Guildford ME/CFS Support Group
(& West Surrey)

Newsletter

Autumn 2009

Future dates

Christmas meal
Wednesday 16th December 7.30pm
Prezzo, 8 Queen Street, Godalming, GU7 1BD

Prezzo offers Italian cuisine and use only the best seasonal products, many of which are imported directly from Italy. The menu includes pizza, pasta, risotto, grilled meats, fresh salads and frequently changing specials.

Directions:

1. Head northwest on A320/Chertsey St toward North St. Continue to follow A320 0.2 mi
2. Turn left at A246/York Rd 0.2 mi
3. At the roundabout, take the 1st exit onto A322/Onslow St Continue to follow A322 0.3 mi
4. Slight left at A3100/Park St Continue to follow A3100 Go through 5 roundabouts 3.9 mi
5. At the 6th roundabout, take the 2nd exit onto Bridge St 0.2 mi
6. Turn left at Queen St 236ft

We have booked a number of seats in a private section of the restaurant which, based on our experience last year, will keep background noise to a more pleasant level. **Please ring Cathy to reserve a seat** well in advance of the night. No deposit required. Tel: 01483 277790

Morning meet - Tuesday 19th January 2010 10.30am
Holiday Inn Hotel - Egerton Road, Guildford, GU2 7XZ

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

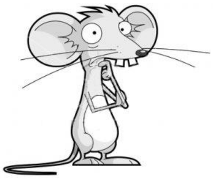
From M25: take junction 10 and follow A3 to Guildford and exit at exit sign for Research Park & Onslow Village. At 1st roundabout take 3rd exit. At 2nd roundabout take 2nd exit. From south: A3 to Guildford and exit signposted for Research Park and Onslow Village. At roundabout take 1st exit.

Afternoon meet - Monday 8th February 2010 4pm
The Seahorse, 52-54, The Street, Shalford, Guildford, Surrey, GU4 8BU

Shalford is about 1½ miles south of Guildford on the A281 (signposted as Horsham).

Food available includes: wood fired pizzas, spit roast chickens, plenty of fresh fish and the finest steaks. Having an excellent chef ensures good food.

XMRV



By © Maija Haavisto
Oct 10, 2009
Source: http://chronic-fatigue-syndrome.suite101.com/article.cfm/cfsme_and_retroviruses#ixzz0UF0RDiEp

A new study published in the prestigious journal Science found the retrovirus XMRV (xenotropic murine leukemia virus-related virus) in 67% of patients with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Only 3.7% of the studied healthy controls harbored this infection. Later, the researchers reported up to 95% of patients test positive with antibody testing.

XMRV belongs to the group of gammaretroviruses and has previously been associated with prostate cancer. Little is known about most types of human retroviruses, aside from the best known one: HIV. XMRV almost certainly came from mice to humans originally. How it got from mice to humans we have no idea yet.

This is not the first time CFS/ME has been associated with a chronic viral infection - it used to be called "post-viral fatigue syndrome," after all. In studies, CFS/ME has been connected with a variety of different viruses, including:

- herpes viruses (especially Epstein-Barr virus, cytomegalovirus and HHV-6)
- enteroviruses (polioviruses, Coxsackie viruses, echoviruses)
- parainfluenza virus 5 (PIV-5)
- parvovirus B19
- various retroviruses

History of CFS/ME and retroviruses

The study group of Elaine DeFreitas reported a link between CFS/ME and retroviruses back in 1991. This virus was most closely related to HTLV-2 (human T-lymphotropic virus 2), which belongs to a different group of retroviruses, deltaretroviruses. None of the healthy controls in the study showed evidence of this virus.

Immunovirologist Michael Holmes described retroviral activity in cells of CFS/ME patients as early as 1986. However, he did not elucidate on the type of the retrovirus. Another researcher, John Martin, reported finding a spumavirus type retrovirus in CFS/ME in the early 1990s.

Conclusions

The XMRV finding does not prove that CFS/ME is caused or triggered by this retrovirus. More research will be needed to confirm the role of XMRV in CFS/ME, and the full effects of this virus in general.

