



# inforME Magazine

InforME Magazine is an informal publication for people concerned with ME, CFS and CFIDS.

(ME: myalgic encephalomyelitis, CFS: chronic fatigue syndrome, CFIDS: chronic fatigue & immune dysfunction syndrome)

Spring 2010

## Brain fog - poor memory, difficulty thinking clearly etc

From Dr Sarah Myhill, MD\*

[\*Dr. Sarah Myhill, MD, is a UK-based fatigue specialist focused on nutrition and preventive medicine. The online version can be found at "www.drmyhill.co.uk/" or "http://www.prohealth.com" with related articles and expanded information.]

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### Introduction

What allows the brain to work quickly and efficiently is energy supply. If this is impaired in any way, then the brain will go slow. Initially the symptoms would be of foggy brain, but if it progresses one will end up with dementia. We all see this in our everyday lives with alcohol being the best example – short term exposures give us a deliciously foggy brain - we stop caring, we stop worrying, it alleviates anxiety. However, it also removes one's drive to do things, one's ability to remember, impairs judgement and impairs ability to think clearly. Medium term exposure results in mood swings and anxiety (only alleviated by more alcohol), longer term use could result in severe depression and the dementia - examples include *Korsakoff's* psychosis and *Wernike's* encephalopathy. Incidentally these two examples also illustrate how most drug side effects result from nutritional deficiencies!

### GOOD ENERGY SUPPLY TO THE BRAIN

A normal *synapse* will pass a nerve impulse in 75 microseconds. The slower the time, the more we "lose it". Reaction times are slowed with alcohol. If this interval extends to 140 microseconds, one has dementia. Longer than that and we go unconscious as exemplified by a general anaesthetic.

What allows good energy supply to the brain is:

#### Good fuel and oxygen supply:

good *blood supply*, adequate *amount of blood*, sufficient *blood pressure*, sufficient *oxygen* and sufficient *fuel*.

**Happy winter? It sure looks like spring to me.** It is so beautiful out there! The snow drops, the crocuses and the blossom trees are breathtaking. I hope that you are able to get out and explore all this new birth that arrives when the weather starts to get warmer. For all those not living in Victoria, I do apologize for mentioning it.

I am wondering if anyone was persuaded to do the Candida diet that was written about in our last edition? I was on it for quite awhile and then life changed and I slowly was distracted from the whole idea. My health did do a backwards tumble, so I am back on track for the most part. For all that were at the Valentines party, please don't judge me by what I ate. I was tempted by a few sweeties. Yum. One of the things that happened was that my belly got bloated, I stop urinating and eliminating solids. I do have a diagnosis of Interstitial cystitis and IBS, like most of us, and the diet helped control the negative effects of these two illnesses. My brain has also been rather vacant, so I am hoping that I will see a positive turn around in that department. On the positive side, look at all the character building that I would of missed out on if I were healthy.

I am interested in what kind of articles you would like to see in the InforME Magazine? I need some help. Please call me with topic ideas, so that I will know where to aim my sites. Are you interested in scientific studies, relationships, legal issues, vitamin therapies or personal stories? The list could go on. Please contact me at [ggray@hotmail.com](mailto:ggray@hotmail.com) or call me at **250-370-2884**.

The Christmas party was a blast. The house was full and it is always a pleasure to see people laugh and share their thoughts. The Valentines party was equily pleasing, just with fewer people. I am guessing maybe 14 people, I even got to meet two new people. When people call to find out what we are all about, I tell them about the amazing, intelligent, fun loving people in our group. When I tell them about our up beat gatherings there seems to be some disbelief on the other side of the phone, but the compliment to everyone is that, people have said, "it's just the way you described it!" Maybe I will see you at the next one; which incidentally is the AGM. Don't let those three little letters turn you off. Come join us! The AGM will begin at 2:00 pm and then we will move on to what we do best, enjoy each other. Consider your role in this organization. If you think you would like to be on the executive contact me and we can talk about what that would look like. There is nothing scary about it.

# InforME Magazine

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For people concerned with ME(Myalgic Encephalomyelitis), CFS(Chronic Fatigue Syndrome), and CFIDS(Chronic Fatigue and Immune Dysfunction Syndrome)

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## Publication Disclaimer

The purpose of InforME Victoria is to offer a wide variety of information about coping strategies, research issues and possible treatments for ME, CFS and CFIDS. There is yet no agreement in the scientific and medical communities with regard to the causes and optimum treatment for conditions. We make every effort to use only responsible sources but some information may be speculative. We recommend that readers consult with a health professional with regard to their own treatment plan.

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## May 12th is M.E. Awareness DAY.

I feel rather embarrassed announcing it as we never do anything to commemorate this very special day. I seem to be exhausted every time this day rolls around. If anyone would like to take this on, please do. We can contact members to see if they want to participate.

**Thank you** to all our MEVA Board Members for all your support over the last year and thank you Lorraine for being brave enough to take on the job of being the producer of the InforME Magazine. your doing a great job!

Blessings to you all!

Gloria Gray, editor

*continued from front page*

### **Good mitochondrial function**

One then has to be able to convert this fuel and oxygen supply into energy that the brain can use, namely ATP. *Mitochondrial Failure as The Central Cause of CFS* is only part of the story!

