allowed.

This is another complex benefit to claim. The ME Association has prepared a detailed leaflet called *Disability Living Allowance – Filling in the Form* to help you make the most of your claim. It is available, price £3, from our main office, tel: 01280 818964.

● Attendance Allowance (AA)

AA is a tax-free benefit for people aged 65 and over who are physically and mentally disabled and need help with personal care or need supervision to remain safe. You do not actually have to be getting any help. It is the need that is relevant, not what help you get. The rules are almost exactly the same as for DLA.

You must have been in need of care for six months before you award can begin, but you can make your claim before the six months are up.

AA can be paid in addition to almost any other benefit, such as state pension or pension credit.

To claim – phone the Benefit Enquiry Line free on 0800 88 22 00 and ask for the AA claim pack. They can help you fill in the form.

The DWP may ask for a short report from your doctor, or another medical person you've named on the form. So make sure the doctor named knows all about you care and/or supervison needs before you apply.

Cash benefits available as follows:

Higher rate..... £70.35 pw

Lower rate..... £47.10 pw

● Travel and parking concessions

If you receive the DLA high rate mobility component, or are registered disabled, it is easier to get reduced fares on public transport and/or taxis, and a Blue Badge for disabled parking. The Blue Badge is awarded to the disabled person, whether driver or passenger, not to your vehicle. Contact you local council to find out more.

● Road Tax Exemption

If you are on DLA high rate mobility, you (or someone you nominate) can apply to be exempted from vehicle excise duty (road tax). The vehicle is only exempt if used solely by or for the purposes of the disabled person.

● Child Tax Credit (CTC)

CTC is a means-tested or income-related payment for people who are responsible for children, whether they are in work or out of work. It replaced Children's Tax Credit and the increases for children within Working Families' Tax Credit and Disabled Person's Tax.

FURTHER INFORMATION

Benefit Enquiry Line: 0800 88 22 00
8.30am-6pm, Monday-Friday; 9am-1pm Saturday. Confidential advice and information, helpline run by the Department for Work and Pensions. They send out leaflets and claims packs.

Government website
The UK Government has a website – www.direct.gov.uk – which carries full information about benefits and tax credits.

Several agencies and local councils employ specialist benefits rights worker who can help with your claim, or advise about what to do if a claim is rejected or you do not received beneft at the level to which you think you are entitled.

Your local Citizens Advice Bureau (CAB) may also be able to help. Check you local phone directory for contact details or go to their website to find the CAB closest to you, or go online at www.citizensadvice.org.uk/index/getadvice.htm

Benefits and Work is an independent, online benefits advice agency, which charges a small membership fee if you want to see the full range of their leaflets and information. www.benefitsandwork.co.uk