The other viruses could still play a part. The authors of the XMRV study believe the retrovirus may reactivate other viruses, such as herpesviruses (the opposite is also possible). There could be many different viruses behind CFS/ME. And it could be that XMRV is an incidental finding secondary to the immune dysfunction in CFS/ME.

The XMRV test is currently only in research use, but if the connection with CFS/ME (and/or other illnesses) is confirmed, it is likely to become more widely available. Many other diagnostic tests for CFS/ME are also being studied.

XMRV is thought to be transmitted in the same way as HIV: not through air or by touch, but through bodily fluids. Could this make CFS/ME a contagious illness? It is already widely considered infectious and numerous epidemics have been reported since the 1930s, but genes and other predisposing factors also appear to play a role in getting sick.

XMRV and cancer
If XMRV causes CFS/ME, does CFS/ME increase the risk of prostate cancer? It is too early to determine. While CFS/ME appears to increase the risk of many cancers, including leukemia, lymphoma, cervical cancer and some brain tumors, no increased risk of prostate cancer has been reported.

The same virus may cause a different illness in different groups of people. For example, Coxsackie B4 virus has been connected to both CFS/ME epidemics and juvenile (type I) diabetes, but an association between type I diabetes and CFS/ME is yet to be reported.

Treatment of XMRV
Antiretroviral drugs are used in HIV infection and could be used to treat XMRV, but they have significant, often permanent side effects. Antiherpesvirals and other antiviral medications have been successfully used in CFS/ME treatment - but they are much less toxic than antiretrovirals. There are dozens of effective treatments for CFS/ME, so if antiretrovirals are not curative (as is the situation with HIV), it is hard to support their use.

Low dose naltrexone (LDN) has been used in AIDS treatment since the 1980s and is currently in a clinical HIV/AIDS trial in Africa. LDN appears to work at least as well as antiretroviral therapy, with negligible side effects. It has also been successfully used in the treatment of CFS/ME.

XMRV leads to immune dysfunction by damaging an antiviral pathway called RNase L. Ampligen, an immunostimulant drug currently waiting for FDA approval for treatment of CFS/ME works by treating this deficiency.

Chronic infections in CFS
By Sarah Myhill
Source: http://www.drmyhill.co.uk/article.cfm?id=457

Whilst there is no doubt that an acute infection is a common trigger for CFS, the question is: to what extent does chronic infection perpetuate the fatigue? I have struggled with this question for years! There is a body of evidence pointing to chronic infections such as Lyme disease, borreliosis, mycoplasma, HHV, Epstein Barr, cytomegalovirus etc. present in CFS patients together with various trials showing benefits from anti-microbials. The trouble is the diagnosis is difficult, the treatments often expensive and all carry potential for harm from toxic drugs.

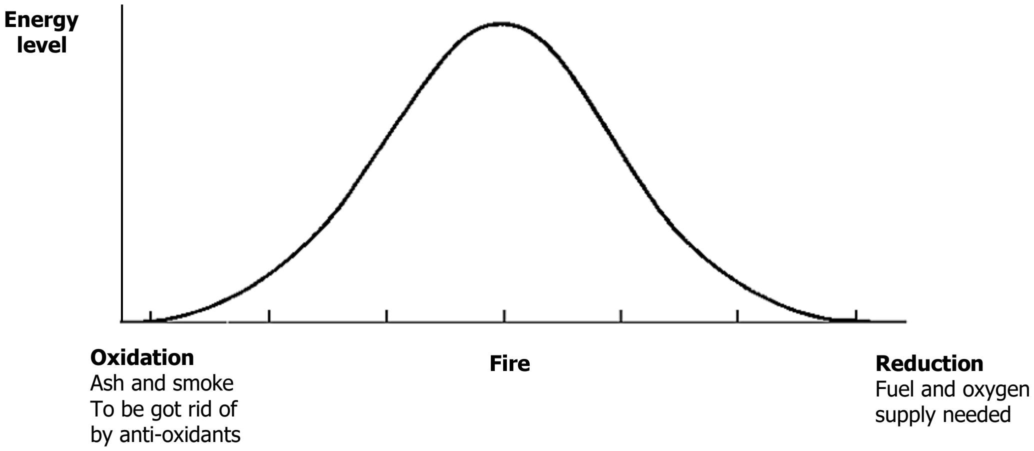
We are all exposed to infections, but only a few get chronic problems. The difference has to do with individual susceptibility ? as Pasteur famously said "The microbe is nothing, the terrain is everything".