### **Myelin sheath function**

There is a further interesting peculiarity with respect to energy supply to the brain, which is different from the rest of the body. Although the brain weighs just 2% of total body weight, in use it absorbs 20% of the body's oxygen requirement and 25% of its glucose needs! This cannot be explained by numbers of mitochondria in the brain (there are not enough), which means there must be another energy generating source. Brain cells are also very different from normal cells. They have a cell body, and very long tails, or dendrites, which communicate with other cells. Indeed, if a nerve cell body from the spinal cord that supplied one's toes was sitting on my desk and was the size of a football, the tail would be in New York! These tails or dendrites are too small to contain mitochondria but it has been suggested that energy supply comes directly from the *myelin sheaths* themselves. They too can produce ATP and it is this that supplies the energy for neurotransmission. Myelin sheaths are made up almost entirely of fats – so we need to look to oils and fats for improved energy supply to brain cells.

Some fascinating work by Dr Mary Newport (*What If There Was a Cure for Alzheimer's Disease and No One Knew?*) shows that coconut oils can cure dementia. The key ingredient is medium chain triglycerides (MCTs). This suggests to me that these are an essential part of this process. MCTs are an excellent energy supply to the brain, which likes also to work with short chain fatty acids or ketones. You can see an interview with Dr Newport on *You Tube in 6 parts*.

My guess is that the myelin sheath membranes have to be just the right fluidity to allow ATP to be synthesized. If this were the case it

would explain how general anaesthetics work – presently no one really knows! If GAs upset membrane fluidity enough then energy supply to nerve cells would be switched off, the nerves would cease to work and... bingo! – not just foggy brained but unconscious!

Do not be concerned about dietary fat and cholesterol causing arterial disease! The results of some studies of Polynesian peoples for whom coconut is the chief source of energy should put your mind at rest [1]. My guess is that statins, by reducing the cholesterol that the brain loves, is contributing to our current epidemic of Alzheimer's disease. Certainly it is rare for my CFS patients to tolerate statins – nearly always they are made ill by them.

So adding coconut oil to the regime of anyone with symptoms of foggy brain to dementia is likely to be helpful, partly by improving fuel supply and partly improving membrane function.

### **Brain fats and oils**

Humans evolved on the East Coast of Africa eating a diet rich in seafood. It is suggested that the high levels of oils, particularly DHA, allowed the brain to develop fast, thus out-stripping other mammals. So Homo Sapiens came to have bigger brains allowing intelligence to develop. There is lots of research showing that essential fatty acids are essential for normal brain function, so oils that would be helpful in addition to coconut oil would be omega 3 (fish)[\*fish not best source of omega 3], omega 6 (evening primrose) and omega 9 (olive oil), together with lecithin (which is phosphatidylcholine – i.e. the main component of all cell membranes).

### **Oils to treat foggy brain and dementia**

A suggested regime to start off would be:

- Lecithin 20ml - One tablespoon plus one teaspoon twice daily
  - Coconut oil 10ml - two teaspoonfuls twice daily
  - \*Eskimo oil 5ml - one teaspoon twice daily
- \*fish oil that has been filtered to remove mercury and pesticides [NB:see ed. note about better

sources of Omega 3]

- Olive oil for cooking

Ideally all these oils should be organic. When you get the hang of it, just slurp it out the bottle! Please, note these are just my educated guesses – there may be other useful tweakings!

Throughout life the brain creates a million new connections every second! This means there is huge potential for healing and repair - it is simply a case of moving things in the right direction! But the brain has to have the energy supply to allow this process to happen!

### **CFS, alcohol and foggy brains**

Alcohol intolerance is almost universal in CFS. This has always puzzled me! It could be partly explained by poor detox, but clinically there seems to be some direct effect on the brain, like a hypersensitivity. The above explains all! Alcohol dissolves readily in fats and would be excellent at changing the fluidity of membranes. It works just like a general anaesthetic – and, indeed, many CFSs are intolerant of anaesthetics. My guess is that the more fat-soluble a chemical, the greater its ability to produce foggy brain in CFS. This would apply to a range of prescription medication.

This knowledge is very useful clinically – those people that are intolerant of alcohol need brain fats and oils, as above. Indeed as we age, intolerance increases illustrating the increased need for the correct fats and oils as we become metabolically less efficient with time!

### **What I mean by brain fog**

- Poor short term memory
- Difficulty learning new things
- Poor mental stamina and concentration – there may be difficulty reading a book or following a film story or following a line of argument
- Difficulty finding the right word
- Thinking one word, but saying another

### **Treatment of the foggy brain**

- The best test for generalised *atherosclerosis* is fitness. All normally healthy people should be able to gently jog one mile without distress. Can

this supply of fuel and oxygen be translated into *ATP - the energy for brain cells to work?* Is there a steady supply of *sugar to the brain*.

- Coconut oils likely to be very helpful - the brain works well on short chain fatty acids and ketones, which are in abundance in coconut oil. **These must be pure cold pressed organic virgin oils**, which are semisolid at room temperature - not hydrogenated oils which are hard at room temperature.
- Allergy can certainly cause foggy brain. Wheat is a common cause of brain fog. Many religious groups will fast for several days in order to ‘clear the brain’. Food allergy usually causes more than one symptom – often several.
- *Sleep - are you getting enough good quality sleep?* During sleep healing and repair takes place and without this one gradually ratchets downhill.
- Could you have hormonal disturbances such as *Hypothyroidism* and *underactive Adrenal Gland?*
- Physical and mental activity is vital. If you don't use it, you lose it! There is a desirable balance between physical and mental activity. Often the best ‘treatment’ for mental stress is physical activity (rather than watching TV!).
- Foggy brain is often accompanied by *Depression* and *Anxiety*, but these are just symptoms which should be investigated by finding the cause.

