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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)

Winter 2010

Family Communication Tips

By Bruce Campbell

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Serious illness puts families under great stress, making good communication more difficult. Working to improve communication can help increase understanding, uncover unrealistic expectations, strengthen relationships and aid cooperative problem solving. Here are some tips for better family communication.

Think Timing, Setting and Approach

If you have something important to discuss, select a time when both you and the person with CFS or FM will be at your best. Find a time when you can give good attention and the person who is ill will not be distracted by pain or brain fog, preferably during his or her best hours of the day. Choose a place that minimizes distractions and interruptions. And bring an intent to find solutions that work for both partners and that strengthen the relationship. The idea is to be able to discuss problems in a constructive rather than a confrontational way.

Treat each other with respect, acknowledging his or her support and effort. Avoid demeaning comments, sarcasm and blaming. Acknowledge your part in shared problems and express appreciation for the other's efforts. Consider having each person ask, "What can I do to make your life easier?" and each person state, "Here are some things you can do to make my life easier." For more, see the discussion of asking for help, below.

Listening

Good communication is based both on speaking clearly and on good listening. The purpose of listening is to understand. Listening means focusing your attention on what is being said. Listening does not mean agreeing, disagreeing, defending yourself or criticizing the other person. It's goal is to understand the speaker's point of view. Listening works best if it occurs without interruption.

After the person is finished speaking, respond by acknowledging having heard them. You might say something as simple as, "I

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Musings from the editor

Here we go again, it's Christmas time again! I remember how excited I was as a child and how excited my son was as a wee lad. We gathered around the tree and opened presents and then proceeded to play with it or fit into what ever was packed in the pretty gift-wrapped box. What fun! But nowadays I am more inclined to have a small peaceful celebration and to reflect on the true meaning of Christmas. Peace on earth and good will toward men and women.

It sounds perfect, doesn't it? Peace on earth comes at a cost though, as Peace starts with you and me. How can a person find peace when you are spending time with people that can push your buttons?

I have made a discovery and it has helped me. I have not perfected it yet, being human and all, but it does work. I have realized that I cannot afford to have negative thoughts; it affects my health and steals my joy. Negativity can become an all-consuming vortex.

To attempt this healthier life style, I set my mind on what is good and lovely. When I have negative thoughts I turn them around by getting a new perspective. I choose to surround myself with good thoughts, encouraging music and TV programs, an inspiring book and hanging out with healthy thinking people. These healthy choices in friends and environment bring me forward.

When I do this I am disallowing toxic situations to harm me. I am also not allowing me, to harm me. I am responsible for my thoughts, feelings and behavior. I cannot control others, only myself.

This process of turning situations around has been a challenge for me. Like many, I have met my fair share of challenging people. This can leave a person feeling hurt, angry or even ashamed.

Guard against shame: there is no room for shame in a healthy perspective. There is no shame in being ill. Peace brings it's own benefit: that peace abides deep down in your core.

This perspective brings a renewed look at oneself and displays the True Beautiful You!

How precious to see the real you, to see how you are truly, wonderfully, and uniquely made.

Once you are there, rest in it with confidence!

InforME Magazine

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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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My wish for you this Christmas is to “Renew and Refresh”! Abandon all efforts to control; feel the peace and let go! Choose to be transformed. You are in charge of you.

Consider having a merry time this Christmas. It is the best gift you can give yourself.

I send you my kindest regards, from my heart to yours. Have a Merry Christmas!

Gloria Gray
Editor

continued from front page

understand.” If you are not clear, you can respond by asking for clarification or more information. You might say something like, “I’m not sure I understand. Can you say something more?”

Test your understanding. From time to time, check whether you have understood the other person’s position by restating it in your own words. You could say, “Let me try to summarize what I’ve heard and you can tell me if I’m understanding you.” Good communication depends on each person’s understanding the other’s views.

Problem Solving

Once you believe you understand one another’s position, focus on searching for solutions or problem solving. Begin by thinking of several ways you could handle the problem differently in the future, not evaluating any of them until your brainstorming is complete. For example, if your problem is how to do household chores when one member of the family is ill, alternatives might include dividing up the chores differently among members of the family, hiring occasional or regular assistance, simplifying tasks (for example, having simpler meals or cleaning less frequently), and moving to a smaller home that is easier to maintain.

Then evaluate each proposed solution, decide which ones are most promising, try one or two and evaluate the results. Some potential remedies may not work, so you may need to have further discussions, but others may prove helpful. A solution may be a combination of several approaches. If several strategies are unsuccessful, you may decide that a problem may not be solvable at the present time.

In many cases, you will be able to solve your problems yourself, but at times you may want to get help, either in understanding the causes of your problem or in finding solutions. So it may help to ask what resources are available to you. For example, to get a fresh perspective on your situation, you might ask other families how they have solved a similar problem or you might ask what community resources (church and public groups) are available.

Asking for Help

It can be difficult and awkward to be on either the asking or the receiving end of requests for help.

Those needing help are often reluctant to ask and may word their request in a general way, such as, “I need help with the housework.” The person being asked may wonder what would be involved in responding to the request. A solution is to be specific. If you’re on the asking side, say something like, “Can you do a load of laundry today?”

If you are the one being asked, it’s reasonable to defer giving a yes or no answer when asked for help, until you are confident you understand what is expected of you. You can ask, “What specifically would you like me to do?” Even if you decide to decline, you can still acknowledge the importance of the request to the person asking for help.

Regular Relationship Discussions

A strategy for nurturing relationships and keeping discussion of issues in a problem-solving context is to set aside time regularly to discuss the relationship you have with the person in your life who is ill. One family calls it their “talk night.” They set aside Sunday evenings as a time to discuss any issue that is on their minds.

The husband explains, “It can be an issue one of us has with the other, problems with friends or children, problems around the house, my work, etc. Anything either of us sees as a problem or causing stress is a likely topic. Even very minor things are ok. A rule is we each openly listen to the other without being defensive, and we each really try to put ourselves in the other’s place and feel what it’s like for them. We problem-solve together to come up with a resolution for each issue.

