

By Request: A Discussion about Carnitine

The role of supplemental carnitine in conditions characterized by excessive obesity, hunger, lethargy, hypotonia, and poor exercise endurance.



Aunt Cathy

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Carnitine is a substance we normally make in the liver, kidney and brain. It is also available in small amounts in meats. It is a tiny substance made from a molecule of methionine and a molecule of lysine — two essential amino acids that we need to make all of our body's protein.

Carnitine plays a critical role in the ability to burn fat for fuel because it is part of the enzyme system "carnitine palmitoyl transferase" which transfers fat molecules into the mitochondria to produce energy as ATP.



This picture of a logging truck illustrates the role of carnitine if you imagine the long trees as long chains of fat. Carnitine “trucks” are needed to get the fat into the saw mill to cut it up into small enough bits to go into the furnace.

[The sign on the door of the truck says that it is the “**Cart-It-In Trucking Company**” to help remember that one very important function of carnitine is to cart fat (the fuel) into the mitochondria (the furnace) to convert it to energy we can use.]

Muscle (including heart muscle and the diaphragm) is very dependent on fat fuels for aerobic energy production. It is especially necessary for physical activity that involves endurance. When carnitine is inadequate people become less able to do endurance exercise like running or walking for more than a short time. They may show wheezing after endurance exercise because the diaphragm is also a muscle and it can't work right without carnitine carting in some fat fuel to keep going. Low muscle tone and muscle pain are also commonly seen for the same reason.

People with insufficient carnitine often gravitate toward exercise activities that do not require endurance exercise ... like pitching a baseball or throwing the shot put (both of which burn carbohydrate via glycolysis and not fat fuel.) Some people end up standing there in the line of scrimmage, playing the position of "large wall" in a football game. All you have to do there is be there in bulk ... no running down the field. By trial and error, many people (including some of my patients) have found a way to participate in activities in spite of energy limitations.

They typically find other kinds of things to do that require very little endurance activity at all ... like working at the computer, reading or watching television. This often results in being labeled a "couch potato" and told that they are fat because of "too much screen time." Keep in mind that although some folks may be very heavy because they are "just lazy," folks who have a relative carnitine insufficiency problem are often labeled "couch potatoes" too. For them being a couch potato is not a choice.

Some folks with inadequate carnitine have **very low muscle tone** and so they not only sit around a lot, they tend to always be leaning against something as well. This is not laziness although it can look that way. Some people have trouble with balance because of low muscle tone which can lead to falls or other problems.

Here is one child's story: An eight-year-old normal-weight girl who could not ride her bike without training wheels and she found this to be very embarrassing. Additionally, she **could not walk up the stairs one foot after another**. She stepped up with her left foot, brought up the right foot, rested again and continued until she finally reached the top. This girl was also memorable because she **had to hold on to the table with one hand when she ate** to prevent tipping over. [You will be happy to learn that she can now ride her bike all over the place, run up the stairs (often yelling "Watch this, Mom!") and she can eat with both hands if she wants to.]

Correcting carnitine inadequacy can help with **muscle strength and stamina**, and people's choices of activity change and they begin to move around a lot more. One of my little "couch potatoes" comes to mind who is now far too busy riding her bike around the neighborhood to sit and watch TV. The point ... and it is a big one ... is that for some folks carnitine inadequacy is the reason they are sedentary and heavy, and that being sedentary is not the primary cause of their weight issue. **Correcting inadequacy can greatly improve quality of life.**

As mentioned earlier, inadequacy of carnitine can also cause **muscle pain**, and children in this situation will often complain a lot about it. One of my “I-play-the-position-of-wall” football players actually came to my attention because his little sister with a metabolic disease was my patient. But his mother asked me about him because he was in such pain after practice that he asked her to “rub his butt” because it hurt so much. Now, this is an unusual request for any teenage boy, right? That made me suspicious that this must be a case of very painful muscles indeed. Cutting to the chase, we did a trial on carnitine supplementation (with his doctor’s approval, of course.) He can now play a variety of positions on the football team ... not just a wall ... and he no longer experiences such pain in his muscles.

Here is one girl’s story: A chubby ten-year-old who used to whine a lot about muscle pain even when the activity was supposed to be fun.

On a family trip, she complained all over Disneyland that she was tired and that her legs hurt, and she had a horrible time. The next year after being on carnitine supplementation, she was thinner and had far better endurance, posture and no muscle pain. The family went back to Disneyland and they all had a wonderful time.

[Older folks may just attribute pain from carnitine inadequacy to “getting older” ...which actually may be the case if inadequate carnitine was not a problem earlier in life. Age-related changes are discussed later.]

Medication that changes carnitine intake requirements:

Some drugs impair the production of carnitine so that one is more dependent on an outside (exogenous) source than normal. The seizure control medication **valproic acid** (also called valproate) is an example of this. As an unwelcome side-effect it tells the body to **quit making carnitine**. Relative carnitine insufficiency can often be a big contributor to the lethargy, weight gain and certain other side effects reported as common with the use of this medication.

Additionally, inadequate carnitine also **compromises the seizure-controlling effectiveness** of the valproic acid drug itself, resulting in break-through seizures and increased risk of liver toxicity. **Carnitine supplementation decreases the liver toxicity of this drug significantly.** We once had a toddler in our pediatric ICU who was “life-flighted” in because of severe liver toxicity. Her home physician had been advised by people here that carnitine should be given with her valproic acid seizure medication, and he simply did not prescribe it.

Immediate I.V. administration of carnitine saved her life and her liver, but she had already suffered some brain injury due to severe hypoglycemia (low blood sugar) and elevated ammonia. This was because inadequacy of carnitine meant that she could not burn fat very well at all, and in order to run her body she had to find another source of fuel. As a result, she used up blood sugar that would normally have been spared and used as the primary fuel for her brain. She also burned more amino acids for fuel than one would ordinarily do (for the same reason,) resulting in an increase in production of ammonia waste that needed to be processed by the liver.

Valproic acid is the seizure medication most studied in relation to carnitine, but other seizure medications appear to affect carnitine requirements as well. Certainly if the child (or an adult) is symptomatic (e.g. lethargy, weight gain, low blood sugar, increased seizures) a trial on carnitine is very reasonable.

Special diets that increase carnitine requirements:

People on extremely low carbohydrate “ketogenic” diets for seizure control also need extra carnitine. Because they are burning fat as almost their primary fuel - - they need much more carnitine than they could be relied upon to make on their own. Additionally, many people on these special diets do continue to need seizure medications, which may further increase the need for an outside source of carnitine.

People with **various liver and kidney conditions** are sometimes supplemented with carnitine because production can be compromised. We also use it with **premature infants** on TPN in the NICU because their ability to produce carnitine is compromised by the immaturity of the liver and kidney. “Fatty liver” ... deposits of fat in the liver ... and “high triglycerides” in the blood can be caused by many things but one of them is relative carnitine inadequacy

People with certain **inborn errors of metabolism** that effect energy production also need supplemental carnitine. One of the most common examples of this is a condition called **MCADD** (Medium Chain AcylCoA Dehydrogenase Deficiency.) It impairs the person’s ability to burn fats of certain sizes and it makes it unsafe to fast. In this kind of condition **carnitine requirements can increase because the parts of fat that cannot be burned have to be removed from the mitochondria.** Failure to move them out can cause a build-up of unusable fat in the mitochondria. That means that people with MCADD need enough carnitine to haul fat in both directions, and they may be unable to manufacture enough extra carnitine to do that.

