Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Autumn 2012

Future dates

The following ME meetings are open to all members and carers.
Please put these dates in your calendar.

16th January 2013 (Wednesday) 11am The Holiday Inn
Egerton Road, Guildford, GU2 7XZ

18th February 2013 (Monday) 7.30pm The Boatman
Millbrook (A281), Guildford GU1 3XJ

21st March 2013 (Thursday) 4pm The Seahorse
The Street, Shalford, Guildford, GU4 8BU

8th April 2013 (Monday) 7.30pm Worplesdon Hotel
Perry Hill, Worplesdon, Guildford GU3 3RY

CDC announces 7-clinic study to characterise ME/CFS and its subsets

Full article: www.prohealth.com/library/showarticle.cfm?libid=17736

The American Centre for Disease Control and Prevention (CDC) has begun a multi-site clinical assessment of ME/CFS which will examine the differences and similarities between CFS/ME patients.

Ultimately, this may: allow patients to be sub-grouped to improve therapy; and allow the underlying biology to be discovered. The study started in 2012 and aims to enroll 450 patients.

There are seven participating clinical sites:

- Pain and Fatigue Study Center, NY [Benjamin Natelson, MD]
- Center for Neuro-Immune Disorders, FL [Nancy Klimas, MD]
- Open Medicine Clinic, CA [Andreas Kogelnik, MD]
- Sierra Internal Medicine Associates, NV [Daniel Peterson, MD]
- Fatigue Consultation Clinic, UT [Lucinda Bateman, MD]
- Hunter-Hopkins Center, NC [Charles Lapp, MD]
- Richard Podell Clinic, NJ [Richard Podell, MD]

International adult & paediatric ME consensus primer for clinicians

One year ago, a 26-member International Consensus Panel, independent of any sponsoring organisation, published the International Consensus Criteria (ICC) for Myalgic Encephalomyelitis, intended to educate primary care physicians and specialists in internal medicine. The ICC was published in the October 2011 issue of the Journal of Internal Medicine (Carruthers BM, et al.).

Now the Panel has created a Myalgic Encephalomyelitis Adult & Paediatric International Consensus Primer (ICP) for Medical Practitioners, building on the ICC to provide easy-to-use diagnostic and treatment guidelines. It is available free in PDF format here:

http://hetalternatief.org/ICC%20primer%202012.pdf

The new ME Primer "can be downloaded, posted on websites, and reprinted, provided people comply with all the conditions listed on the title page," writes co-editor Marj van de Sande in the following announcement issued Oct 3, 2012.

> **From: Marj van de Sande (Co-editor) Oct. 3, 2012**
> **Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners**
>
> The Myalgic Encephalomyelitis International Consensus Panel is pleased to announce that the International Consensus Primer (ICP) for ME has been completed. The ICP is a one stop, user-friendly reference that specifically targets primary care physicians and specialists in internal medicine.
>
> **Background:**
> An International Consensus Panel was formed with the purpose of developing criteria and a physicians' primer for ME based on current knowledge. The 26 member panel, consisting of clinicians, research investigators, teaching faculty, and an independent educator, represent diverse backgrounds, medical specialities and geographical regions. Collectively the members of the panel have diagnosed and/or treated more than 50 000 patients who have ME, have approximately 500 years of both clinical and teaching experience and have authored hundreds of peer-reviewed publications.
>
> **Criteria:**
> The International Consensus Criteria (ICC) were published in the Journal of Internal Medicinein 2011.
> (http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/full)
>
> **Primer:**
> The (ME-ICP) includes a summary of pathophysiological findings, the ICC, diagnostic and treatment guidelines and appendices. The ICP represents the collective wisdom and experience of the members of the panel gleaned through research and hundreds of thousands of hours of clinical investigations, upon which the ICC and ICP are based. The panel hopes that the ICP will enhance clarity and understanding of ME, consistency of diagnosis and optimal treatment internationally.
>
> The ICP is a not-for-profit educational document that can be downloaded, posted on websites, and reprinted providing people comply with all the conditions listed on the title page.