After doing talk night we start each week refreshed and with the feeling that comes from having dealt with whatever problems were there. Talk night has worked exceptionally well for us.”

Family and Friends

Read other articles suggesting solutions for common problems of family and friends of people with CFS and fibromyalgia. <http://cfidselfhelp.org/library/family-communication-tips>

Pepper & Potato Tortilla: *Submitted by Krissoula Vincent*

A thick omelette or pastry-less quiche
Could be eaten at Christmas breakfast...due to the red, & green colours. Use a hard Spanish cheese, like Mahon, or a goat's cheese; mature cheddar makes a good substitute too. Serves 4

2 medium size potatoes
45-ml/ 3 Tbsp olive oil
1 large Spanish onion, thinly sliced
2 garlic cloves, crushed
2 peppers, one green, one red, thinly sliced
6 eggs, beaten
115 g/4 oz mature cheese, grated
Small handful freshly chopped coriander (a.k.a.)
cilantro leaves
1/4 tsp cumin powder
1 tsp fresh basil or 1/2 tsp dried
1/4 tsp cayenne pepper (optional)
1/4 tsp Chile powder

Sea salt & freshly ground black pepper

1. Do not peel the potatoes, but wash them thoroughly. Par-boil them whole for about 10 mins, then drain, & slice them thickly. Switch on grill so that it has time to warm up while you prepare the tortilla.

2. In a large well-seasoned frying pan, heat the oil, & fry the onion, garlic, & peppers on a moderate heat for 5 mins until softened.

3. Add the potatoes, & continue frying, stirring occasionally until the potatoes are completely cooked, & the vegetables are soft. Add a little extra oil if the pan seems rather dry.

4. Pour in half the eggs, then sprinkle over half the cheese then the rest of the egg, seasoning as you go. Finish with a layer of cheese.

5. Cook on a low heat, without stirring, half covering the pan with a lid to help set the eggs.

6. When the mixture is firm, flash the pan under the hot grill to just lightly seal the top. Leave the tortilla in the pan to cool. This helps it firm up further, & makes it easier to turn out.

VARIATION: Add any sliced, & lightly cooked vegetable, such as mushrooms, courgettes [summer squash] or broccoli, instead of peppers.

Gloria's Favorite Pumpkin or Squash Pie Recipe

A few people asked for my pumpkin pie recipe at MEVA Thanks Giving, so I thought this would be an easy way to share this. You can go crustless! Or if you would like a flaky pastry you can make life easier and buy a Tender Flake piecrust from the store. Poke holes in the bottom with fork (so that it doesn't get puffy) and bake according to the directions on the box.

The guts of it all!

Mix the following ingredients in the top of a double boiler until thick. (I don't, but that is what they suggest.) Stir often.

1 1/2 cups cooked pumpkin or squash
1 1/2 cups undiluted evaporated milk or rich cream
1/2 brown sugar (using less sugar is an option)
1/4 cup white sugar
1/2-teaspoon salt.
1-teaspoon cinnamon
1/2-teaspoon ginger
1/8-teaspoon cloves
4 slightly beaten eggs
Cool slightly and add: 1-teaspoon vanilla or 2 tablespoons brandy or rum
Pour the mixture into pie plate (for crustless) or a 'baked' Tender Flake shell.

Ingredients for two pies: Use 1 (796 ml) can pumpkin, 2 x (370 ml) cans of milk and double the rest of the ingredients. ENJOY!

Thank you to 'Joy of Cooking' for adding joy to our Thanks Giving.

I will honor Christmas in my heart, and try to keep it all the year." ~ Charles Dickens

Curing the Constipation Blues *Dr Zoltan Rona*

"When I got up this morning I took 2 Ex-Lax in addition to my Prozac. I can't get off the john, but I feel good about it."
Anonymous

A 45-year-old patient recently told me that her family doctor and

Gastroenterologist both believed there was nothing wrong with her having only one bowel movement each week. In the doctors' own words: "This is normal for you."

Believe it or not, this small-stool philosophy is promoted by many conventional medical groups, including the National Institute on Aging. Here's a direct quote from their Web site (<http://www.nih.gov/nia/>): "Do not expect to have a bowel movement every day or even every other day."

Dr. Dennis Burkitt, MD, famous for his scientific research on bowel health, would definitely not agree with this waste-holding attitude. Neither would the authors of over 40 books on the subject. Dr. Burkitt and many other experts have noted the inverse relationship between the frequency and size of bowel movements and good health. The doctor found that citizens of those cultures which had larger, softer and more frequent bowel movements were also the healthiest. Furthermore, these groups had the smallest and fewest hospitals. They ate a primarily vegetarian diet, with animal products used only as flavourings or for an occasional feast. Individuals also had a bowel movement following each meal.

Naturopaths have often said, "death begins in the colon." I agree. Waste material, which is not eliminated in a timely, efficient fashion, can potentially poison healthy cells and organs far removed from the large bowel. Common ailments in the "civilized" world resulting indirectly and directly from constipation are virtually unknown in rural Africa and India. These include colon cancer, obesity, diverticulitis, diabetes, heart

disease, appendicitis and varicose veins.

Causes of Sluggish Bowels

A healthy colon eliminates waste in 12 to 18 hours with a frequency of one bowel movement per meal per day. That's three bm's daily if one has three meals each day, four bm's for four meals, etc. Anything slower is just a varying degree of constipation, a problem shared by at least 60 per cent of North Americans.

The commonest cause of sluggish bowels is a lack of fibre and water in the diet. Other possibilities include a low thyroid condition, neurological diseases like multiple sclerosis, and the use of drugs that affect motility (opiates, diuretics, antidepressants and muscle relaxants

Antacid and laxative abuse can also lead to chronic constipation. Chemical laxatives and frequent enemas can encourage dependency creating weaker bowel muscle and nerve function leading to worse constipation than before their use. In fact, it may take some people hooked on laxatives months before bowel function returns to normal through the use of natural remedies.