### **Are you being poisoned?**

#### **From within the body:**

- Gut fermentation - fermented foods result in alcohol, D-lactate, hydrogen sulphide and other toxins being produced. Any tendency to constipation will make this worse. This may explain why colonic irrigation allows a "clearing" of the brain.
- Caffeine in the short term is a mental stimulant. This can be helpful if you have to “perform”, so long as you can rest and recover afterwards. If you are having more than 3 cups a day (tea, coffee, coca cola), then it is probably having an overall deleterious effect.
- As a result of a detox regime - which mobilises

toxins, which have been previously dumped in fat.

### **From outside the body:**

- as a result of diet - again, alcohol is also a neurotoxin. If you are drinking more than one glass of wine daily, then you will be thiamine deficient. Thiamine is essential for normal brain function.
- Prescription drugs often have profound effects on the brain, especially in older and younger people

### **Chemical poisoning**

Look at the possibilities of *Chemical poisons and toxins* ; the more you look for it, the more you see!

### **Is there pathology?**

**Progressive** brain symptoms always need investigating with an MRI scan to exclude tumours and other such anatomical lesions. Such as:

- *Prion disorders: Alzheimer's Disease; Parkinson's Disease; Creutzfeldt-Jacob's Disease & Motor Neurone Disease*
- *Multiple sclerosis*

### **Vitamin B12 by injection**

This is an excellent treatment for foggy brain! There are many possible ways in which it may be helpful. Indeed I was interested to hear that when the top chess grand Masters are competing they inject themselves daily with B12 for improved performance. My organophosphate poisoned farmers love B12 as do many CFSs!

### **Articles**

- *Energy supply to the brain via myelin - Ravera 2009* The science behind oils and fats being so important for energy supply to the brain
- *Scientific American 2009 - ATP as a neurotransmitter* - fascinating insights into how ATP is necessary for other neurotransmitters to work! Poor energy delivery could mean depression and neurological disease

### **References**

[1]Prior IA, Davidson F, Salmond CE, Czochanska Z. Cholesterol, coconuts, and diet

on Polynesian atolls: a natural experiment: the Pukapuka and Tokelau island studies. *American Journal of Clinical Nutrition* 1981, Vol 34 (8): 1552-61

[ed. note: Fish oil is no longer a reliable source of Omega 3 due to overfishing and pollution. Every animal gets Omega 3 from eating wild green plants According to <http://www.earthsave.ca/node/130>. fish do not make Omega 3 they get it from eating algae."So, forget the fish oil. Supplement your diet with an algal extract instead. It'll do all that fish oil can do for you and you won't be contributing to the decimation of the world's oceans. Short chain omega 3 fatty acids are available in other foods as well, notably flax oil, walnuts and tofu. Because our bodies are not so good at converting these to the more beneficial EPA and DHA," they recommend V-Pure available online from Water4Life (<http://www.water4.net/>) or from Vegan Essentials (<http://www.veganessentials.com/>). Ask around town for plant based Omega 3 supplements, I found Udo's Oil DHA 3.6.9 blend with algal oil bottled in the refrigerated section and as gel caps I found Udo's Unrefined Algae DHA and the Eskimo Oil mentioned in the article all at Thrifty Foods~Lorraine]



# Interstitial Cystitis

*By Maxine Rogers and Gloria Gray*

Most people would say that having M.E. or F.M. was enough for anyone's discomfort and they would be right. Unfortunately a large number of people suffering of M.E. and F.M. also suffer from Interstitial Cystitis. IC is a chronic and painful condition of the bladder. Its cause is poorly defined. It has been suggested that a defect in the bladder lining allows irritation from unknown substances in the urine. A bad case can cause one to urinate up to 60 times a day. The bladder can become stiff, scared and irritated. There is a lot of pain, which maybe caused by the tiny hemorrhages in the bladder walls. Symptoms of IC may resemble those of a urinary tract infection, but tests do not show infection and antibiotics are ineffective. Women are affected much more than men in 90% of cases. Treatment is available to manage the symptoms but no cure has been found.

Some doctors say it must be a immune disorder. Researchers think that several diseases cause it as the symptoms can vary so between patients. A bladder can also be damaged during surgery or perhaps during an ultra sound. It is also known as Painful Bladder Syndrome. A syndrome is just a collection of symptoms found together that cannot be explained. Researchers have isolated an antiproliferative factor in the urine of people that suffer with IC. This compound appears to block the normal growth of cells that line the inside of the bladder.

## **Symptoms and Diagnosis**

Symptoms of IC vary in nature and severity. They may include: increased frequency of urination, both day and night. Urgency, the uncontrollable urge to urinate, often accompanied by increasing pelvic pain or pressure. There is a burning, aching pain in the pelvic area, including the bladder, urethra, vagina, testicles, scrotum, or crotch. This pain is often worse before or after urination and in some cases, with sexual intercourse. Other symptoms may include

general muscle aches, depressed mood, and other chronic illnesses like irritable bowel syndrome and other pain conditions.

Sex can be really difficult for people with IC. The pain can keep men from getting an erection and women can have a hard time getting aroused when she knows it is going to hurt. Even getting aroused can increase pelvic pain. Orgasm can hurt, should they be able to have one. The key to having a sexual relationship with a person with IC is being loving enough to work around what they need. Outercourse can be a lot more pleasing than intercourse. For more details please read the article on Illness and sex.

IC is diagnosed only after the exclusion of all other possibilities including UTI, sexually transmitted diseases, bladder cancer, and other disorders with similar symptoms.