CFS service at St Helier and Sutton hospitals

The only official 'treatment' for ME/CFS in the UK has been Graded Exercise (progressive level of movement/exercise over time) and Cognitive Behaviour Therapy (CBT, a form of psychotherapy to assist cognitive processes and contents).

At best it has been viewed as: a way of preventing deterioration of the body due to a lack of movement (deconditioning) and helping to offer healthier ways-of-thinking and coping strategies for the many life problems the illness causes. At worst it has been viewed as trying to cure a biological illness with psychological methods.

I experienced a well-intentioned but limited Graded Exercise/CBT course many years ago so I understand the contrast between the illness and the helpfulness of the course. But having spoken at length to a member who has first-hand experience of the CFS service at St Helier/Sutton Hospitals I now am comfortable recommending the service to ME sufferers (via GP referral). I understand that the service has a modern biological understanding of the illness and meaningful insights into the many impacts the illness has on a sufferers life and well-being. Some information about the service is included below.

The chronic fatigue service (CFS) at St Helier and Sutton hospitals is the local multidisciplinary team (LMDT) and clinical network co-ordinating centre for people with chronic fatigue syndrome in southwest London and Surrey.

Epsom and St Helier University Hospitals NHS Trust

The chronic fatigue service was opened in early 2005 under the leadership of Dr Amolak Bansal, consultant immunologist at St Helier Hospital. The service was part of the department of health chronic fatigue clinical network collaborative to introduce services for individuals with chronic fatigue syndrome where none existed.

As there is currently no cure for chronic fatigue syndrome, treatment is presently based on the management of symptoms to improve function and quality of life. Management of symptoms will not necessarily take the symptoms away; however, there is evidence which supports a significant reduction in symptoms with improved quality of life through the implementation of lifestyle management strategies. We use a combined bio-psycho-social and cognitive behavioural therapy model in teaching patients to manage their symptoms.

We provide one-to-one consultations to patients, lifestyle management and education groups. We have a domiciliary service for severely affected patients. The purpose of home visits is to confirm diagnosis and provide advice on management to primary care providers.
Our section on this website is designed for patients being seen in the service to enable them to access information sheets and other resources mentioned in our clinics and groups programmes.

Please be advised that due to limited resources we can only provide advice and information regarding the management of chronic fatigue syndrome to patients currently in the service. If you have any queries of a general nature we advise you to contact your local support group or other voluntary CFS/ME organisations. We do encourage local support services to contact us for information on management of CFS/ME in general and to liaise with us in the management of patients who are being seen in their services and ours.

Key staff include: Dr Amolak Bansal (Consultant Immunologist), Dr Zoe Clyde (Consultant Clinical Psychologist), Dr Yasmin Mullick (Clinical Psychologist), Karen Tweed (Clinical Nurse Specialist), Mandy Cole (Secretary), Debbie Breach (Appointments Clerk - Team Leader).

Partial source: www.epsom-sthelier.nhs.uk/our-services/a-to-z-of-services/clinical-services/pathology/immunology/chronic-fatigue-syndrome

Partial source: Neil Perrett (Newsletter Editor)

NT Factor

There are a range of energy related supplements that may offer some support for ME. An overview of some of the common ones were included in our Autumn 2010 newsletter (available in the members section of our website). Another supplement that may be useful is called NT Factor. NT Factor, however, is quite expensive especially at the dose that is recommended for severe fatigue. I've included information about the supplement in the newsletter for those who have the money to explore expensive supplements that may be helpful. I've included below information about Lipid replacement therapy, NT Factor and several purchasing examples.

Neil Perrett – Newsletter Editor

Lipid replacement therapy

As an approximation there are 120 trillion cells (everyone is different) that make up the human body. In each cell there are between 1 and 10,000 mitochondria (average 200-1000) which create the energy called ATP that we use.

When our mitochondria create energy (from oxygen and glucose from our food) they create a by-product called free-radicals which shoot out like radiation throughout our bodies causing damage to our cells and mitochondria.

Damaged cells and mitochondria are less able to generate energy and simply die if too damaged. Replacing them robs us of energy and ages us because replacement cells tend to be less perfect than their predecessor.