Constipation may be a feature of irritable bowel syndrome, unsuspected food allergy, high dose calcium and iron salts supplementation, fungal (candida overgrowth) or parasitic infestation, diverticulosis, and other types of abdominal infection, dehydration, bowel obstruction, long periods of immobility, stress and depression.

Parasites like *Giardia lamblia*, *Blastocystis hominis* and *Entamoeba histolytica* are often overlooked causes of colon troubles. One can easily pick these up from travels to third world countries, day care centres, contaminated fruits, vegetables, animal products and household pets.

Another less recognized cause of constipation is magnesium deficiency. Magnesium is the central element of chlorophyll and is found in all greens. Folic acid and vitamin B5 (pantothenic acid) deficiency can also lead to lazy bowels.

The spiritual view of constipation sees it as refusing to release old ideas, being stuck in the past and expressing stinginess or inflexibility. Psychoanalysis theory believes that defecation is an act of giving and generosity, while constipation is an expression of a desire to hang

onto things too tightly, usually material things. Constipation may represent an attempt to keep unconscious, repressed emotions locked up within us.

“Success consists of doing the common things of life uncommonly well.”

Anonymous

Eliminate Constipating Foods

If you are otherwise healthy, the first step needed to cure constipation is to increase water intake to more than eight large glasses of spring water per day. Avoid coffee and regular tea. Dilute fruit juices are fine. Eat more high fibre foods such as whole grains, legumes, fruits, seeds and nuts, provided you tolerate these foods. Dairy products are frequent causes of sluggish bowels and are best avoided.

It's also very important to eliminate constipating refined carbohydrate foods such as sweets, chocolates, cakes, all white flour products, white rice and other processed foods. Wheat bran, apple pectin and psyllium seed husks may not only help move your bowels better but will also decrease cravings for sweets.

The average healthy adult requires at least 40 grams of fibre per day for optimal bowel function. Some people may not be able to tolerate such high levels initially, but can easily get used to the higher roughage over a period of weeks to months.

Two foods that are very effective at stimulating the bowels are bran and prunes. It's best to start with half a cup (125 mL) of bran cereal per day, preferably organic and unsweetened. Over a two-week period, increase this amount gradually to two cups (500 mL). With prunes, one needs to eat at least 8 ounces (227 g) daily for healthy evacuation.

Increasing physical activity also plays an important role. Exercise optimizes circulation to the bowel and improves its performance.

Many natural remedies have worked well for a stubborn colon. Examples are whole leaf aloe vera juice, digestive enzyme supplements,

bromelain, B-complex vitamins, especially B5 (pantothenic acid) and folic acid, vitamin C, magnesium citrate or oxide, liquid chlorophyll, flaxseed oil and *Lactobacillus acidophilus*.

The occasional use of Swedish bitters, cascara sagrada, comfrey, goldenseal and senna leaf may be an effective approach for some people.

Seeking Professional Help

If chronic constipation doesn't respond to natural approaches – or there is a coexisting medical condition – seek professional help. Each case needs individual assessment, and special medical or nutritional tests may be necessary.

One such test is the comprehensive digestive and stool analysis. The CDSA is a battery of 24 screening tests of gastrointestinal status. It assesses how well a person digests and assimilates food, and it can detect bacterial flora imbalances, hidden infections with candida, fungi or parasites, or digestive enzyme insufficiencies. Check with your naturopath or holistic medical doctor for such testing and personalized treatments.

Remember, you needn't move through life singing the constipation blues, when nature offers a smorgasbord of safe and gentle solutions.

SIDEBAR:

The Constipation Quick Fix

If changing your diet and lifestyle is beyond your present capabilities, there's a relatively safe and effective quick fix for constipation. It entails using high doses of vitamin C and/or pantothenic acid (vitamin B5). Much safer than taking laxatives or drugs, the only significant side effect of taking too much of either vitamin is diarrhea. Once one finds the optimal amount that yields more efficient bowel clearing, this bowel tolerance dose can be safely continued as needed.

With both vitamins, start at 1,000 mgs three times daily. Increase by increments of 1,000 mgs each day until the bowels are functioning as desired.

Some people respond better to one vitamin than the other. It's simply a matter of trial and error to see what works best for you. If gas develops, this means the dose is too low – just increase it until the gas clears.

CoQ10 (ubiquinol), L carnitine, D ribose and M.E.

This paper looks at questions such as: Why are these three supplements (plus magnesium) so important for heart health? What is the appropriate dosage of each of these supplements? How well tolerated are these supplements in M.E.? Which drugs dangerously deplete the body of CoQ10?

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From www.hfme.org

Metabolic cardiologist Dr Stephen T. Sinatra considers coenzyme Q10 (CoQ10), L carnitine, D ribose and magnesium the 'awesome foursome' of cardiovascular health.

Dr Sinatra explains that while 1 + 1 will always equal 2 in mathematics, in metabolic cardiology and nutritional medicine, when you are talking about substances that are synergistic with each other such as the 'awesome foursome', 1 + 1 might equal 5 or even 10. In other words, the benefits of taking more than one of these substances at a time may far outweigh the benefits seen from taking any of them alone.

The heart and the brain are especially rich in mitochondria. This makes them especially vulnerable to mitochondrial damage and the resulting decrease in energy output. Both the brain and the heart (with its extraordinary non-stop work) need an enormous amount of energy.

Dr Sinatra explains that it's all about ATP (adenosine triphosphate). Hearts, skeletal muscles and every other tissue in our bodies have an absolute need for ATP as their primary energy currency. Cells and tissues will cease to function if they are not provided with a constant and stable supply of energy. Both the total pool of energy substrates (ATP) in the cell and the cell's ability to recycle these compounds are fundamental to healthy energy metabolism and cell function.

When hearts are stressed by disease, energy substrates, called purines, wash out of the cell and the total pool of cellular energy becomes severely depleted. Disease also disrupts the heart's ability to recycle its remaining energy through the oxidative phosphorylation mechanisms.

The combination of energy pool depletion and metabolic dysfunction contributes to the severity of the disease and impacts the physiological health of the heart. The same is true for skeletal muscles that are stressed through disease or high-intensity exercise.