Age-related changes in carnitine intake requirements.

People may gradually be able to make less carnitine than they need as they get older. For some it can be a player in the development of “middle-age spread” and general weight gain. There is evidence that it can also contribute significantly to the muscle weakness, poor tolerance of exercise and muscle pain that can accompany aging.

Relative carnitine inadequacy also appears to be a factor in the **maintenance of cognitive ability** as we age. Production of any many things our bodies normally made in adequate amounts when we are young can fail to keep up production as we age. Examples of this include estrogen, (and babies!) testosterone, hair, thyroid hormone, and the ability to continue making vitamin D in the skin. For some people, production of carnitine in the brain may also follow this timetable.

Bottom line: Assuring adequacy is a very good idea, and again, I would recommend doing a trial on carnitine for any person who is symptomatic. I have personally seen significant improvement in strength, stamina, pain, quality of life, and cognition in several older adults.

Carnitine-related problems contribute to difficulty burning fat for fuel and result in symptoms that may include:

- 1. Excessive fat storage**
- 2. Low muscle tone (“hypotonia”) and muscle weakness.**
- 3. Excessive appetite due to failure to make the needed amount of ATP (usable energy) from the food consumed.**
- 4. Very poor tolerance of aerobic activity and endurance-type of exercise.**
- 5. Abnormally high sense of fatigue or excessive sleeping.**
- 6. Muscle pain with exertion.**
- 7. Cardiomyopathy ... impaired functioning of heart muscle.**

8. **Progressive Emphysema (new just since 2/16)**
9. **Episodes of dangerously low blood sugars that can result in brain damage, or even death ... in infants sometimes labeled a “SIDS” event (“Sudden Infant Death Syndrome.”)**
10. **Unusual difficulty with control of blood sugar in people who have insulin-dependent diabetes ... we should be especially suspicious of carnitine inadequacy among those with blood sugar volatility in spite of carefully following their nutrition plans and medications.**
11. **Difficulty abandoning a pattern of eating high carbohydrate-containing foods in spite of obesity or diabetes and the strong advice to discontinue them. Sugar is sometimes the only reliable fuel for the individual. If their ability to adequately burn fat for fuel is limited, they can have trouble maintaining blood sugar when fasting for very long. In this situation, the drive to take in foods such as regular soda, juices, jellybeans, etc., can go well beyond just “wanting to snack all the time.” Correcting carnitine inadequacy can change this situation.**
12. **Failure to maintain weight loss achieved via medical fasts or bariatric surgery.**

These are among the symptoms that have been corrected by carnitine supplementation in at least 40 people (not counting premies) that I have worked with personally who turned out to have had unrecognized metabolic abnormalities.

[This also does not count the patients for whom we automatically initiated carnitine therapy in anticipation of need, thereby preventing the problems described.] If someone way out here in Fargo, ND has found that many patients with what turned out to be (previously unrecognized) carnitine-related health problems, **the likelihood is good that there are lots of folks out there whose carnitine problems are simply not being looked for and therefore not recognized.**

There are clearly many people who have some of the symptoms described above for whom carnitine adequacy/inadequacy is completely unrelated. To determine if carnitine is a problem for an individual, a trial of carnitine supplementation will often result in noticeable changes within few weeks ... sometimes days.

If carnitine is apparently not a factor for a particular person because no measurable benefit was observed, supplemental carnitine could be discontinued after a trial of about a couple months. We would normally continue the trial at least that long before writing it off as unhelpful because some conditions result in a degree of carnitine depletion so pervasive that it takes a while to get enough cells operating well enough to see a benefit.

[Please see the note on page 23 regarding special carnitine issues to consider for people who are candidates for bariatric surgery.]

A Trial on Carnitine:

Carnitine used as described is very safe. The only problem with the stuff is that it can be pricey. Insurance will sometimes cover it (ordered as "Carnitor, or the generic equivalent,") but the amount of coverage varies. For this reason, we do not do this kind of trial casually. However, as I mentioned earlier, **the metabolic abnormalities in symptomatic patients that I have seen who benefitted markedly from carnitine supplementation were undetected at the time the trial was initiated.**

As you know, what we often think is extremely rare can sometimes be fairly common but just rarely recognized. **The only way to know for sure is a trial on carnitine.** I prefer a **prescription form of carnitine for the trial if insurance will cover it.** People can use over-the-counter carnitine but insurance will usually not pay for that form. However, if the prescription form is unavailable for financial reasons, these days there are a number of reputable products that could be used.

I prefer to use a form called **acetyl-L-carnitine (or just acetylcarnitine)** because there is some evidence that that form may have superior absorption ... and nothing works well if it is not absorbed but just passes right through. **Carnitine fumerate** is also well utilized. If using a particular over-the-counter product and no benefit is observed after a reasonable time, it would be worth trying a different form or a product by a different company. At present there is no clear-cut best product for all people, and research is needed to sort out this kind of question.

Should We Get Labs?

Blood carnitine levels can reflect inadequacy when they are low or if the **“total:free carnitine ratio”** is disturbed. [The total:free ratio is an indication of how many empty trucks are available to haul fat. If one has a normal total amount of trucks, but all the trucks are already in service, the ratio shows whether or not a person has enough empty trucks available to be able to keep up with the workload.]

However, the blood level apparently does not necessarily reflect the muscle tissue level, including the level available to the heart and diaphragm muscles. So even if a person's labs were normal one would still do the trial if a person is symptomatic, and watch for changes in symptoms.

In other words, there is probably little reason to get labs in this situation except for curiosity or research. Certainly, when labs do indicate deficiency, we would supplement. But when labs do not reflect a deficiency state, we would still do a trial of supplemental carnitine in a symptomatic patient. So, the labs are really not of great use in this situation. As the health effects of carnitine inadequacy (for whatever reason) are not benign, my prejudice is to do a rule-out trial with symptomatic patients. It also saves the cost of getting an unlikely-to-be-very-useful lab.

Dosage Specifics

So, that is the story in a nutshell. **If you decide to do a trial**, the usual trial in adults is about 1 gram three times a day (i.e. 3000 mg/day.) The pills are available in several sizes: 250 mg, 330 mg, 500 mg and 1000 mg sizes. [Math examples: The 3000 mg can be adequately approximated by three 330 mg pills 3 times a day. Happily, some products now are available that provide more per capsule, so the dosage to give 3000 mg/day in that case would be two 500 mg pills 3 times a day, or one 1000 mg pill three times a day.]

It is also available as a liquid by prescription. It usually provides 1 gram of carnitine per 10 mL, which is equal to 100mg carnitine per mL. This can be helpful with young children, for people being fed by tube and for anyone with swallowing problems. There is now over-the-counter liquid carnitine readily available as well.

The pills or drops are spread out (any way that is comfy for the patient) to avoid an osmotic diarrhea that can result from giving the whole lot of any kind of tiny particles all at once. The pediatric dose (PDR info) is 50-100 mg/kg/day divided into 3 doses, with a 3000 mg/day the (usual) upper level.