A benefit of anti-oxidants is their ability to soak-up/disarm free-radicals limiting their damage. However, Lipid replacement therapy aims to repair the damage done to the cell and mitochondria, thereby restoring their ability to create the ATP energy that we need.

The cell membrane is made of a very special blend of lipids, in a unique composition and structure. These lipids can be replaced when damaged. In fact, healthy cells replace damaged lipids all the time. But in modern life, as we age, face environmental insults, or suffer from chronic infections, toxins and illnesses, we need a bit of help. That comes in the form of Lipid Replacement Therapy (LRT) — offering the body pristine, undamaged lipids in the same ratio and composition that the cell membrane has.

Lipid Replacement Therapy (LRT) affects all the cells of the body. Cells get much more than a new skin. They actually get a total reconstitution of every membranous structure from the actual cell itself down into its very heart, its mitochondria.

Neil Perrett – Newsletter Editor
www.nleducation.co.uk/news/repair-the-membrane-restore-the-body-a-breakthrough-discovery-comes-of-age

NT Factor (a Lipid Replacement Therapy)

NT Factor is a supplement that contains phosphoglycolipids, pre-biotics and pro-biotics. Phosphoglycolipids are building blocks of cell membranes. The pre and pro-biotics work to balance friendly bacteria in your large intestine helping with the absorption of the phosphoglycolipids.

NT Factor is designed so that the phosphoglycolipids match the human cell membrane and are not digested but instead are able to get into the wall of the gastrointestinal tract while still intact. From there they spread throughout the body.

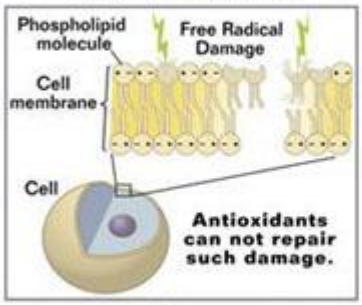
When the phosphoglycolipids in NT Factor get to the cell membrane, they fill in and plug any holes (damage caused by free-radicals). This enables the cell to once again function as it is meant to.

Further information: www.prohealth.com/library/showarticle.cfm?libid=15150

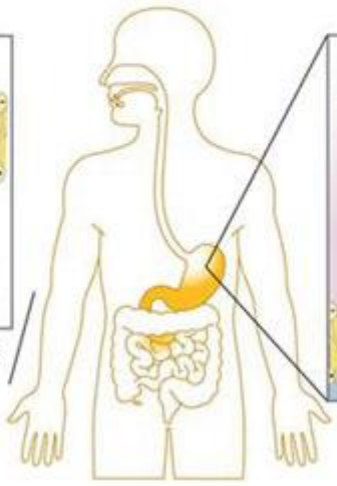
NT FACTOR® CUTS YOUR BIOLOGICAL AGE IN HALF

Here's how it happens as proven in clinical studies!

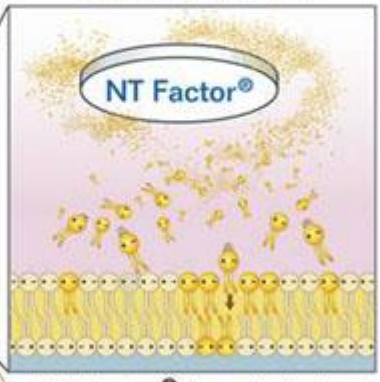
THE PROBLEM:



As we get older we get holes in our cells. These holes cause us to lose energy and all the other characteristics associated with aging.