CoQ10 and L carnitine are major players in the energy recycling metabolic pathways. D ribose is the only compound used by the body to replenish depleted energy stores and rebuild energy pools. Magnesium is a vital mineral used by the enzymes that make energy synthesis and recycling possible.

Or as Dr Sinatra explains; *D ribose fills the tank, CoQ10 and L carnitine helps convert this fuel to energy (helps the engine run properly) and magnesium is the glue that holds it all together.*

Coenzyme Q10

CoQ10 is an enzyme that occurs naturally in the mitochondria of every cell in your body. It plays a key part in metabolizing energy from food. CoQ10 was first isolated in 1957. Since then, scientists have studied its effects on a wide variety of illnesses and conditions.

CoQ10 plays an important role in stabilizing cell membranes.

CoQ10 is essential in directly supporting ATP recycling in the mitochondria of the cells. This is especially important for tissues that use a lot of energy, such as the heart and the brain.

Dr Sinatra explains that CoQ10 helps any type of cardiomyopathy, congestive or even hypertropic. It impacts on both systolic and diastolic dysfunction, improving quality of life. (This is an important distinction for M.E. patients as Dr Cheney recently explained the type of cardiac insufficiency that lies at the heart of M.E. is best described as *diastolic* heart failure or ('compensated') *diastolic cardiomyopathy*. The right ventricle circulates blood to the lungs, while the left ventricle circulates blood to the rest of the body. The ventricles empty when the heart contracts to pump out blood (the systole), and fill when the heart relaxes (the diastole). Diastolic dysfunction means that the heart does not have enough energy to relax between contractions, so the ventricles fill with blood in a dysfunctional

way and an inadequate amount of blood is pumped by the heart with each contraction. (Dr Sinatra explains that a great deal more energy is needed for the heart muscles to relax, than for them to contract. It requires immense cellular energy.) This diastolic dysfunction is best measured using an impedance cardiograph machine.

Without CoQ10 the electron transport chain would completely break down. This loss would be catastrophic. There has to be an EXCESS of CoQ10 in the mitochondria to be maximally effective.

CoQ10 is an antioxidant and reduces cancer risk.

ATP supports such as CoQ10 support immunity, as the immune system has high ATP needs.

CoQ10 has neuro-protective effects against mitochondrial toxins.

CoQ10 plays an important role in reducing platelet size, distribution, stickiness and limiting platelet aggregation and activation. CoQ10 helps prevent blood clot formation.

Diseased gums may be a sign of low CoQ10 levels.

Spontaneous abortion is linked with low CoQ10 levels.

Research indicates that if levels of CoQ10 decline by 25% our organs may become deficient and impaired. If levels decline by 75% serious tissue damage and even death may occur.

CoQ10 decreases cardiac mortality.

Dr Sinatra found that while 85% of his cardiac patients responded to CoQ10 alone, 15% needed to take CoQ10 *and* L carnitine before significant benefits were seen (even where blood levels of CoQ10 were shown to be high).

Although CoQ10 comes in two forms, ubiquinone and ubiquinol, for many years ubiquinone was the only CoQ10 supplement available. Advances in CoQ10 manufacturing processes in Japan have recently led to ubiquinol supplements becoming widely available.

According to Dr Sinatra, 15 mg of the (reduced) ubiquinol form of CoQ10 is equal to 50 mg of the ubiquinone form of CoQ10. So ubiquinol raises blood levels of CoQ10 just over three times as

well as standard ubiquinone.

(To create cellular energy, the body has to convert ubiquinone into ubiquinol. Aging and other factors however slow down or stop this conversion from happening, leading to low CoQ10 levels. If you are one of these that have a problem converting ubiquinone, then ubiquinol will have an even stronger effect, in comparison with ubiquinone. The ability to convert ubiquinones into its usable form decreases with age. Some studies show ubiquinol as being up to 8 times as bioavailable as ubiquinone. The contradictions in some CoQ10 clinical research are mostly due to the reduced bioavailability of some types of CoQ10. Water miscible forms are best absorbed, while powder forms are least well absorbed. The other problem is that many studies use only very low doses of ubiquinone, such as 200 mg.)

Ubiquinol is the preferred form of CoQ10 and is better value than ubiquinone, per absorbed milligram. Ubiquinone may cause some side effects at high doses (e.g. 1200 mg), however, as ubiquinol supplementation can give these same high blood levels at much lower doses, the potential for side effects is also much reduced. Ubiquinol has been shown to peak blood levels 6 hours after ingestion.

L carnitine

The name carnitine is derived from the Latin 'camus' for flesh as carnitine was first isolated from meat sources. Nutritionist Robert Crayhon, author of *The Carnitine Miracle*, explains that strictly speaking, carnitine is not an amino acid and that carnitine does not in fact contain the amino group (NH₂). He explains that carnitine is a coenzyme, a water-soluble vitamin-like compound. And that carnitine is similar to choline, one of the B vitamins-and, like various B vitamins, carnitine helps us turn food into energy. More specifically, it is essential for the burning of long-chain fatty acids.

The heart depends on adequate concentrations of carnitine for normal heart function.

The primary role of carnitine is to help transport fatty acids into the energy producing units in the cells - the mitochondria, where they

can be converted to energy. This is a major source of energy for the muscles, including those of the heart. Carnitine increases the use of fat as an energy source.

Carnitine is useful in clearing the bloodstream of ammonia and aids in creating glycogen, used to store essential glucose. Carnitine transports waste products out of the mitochondria, thus ensuring that toxic metabolic waste products do not accumulate. Carnitine reduces the accumulation of lactic acid, which is responsible for the burn felt inside the muscles with exercise.

Carnitine can help to prevent muscle atrophy.

Carnitine protects the heart from damage when a heart attack or a spasm cuts off the oxygen supply. Recent research has shown that carnitine can aid in recovery after a heart attack. Michael Murray N.D., author of 'The Pill Book: Guide to Natural Medicines' writes, 'Subjects taking carnitine showed significant improvements in heart rate, blood pressure, angina attacks, rhythm disturbances, and clinical signs of impaired heart function compared to the subjects taking placebo.'