It is also smart to spread them out so that some carnitine is **available** throughout the day. Taking all at one time could result in taking in more than is immediately needed, and then excreting the extra ... which then leaves people with no carnitine coming in to help run their bodies later in the day or evening. Later on, a person can tinker with how much and when they take it, but when trying to do a careful test to see if carnitine can help at all for a person struggling with some of the symptoms described, it makes sense to take it as described.

The therapeutic/maintenance amount may turn out to be much less than this, but the higher end of the usual range is often best in a test situation, since the person may be starting out with a significant deficiency. If we under-shoot with a low dose, there may not be enough carnitine to see changes during the trial period. I don't want to miss something if it is there.

Some People May Need More than 3000 mg Carnitine per Day

I have had some **very large patients** whose symptoms (hypotonia, excessive hunger, lethargy, excessive weight gain and poor endurance, etc.) have responded very well to carnitine supplementation, but an amount above the theoretical 3000 mg “top” was sometimes needed to bring the positive changes about. **As is usually the case, when one is very far outside the “normal” range for body weight, a standard “per/kg” intake level may no longer directly apply.**

One pair of very heavy and fatigued adolescents responded beautifully to carnitine supplementation, but they required 6000 mg/day to bring about the changes we were looking for. Here is their story:

They would come home after school and go directly to bed. The sister told me that she walked through mud puddles instead of going around them because walking around is just too tiring. Both were very smart, very hungry, and very weak. The girl wanted very much to be a veterinarian although she expressed doubt that she could do it because of physical incapacity.

The 3000 mg was insufficient to result in the hoped-for changes, but instead of calling the trial a failure, we bumped the dosage up to do a trial on 6000 mg (with the approval of their physician, of course.) Happily, today both brother and sister continue on a (normal) maintenance dose of carnitine and they are now of normal weight. The sister is now a veterinarian with two healthy children, and the brother just finished college.

This brother and sister were the first people for whom I ever suggested a trial on carnitine. I initially wrote this carnitine paper just for their physician, explaining why carnitine might help, and describing how to very safely do a trial. (They lived in a different state so we had to do everything via mail and phone ... not even any email then!) My carnitine paper is substantially longer now...

[Note that I do not “order” anything ... I suggest things (also described as “nag about things”) but the health care provider (MD, PA, NP, etc.) is always the person who orders a trial on carnitine. I only do any of this in conjunction with one of these health care professionals. I am the wrong kind of doctor for writing orders ... I am a PhD and not an MD. ☺]

A number of patients I have seen (including the boy and girl described above) have been described in their medical charts as having “**familial hypotonia of unknown etiology.**” This is not a diagnosis ... it is just a description that means: “A person has low muscle tone for unknown reasons, and others in the family seem to have the same problem.” It does not identify WHY they have such low muscle tone, or what might be done about it.

Many people who are in this situation have responded amazingly well to this therapeutic intervention even though as yet no one has ever identified their actual metabolic problem. All we know is that something about their genetic pattern causes problems, some of which may be ameliorated by providing supplemental carnitine.

Adjusting Carnitine dosage as Children Grow.

When a pediatric patient demonstrates that supplemental carnitine is helpful, the level that seems to be effective needs to progress with growth (i.e., mg of carnitine per kg body weight). I have seen some situations in which a child out-grew his prescription because this aspect of his care was not being monitored and the treatment became less effective the more the child grew.

With math-competent parents (and the doctor’s permission, of course) I teach the parents how to increase the dosage as the child attains certain weights. Other families call me each month with the baby’s weight and I calculate the level for them. To facilitate this, the physicians write the order as “___ mg carnitine /kg body weight,” so the carnitine dose can easily be progressed as baby grows without requiring a new prescription every five minutes.

Changing from a Therapeutic Dose to a Maintenance Dose

When initiating treatment, the carnitine dose is generous in an attempt to correct a possible inadequacy ... that is, the bucket may be empty so we need to fill it up as part of our test. However, once the bucket is appropriately full, the therapeutic level is no longer needed and a maintenance level should be identified. This will be quite individual.

As a marker for having reached the point of having a “full bucket” I tell parents that one indication of this will be that the child may “start to smell a bit like a little fish” (reflecting getting rid of unneeded carnitine.)

One mother called me and left this message: “At last! We have achieved fishiness!” At that point we dial the dosage back and set about to find the maintenance level for that particular child. I have also had many patients ... in fact, MOST patients ... who never smelled funny even at very high levels, suggesting that even at a very generous intake, there was not enough being given beyond actual requirements to produce this particular side effect.

Carnitine Inadequacy Can Be Found among People Who Have Other Medical Conditions.

Other conditions can be characterized by the same symptoms (lethargy, weight gain, hypotonia, exercise intolerance, etc.) Some of my patients with **Down Syndrome (Trisomy-21 or DS)** or **Phenylketonuria (PKU)** have struggled with the same set of energy-related problems, and in several cases, the carnitine supplementation has helped tremendously. People with Down Syndrome often are described as having low muscle tone. Like everything else, this is highly variable among people with DS. However, I have worked with several infants and children for whom it was markedly helpful, resulting in the mastering of sitting up and walking in little folks who had been able to accomplish neither on their own even by age three.

While carnitine certainly does not cure Down Syndrome or PKU, it has been life-altering in a very positive direction. For others, the carnitine was not shown to alter the situation at all. The only way to know which person with these symptoms will respond to carnitine supplementation is to do a trial.

The exact nature of a person’s possible carnitine insufficiency does not have to be known ... one only needs to be alert to the symptoms.

When the symptoms are not recognized as being potentially related to carnitine insufficiency, there is often an unfortunate tendency to blame the parents for children’s obesity or lethargy and accuse them of serving unhealthful meals and allowing too much TV time. Those are certainly contributory if the allegations are true. However, I saw one very memorable obese sixteen-year-old patient who illustrates our need to be suspicious of the possibility of contributory carnitine issues before leaping to that conclusion. Here is his story:

An Adolescent Boy Being Worked-up for Possible Bariatric Surgery:

A sixteen-year-old boy was very short and very round, as was his mother. His father was tall and very thin. The mother had been accused for years of causing her son's obesity by serving a high calorie diet. She had been referred several times to health professionals to learn how to serve a low calorie diet, and she had followed their advice although both she and the boy always felt very hungry. [Actually, their usual diet described was much lower in calories than average, although she also told me that no one believed that this was how she actually prepared food.

What crossed my mind initially when I met them was that mother and son looked amazingly alike in terms of being very obese and markedly short. They were very nearly round. If this scenario was caused by the food she served and she and the family ate, why was the father so thin if he ate the same foods? And he told me that he did ... he described himself as having a hearty appetite. This raises questions about the possibility that some factor(s) other than Mom's cooking or general overeating might be in the picture.

The boy was currently being "worked up" to see if he was a candidate for bariatric surgery, which was just beginning to be done then to treat obesity in adolescents. [Please see the notes about carnitine issues in anyone having bariatric surgery at the end of this paper.]

I asked him about his ability to do endurance exercise with questions like "Can you run around the track with no problem?" He told me that he could do that easily and that he "exercised all the time" and that he was very physically active. So I explained that he was probably unlikely to have the kind of metabolic trouble for which people would see me. I explained that in general the people I may be able to help in a special way with weight are the people who could never easily run around the track and who struggle greatly with certain types of physical activity.