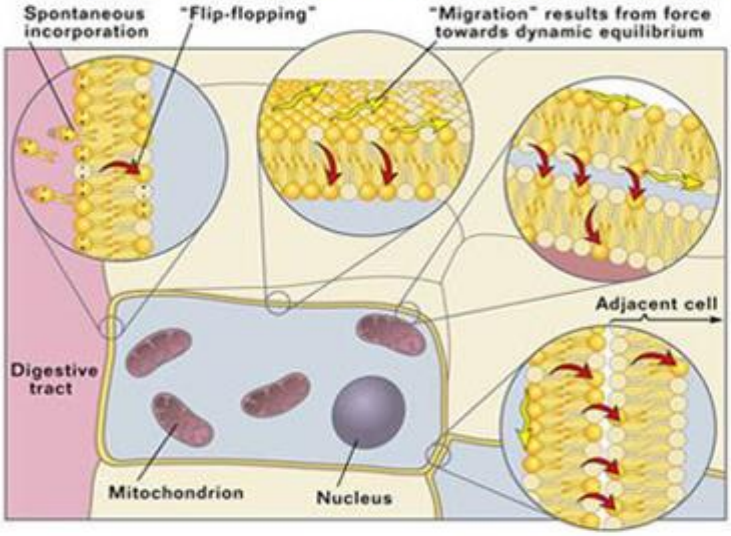


THE SOLUTION:



NT Factor® plugs the holes with healthy unoxidized phosphoglycolipids.

HOW NT FACTOR® REPAIRS DAMAGED CELLS

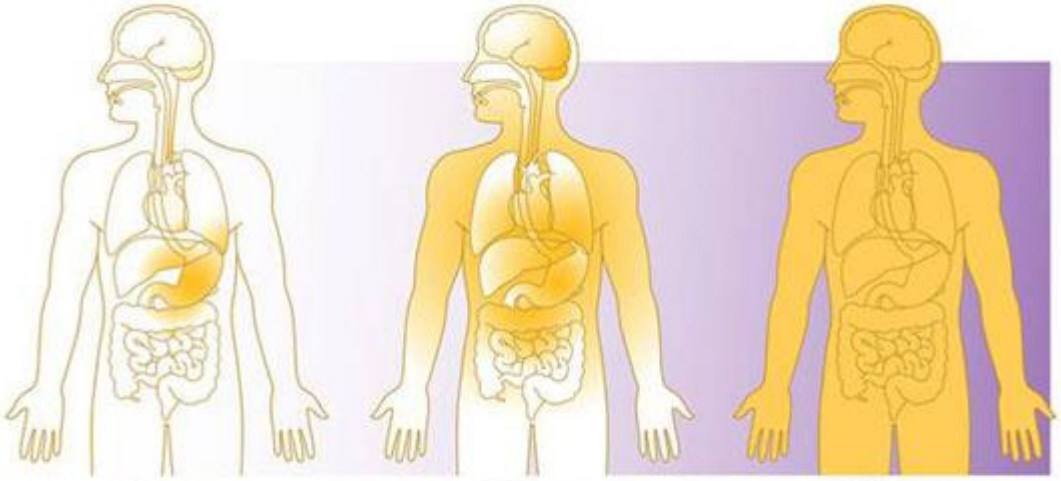


NT Factor® proprietary formula containing phosphoglycolipids gets from tablets in the GI tract to the intestinal cell membranes by the process of **Spontaneous Incorporation.**

NT Factor® proprietary formula reaches every cell and organ in the body by the dynamic equilibrium of bio-membrane lipids.

NT FACTOR® SPREADS TO THE BODY

Repairing and Restoring Damaged Cells over Time



3 Days
Surveys showed start of fatigue reduction and increased energy.

30 Days
25 to 30% increase in cell function. Corresponding reduction in fatigue with increase in energy.

60 Days
Fatigue dramatically reduced as scientifically measured. Cell function improved 45% - Better than controls half their age.

Purchasing examples
There are a number of products available in the UK that include NT Factor. The two examples I have included below are:

- Mitochondria Ignite with NT Factor; and
- NT Factor Energy Lipids

Mitochondria Ignite with NT Factor
Mitochondria Ignite with NT Factor is available from the following website:
www.yourhealthbasket.co.uk/index.php?l=product_detail&p=81

It costs £43.99 for one bottle of 45 tablets. One serving size is 2 tablets. Due to the cost I'd suggest one serving a day but the website suggests 3 tablets 3 times a day for those with severe fatigue.