Low thyroid function may indicate a need for carnitine to help overcome low energy levels and the tendency to gain weight.

Carnitine can improve insulin sensitivity in those with type II diabetes.

Kidney dialysis rinses away amino acids, causing weak, tired condition, which is threatened by high triglycerides. Carnitine supplements may be advisable in such situations.

At doses of 1 - 3 g carnitine reduces blood triglycerides. (As the LEF website explains, 'Carnitine combines with enzymes found in the mitochondrial membrane to transport fatty acids into the interior of the mitochondria, where they are oxidized to provide fuel for the generation of energy. In the absence of carnitine, fatty acids are not oxidized, but, instead, are transformed into dangerous triglycerides.')

Carnitine is an antioxidant and enhances the effectiveness of antioxidant vitamins C and E. Carnitine is synergistic with pantethine (vitamin B5).

Carnitine is manufactured by the body if

sufficient amounts of iron, vitamin B1, vitamin C, niacin, vitamin B6, lysine, and methionine are available. Food sources of carnitine include meat, poultry, fish, and dairy products are the richest sources of L-carnitine. Grains, fruits, and vegetables contain little or no carnitine. Robert Crayhon points out that due to high consumption of red meat, the Stone Age hunter probably got at least 500 mg of carnitine a day, and possibly as much as 2 grams. Today the average carnitine intake is estimated at a mere 30 to 50 mg a day. Strict vegetarians consume practically no carnitine.

L-carnitine is generally not well absorbed, and is best absorbed on an empty stomach. There are several different forms of carnitine;

L-carnitine fumarate is absorbed at a slightly higher rate than pure L carnitine and L carnitine tartrate. It is stable enough to be available in capsule form. L carnitine fumarate has a double effect as the fumarate is a free radical scavenger and also plays a part in the Krebs energy cycle.

Pure L-carnitine draws moisture and so is not suitable for use in capsules and tablets. It is commonly used in liquid carnitine products and pure carnitine powders. It has a very mild taste when mixed with water and is a good choice of carnitine.

For angina and other cardiovascular applications, a new form of carnitine known as L-propionylcarnitine appears to be the most effective form of carnitine, although it may also be the most expensive and difficult to source. (Look for products labeled Glycocarn.)

L carnitine tartrate is an adequate form of L carnitine. When mixed with water it has an unpleasant tart taste.

L carnitine is thought to be one of the safest nutritional supplements on earth, according to Dr Sinatra.

A special warning about buying low quality carnitine supplements : If you are using a Chinese made product, you could be putting your health in danger. Products containing the D isomer can cause cells to not function properly and possibly die. If you cannot find out the D isomer content of a product, then do not buy that brand of carnitine.

D-carnitine supplements should be avoided. The D isomer, which is not biologically active, can compete with the L isomer. To ensure a safe product, buy only Sigma Tau or Lonza carnitine products.

Information on acetyl L carnitine: Nutritionist Robert Crayhon, author of *The Carnitine Miracle*, explains that for neurological disorders it appears that acetyl L carnitine (ALC) is the best form of carnitine. ALC improves cognitive function and increases mitochondrial energy output (especially when combined with lipoic acid). Besides enhancing fatty acid transport and utilization, ALC also increases the density of neurotransmitter receptors, the levels of neurotransmitters such as acetylcholine and dopamine. It also reduces the accumulation of lipofuscin (a metabolic waste product related to lipid peroxidation, seen at particularly high levels in dementia), counteracts glycation and promotes melatonin production. Acetyl-L-carnitine also restores cortisol receptors, acts as an antioxidant and boosts the levels of glutathione and CoQ10.

Supplementation with ALC has been shown to reduce degenerative processes in the nervous system, and improve memory and learning ability. According to Nutritionist Robert Crayhon, ‘acetyl-L-carnitine qualifies as the superstar of neuroprotection.’

One side effect of acetyl L carnitine is vivid dreams, possibly due to increases melatonin production. Too much ALC can also cause neurological over-stimulation for those with neurological diseases involving seizure states such as M.E. and so a small dose of just 500 mg is recommended. ALC is not recommended where seizure problems are severe.

ALC is one of the most important supplements to be taken after a stroke, to help speed recovery. For stroke patients, the recommended dosage is usually 1500 mg.

D ribose

D ribose (or ribose) is a simple 5-carbon sugar found in all living cells. Dr Sinatra explains that, *Until 1944, D-ribose was thought to be primarily a structural component of DNA and RNA with little physiological significance. But a series of*

studies, culminating in 1957, revealed that this sugar molecule played an intermediate role in an important metabolic reaction called the pentose phosphate pathway. This reaction is central to energy synthesis, the production of genetic material, and for providing substances used by certain tissues to make fatty acids and hormones. Several notable papers were published in 2003. One study showed that D-ribose improved diastolic functional performance of the heart, increased exercise tolerance, and significantly improved the quality of life of patients.

Research continues here and abroad. Yet, despite the powerful scientific evidence, very few US physicians have even heard of D-ribose outside of their first-year medical school biochemistry class, and fewer still recommend it to patients. We lucky ones who are familiar with it have the wonderful gratification of seeing it help our patients on a regular basis.

Ribose is a very well studied product. More than 100 papers have been completed or published on its cardiovascular health benefits. In short:

Ribose plays a role in the manufacture of glucose, which is used in the body in metabolic processes, including energy production and, cyclically, production of ribose. Ribose also converts to pyruvate, which can combine with oxygen in the metabolic pathways to produce adenosine triphosphate (ATP) - the energy source for all muscles. Ribose is the prime ingredient in the production of ATP.

Ribose is found in heart and muscle cells, but the body cannot manufacture it quickly enough to meet the demands of metabolic stress experienced during strenuous exercise or diminished blood flow or where there is metabolic insufficiency.

Ribose improves the relaxation of the heart that allows it to fill properly with blood. Thus ribose improves diastolic heart function. (As explained previously, this has special relevance and importance for M.E.)