He started to cry ... and sixteen-year-old boys don't usually do this. He said "I've been lying to you. I can't run around the track or do any of the things you asked about. But I keep getting told by everybody 'You need to get more exercise!' and I know that's true. But I just can't do it! So I just tell everybody "I'm exercising! I'm exercising!"

This story also has a very happy ending. A trial on carnitine was initiated, and bariatric surgery was cancelled. Now both he (and his mother!) are of normal weight for their height. Note that nobody, including me, has a clue what their underlying genetic problem might be, but the **symptoms** were suggestive that providing some extra carnitine might be helpful. And it was.

Another clue about carnitine-related exercise tolerance problems is that while all the other kids in class tend to get better and better at this kind of activity, the child with relative carnitine inadequacy often simply **fails to improve** in spite of continued effort. They are also often

labeled as having “**exercise-induced asthma**” with gasping and noisy breathing after running or other aerobic activity. But it turns out that in some folks it is not actually asthma but breathing problems related to the diaphragm muscle having no fuel to keep up. This symptom also often goes away with carnitine supplementation when inadequacy is the problem.

A story about an interesting presentation of carnitine inadequacy:

A very obese teen-aged girl who refused to give up her very high sugar intake.

This very bright young lady was extremely obese and sedentary. The weight loss plan that had been devised for her earlier elsewhere was a standard low-calorie, low-fat plan that also included getting rid of the 3-5 cans of regular pop that she drank throughout the school day. It included an exercise component. The girl had been taught all about the 150 calories in every can of pop and she had seen the test-tubes illustrating the sugar content that her dietitian had shown her. She could recite the caloric content of pretty much everything.

She was described as being extremely stubborn and even as having some degree of an “oppositional personality disorder” because she adamantly refused to give up the pop or even to switch to diet versions in spite of everyone coaxing her to do it. She also remained very sedentary and was regularly accused of being a “couch potato.” She said she was “just too tired to exercise” ... so she was accused of just being lazy.

A trial on carnitine showed very positive results in terms of great weight loss, decreased sugar intake and increased exercise ... very good evidence that the carnitine was a big help to her. This girl’s story is included here primarily because one of her symptoms was very memorable: her insistence on drinking all that soda no matter what. She is also included because she is such a fine example of a situation in which much of our generally applicable scientific weight loss and fitness advice does not seem to help much in these extreme circumstances. Concerned health professionals and patients can certainly become very discouraged.

Her pop-drinking behavior was actually a marker that without supplemental carnitine her ability to use fat for energy was so impaired she was extremely reliant on very frequent intake of carbohydrate just to get through the day. She could not fast without dropping her blood sugar significantly so she essentially kept “self-medicating” with carbohydrate throughout the day. She was quite unable to do any endurance-type of exercise. As it turns out she was neither piggy nor lazy nor defiant ... she just had a metabolic problem that was hugely improved by providing supplemental carnitine. Her life is much better now.

The young lady described above is also an important example of something else. All of us have seen some very obese individual on TV being hauled into the hospital because of failing health. I remember seeing one who weighed over 600 lbs., and they had to break a door down in his home to get him out. And yet he was still hungry and eating on the way to the hospital. The comments that I heard were phrases like “You’d think he would have more self-respect!” and other derisive comments.

Someone said “What a pig!” ... but I remember thinking: “What a metabolic disease!” That’s because nobody could ever weigh 600 pounds no matter how hard they try unless there was something unusual about their metabolism. (Could you eat that much for that long? And still be hungry and driven to eat?) My point is just that a little compassion is in order instead of derision.

As you are likely aware, there is ample research showing that many people, including many health professionals, perceive their obese patients as being, (in one example,) “undeserving of care.”

[Just a few examples: "You better not leave me shaming!": Conditional indirect effect analyses of anti-fat attitudes, body shame, and fat talk as a function of self-compassion in college women. *Body Image*. 2016 May 26;18:5-13. Social exclusion and shame in obesity. *Eat Behav*. 2015 Apr;17:74-6. The burden of obesity: personal stories, professional insights. *Narrat Inq Bioeth*. 2014 Summer;4(2): 129-33. If shaming reduced obesity, there would be no fat people. *Hastings Cent Rep*. 2013 May-Jun;43(3):4-5; discussion 9-10; "Fat is your fault"; Gatekeepers to health, attributions of responsibility and the portrayal of gender in the Irish media representation of obesity. *Appetite*. 2013 Mar;62:17-26. Obesity stigmatization as the status quo: structural considerations and prevalence among young adults in the U.S. *Eat Behav*. 2014 Aug;15(3):366-70. Beliefs, attitudes and phobias among Mexican medical and psychology students towards people with obesity. *Nutr Hosp*. 2014 Jul 1;30(1):37-41. Weight bias among UK trainee dietitians, doctors, nurses and nutritionists. *J Hum Nutr Diet*. 2013 Aug;26(4):395-402. Are anti-stigma films a useful strategy for reducing weight bias among trainee healthcare professionals? Results of a pilot randomized control trial. *Obes Facts*. 2013;6(1):91-102. Physician assistants' attitudes about obesity and obese individuals. *J Allied Health*. 2012 Summer;41(2):e45-8. Obesity: attitudes of undergraduate student nurses and registered nurses. *J Clin Nurs*. 2009 Aug;18(16):2355-65.]

This negative attitude toward obese people is not something new that evolved in response to “the Obesity Epidemic.” I still have a picture in my files that was the official cover of the manual that accompanied a skinfold caliper used at the hospital where I worked. The booklet was printed in 1973, but it was still the official booklet cover until much later (mid ’80s) when I bought it.



Happily, this artwork is no longer the featured cover, but it was for a very long time. It shows an obese woman with a ridiculous dress and head bow and a supercilious facial expression. The doctor and nurse are making a clinical assessment of the creature ... pointing from a distance with an instrument just in case obesity is contagious. (They are very attractive people, of course.) I never forgot that picture that came officially with a medical instrument because it just seemed so very unnecessarily rude. Does it strike you as a bit judgmental or at the very least insensitive?

There will likely be found a great many similar metabolic glitches that result in weight problems for some people, and hopefully we will be able to use that information to do some serious good. And while carnitine supplementation is unlikely to be the only adjustment that can help folks with this kind of health picture, it is certainly a tool already in our tool box that may be just what some individual needs. And we need to keep looking for others.

Carnitine Supplementation for People with Prader-Willi Syndrome.

This picture (hypotonia, excessive hunger, lethargy, excessive weight gain and poor endurance) is intriguingly like some of the typical symptoms observed in **Prader-Willi Syndrome**. The #15 chromosome is missing all or part of a leg, but exactly what disturbance in metabolism results from the deletion is not well understood, nor is it the same in all people with PWS.

However, as these individuals suffer greatly from their condition, it is reasonable to do a trial as described above. It will either help or it won't in any individual, but I do have several patients with PWS for whom supplementation appears to significantly help control the symptoms, making their lives and those of their families much better.

Infants with Prader-Willi Syndrome are usually born with extremely low muscle tone and they traditionally have required a gastrostomy tube for feeding because of extremely poor suck. There is evidence of abnormal carnitine metabolism in this population, and giving carnitine can improve their muscle tone and ability to suck significantly. (e.g. Nutritional and metabolic findings in patients with Prader-Willi syndrome diagnosed in early infancy. *J Pediatr Endocrinol Metab.*2012;25(11-12):1103-9.)