In addition to 1350mg of NT Factor, Mitochondria Ignite also includes: Calcium 160mg, Phosphorous 50mg, Magnesium 50mg, Carnitine Fumarate 140mg, and Creatine Monohydrate 100mg and Pantethine 50mg.

NT Factor Energy Lipids (powder)
NT Factor Energy Lipids can be ordered in the UK from:

www.health-energy-fitness.co.uk/The-Shop/NT-Factor-EnergyLipids-powder-150g?productId=339

It costs £59.95 per container.

As a dietary supplement, ¼ teaspoon two times daily, or as directed by a healthcare practitioner. A larger dose of ½ teaspoon two times daily may be taken during an initial one to two month loading period. May be mixed with water, juice, or food.

Serving Size¼ Teaspoon (1.25 g)
Servings per container 120

Amount per serving:
Calories 8
Calories from Fat 5
NT Factor Proprietary Lipid Blend (soy lecithin extract) 1087 mg
Phosphatidic acid (PA)
Phosphatidyl-choline (PC)
Phosphatidyl-ethanolamine (PE)
Phosphatidyl-glycerol(PG)
Phosphatidyl-inositol (PI)
Phosphatidyl-serine (PS)
Digalactosyldiacylglyceride (DGDG)
Monoglactosyldiacylglyceride (MGDG)

The effects of Influenza vaccination on immune function in patients with ME/CFS

The findings of this small trial suggest that flu shots may provide immunity, but the trade-off is that later they may create dysfunctional, potentially toxic immune reactions not seen in controls.

Immune dysfunction is a hallmark of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME). The purpose of this pilot study was to identify the effects of influenza vaccination on immune function in patients with CFS/ME.

We included 7 patients meeting the Centre for Disease Control and Prevention criteria (CDC 1994) for ME/CFS and 8 control subjects. Bloods were collected from all participants prior to vaccination with Influvac, a trivalent inactivated influenza vaccine (TIV), 14 and 28 days following vaccination. The immune parameters examined include Natural Killer (NK) phenotypes, NK cytotoxic activity, FOXP3 and Th1/Th2/Th17 related cytokines. Flow cytometric protocols were employed.

There was no significant difference in NK phenotypes and Tregs numbers between CFS/ME patients and healthy controls.

However, NK activity was significantly decreased at baseline and at 28 days while at 14 days it was significantly increased in the CFS/ME patients compared to the healthy controls.
Th1 pro-inflammatory cytokines were much more increased in the CFS/ME patients at 28 days compared to the non-fatigued controls.

Only one Th2 cytokine, IL-4, was increased in the CFS/ME participants. FOXP3 expressing Tregs were significantly increased only at day 28 post vaccination in the CFS/ME patients compared to the healthy controls.

Self-rated well-being was lower for patients at day 28 while at baseline and day 14 no differences were observed.

In this pilot study immunisation with influenza vaccine is accompanied by a degree of immune dysregulation in CFS/ME patients compared with controls.

While vaccination may protect CFS/ME patients against influenza, it has the ability to increase cytotoxic activity and pro-inflammatory reactions post vaccination.

The role of Tregs [regulatory T cells] in promoting a toxic effect at 28 days post-vaccination in our patient group cannot be ruled out. The benefits of influenza vaccine still likely outweigh the risks CFS/ME patients experience following vaccination.

Source: International Journal of Clinical Medicine, Nov 2012 by Brenu EW, van Driel M, Staines DR, Kreijkamp-Kasper S, Hardcastle SL, Marshall-Gradisnik SM. Faculty of Health Science and Medicine, Population Health and Neuroimmunology Unit, Bond University, Robina, QLD, Australia; School of Medical Science, Griffith Health Institute, Griffith University, Gold Coast Campus, Gold Coast; Discipline of General Practice, School of Medicine, University of Queensland, Brisbane, Australia; Queensland Health, Gold Coast Public Health Unit, Robina, Gold Coast, QLD, Australia. [Email: e.brenu@griffith.edu.au]

Dr. Myhill explains ME/CFS mitochondrial support protocol & results

Source: www.prohealth.com/library/showarticle.cfm?libid=17725

The following article is a discussion of the release of the paper:
"Targeting mitochondrial dysfunction in the treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) – a clinical audit" Int J Clin Exp Med 2013;6 (1):1-15. Sarah Myhill, Norman E Booth, John McLaren-Howard.