Basic urine and blood tests are often normal. Visual inspection of the bladder (cystoscopy) may be helpful in ruling out other problems. The involves a instrument being passed through the urethra into the bladder to allow inspection of its lining. Some patients have characteristic red patches in the bladder lining called Hunner's ulcers. Gently filling up the bladder with water at a controlled pressure (hydro distension) may cause point areas of bleeding (referred to as "glomerulations") in its lining. This examination is performed under anesthesia because such stretching would be very uncomfortable otherwise. The stretching may also help relieve the symptoms of IC.

Diagnosing of IC is much like putting together the pieces of a puzzle; gradually the picture becomes clear as the pieces fall into place. The main pieces necessary to make a diagnosis of IC are the presence of typical symptoms, the absence of other conditions and the response to treatment. The process of establishing a diagnosis requires patience. The symptoms of IC are real and not imagined. Once the diagnosis is clear a comprehensive treatment plan will help you to relieve and control symptoms.

## **Treatment**

The treatment of IC includes many components: patient education, self-help, modification of diet and other external contributing factors, and often, medication. Surgery may be helpful in rare cases, cure may not be possible but relief can be achieved.

Helpful self-help tips include: exercise, warm baths, massage and hot and cold packs on the perineum (area of skin between genitals and the anus) might be tried to see if one will make you feel better. Stress can make the condition worse; learning relaxation techniques to reduce stress may reduce your symptoms and /or make them tolerable. There is even pure cotton toilet paper for sensitive skin.

Oral medications such as tricyclic antidepressants (e.g. Amitriptyline) can relieve pain at doses much lower than those used to treat depression. They often cause bladder relaxation, increasing storage capacity and decreasing voiding frequency. Finally, their sedative effect is particularly helpful in reducing nighttime urination. Pentosan polysulfate (Elmiron) is a medication used specifically for treating IC. Over time, it may restore and maintain the defective protective coating of the bladder lining. Elmiron must be used for a few months before it becomes fully effective. Antihistamines, like hydroxyzine (e.g. Atarax) may be helpful. They also have sedative and relaxing effects. In some cases other classes of medications may be prescribed. These include anticonvulsants (e.g. Gabapentin), anti-inflammatory drugs (e.g. Ibuprofen), narcotic painkillers (e.g. Codeine or oxycodone), the bladder relaxants (e.g. Tolterodine or oxybutin), drugs to reduce urinary acidity, and others.

Bladder installations: Some patients with IC may respond to medication placed directly into the bladder through a narrow tube passed through the urethra. These medications may work by reducing inflammation or restoring a protective coating of the bladder lining. Medications administered by bladder installations include DMSO (Rimso), Glycosaminoglycan (heparin or Cystistat) or Clorpactin (usually requiring

administration under an anesthetic as it and it can be painful). Bladder installations often start weekly and then decrease in frequency.

Surgery: Cauterization of Hunner's ulcers, when present at cystoscopy, may provide some symptom relief. As a last resort surgery may be considered for treatment of IC. This may involve bladder enlargement, removal or diversion of the urine away from the bladder into a new external or internal reservoir. These procedures may have serious complications and pain relief may not be reliable.

## **Diet:**

Many interstitial cystitis patients find that diet modification helps to control symptoms and avoid flare-ups, others can eat and drink what they like and it will have little effect on how they feel. Many IC patients report that restricting their diet is an effective form of treatment and believe it is worth the effort. If you would like to explore the role diet may play in your symptoms, it is best to begin with an elimination diet. Try eating several small meals instead of one large one. Keeping a diet diary where you record everything you eat and drink is usually a useful technique for monitoring diet. After a few weeks, start introducing the foods and beverages, adding one at a time. If after consuming a given food or beverage, you have no flare up in symptoms, you should be able to continue consuming this item without problems. If any symptoms do occur eliminate the given food from your diet after you've completed the work of determining which foods and beverages to eliminate from your diet, you may find that you can tolerate some troublesome items on a rotation basis. Try introducing these foods and beverages in small amounts once every five to seven days. If symptoms do not flare excessively, this can be a good alternative to giving up favorite foods entirely. Discovering which foods and beverages you should restrict can be a lengthy process that requires discipline. You may also want to consider working with a nutritionist and/or a specialist in food and environmental allergies.



A list of foods to avoid may initially appear daunting, but remember that there are still many foods you can enjoy. Some IC patients report that they have the least trouble with lightly seasoned rice, potatoes, pasta, common vegetables, meat and chicken. With these foods as a base for your diet, you can create nutritious and flavorful meals. You can still cook for family and friends and share meals with them because the foods you eat are the basic elements of the healthy, balance diet. You may also want to consider adding a source of fiber to your diet to promote regular bowel movements.

### **Diet suggestions: dues and don't s**

Dairy products to avoid are aged cheese, sour cream, yogurt and chocolate. It's okay to try white chocolate, not aged cheeses such as cottage cheese or American cheese, frozen yogurt or milk.

Vegetables to avoid are fava beans, lima beans, onions, tofu, soy beans or soy-based products, and tomatoes. It's ok to try other vegetables, beans, green onions and homegrown tomatoes (which may be less acidic).

Fruit to avoid are apples, apricots, avocados, bananas, cantaloupes, citrus fruits, cranberries, grapes, nectarines, peaches, pineapples, plums, pomegranates, rhubarb, strawberries and juices made from these fruits. It's ok to try melons (other than cantaloupes), blueberries and pears.

Carbohydrates and grains to avoid are rye and sourdough bread. It's ok to try other breads, pasta, potatoes and rice.