In our own NICU, carnitine supplementation has allowed newborns with Prader-Willi Syndrome to be able to be fed orally and to not require placement of a gastrostomy tube. They also go home with a more vigorous cry and they wiggle about a lot more ... like babies normally do. As they grow, the children I have seen with PWS who receive carnitine also have **more energy to learn** and to engage in play. They also learn better because they are **not as obsessed with accessing food**. Both of these changes from the usual expected behavior patterns are very welcome.

As alluded to earlier, carnitine supplementation has also been associated with improved suck and muscle tone in infants in our NICU who have Down Syndrome or unusually low muscle tone as part of their clinical picture.

The obesity and muscle-tone issues in people with Prader-Willi Syndrome are currently treated with growth hormone in some children, so one cannot ascribe all of any observed benefit to carnitine in children treated with both. However, **it is reasonable to do both**, as the efficacy of the (extremely expensive) growth hormone treatment could certainly be compromised if energy metabolism was limited by a relative problem with carnitine adequacy.

Certainly a trial would be in order if the symptoms described above continue to be observed after growth hormone therapy has been initiated. People with PWS also seem to benefit from supplemental CoQ10 along with the carnitine and growth hormone. (I do have a separate paper available just on PWS nutrition issues if you want to see more on that condition.)

Carnitine Inadequacy in Thin or “Normal-Weight” People with Low Muscle Tone, Weakness, or Impaired Ability to Exercise.

For reasons that I cannot explain, some people apparently express relative carnitine inadequacy with muscle tone and weakness problems, or exercise tolerance problems, but they do not have the tendency to retain excessive fat or to experience excessive hunger. As a working model, I view this as possibly related to a carnitine problem only in certain tissues, but I am totally making up this explanation. The eight-year-old girl described earlier (who needed training wheels, could not do stairs normally and held onto the table in order to eat) was not overweight.

Here are two more examples of real cases:

A Toddler Who Demanded to be Carried Everywhere

A 16-month old boy was refusing to walk and cried to be carried everywhere. His muscle tone was “floppy” but he was not overweight nor did he ask for food with greater than normal intensity. His mother was accused of spoiling him by giving in to his demands. After ruling out other explanations (e.g. leg pain from rickets,) his physician and I decided to do a trial on carnitine.

When one does this kind of trial it can be helpful to carefully note the situation prior to supplementation so that there is something concrete to compare the outcome with after

supplementing. Otherwise, it can be quite hard to remember just how things were at the start. Not having these kinds of records can result in inappropriately continuing a therapy because you just can't tell if it helped or not. Or, a trial may be judged to be a failure even though it was actually helpful, for the same reasons.

In this child's case, I asked the mother "If you took him to the mall and went in the end by the food court, how far he would walk before putting up a big fuss and refusing to walk further?" She said, "Oh, we would never even get half-way out of the food court!" So, that was one of our high-tech evaluation tools. After supplementation for only a few weeks, she took him to the mall for a comparison test. He walked all the way to the Penney's wing! (Trust me ... that is an amazingly long way for a little guy to walk.) But he did it willingly ... because now he could.

When I talk about carnitine at conferences for health professionals, people often come up afterword or email me to ask about the possible usefulness of carnitine supplementation for a family member or a patient. We talk about it and then I give them this paper to take to that person's doctor ... and sometimes the person interested and asking IS a doctor. One particular time an RD (a Registered Dietitian) came up and described her son. Here is his story:

The Oceanographer

The young man was finishing high school and looking at college. He had always dreamed of being an oceanographer, but he realized that his really limited exercise tolerance and major fatigue would make him a poor shipmate who could not pull his weight on board a ship. He just could not follow that dream.

He was VERY bright, and he told his mother that unfortunately he would "probably have to be a calculus major and sit down at a desk all day." He was not at all fat, and he was actually considerably less hungry than the more average guys his age including his brothers. Boys this age often have what I call "TBD" ... "Teenage Boy Disease." [Are you familiar with this condition? Symptoms of TBD include drinking a half gallon of milk in one big gulp while standing beside the refrigerator and leaving the door open and asking "What's for dinner?"]

Cutting to the chase: his doctor approved a trial on carnitine and the result was that his mother called me a month later excited to report that "He's going to be an oceanographer!"

How cool is that?!

Carnitine Issues in Managing Diabetes

Sometimes I talk about carnitine issues at conferences because it has special applications to particular audiences. For example, when I talk at conferences for diabetes professionals, the research we focus on that describes the importance of assuring carnitine adequacy is both very important and generally not well known. As you can imagine, there are several places where relative carnitine inadequacy could affect diabetes and its management. A few examples:

- obesity is often associated with diabetes
- the need for exercise in diabetes management is very important
- experiencing excessive hunger can prevent people from succeeding at following a prescribed low calorie diet
- there is even fluctuation in blood sugar control among people using insulin because of inability to fast
- some people with type 1 diabetes have been found to have low blood carnitine levels when they were checked. [More on this follows.]
- carnitine is an important antioxidant and inadequacy could contribute to damage from the higher free radical production seen in diabetes.

Additionally, there is increasing evidence that supplemental carnitine can be of significant help in prevention or improvement of a number of complications of diabetes. For example, as far back as 2007 a study found that the average serum free-L-carnitine levels in patients with diabetes who had complications was almost 25% lower than in the patients with no diabetes-related complications. On the basis of the study results, the researchers suggested that “carnitine supplementation in diabetic patients, especially in patients with diabetes complications, might be useful.”

Relative carnitine inadequacy has also been found to be a factor in a number of other related health conditions, with special importance in kidney disease, high triglycerides, obesity, poor wound-healing and poor eye health ... all of which are associated with diabetes. Carnitine is also a very potent protective antioxidant. More recent literature is reporting several beneficial effects of carnitine adequacy in diabetes of both types and in kidney disease. Here are just a few references so you won't think I made this up:

Effects of acetyl-L-carnitine and methylcobalamin for diabetic peripheral neuropathy: A multicenter, randomized, double-blind, controlled trial. *J Diabetes Investig.* 2016 Feb 9. Melatonin and L-carnitine improves endothelial dysfunction and oxidative stress in Type 2 diabetic rats. *Redox Biol.* 2016 Aug;8:199-204. Combination therapy with losartan and L-carnitine protects against endothelial dysfunction of streptozotocin-induced diabetic rats. *Eur J Pharmacol.* 2014 Dec 5;744:10-7. Acylcarnitines: potential implications for skeletal muscle insulin resistance. *FASEB J.* 2014 Oct 23. Dietary and nutraceutical approach to type 2 diabetes. *Arch Med Sci.* 2014 May 12;10(2):336-44. Correlation of Serum Free Carnitine with Serum Ferritin and Vitamin C Levels in Type II Diabetic Men. *Iran J Public Health.* 2013 Jul 1;42(7):767-74. Acetyl-L-carnitine: from a biological curiosity to a drug for the peripheral nervous system and beyond. *Expert Rev Neurother.* 2013 Aug;13(8):925-36. Effect of cholecalciferol and levo carnitine on plasma glucose, plasma insulin and insulin resistance in type 2 diabetes. *J Pak Med Assoc.* 2013 Mar;63(3):374-9. Serum levo-carnitine levels and skeletal muscle functions in type 2 diabetes mellitus in rodents. *J Coll Physicians Surg Pak.* 2013 Feb;23(2):132-6. Effect of levocarnitine on endurance capacity in type-2 diabetic rats. *J Ayub Med Coll Abbottabad.* 2013 Jul-Dec;25(3-4):64-7 Carnitine and fat oxidation. *Nestle Nutr Inst Workshop Ser.* 2013; 76:13-23. Skeletal muscle carnitine loading increases energy expenditure, modulates fuel metabolism gene networks and prevents body fat accumulation in humans. *J Physiol.* 2013 Sep 15;591(Pt 18):4655-66. Levo-carnitine reduces oxidative stress and improves contractile functions of fast muscles in type 2 diabetic rats. *Iran Biomed J.* 2013;17(1):29-35. Potential inhibitory effects of L-carnitine supplementation on tissue advanced glycation end products in patients with hemodialysis. *Rejuvenation Res.* 2013 Dec;16(6):460-6. Effect of hemodialysis session on the dynamics of carnitine ester profile changes in L-carnitine pretreated end-stage renal disease patients. *Int Urol Nephrol.* 2013 Jun;45(3):847-55. Role of carnitine in the regulation of glucose homeostasis and insulin sensitivity: evidence from in vivo and in vitro studies with carnitine supplementation and carnitine deficiency. *Eur J Nutr.* 2012 Feb;51(1):1-18. Role of carnitine in the regulation of glucose homeostasis and insulin sensitivity: evidence from in vivo and in vitro studies with carnitine supplementation and carnitine deficiency. *Eur J Nutr.* 2012 Feb;51(1):1-18. Decreased serum carnitine is independently correlated with increased tissue accumulation levels of advanced glycation end products in haemodialysis patients. *Nephrology (Carlton).* 2012 Nov;17(8):689-94. Caloric restriction and L-carnitine administration improves insulin sensitivity in patients with impaired glucose metabolism. *JPEN J Parenter Enteral Nutr.* 2010 May-Jun;34(3):295-9

What started me to think about carnitine and diabetes in the first place was the following eye-opening report of 54 children with Type I diabetes screened for serum carnitine level. About 1/4 were found to be carnitine deficient and about half had other evidence of carnitine inadequacy. This was in 1989.

An important question: How many children in any group would one expect to have inadequacy or deficiency of a substance one easily makes oneself?

The answer to that should be “zero.”

But then why was low carnitine a common problem found in these children with diabetes?

Maybe the ability to readily make adequate carnitine is also something that can be lost as a consequence of developing an autoimmune disease ... or in some cases maybe even as a consequence of aging. In many autoimmune diseases the loss of the ability to make or maintain a key substance is the hallmark of the condition. Examples include:

pernicious anemia (quit making adequate intrinsic factor),
parkinsonism (quit making adequate dopamine),
lupus (quit maintaining connective tissue normally),
multiple sclerosis (quit maintaining myelin),
autoimmune thyroid disease (quit making thyroxine normally) and, of course,
type 1 diabetes (quit making insulin.)

Additionally, many folks who develop an autoimmune disease are at much higher risk than other people of developing another one. It is well recognized, for example, that people with Type 1 diabetes are at higher risk for also having celiac disease, pernicious anemia and thyroid problems ... so much so that we automatically screen for these conditions among our patients with Type 1 diabetes.

Could a disproportionate amount of them also have experienced some loss of the ability to make adequate carnitine? If so, that would mean that carnitine would be an “essential nutrient” for them ... a situation referred to as being “conditionally essential.” **That means that even if nobody else needs to take in carnitine ready-made, some folks clearly do, and for them that substance becomes “essential” just like essential vitamins, minerals, and certain fats and amino acids are for everyone.**

Just thinkin’ This has not been studied yet as far as I know.

Here’s the abstract of that key 1989 report ... I am including it here in its entirety because it is not at all new but it is such an important finding ... and it has received amazingly little attention in spite of my going on and on about this all the time:

**Relative carnitine insufficiency in children
with type I diabetes mellitus.**

Winter SC, Simon M, Zorn EM. Am J Dis Child. **1989** Nov;143(11):1337-9.
Department of Pediatrics, University of California, San Francisco.

“Recognizing the similarity of type I diabetes mellitus to inborn errors of metabolism that have responded to carnitine therapy, we initiated a study of **54 children with type I diabetes mellitus**. Examining a fasting blood sample for levels of carnitine, glucose, and glycosylated hemoglobin A1c, and a urine sample for levels of ketones and glucose, we found **13 children were deficient of free carnitine (less than 20 $\mu\text{mol/L}$) and 30 had elevated acyl carnitine levels (greater than 11 $\mu\text{mol/L}$)**.

Statistical tests confirmed a significant difference between the diabetic population and normal population for reduced free carnitine, elevated acylcarnitine, and an elevated ratio of acyl carnitine to free carnitine.

Also, a significant correlation was found between the levels of urine glucose and ketones and the level of acylcarnitine. **Our data indicate that carnitine deficiency and relative insufficiency may be an overlooked component in the management of diabetes.”**

Interestingly, since we now know that carnitine lab values underestimate the number of people with carnitine problems (because they do not reflect all the tissues likely to be affected,) the number of children in the study above found to have inadequate or deficient carnitine likely is an underestimate of the prevalence of this problem as well.

Since that report was published, I have worked with several children with Type I diabetes whose blood sugar was very hard to manage in spite of the family doing everything right in terms of insulin shots, carbohydrate consumption and exercise. They had frequent episodes of very low glucose. **A trial on carnitine worked amazingly well for doing away with the troubling low blood sugar episodes in these children.**

Bottom line: if a person experiences this kind of yo-yo blood sugar pattern with no identifiable cause, a trial on carnitine would be a very good idea. Getting a blood level is not as helpful (even though they did it in the study,) because if it is low, then one would prescribe some carnitine. However, even if the lab is “normal,” the blood levels do not necessarily reflect adequacy in the other tissues like the heart muscle. Carnitine deficiency is well known to contribute to severe cardiomyopathy. **So, if there are suggestive symptoms at all, one would want to do a trial anyway.** Won’t hurt ... Might help.

[For more on this, please see my paper called “Thinking about OTHER Nutrition Issues in Diabetes.”]

Another function of carnitine:

As mentioned above, carnitine is now recognized as also being a very potent antioxidant in addition to its role in fat metabolism. That means that assuring adequacy of

carnitine is also a good idea because a generous antioxidant intake has benefits in a great many situations, including any condition that results in unusual metabolism and in excessive free radical production.

Some of the damage from these situations is linked to the excessive free radical production in the absence of more generous antioxidants. “Unusual metabolism” can be any situation in which one does not burn fuel normally, (like diabetes,) or having a diet that has a goofy fuel supply to start with (like having half of one’s calories coming from Jack Daniels... I’m pretty sure that that was not part of the Grand Design for Humans.)

Both situations result in similarly excessive production of free radicals that can do significant harm. This is true in the health of the individual, but it has a critical application in pregnancy because free radicals increase the development of birth defects associated with poorly controlled diabetes or with alcohol abuse alone.