We are pleased to announce our third publication which looks at targeting mitochondrial dysfunction in the treatment of ME/CFS.

Our first two papers established that mitochondrial dysfunction is a central pathophysiological lesion [pathological change] in ME/CFS:

www.ijcem.com/files/IJCEM812001.pdf

and

www.ijcem.com/files/IJCEM1204005.pdf

Those papers demonstrated that:

- the patients with the worst levels of fatigue had the worst levels of mitochondrial (energy) function and vice versa;
- there was a very strong relationship between mitochondrial energy scores and patient fatigue scores; and
- these studies clearly place ME/CFS as a physical disorder.

Mitochondrial (energy) function scores are calculated from the ATP profile test. This is a test that measures:

- how efficiently mitochondria can make ATP;
- how well they move ATP from the mitochondria into the cell where it is needed and recycled back; and
- how efficiently energy can be released from ATP once in the cell.

These are important measurements because from them one can further deduce whether the mitochondria are "going slow'' either:

- because they are lacking the “raw materials'' to “do the job''; or
- because they are “blocked'' from doing their ‘'job''. This ‘'blockage'' could result either from an external source [a toxin] or from an internal source, notably the fermenting gut.

Knowing and understanding what the biochemical lesions [problems] are, and whether they derive from “internal'' or “external'' sources, means that treatment packages can be tailored to individual patients.

The aim of this third study was, therefore, to see:

- how well patients respond to this tailored package of treatments; and
- what impact, if any, did those treatment packages have on both the ATP profile test results and also on the patient fatigue scores.

The nature of this study was an audit – that is to say clinical decisions were made for the benefit of the patient, not for the doctor or researchers.

However, the information that this audit yields is very encouraging. Essentially what is shown is:

- those patients who are able stick to the demanding treatment packages, involving a ''stone age'' low carbohydrate diet, discipline about sleep and pacing, together with a package of nutritional supplements, do indeed improve biochemically reliably well. That is to say their ATP Profile test results improve consequentially with their treatment package compliance;
- most of these biochemical improvements were accompanied by clinical improvements, as measured by patient fatigue scores; and
- four patients who did not adhere to the treatment packages either saw no improvement or indeed worsened.

In a clinical setting, therefore, it is incumbent upon the physician both to understand the difficulties that patients face with such a wide-ranging treatment package and also to support fully the patient with the challenges they face.

It is clear from these studies that mitochondrial function is not the only factor in ME/CFS, but it is an important one and correcting mitochondrial function is an essential part of improving functionality and therefore of recovery.

Pearls of wisdom from CFS Physician Lucinda Bateman, MD

Dr. Lucinda Bateman, an internal medicine specialist with more than 20 years of experience in the treatment of ME/CFS and Fibromyalgia, directs the Fatigue Consultation Clinic in Salt Lake City, Utah. In this article she shares five common truths she has learned about treating this illness. For patients and healthcare professionals alike, these basics may help guide care.

The following pearls of wisdom aren't listed in any particular order. I've found them all to be greatly helpful in managing CFS patient care. Hopefully they'll help you identify areas you and your health care team can explore.

Pearl 1: Build emotional resilience

From day one of a CFS diagnosis, it's bad news. People around an individual with CFS may not understand the illness, how it feels or what to do about it. At first a CFS patient might receive attention, but as months go by without the kind of physical improvement people expect, those who once offered support may disappear. The on-going physical limitations are accompanied by on-going emotional trials.

An acute illness is definitely traumatic, but most can muster a good fight while actively seeking a diagnosis and some type of rescue care. It's living with the "C" in CFS that really gets old. CFS can be especially punishing compared to other chronic illness. Because the symptoms are difficult to measure or prove clinically, they may be met with doubt or disapproval by those whose support is needed most. Because CFS follows a relapsing and remitting pattern, in addition to feeling limited most of the time, patients can't predict when they'll feel even moderately better or worse. Because of the characteristic post-exertional symptoms of CFS, an honest effort to function or simply have a little fun is often punished mercilessly by a relapse of pain, fatigue and brain fog.