Avoid meats and fish that are aged, canned, cured, processed or smoked meats and fish, and anchovies, caviar, chicken livers, corned beef, and meats that contain nitrates or nitrites. It's ok to try other poultry, fish and meat.

At this point your thinking OH NUTS! The diet also suggests we avoid most nuts but it's ok to try almonds, cashews, and pine nuts.

Beverages to avoid are: alcoholic beverages, carbonated drinks, coffee, tea and fruit juices, especially citrus or cranberry juice. It's ok to try non-carbonated bottled water, decaffeinated, acid-

free coffee and tea, and some herbal teas

Seasonings to avoid are mayonnaise, ketchup, mustard, salsa, spicy foods, soy sauce, miso, other soy-based condiments, salad dressing and vinegar, including balsamic and flavored vinegars. It's ok to try garlic and other seasonings.

Avoid preservatives and additives like benzol alcohol, citric acid, monosodium glutamate (MSG), artificial sweeteners such as aspartame and saccharine, foods containing preservatives and artificial ingredients or colors. Other miscellaneous things to avoid are tobacco, caffeine, diet pills, junk foods, recreational drugs, cold and allergy medications containing ephedrine or pseudoephedrine, and certain vitamins. Wow!

Lorraine had a severe episode of bladder pain with bleeding a few years ago and has been able to alleviate any further symptoms by avoiding certain foods. Now that she understands the early mild symptoms, which she had for years and thought was just due to CFS sensitivity, she is able to adjust her diet before symptoms get worse. She considers herself very lucky to have had good advice early

I (Gloria) have two tears in my bladder that are constantly reminding me not to run, jump or sneeze 😊 I do not use medication, I drink loads of water and try my best to manage with a proper IC diet.

For more information:e-mail: ICAMail.ichelp.org or call 1-800-help-ICA. Websites include [www.ichelp.org](http://www.ichelp.org), [wwwic-network.com](http://wwwic-network.com) and [www.mayoclinic.com/health/interstitial\\_cystitis/DS00497](http://www.mayoclinic.com/health/interstitial_cystitis/DS00497)

### **The Victoria Fibromyalgia Group meetings**

will be held at the Arthritis Centre.

Every third Monday of each month at

**1:00 pm.**

At 2680 Richmond (at Kings)

Parking is at the far side of the parking lot, or on Kings and Newton



# Illness & Sex: Six Strategies for Improving Intimacy

By Bruce Campbell

*(from Recasting Relationships and Building Support series at [cfidselfhelp.org](http://cfidselfhelp.org))*

When CFS or fibromyalgia enters a marriage, one casualty can be intimacy between the partners. Pain, reduced energy, reduced interest, health problems of the partner, and increased responsibilities for the healthy spouse can all affect a couple's sex life, but, like other aspects of long-term illness, intimacy problems can be reduced as well.

When we asked people in our program to describe the effects of their illness on their sexuality, all those who responded said that illness had reduced their sexual activity. Many people mentioned having a much lower level of sexual desire than before, due to factors like ongoing fatigue and pain, and the side effects of medications. Other causes of sexual problems included the effects of menopause, relationship strains, and the medical problems and/or impotence of their partner.

Even though people said that they had either reduced their sexual expression or given up sex, most also reported using a variety of strategies that have either enabled them to adapt their sexual life to their illness or to connect with their partner in other ways.

Here are six of the most common adaptations.

## 1) Talking

Several people reported that their relationship with their partner improved after they talked openly about their reduced interest in sex. As one said, "I explained that I still loved him and felt the same (or more strongly) about him, but I just couldn't show that through initiating sex...I have no desire for self-pleasure either. Explaining that sure made a difference to his acceptance of my state!" Others reported that they benefited from open communication in bed. One said, "I let him

know if a certain position hurts and we change positions."

## 2) Alternative Activities, In Bed and Out

Another very common theme was adapting to illness by focusing on alternatives to conventional sex, both in bed and out. One person wrote, "The times I am not up to having intercourse, he knows I am usually up for some cuddling and happy to satisfy him another way." Others wrote of alternatives to intercourse, for those who think that appropriate. "You don't have to have intercourse to be sexually connected...You can be satisfied by manual stimulation and also oral sex."

Others have found other ways to express their affection, through hugging, kissing, and holding hands, through words of appreciation and thoughtful acts, and through shared activities like going out for dinner together, watching a favorite TV program or giving one another a massage. One said, "We still hug, kiss and say 'I love you' lots. I feel we have a very strong and healthy relationship."

## 3) Planning

Another common adaptation is planning for sex. Several people mentioned taking extra rest or reducing their activity level on days they anticipated having sex. Also, a number said they and their partners plan "dates." One said, "What my husband and I have learned is that we need to schedule a 'date'. I actually put it on my calendar." Another said, "The 'date' planning has worked for me because I tend to do less of the things that I know will cause me residual pain."

Others mentioned being mindful of time of day. Pain and other symptoms may be lower during certain hours of the day. By timing intimacy for those times, couples minimize discomfort and increase pleasure and enjoyment.

Another couple is increasing the frequency of sex through making a commitment to having sex once a week. The wife reported that sex is becoming less painful and her husband "is much more cheerful and doing more around the house."

## 4) Flexibility and Experimentation

Given the often unpredictable course of CFS

and FM, it helps to be flexible about when sex occurs and what positions and activities are involved. One person said, "We've experimented with timing (morning is best), position (I seem to do best on my side) and lubricants." Others use observation as a basis for experimentation. One person wrote, "I noticed that in the summer I had more desire and realized it had to do with the heat, so we started to shower together."