Generous antioxidant intake has the potential to make having inflammatory conditions hurt a person less, because although some of the cellular injury is due to the underlying condition, some is a secondary injury from the excessive production of free radicals. Generous antioxidant intake assists in “quenching” the extra free radicals before they injure cell membranes, or in some cases, they patch up the injury after the fact.

Some of the many other applications of supplemental carnitine being studied and showing benefit:

Inborn metabolic errors like PKU (Phenylketonuria), MSUD (Maple Syrup Urine Disease, MCADD (Medium Chain AcylCoA Dehydrogenase Deficiency, (PA) Propionic and (MA) Methylmalonic Acidemia and others.	Renal (Kidney) disease Cardiovascular disease, Hypertriglyceridemia Metabolic syndrome Diabetes, Fatty liver Osteoporosis, Amyotrophic Lateral Sclerosis Parkinsonism Emphysema
Seizure control (with ketogenic diet or certain medications Chemotherapy adjunct to minimize neurologic damage / fatigue. Chronic conditions characterized by fatigue, Aging-related cognitive impairment, Retinal health/ both retinal development and macular degeneration, Decreased liver toxicity of certain medications.	

Just in case you think I am making this stuff up, here is a sampling of some recent (2013-16) reports:

A few examples: *Clin Sci (Lond)*. 2016 Feb;130(4):273-87. Metabolomics screening identifies reduced L-carnitine to be associated with **progressive emphysema**. Melatonin and L-carnitine improves endothelial dysfunction and oxidative stress in **Type 2 diabetic** rats. *Redox Biol*. 2016 Aug;8:199-204. Antioxidants and **vascular health**. *Life Sci*. 2015 Dec 15;143:209-16. L-Carnitine supplementation decreases **DNA damage** in treated **MSUD** patients. *Mutat Res*. 2015 May;775:43-7. Prevention of DNA damage by L-carnitine induced by metabolites accumulated in **maple syrup urine disease** in human peripheral leukocytes in vitro. *Gene*. 2014 Sep 15;548(2):294-8. Combination therapy with losartan and L-carnitine

protects against endothelial dysfunction of streptozotocin-induced **diabetic** rats. Eur J Pharmacol. 2014 Dec 5;744:10-7. Randomized double-blind placebo-controlled trial of acetyl-L-carnitine for **ALS**. Amyotroph Lateral Scler Frontotemporal Degener. 2013 Sep;14(5-6):397-405. Effects of acute l-carnitine supplementation on nitric oxide production and oxidative stress after exhaustive exercise in young **soccer players** Eur J Pharmacol. 2014 Oct 2;744C:10-17. Combination therapy with losartan and l-carnitine protects against endothelial dysfunction of streptozotocin-induced **diabetic** rats. Pharmacology. 2014;94. L-carnitine supplementation as a potential antioxidant therapy for inherited **neurometabolic disorders**. Gene. 2014 Jan 10;533(2):469-76. Effects of L-carnitine supplementation on oxidative stress and antioxidant enzymes activities in patients with **coronary artery disease**: a randomized, placebo-controlled trial. Nutr J. 2014 Aug 4;13:79. l-Carnitine attenuates H2O2-induced **neuron** apoptosis via inhibition of endoplasmic reticulum stress. Neurochem Int. 2014 Dec;78:86-95. Degenerative events in **retina and optic nerve** induced by inhibition of carnitine transport. J Biol Regul Homeost Agents. 2014 Apr-Jun;28(2):263-70. L-carnitine prevents progression of **non-alcoholic steatohepatitis** in a mouse model with upregulation of mitochondrial pathway. PLoS One. 2014 Jul 1;9(7):e100627. Here's s nice old one: Determination of free L-carnitine levels in type II diabetic women with and without complications. Eur J Clin Nutr. 2007 Jul;61(7):892-5.]

Some Thoughts about BARIATRIC SURGERY in Individuals Who Have a Carnitine-Related Weight Problem:

I think it would be very reasonable to do a trial on generous carnitine in severely obese individuals prior to moving to bariatric surgery.

One reason is that people who do respond to carnitine can likely avoid the costs, pain and complication risks of bariatric surgery. Carnitine use does not interfere with an individual's ability to absorb micronutrients the way the surgery does.

This avoids the documented problems of clinically significant vitamin and mineral deficiencies like copper, vitamin B12, thiamin (vitamin B1) and many others months or years after surgery. These three nutrients are mentioned specifically because neurologic injury (sometimes irreversible injury) from deficiency is documented in spite of (theoretically) generous oral intake in some bariatric surgery patients.

Long term follow-up of these critical micronutrient issues is absent in many bariatric surgery programs. Often the only outcome of professional interest has been whether or not weight loss occurred, and whether there were improvements in dyslipidemias (like high cholesterol or triglycerides) or diabetes management. Careful study of most micronutrient issues is often not included, especially several years after the surgery, by which time they might have reached serious and symptomatic (but still unrecognized) deficiency levels.

Failure to establish long-term nutrient adequacy is particularly problematic because many women of childbearing age do become pregnant after bariatric surgery. That increases the risk of birth defects and other types of poor pregnancy outcome. And now some places have begun to do bariatric surgery on pediatric patients. The children do lose weight post-surgically ... but they are likely to lose much more than weight unless overall nutrition is carefully monitored. This is especially important because in children and teens one is inducing a LIFE-LONG impairment of micronutrient status that is potentially much more problematic than bariatric surgery on middle-aged adults who have already grown and had families.

One other reason for doing a trial on carnitine before moving on to surgery is that if patients do have an unrecognized carnitine-related weight problem they will continue to have it after surgery. The surgery does not correct the problem. That means they will continue to be unable to burn fat efficiently, and they will continue to experience significant hunger that may drive them to overeat in spite of surgery. This may be a factor especially in the number of individuals who regain their weight after surgery or who undergo a second bariatric surgery.

Therefore, a trial on carnitine would help to identify the people who might fail to do well in terms of maintaining weight loss after surgery unless carnitine supplementation was a continued part of their regimen. **For those bariatric surgery patients who are identified as needing supplemental carnitine, continuing to provide it can play a role in successfully keeping the weight off.**

One last case study:

An odd discovery of an unrecognized carnitine problem in a health care professional who had been treated for cancer.

There was a lady who had a “weight problem” her whole life, and great difficulty with any kind of endurance exercise. Because of continually experiencing severe wheezing after trying to run around the track at school, she was diagnosed as having “exercise-induced asthma” in grade school, but it never was found to be affected by any asthma treatment.

Her endurance exercise tolerance never improved in spite of considerable effort throughout the first 50 years of her life. She chose to be in the Latin Club instead of participating in track. She sat around and read a lot, and was perceived by herself and others to be just a fat and lazy girl who grew up to be a fat and lazy older lady. Nothing unusual there.

But just before she turned fifty she was diagnosed as having an aggressive cancer that required her to be given a really large amount of chemotherapy all at once to kill the cancer, followed by a stem cell transplant afterward to rescue her bone marrow

Unsurprisingly, that big bunch of chemo made her a pretty sick little turkey, and she could barely eat at all for many weeks. She tried very hard but the most she could choke down was only about 300 calories a day. Yes ... she kept tract. Also unsurprisingly, she lost quite a bit of weight over those weeks, which she thought might actually be a pretty nice side effect overall.