There are innumerable personal losses in the present, and potential losses projected far into the future. Focusing on the loss can lead to a downward spiral that can impact life in very tangible ways.

In order to thrive, anyone living with CFS must repeatedly rejuvenate the will to live and to find joy in living, even while chronically ill. It can be done! No one and no disease can take away the freedom to choose how to respond to a difficult situation.

Two very important roles I play every day for my patients in the clinic are to be a strong advocate and to be a cheerleader when the going gets tough. I do this because the patients who do best over the long term are those who build their emotional resilience. They develop insight. They learn how to get out of an emotional slump or calm paralyzing fears. They learn to get back up and take one step forward. They cultivate the resources needed - among family, friends, counsellors and medical providers - to stay as positive as possible. Anything I can do to support this is valuable to care.

Remember that much of what we know about CFS physiology is centred in the brain, and the brain responds strongly to the mind. Emotional resilience can help lead to physical resilience.

Pearl 2: Achieve the most restorative sleep possible

Universally I've heard from patients that the better they sleep, the better they feel and function. The trick is figuring out how to accomplish this, and the solutions definitely vary by patient. Improved sleep immediately helps not only fatigue, but pain as well, and it probably improves cognition, mood, headaches and immune function to some degree.

Natural sleep is always best, but the unfortunate fact is that most CFS patients struggle with chronically disrupted and unrefreshing sleep that's not easily fixed. There is no doubt that left untreated, even for a few days, sleep disruption worsens most aspects of CFS.

Unfortunately there's no perfect remedy for sleep. Practicing good sleep hygiene - such as consistent bedtimes and reducing caffeine intake - is imperative, but often not enough. Even the best of medications used for sleep have modest success, and some may even have adverse effects that can actually make sleep less restorative.

Sleep medications may change the architecture of sleep, alter daytime cognition or worsen fatigue, so they should be used in the lowest effective doses and, as much as possible, directed at the cause(s) of sleep disturbance. It may be useful to undergo polysomnography (a sleep study) if single drugs or low doses are ineffective.

If medication is necessary, it may be helpful for your health care professional to choose one that also treats other symptoms you may have. For example, while primarily improving sleep, drugs like Lyrica (pregabalin) or Neurontin (gabapentin) may reduce pain, and Elavil (amitriptyline) may keep IBS symptoms in check.

Achieving restorative sleep is an on-going mission, but one well worth the attention.

Pearl 3: Achieve reasonable pain control
Unrelenting or severe pain is physically and mentally exhausting; it disrupts sleep, worsens mood and prevents physical activity. These are all important reasons to work on reasonable pain control. I say "reasonable" because it may be impractical to eliminate pain completely, so the goal is to push pain into the background, to feel more in control and less frightened by the pain. This can be done by both reducing the pain and by learning to manage pain psychologically.

The first areas to consider when pain escalates are related to sleep, emotion and physical activity. Remember that restorative sleep improves generalized pain. It's also important to note that emotional distress such as fear, depression, guilt or grief can dramatically escalate pain and reduce pain tolerance. With CFS in particular, overextending physically, such as attempting vigorous or prolonged exercise, can raise pain levels both immediately and for days afterward.

Inactivity, such as staying in bed too long, can also increase stiffness and overall achiness. So when pain increases, first re-examine sleep quality, emotional health and physical activity.

The decision to use pain medications, intermittently or persistently, should be made carefully with a qualified medical professional and adapted to each individual situation. Always be sure that appropriate investigations have been done to understand the cause and/or nature of the pain, so that treatment can be directed and maximally effective. Some focal pain conditions can be treated very effectively with high-tech procedures. Fortunately there are a growing number of effective pain-modulating drugs for the broad spectrum of conditions that can cause pain. Finding the right medication for your system and specific type of pain is key.