#### 5) Addressing Pain and Hormone Problems

Several people reported that their sex lives improved after treatment of pain and hormone problems. People reported treating pain by the use of pain pills, topical ointments, massage, and heat and by adapting how intimacy occurs. There are several factors involved in the use of medication. One solution is for the person who is ill is to time the taking of pain medication so that it will be at peak effectiveness when you plan to have sex. The type of pain medication is also important. The person with pain may want to avoid narcotic pain medications and tranquilizers, which dull the senses as well as reducing pain.

Other means of pain reduction include taking a bath before sex, stretching and massage. Pain can be reduced by using positions that are comfortable, by changing positions periodically during intimacy and by alternating activity and rest. Another pain control approach is the combination of distraction and meditation. Distraction means reducing pain by placing attention elsewhere, focusing on sensations, both those given and those received. Also, concentrating on mental images of making love keeps the mind focused on pleasure, distracting attention from pain.

Several people in our groups also commented on how their interest in sex had improved with hormone treatment either estrogen, testosterone or both. One said that testing showed that both her estrogen and testosterone levels were low. Treatment of the latter "not only helped libido, but my energy level as well." Hormone problems can also affect men.

#### 6) Emphasis on Caring

A number of people distinguished between intimacy and sex, and said they and their partners focused on closeness and mutual caring. One wrote, "Sex is important in a relationship, but I don't feel that it is the most important. I think all of the little everyday things that we do for each other and being supportive of each other is what really makes a marriage."

Another said, "My husband and I have found we don't NEED to express our affection sexually...For us, sex does not compare to the kind of fulfillment which is a beautiful thing when shared between two people who are filled with warm, tender, loving feelings toward each other." She wrote of expressing affection through sharing time together, touching, caressing, and cuddling.

#### In Conclusion

CFS or fibromyalgia do not have to mean the end of sex. Using flexibility, experimentation and good communication, couples can continue to enjoy sex and may be able to strengthen their relationship. For those who decide that sex will no longer be a part of their relationship, a focus on other aspects of the relationship can foster closeness and caring



# Find Your Limits - How to Put the Push-Crash Cycle Behind You

by Bruce Campbell, PhD\*

It's not just physical activity that can drain energy needed to gain better control over symptoms, Dr. Campbell emphasizes, it's also mental and social activity, and the drain of emotions and stress. Having a chronic illness can often feel like living on a roller coaster. You swing between intense symptoms and rest, in a frustrating cycle of push and crash.

When your symptoms are low, you push to get as much done as you can. But doing more than the body can tolerate, you intensify your symptoms and crash. You then rest to reduce symptoms, but then, if you feel frustrated and try to make up for lost time, you may plunge into another round of over-activity leading to another crash.

There is an alternative to this cycle of push and crash: living within limits. Your activity level and the way you live your life affect your symptoms. If you honor your limits, you can gain some control over your symptoms and bring predictability to your life. This article explains how to find your limits; the online article "*Finding Your Energy Envelope*" (<http://www.cfidsselfhelp.org/library/finding-your-energy-envelope-part-1>) shows how to live within them

## The Energy Envelope

One way to explore the idea of limits is through the concept of the Energy Envelope. You can think of your situation in terms of three factors:

1. Available energy: The energy you have. It is limited, and is replenished by rest and food;
2. Expended energy: The energy you lose through physical, mental & emotional exertion; and
3. Symptoms: fatigue, brain fog, pain, and so on.

If you expend more energy than you have available, you will intensify your symptoms. This is called living outside the Energy Envelope. This approach commonly leads to the push and crash cycle described above.

An alternative is living inside the Energy Envelope.

- If you keep your expended energy within the limits of your available energy, you can gain some control over your symptoms.
- If you accept your limits (keeping your activity level within the limit of your available energy), you can reduce symptoms and the severity of relapses, and over time may be able to expand your limits.

This is an upward spiral.

## The Fifty Percent Solution & the Bowl of Marble

Let me suggest a couple of ideas you might use if you wanted to apply the concept of the Energy Envelope.

### *The first is called the fifty percent solution.*

Each day estimate how much you think you can accomplish. Then divide this in two and make it your goal to do this lesser amount. The unexpended energy is a gift of healing you are giving to your body.

*The second idea is to imagine your available energy as a bowl of marbles.* You have a limited number of marbles to use each day. The number may vary from day to day. Physical activity uses some, but mental and emotional activity do as well. With every activity, you take one or more marbles out of the bowl, remembering that stress is a big marble-user and so lessening stress will preserve your supply of marbles for other uses.

The overall idea in both the fifty percent solution and the bowl of marbles is that our limits force us to set priorities in order to control symptoms and bring stability to our lives. Both techniques are ways you can reframe your situation to give yourself permission to do less in order to improve quality of life.

## Defining Your Limits

Another way to use the idea of the Energy Envelope is to develop a detailed description of your limits.

This can give you a thorough understanding of what you individually have to do to minimize symptoms and improve your quality of life. If

you want to do this, I suggest you look at five different aspects of your life:

1. Your illness,
2. Activity,
3. Rest,
4. Emotions,
5. And stress.

**Illness:** The severity of your illness suggests your safe level of activity. To get an initial idea of a safe activity level, you can rate yourself in comparison to other patients on the *CFS/Fibromyalgia Rating Scale [on page 14]*.

Most of the students in our course have rated themselves between 25 and 45, but we have had people across almost the full range of the scale.

**Activity:** This factor refers to how much you can do without making yourself more symptomatic. You can divide this into three areas: physical, mental and social activity.