However, when she got ready to go home from the “medical apartment” she had lived in for 6 weeks, it was found that she hadn’t lost body fat, but had instead burned up a lot of her leg muscles to make energy to run her body. Throughout the treatment she was physically very weak, and weakness had increased until she could barely walk across the room. She had to lean against walls waiting for the elevator to take her up to the transplant clinic for a daily I.V. to prevent dehydration.

Apparently people were expected to gradually gain strength during recovery from transplant, but she just got weaker and weaker ... and nobody noticed this unusual response. Interestingly, back home she worked with patients who had clear metabolic problems that sometimes necessitated carnitine supplementation, but she never saw the pattern in herself. She was too fuzzy-headed at the time from the whole chemo-experience to think “Hmmm ... a person has generous fat stores but when she could not eat adequately, she just burned up her muscles for fuel instead of burning the fat. Now that’s metabolically odd!”

It took her a long time to regain much strength and endurance. Some years later walking up stairs was still a huge effort involving rest stops and wheezing. The biggest problem with exercise came from the fact that she flew around quite a bit every year and if her plane was late and she had to run to make a connection, it was essentially a “near-death experience” ... functionally problematic but also mortifyingly embarrassing to be wheezing and gasping and turning red and tipping over just from a bit of trotting. She just thought “I am SUCH a weenie!”

The “Aha!” moment came when her normal-weight colleague in her 40s had been trying to stay fit by working-out after work, but she found that she just couldn’t keep up with the other ladies at all. Instead of experiencing “endorphins” from her work-out, she experienced severe exhaustion and muscle pain that lasted into the next day. Then, she thought about the carnitine that the lady in this story was always going on about at workshops and its application in helping patients with metabolic diseases that made them struggle to tolerate endurance exercise. Hmmm ... It was over-the-counter and not dangerous so she tried it. Bottom line, she was able to exercise without the unpleasant side effects. She then described her experience to the lady in this story.

Now, there had been no symptoms or indications of “metabolic disease” or even overweight in the “work-out lady” but in spite of that, a carefully designed trial on carnitine supplementation showed that it had made a significant contribution to her ability to exercise and enjoy it. So when she told the “metabolic nutrition specialist” about her experience (you know ... the lady with the transplant and the wheezing and the chubbiness and the exercise-induced asthma,) a light-bulb finally went on.

She started to realize that she herself may actually be the poster child for a mild problem with carnitine inadequacy. It was most likely “mild” because in general she had not been hugely obese as some of her patients were, and she could “get by” with exercise as long as one could put up with embarrassment and wheezing and dropping out too early.

Really the only big metabolic clue was the abnormally high and disproportionate muscle loss after chemotherapy combined with inability to eat for a long time. An inability to efficiently burn fat for fuel was revealed only because of the extreme metabolic stress of the whole cancer-fighting episode.

Bottom line: The lady takes supplemental carnitine (with the approval of her physician, etc.) and she lost about 50 lbs in a few months and now looks a lot more average weight. She is still definitely chubby, but at least some of that is most likely related to sitting at her desk all day for her job (which includes bossing other people around about metabolic nutrition issues and ... oh, yeah ... about carnitine.)

She was much less hungry during the period of weight loss ... theoretically because she now had access to all of those calories stored on her thighs. She still is much less hungry and eats a lot less without even trying to at all.

But the best outcome she experienced is having the energy to walk briskly all around the hospital where she works, going up and down the stairs with ease (sometimes running ... not bad for 65), and being able to trot all the way through that big Minneapolis airport with no distress at all.

As you have likely guessed by now, the “metabolic nutrition specialist” lady with the newly unmasked carnitine problem is me. Until 12/12/14 I had never written this story out as one of my “case studies,” although many people I work with are well aware of my story.

This hesitation about putting my own story down in writing and making it official was in part because in the past I was afraid that some health care professionals might tend to disregard my recommendations for doing a trial on carnitine for a patient because they thought I was just on some sort of bandwagon. (There was reason for this hesitancy.)

But at this point in my life I am more convinced than ever that we need more tools in our tool-box and this may be one of them for some folks. I now have LOTS of case studies besides my own to share, and as described earlier, the professional research is now identifying many other conditions for which supplemental carnitine is potentially beneficial. Adding my own peculiar story to my (already lengthy) “Carnitine” paper now is just icing on what is turning out to be a pretty big cake.

Quick Carnitine Fact List

1. Typical carnitine intake from food:

Generally, **20 to 200 mg are ingested** per day by those on an **omnivorous** diet, while a strict **vegetarian** diet may provide **only 1 mg/day**. That is likely sufficient for a person who is very competent at making their own carnitine. But as you can see, amounts from **2000-6000 mg** can be needed in folks whose carnitine needs are higher or whose carnitine production is impaired.

The word carnitine comes from the Latin word for meat (as in “chili con carnitine” ☺) but the amount varies with type of meat. Also note that there is high variability in carnitine in commercial “complete nutrition” products.

2. Production:

In animals (including people,) **carnitine is biosynthesized** (made) in the liver, kidneys and brain from the amino acids lysine and methionine. Vitamin C (ascorbic acid) is essential to the synthesis of carnitine.

3. Requirements:

During **growth, pregnancy or wound healing** requirements for carnitine can exceed its natural production. That is, it is **conditionally essential** during periods of anabolism (growth), and also in a variety of other metabolic conditions.

People with liver or kidney problems may have difficulty producing it. Renal (kidney) patients may also be eating a low meat diet, so the diet is also low in pre-formed carnitine. It is also lost in dialysate, so needs of dialyzed patients are greater than they would otherwise be.

The **seizure medication valproic acid** (“Depekene”) impairs production of carnitine, but it also needs it to work. Inadequate carnitine reduces the **effectiveness** of the drug, and it greatly increases the potential for **liver toxicity**. The relative inadequacy of carnitine that results in this situation accounts for some of the **reported side effects** such as lethargy and weight gain associated with using this medication.

4. Beneficial Applications:

As mentioned, supplemental carnitine has a role in many health conditions, including improving low muscle tone and exercise tolerance, slowing macular degeneration, decreasing obesity, heart failure, cancer-related and HIV-related fatigue, diabetes, male infertility, emphysema, ischemia / reperfusion brain injury, peripheral neuropathies (nerve damage), dementia, depression and cognitive impairment. Many were discussed earlier.

For more information about specific carnitine issues in particular health conditions, please see my other papers that more thoroughly address the application of carnitine in helping to manage them. These include:

“Thinking about OTHER Nutrition Issues in Diabetes”

“Drug/Nutrition Interactions”

“Nutrition for Children with Special Health Needs,”

“Nutrition Issues in Pregnancy”

“Nutrition and Prader-Willi Syndrome

“Nutrition and Eye Health”

And finally ...

All my papers are available for free to anyone.

They represent my best guess at the time of writing, and they are updated regularly.

They are not reflective of the official recommendations of any professional organization ...they are just the musings of one old lady in Fargo, ND.

I do not sell anything.

All of the research described is from the legitimate scientific literature and not goofy stuff on the internet.

Much of the information they contain will be based on pretty new research, so please feel free to share them with your health care providers.

And yes, more research is necessary ... more research is ALWAYS necessary. But research has already elucidated some really interesting stuff, including the safety of a trial on carnitine, and the potential lack of safety associated with failing to do a trial with a person who is symptomatic of deficiency.

Also as always, my papers are not intended to take the place of the advice of your health care provider.