Ribose is vital in the formation of nucleotides, compounds needed by the heart and skeletal muscles, as well as other body cells. Nucleotides are required for the body to produce energy for

muscle cells; manufacture protein, glycogen and nucleic acids (RNA and DNA); form the cyclic nucleotides responsible for controlling calcium and other electrolytes; and relax the heart and muscle cells

Dr Sinatra goes on to write, *Supplemental D-ribose absorbs easily and quickly through the gut and into the bloodstream. About 97% gets through. Studies have shown that any amount of D-ribose you give to energy-starved cells gives them an energy boost. At the University of Missouri, researcher Ronald Terjung has shown that even very small doses (the equivalent of about 500 mg) of D-ribose increase energy salvage in muscles by more than 100%. Larger doses increase the production of energy compounds by 340-430%, depending on the type of muscle tested, and improve the salvage of energy compounds by up to 650%. Most amazing is that when muscles are supplemented with D-ribose, they continue to add to their energy stores even while they actively work! Until this study was reported, it was thought that muscle energy stores were only refilled in muscles at rest.*

An adequate dose of D-ribose usually results in symptom improvement very quickly-sometimes within a few days. If the initial response is poor, the dose should be increased until the patient feels relief. Logically, the sickest patients stand to gain the most.

The half-life of ribose is only 30 minutes.
Restrictions and cautions on the use of CoQ10, L carnitine and D ribose

Certain drugs, such as those that are used to lower cholesterol or blood sugar levels, may reduce the effects of CoQ10. The LEF explains that, *A large number of drugs deplete Coenzyme Q10. These include such widely used tricyclic antidepressants as Elavil (amitriptyline) and Tofranil (imipramine), the anti-psychotic drug Haloperidol, cholesterol-lowering statin drugs such as Lovastatin and Pravastatin, beta-blockers, anti-diabetic sulfonylurea drugs such as Glucotrol (glipizide) and Micronase (glyburide), and the anti-hypertension drug Clonidine. These common drugs, as well as several others, interfere with the body's synthesis of CoQ10*

and may cause a deficiency of this crucial compound, so important for energy production and protection against free radicals. This drug-induced depletion can be particularly serious in the elderly, who already suffer from aging-related CoQ10 deficiency. It is particularly ironic that drugs prescribed to heart patients result in lower levels of CoQ10, since the heart has an enormous need for CoQ10 for its energy production. In fact, a CoQ10 deficiency first manifests itself in cardiovascular symptoms. The authors warn, “The results of some studies suggest that congestive heart failure is primarily a coenzyme Q10 deficiency disease.” The same may be true of cardiomyopathy, heart muscle impairment, which may lead to heart failure. The authors also list other symptoms of CoQ10 deficiency, including angina, cardiac arrhythmias, mitral valve prolapse, high blood pressure (which may lead to stroke), gum disease, low energy and a weak immune system (which may result in greater susceptibility to cancer). Recently it has also been discovered that CoQ10 is very important for brain health, and may help prevent Parkinson’s disease and Alzheimer’s disease. The importance of CoQ10 can hardly be overemphasized.

To reiterate; statin drugs, tricyclic antidepressants and beta blockers deplete CoQ10 and if CoQ10 is not given at the same time as these drugs, cardiomyopathy or CHF may result. Overactive thyroid or a pulsating heart requires additional CoQ10. CoQ10 may alter the body’s response to warfarin and insulin.

CoQ10 shows very few significant side effects, though some patients report insomnia and restlessness when treated with high doses of CoQ10 supplements. If this occurs, the dose should be lowered until the symptoms resolve. No serious side effects have been reported from the use of coenzyme Q10. Some patients using CoQ10 have experienced Other possible side effects include rashes, nausea, upper abdominal pain, dizziness, visual sensitivity to light, irritability, headache, heartburn, and fatigue. Generally CoQ10 is well tolerated in M.E.

However, some M.E. patients say they can only tolerate low doses of CoQ10, while others find they need very high doses to see the full benefits of CoQ10.

The effects of CoQ10 on pregnant and nursing women and very young children have not been studied and so this supplement is not recommended for these patient groups.

Patients being treated with AZT, Doxorubicin, Isotretinoin or Valproic acid should speak to a physician before taking any L-carnitine supplements. Anticonvulsant drugs may lower the effectiveness of carnitine supplements. Renal patients may need a lower dose of carnitine. Carnitine supplementation will often mean that the dosages of various heart drugs will need to be lowered; this process should always involve the doctor that prescribed the drugs and be very gradual - do not stop taking any medication suddenly.

Carnitine is a very well tolerated and safe supplement. It does not appear that L-carnitine causes significant side effects, although high doses taken on an empty stomach may cause diarrhea. Other possible but rare side effects include body odor, rash, and increased appetite. This supplement is generally very well tolerated in M.E.

Dr Sinatra explains that, *The toxicology and safety of D-ribose have been exhaustively studied. The supplement is 100% safe when taken as directed. There are no known adverse drug or nutritional interactions associated with D-ribose use. Thousands of patients have taken D-ribose at dosages up to 60 grams per day with minimal side effects. However, even though there are no known contraindications of D-ribose therapy, we recommend that pregnant women, nursing mothers, and very young children refrain from taking D-ribose simply because there is not enough research on its use in these populations. D-ribose can actually lower blood glucose levels; therefore, insulin-dependent diabetics should check with their physicians before starting on the supplement.*

The only problems usually mentioned with regard to D ribose (in books are articles) are

infrequent minor gastrointestinal side effects or feelings of faintness where a large dose is taken on an empty stomach. However, of all the supplements listed here D ribose by far the one most likely to cause problems or to not be tolerated even at lower doses in M.E. (Unfortunately many D ribose experts seem to not have encountered many or any M.E. patients and are unaware of this problem.)