Physical activity means any activity involving physical exertion, including housework, shopping, standing, driving and exercise.

- To define your limits in this area, estimate how many hours a day in total you can spend in physical activity without intensifying your symptoms.
- Because the effects of exertion can be cumulative, you might ask yourself how many hours a day you could sustain over a week without worsening symptoms.
- Also, you can note whether some parts of the day are better than others.
- Finally, you can estimate how long you can do various specific activities, such as housework, shopping, driving, etc.

Mental activity means activities requiring concentration, like reading, working on the computer or balancing a checkbook. Three questions to ask in this area are:

- How many hours per day can I spend on mental activity
- How long can I spend in a single session?
- What is my best time of day for mental work?

Some people, for example, find they can work at the computer for 15 minutes or half an hour without problem, but that they experience symptoms if they work longer. They may be more productive at some times of the day than at others. They may be able to avoid triggering brain fog or other symptoms if they have two or more brief sessions a day rather than one long one.

**Social activity** refers to the amount of time you spend interacting with other people. I suggest you think of social activity in two forms: in person and other (e.g., phone and email). Questions to ask yourself about each type include:

- How much time with people is safe for me in a day? In a week?
- Is the amount of time dependent on the specific people involved and the situation? (You may tolerate only a short time with some people, but feel relaxed around others.)
- For in-person meetings, you might also ask yourself whether the setting makes a difference.

Meeting in a public place or with a large group may be stressful, but meeting privately or with a small group may be OK.

**Rest:** This factor refers to the quantity and quality of sleep at night and rest during the day. Questions you might ask about sleep include:

- How many hours of sleep do I need?
- What is the best time to go to bed and to get up?
- How refreshing is my sleep?

Daytime rest means lying down with eyes closed in a quiet environment. Questions here might include:

- How much total daytime rest do I need?
- How frequently should I rest?

**Emotions:** Strong emotions like fear, anger, grief and depression are normal reactions to having a chronic illness. This factor refers to the emotions we experience as part of being ill and also to the sensitivity we have to emotionally-charged events. Questions in this area include:

- What emotions are important in my life now and how intense are they?
- What is the effect of emotionally-charged

events? (Events with strong emotion often trigger the release of adrenaline, which can be very taxing.)

Stress: This refers both to the sources of stress in our lives - and to our sensitivity to those stressors. In terms of sources, three are crucial: finances, relationships, and things.

- Finances can impose severe limits and be a major source of stress.
- Relationships can be sources of support and help, sources of strain or both.

Physical sensitivities refers to:

- Food,
- Sense data (light and/or sound sensitivity, sensory overload),
- Seasons and the weather (intensification of symptoms at certain times of the year or with different weather conditions).

Your Energy Envelope is a list of your limits. Having an understanding of your envelope can help you to set priorities. After completing the exercise of defining your envelope, you might decide that poor sleep was the crucial issue for you at this time. Or you might find that a stressful relationship needs attention. In any case, the idea is to understand your limits in detail, so you can control symptoms and decide where to focus your efforts for improvement.

*Dr. Bruce Campbell is a recovered ME/CFS patient and former consultant to self-help programs for chronic illness at Stanford Medical School. His nonprofit site ([www.cfidsselfhelp.org](http://www.cfidsselfhelp.org)) offers articles, low-cost online self help courses (<http://www.cfidsselfhelp.org/online-courses>) in moderated discussion group format, and free follow-up programs & support.*

**More Information:** “Living Within My Envelope: A How-To Story” (<http://www.cfidsselfhelp.org/library/living-within-my-envelope-a-how-to-story>) CFS patient JoWynn Johns describes how she reduced her symptoms and brought stability to her life by finding and

honoring her body's limits.

Discussion on how to complete the Energy Envelope Log in the “*Energy Envelope*” chapter of our course textbook. Or see: <http://www.cfidsselfhelp.org/library/9-the-energy-envelope>)

“Finding Your Energy Envelope” (<http://www.cfidsselfhelp.org/library/finding-your-energy-envelope-part-1>) A two-part article on controlling symptoms by finding and honoring the body's limits.

## Seven Layer Dinner

Grease a nine inch casserole dish.

1. Place 1/2 inch layer of thinly sliced raw potatoes.
2. A layer of thinly sliced raw onions.
3. A layer of thinly sliced raw carrots (4 or 5)
4. Sprinkle one quarter cup uncooked rice over these three layers.
5. Add one can of peas and their liquid.
6. 1 pound of pork sausage arranged on top or use hamburger instead.
7. Pour one tin of tomato soup diluted with one can of water overall.

Salt and pepper to taste.

Bake, covered, in a medium oven for 1 hour. If using sausage, at the end of that time turn sausages over and leave casserole uncovered for one more hour of baking.

Possible options are to substitute 1 cup of frozen peas and 1/4 cup water for the canned peas and/or tomato sauce for tomato soup.

## CFS & Fibromyalgia Rating Scale

100	Fully recovered. Normal activity level with no symptoms.
90	Normal activity level with mild symptoms at times.
80	Near normal activity level with some symptoms.
70	Able to work full time but with difficulty. Mostly mild symptoms.
60	Able to do about 6-7 hours of work a day. Mostly mild to moderate symptoms.
50	Able to do about 4-5 hours a day of work or similar activity at home. Daily rests required. Symptoms mostly moderate.
40	Able to leave house every day. Moderate symptoms on average. Able to do about 3-4 hours a day of work or activity like housework, shopping, using computer.
30	Able to leave house several times a week. Moderate to severe symptoms much of the time. Able to do about 2 hours a day of work at home or activity like housework, shopping, using computer.
20	Able to leave house once or twice a week. Moderate to severe symptoms. Able to concentrate for 1 hour or less per day.
10	Mostly bedridden. Severe symptoms
0	Bedridden constantly. Unable to care for self.