The goal is to keep pain in reasonable control with thoughtful prevention and treatment, and to seek more intensive treatment from a specialist when this is difficult to accomplish.

Pearl 4: Balance physical pacing with physical conditioning
Perhaps the most important fact I've learned from thousands of hours treating patients with CFS is that the most effective intervention for CFS is learning to control the type, duration and intensity of activity to avoid a "crash" or relapse. This is called pacing, or avoiding the push-crash cycle, and it works. Every patient should become familiar with his or her own threshold of relapse, even when it seems like a moving target, and learn to avoid triggering relapse symptoms by keeping activity within a safe level.

On the opposite end of the spectrum, activity limitation can cause diminished strength of both the skeletal muscles and the heart muscle. Without enough use, these muscles actually atrophy, getting smaller and weaker as time goes on.

This global decline in strength and stamina is called physical deconditioning, and unfortunately it's often accompanied by weight gain as well. Being deconditioned can worsen pain, fatigue, balance/ stability, orthostatic intolerance and sleep, not to mention self-esteem.

A thorny problem, deconditioning is not easily repaired because initial attempts to exercise invariably result in a flare-up or relapse of CFS symptoms.

These factors make both pacing and physical conditioning important for people with CFS. The objective is to carefully and regularly engage in a controlled level of physical rehabilitation that won't trigger relapse symptoms. The trick is figuring out how to do it -and especially how to adapt to a changing threshold of relapse. Tolerance for stretching, strengthening and cardiovascular exercise varies widely among patients with CFS.

It's helpful to start with these guidelines: short duration (five minutes), low intensity (not strenuous), adequate rest/recovery periods (even a day or more) and utilization of a position (reclining or in water) that won't worsen orthostatic intolerance if that's an issue.

The process of learning to effectively pace activity while still minimizing deconditioning can be a frustrating challenge, but it's an effective and self-empowering tool when it can be accomplished.

Pearl 5: Identify and treat comorbid conditions
There are a number of medical conditions, often subtle in presentation, that frequently overlap or occur in combination (are comorbid) with CFS. These conditions have well known diagnostic and treatment plans that a medical professional can follow whether familiar with CFS or not. Since each untreated condition may worsen CFS symptoms, any improvement in symptoms of comorbid conditions is progress in reducing the severity of CFS.

Here are some of the more common comorbid conditions present in people with CFS:
Sleep disorders (such as obstructive or central sleep apnea; restless legs syndrome, periodic limb movement or myoclonus; excessive sleepiness)

- Allergies, chronic sinusitis and reactive airway disease (asthma)
- Irritable bowel syndrome (IBS), reflux and heartburn (GERD), lactose intolerance, celiac disease
- Focal pain conditions such as osteoarthritis, cervical or lumbar disc disease
- Primary or secondary mental health conditions (such as attention deficit disorders, depression, anxiety)
- Metabolic syndrome (primary or secondary) and type II diabetes
- Hormone imbalances or dysregulation (such as menopause, low testosterone, hypothyroidism, polycystic ovarian syndrome)
- Chronic or recurrent infections (such as herpes or shingles outbreaks)
- Vitamin D and vitamin B12 deficiency or "low normal" values

People with CFS should learn about their own comorbid conditions, and in partnership with a medical professional, see that they get the best supportive treatment available.

The relevance of these clinical pearls of wisdom depends on the features of each individual's illness, but I've seen them all benefit CFS patients by improving functionality and quality of life. With a chronic condition like CFS, this can go a long way toward helping patients manage their illness while we search for targeted interventions and ultimately a cure.

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Lucinda Bateman, MD, specializes in the diagnosis and management of unexplained chronic fatigue, CFS and fibromyalgia. She is the cofounder of OFFER, the Organization for Fatigue and Fibromyalgia Education and Research. A few of her many leadership roles have included service on the boards of the CFIDS Association and the IACFS/ME, and as an appointed member of the federal CFS Advisory Committee.

Note: This information is based on the research and opinions of Dr. Bateman unless otherwise noted, and is not intended as medical advice, or to replace the personal attention of a qualified healthcare professional.