Many M.E. patients become very ill when trialing D ribose and so it is very important to start at doses much lower than the 5 g usually recommended as a starting dose. D ribose can cause far more than gastrointestinal upset in M.E., it can cause severe relapse and loss of quality of life. (A short improvement in function maybe also followed by a 'crash.' Dr Cheney has commented that in a small number of patients ribose seems to be metabolized as a sugar rather than a component of ATP production, or metabolized anaerobically which results in lactic acid build up in the body - rather than the ribose being used primarily to make more ATP, which is the idea behind ribose supplementation.

Thankfully, the negative affects from D ribose do pass quickly, usually within a few days. D-ribose should be taken with meals (or at least mixed into juice, milk, or fruit) to offset the blood-glucose-lowering effect.

D-ribose should be discontinued if no benefits are seen or only very small benefits are seen, as there is a possibility that the sugar content could feed 'bad' bacteria and contribute to Candidiasis or gas and bloating. Dr Cheney made a complete turnaround in 2009 on ribose, commenting that it is 'toxic' to patients and makes problems worse. While Dr Cheney should by no means be assumed to be absolutely correct in his every comment (he does NOT study a 100% M.E. patient group after all and is not what one might call politically aware), this is another reason to cease ribose supplementation unless it is very clearly helping significantly. Where D-ribose is not helpful, patients may want to instead try sublingual NADH or ATP lozenges.

There are still enormous benefits to be had from the combination of CoQ10, L carnitine and

magnesium, with *or without* additional D-ribose supplementation.

CoQ10, L carnitine and D ribose tests

Testing the blood levels of CoQ10 may be very helpful, both in determining the correct dose of CoQ10 needed and to determine, where there is a lack of response to CoQ10, if this may be caused due to a lack of absorption (or perhaps a product not containing the amount of CoQ10 stated on the label, and so on). This test is widely available.

Dr Sinatra explains that researchers agree that CoQ10 blood levels of 2.5 ng/ml and preferably 3.5 ng/ml are required to have an impact on severely diseased hearts. Dr Sinatra recommends Quest labs for CoQ10 tests. The LEF also offers a CoQ10 blood test, for US patients.

Testing of carnitine levels is not usually necessary before carnitine supplementation according to Dr Sinatra. (For information on the tests necessary to diagnose carnitine deficiency see the *eMedicine/Web MD* website)

Testing D-ribose levels is useless as ribose has such a short half-life in the body.

Dosage recommendations

CoQ10/ubiquinol: Dr Sinatra recommends the following daily CoQ10 dosages

Ubiquinol dosage (rounded figures)	Ubiquinone dosage	Recommended:
25 - 50 mg	90 - 150 mg	As a cardiac disease preventative.
75 - 100 mg	240 - 360 mg	For cardiac arrhythmia, angina and those taking statin drugs.
100 - 175 mg	360 - 600 mg	For dilated cardiomyopathy and congestive heart failure.
175 - 350 mg	600 - 1200 mg	To improve quality of life in Parkinson's disease.
350 mg or more	1200 mg or more	Where there is greatly reduced immunity, such as in cancer.

Although there is no specific dosage given for M.E. (nor for many other diseases) by Dr Sinatra this is not necessarily a significant problem. Dosage will depend on disease severity which can vary considerably in M.E. and there are also significant differences in the dose needed from person to person and so dosage recommendation can only ever be general guidelines, as Dr Sinatra explains.

In addition, we do know that M.E. has some similarities to Parkinson's and can be a similarly disabling neurological disease and that (anecdotally) those with moderate - severe

M.E. will most often need doses the same as those listed for Parkinson's disease, in order to experience an improvement in quality of life. (1200 mg of ubiquinone daily is often quoted as a standard dosage for Parkinson's patients.)

The dosage of CoQ10 in M.E. can be guided by blood levels of CoQ10 or by raising the dose until the patient experiences significant improvement, or both. The maintenance dose of CoQ10 should then be adjusted downwards as much as possible, without losing the benefits. For patients that are severely affected the maintenance dose may need to start the same as the initial dose, in order to prevent relapse.

CoQ10 should be taken in 2 - 3 divided doses (with food). Do not take medium - large doses all at once.

Dr Sinatra recommends that patients be pre-treated with CoQ10 prior to any type of cardiac surgery. He also comments that very severely ill patients may need three times as much CoQ10 as others. Benefits from CoQ10 will often be seen in 1 - 4 weeks but it may take several months for the full effect to become apparent.

L carnitine: For those with serious cardiac issues, as in M.E., pure L carnitine should be

trialed at 250 - 750 mg taken 4 times daily, according to Dr Sinatra, for a total intake of 1 to 3 grams daily.

If improvement is not seen at 3 g, the dose may need to be raised to 4 g or in severe cases, 5 or 6 g. The maintenance dose may be able to be significantly lower than the initial or pharmacologic dose, although in severe cases the initial dose will need to be maintained long-term to prevent relapse. How you feel should be your guide to determining your best L carnitine dosage long-term.

Do not take doses larger than 1 - 1.5 g at a time

as absorption is greatly reduced with large doses. L carnitine is best taken in 3 - 4 divided doses.

D ribose: The usual recommendation for D ribose where there are serious cardiac issues is to take 5 g (roughly two teaspoons), two or three times daily, according to Dr Sinatra, for a total intake of 10 to 15 grams daily.

In very severe cases doses of 15 - 30 g may be recommended. (Two teaspoons = 4.5 g D ribose. 1 teaspoon = 2.25 g, ½ teaspoon = 1.125g, ¼ teaspoon = 562 mg.)

A very cautious starting dose in M.E. may be 280 mg (1/8th of a teaspoon) taken daily, in divided doses, for the first week and raised 280 mg a week or a fortnight until a dose of 5 g (or more) is safely reached or the treatment must be stopped due to its causing relapse. Note that having smaller doses less often may increase your tolerance of D-ribose and that buying powders rather than tablets may make taking (and measuring) smaller doses easier to manage. (If you can work out how to measure 1/16th of a teaspoon, you could make this your daily starting dose instead. Or you could even have 1/8th or 1/16th of a teaspoon of D-ribose every second day or a week, to start with.)