### For Women with FM, CFS/ME or Other Health Challenges

### *Befriending the Body* from home by phone\*

Gently guided personalized: physical movement, body/self-awareness and restorative rest. ~ All you need is curiosity and respect. Time/place/fee: By appointment, 11-4, Tuesday-Thursday, from the comfort of your home (or inquire about in-person options). Sliding scale for 20, 30 and 45 minute calls: minimum \$10, maximum \$35. Guided by: **Connie Frey**, certified coach, 2006; and specialist in a variety of body-focused practices since 1979. To book or inquire, call: **250-388-5393**

## What's going on in your Neighbourhood?

Community centre offer many gentle activities and various helpful education classes. Consider giving yoga or meditation a try. Contacting the instructor ahead of time will help you ensure you will be able to address your needs. Tell them of your limitations and ask them about laying down, leaving early or anything else you may need to look after yourself. The following is just a small sample of what could be going on in your neighbourhood.

Jenny Blackham is offering 2 one day workshops as well as ongoing FM classes: **FIBROMYALGIA AND THE INDIVIDUAL** This information session for people with FM will focus on steps you can take to gain increased quality of life. Sat Mar 20th 11:45-1:45 \$29 **FIBROMYALGIA AND EXERCISE** Jenny will provide you with new ways to exercising and stretching that have helped many people through her 16 years of private practice and teaching FM classes. Jenny herself has personal experience with FM. Contact Jenny at

250-474-0543 or [www.awayoflife.ca](http://www.awayoflife.ca) for more information. To register [www.recreation.saanich.ca](http://www.recreation.saanich.ca) or call Commonwealth Place 250-474-7600

### **Disability Tax Credit**

#### **Victoria Arthritis Centre**

Located at 2680 Richmond Road

Please call 250-519-4000

This was full when offered Feb 23<sup>rd</sup> but they are taking a list of names and hope to put on a second one.

Are you getting what you are entitled to? Pager taxes? Want to get some \$\$\$back? (refunds can go back 10 years!) Eligibility assessments are FREE. Get help with bridging the gap between your doctor and Canada Revenue Agency. Legal advisers and Certified General Accountants offer a 95% success rate. Presenter: Linda Chornobay, Disability Refund Specialist of Enabled Financial Solutions Ltd.

### **Arthritis tips and strategies for the kitchen:**

April 21st, 6:30 - 8:30 pm

#### **Yakimovich Wellness Centre**

Located at 1454 Hillside Avenue. -

Free but you must register at 250-370-5641

Kitchen set up, sitting/standing, planning and pasting, choosing tools, -- holding, opening, cutting; splints, cleanup, shopping, carrying/lifting, reaching, problem solving. Let's problem solved together!

Presenter: Linda Frodyma, Occupational Therapist with the Arthritis Centre

### **Gardening with Arthritis**

March 3, Wednesday, 1- 3 p.m

Free but you must register at 250-477-7111

#### **Nellie McClung Library**

Located at 3950 Cedar Hill Road

Have you dreamed of creating your own garden utopia but worried that your arthritis slow you down or hurt you too much? If so, the Arthritis Society has a workshop for you! Presented by an occupational therapist, the gardening with arthritis workshop is designed to educate you about ways that you can enjoy this popular

leisure activity without putting additional stress on your joints.

Presenter: Charl Young, Occupational Therapist with the Arthritis Center

### **Chronic Pain Management Workshop**

Wednesday, April 14, 1-3 p.m.

Located at **Saanich Silver Threads 286**

Hampton Rd. Register at 250-519-4000

Multiple factors contribute to managing chronic pain. Whether it's medications, physical management, or mind-body connection strategies - you can learn about what you can do and how to work better with your health care professionals to manage chronic pain.

For more programs contact the Victoria Arthritis Centre at 250-519-4000 or [www.arthritis.ca](http://www.arthritis.ca)



*The bud stands for all things,  
even for those that didn't flower,  
for everything flowers from within,  
of self-blessing;*

*though sometimes it is necessary  
to retrace a thing its loveliness,  
to put a hand on the brow of the  
flower  
and retell it in words and in touch it  
is lovely  
until it flowers again from within,  
of self-blessing....*

*(excerpt from "St. Francis and The Sow" by  
Galway Kinnell)*

This was given in a card as a Secret Valentine at a MEVA party. Thank you to who ever brought this card; it is too special not to share.



# UPCOMING EVENTS!

**MEVA's AGM** will be held on April 8th  
At 1908 Stanley Ave. Starting at 2:00 pm.

After the meeting there will be a lively social time to **connect**  
with our newly elected executive and other respected members.

For details on how you can get involved and active,  
call me at 250-370-2884 or [ggray@hotmail.com](mailto:ggray@hotmail.com)  
Energy not required.



You are welcome to join us on June 30th for a lovely  
**Garden Party**

The setting is peaceful, the flowers are beautiful and  
the people are wonderful.

This is a good place to tell your stories and ask your questions.  
Time: 2:00 pm & Place: 1908 Stanley Ave.  
What to bring? A friend and snacks to share!



If you want any information on events please contact us at 370-2884 or  
e-mail us at [me.victoria@shaw.ca](mailto:me.victoria@shaw.ca)