Make sure to take D-ribose with food to minimize its effect on blood sugar levels. D-ribose is best taken in 2 - 3 or more divided doses. Ribose gives improvements in a few days.

All three of these supplements are very safe to take long-term.

Additional notes on antioxidants and mitochondrial supports

Nutritionist Robert Crayhon explains that mitochondrial supports 'should be combined with antioxidants to compensate for the increased production of free radicals that is a by-product of greater energy output. Older people especially need to take extra antioxidants to compensate for this.' Lipoic acid is one of the most important antioxidants, along with vitamin E and vitamin C. CoQ10 is also an antioxidant.

Dr Sinatra recommends that 50 -100 mg of lipoic acid (and also a daily multivitamin, extra vitamin C and fish oil) always be taken

along with the 'awesome foursome.' He states that to help neutralize free radicals, nurture your mitochondria and delay aging, life-long supplementation with CoQ10, L-carnitine, lipoic acid and vitamins C and E is essential.

"Both carnitine and CoQ10 promote energy to cardiac muscle cells. It is important to note that this action is physiological and is not similar to the pharmacological effects of drugs that affect the heart rate and contractibility of the heart."

Dr Sinatra in 'The Sinatra Solution'



The First Christmas Joke - and it's Scottish.....

A man in Scotland calls his son in London the day before Christmas Eve and says, "I hate to ruin your day but I have to tell you that your mother and I are divorcing; forty-five years of misery is enough".

"Dad, what are you talking about?" the son screams.

"We can't stand the sight of each other any longer", the father says. "We're sick of each other and I'm sick of talking about this, so you call your sister in Leeds and tell her".

Frantically, the son calls his sister, who explodes on the phone, "Like heck they're getting divorced", she shouts, "I'll take care of this".

She calls Scotland immediately and screams at her father, "You are NOT getting divorced. Don't do a single thing until I get there. I'm calling my brother back and we'll both be there tomorrow. Until then, don't do a thing, DO YOU HEAR ME?" and hangs up.

The old man hangs up his phone and turns to his wife. "Done! They're coming for Christmas - and they're paying their own way."

XMRV Updates

By Chris Heppner

Not a great deal of news—we are still waiting for major reports from the Blood Group and Dr. Singh, both of which should be seriously informative; we hope. But, apart from a couple of small and expected failures to find the virus, and the fact that apparently the Whittemore Peterson Institute has had three grant applications turned down by the NIH, there have been a few developments worth taking note of.

The first was the poster presentation by Mikovits and her group at the recent XMRV workshop conference. This showed that antiretrovirals had a pronounced positive effect on a very small group of CFS patients who over the years had developed either Chronic Lymphocytic Leukemia or Mantle Cell Lymphoma, cancers to which we are prone at rates very much higher than the general population. Three months of antiretroviral therapy produced improvement or normalization of cytokine/ chemokine signatures, infectious XMRV load, and tumour markers; these improvements correlated with clinical improvement. This is a small but significant step—a small scale but successful drug trial, made possible by the coexistence of a cancer with CFS, which justified the risk.

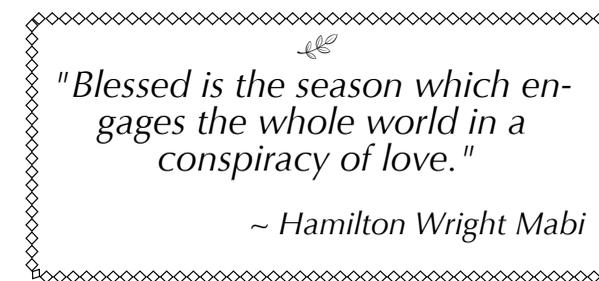
The second is that a group in Norway has detected XMRV in CFS patients at a rate approximating the rate found in the *Science* paper of a year ago: over 60%. That, in conjunction with the announcement that the Mikovits team has, with the help of some others over there, found similar % in ME sufferers in England, makes it very clear that XMRV is not confined to North America.

The third is that another group in Spain has also detected XMRV in CFS patients at a high rate; the vice-like grip of the psych lobby over ME/CFS in Europe is beginning, maybe, to be loosened. The British are beginning to look a little isolated.

The fourth event is the recent solution of the structure of a key protein needed for replication by the XMRV virus, which means that this

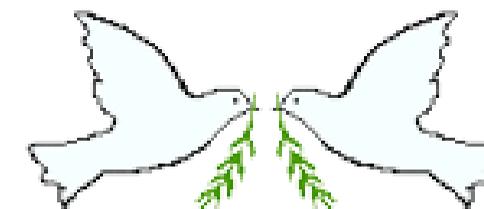
protein now becomes a possible target for new drugs and drug companies just love having a clear target. This story can be found at <http://bondix.missouri.edu/news/story/38/1>.

So no huge new breakthroughs, but progress is being made, and we are made aware from time to time of work going on in the background, including an anticipated statement from the Blood Working Group and ongoing clinical trials, one for our old friend Ampligen, and some new ones, including something identified as L-000870812 from Merck, which has shown activity against XMRV in vitro. There will be much more to come on this unfolding story in the coming months.



★ CHRISTMAS BONUS ★

Persons on disability/income assistance who normally receive an application form for Christmas assistance from local charities along with their monthly cheque will not receive one this year. The Christmas Bureau, which used to gather the information for requests has been disbanded. Application forms for help can be picked up at the front desk of the Times-Colonist



Up coming Events

M.E.V.A CHRISTMAS

~ December 8th at 2:00 pm ~

Come share your goodies, your stories and maybe a greeting card to cheer one another. Bring a friend and sit back and enjoy.

Valentines Party

~ February 9th at 2:00 pm ~

As always, we would LOVE to see you!
Come and have a heart to heart with the gang and bring a note of kindness for a secret Valentine.



All events will be held at 1908 Stanley Ave.

MEVA will be having an Art Show in March. All members wanting to present their art work should contact us and we will give you the details!

This is an exciting opportunity!

For more in formation, contact us at 370-2884 or at me.victoria@shaw.ca

www.members.shaw.ca/me.victoria

PEACE