What is central to CFS is mitochondrial function. I believe this will be the most important marker of CFS and testing mitochondrial function often points to nutritional deficiencies or toxic blockages which, when corrected, in many case result in clinical improvement. However, Dr Paul Cheney believes that one's redox state is also central in the control of mitochondria. See CHENEY ON CFS MECHANISMS, also FERMENTATION IN GUT, FREE RADICALS and CFS.

What is the redox state?
Think of redox state as a fire. For the fire (mitochondria) to burn brightly we need optimum conditions of fuel, oxygen and the molecular machinery to handle this. If the fuel supply is sluggish, the fire burns low. If the oxygen supply is sluggish, the fire burns smokey (free radicals). Getting the right balance between fuel, oxygen and the molecular machine (magnesium, coenzyme Q 10, acetyl L carnitine, magnesium D-ribose, NADH etc) together with adequate antioxidant cover to mop up smoke (superoxide dismutase, co-enzyme Q 10, glutathione peroxidase, vitamins A,E and C etc) is necessary for the efficient use of energy.

The graph below illustrates this. To have adequate supply of energy, the redox state must be central. At this level, the fire is burning brightly; we have a good balance of supply of fuel and oxygen on the one hand, with good antioxidant cover on the other to carry the smoke (free radicals) away.

Diagram: redox state



If one falls to the right side, the fire burns low because we do not have the raw materials to feed it so energy levels are low. One would see this in starvation, or chronic poor oxygen supply from lung disease or anaemia.

If one falls to the left side, there is too much free radical production, which overwhelms the antioxidant mopping up system. The free radials then inhibit mitochondrial function directly and the fire burns low and again we see low levels of energy.

There is a further complication. Mitochondria have to adjust the level of their fire from second to second so that energy supply is coupled to energy demands. Mitochondria need to supply energy at a millisecond's notice! In the micro-respirometry studies that John McLaren-Howard does, we often see uncoupling of oxidative phosphorylation so this link is lost and energy is wasted.

Why is this important?
Using his methods of assessing heart function (also a measure of mitochondrial function), Dr Cheney has shown that CFS sufferers respond to oxygen very differently from healthy controls. People with normal energy levels who function in the middle of this redox state perform better with additional oxygen. Their fire glows brighter! In contrast, CFS sufferers get worse. Cheney postulates that this is because they are sitting to the left side ? with low levels of energy and poor anti-oxidant status. They cannot cope with free radicals which are already making their mitochondria go slow. Give them oxygen and this creates further pro-oxidant stress which worsens the situation by pushing them further to the left. Indeed, this is how he distinguishes experimentally between people with CFS and normals.

Why is this relevant to viral infection?
A paper published in 1991 by Fauci looked at the ability of viruses to replicate according to redox status of the host. What was so fascinating about this paper is that in those individuals with normal redox status viruses were unable to replicate and so their hosts were markedly resistant to viral infection. This explains why when we see an epidemic of infectious disease such as influenza, not all people are equally affected. Some have no symptoms, whereas others are completely flattened. In those people with poor redox state, the virus was able to replicate easily and it is high numbers of viruses in a human host which dictate the severity of the illness. Furthermore, if the immune system moves into "overdrive", one can get a "cytokine storm" resulting in massive tissue damage and possible death. Indeed, this is what kills people in flu epidemics.

So, if one gets an acute viral infection, and one cannot drag oneself back from the left pro-oxidation side into a normal redox state, one will be stuck with low levels of energy because the mitochondria cannot work. A recent article in the New Scientist (29.8.09) shows that some viruses generate oxygen. If this were the case, it could partly explain how viruses keep one in this pro-oxidant state. The virus has manipulated the host?s biochemistry to suit itself and allow it to multiply!

So how does one get rid of a chronic infection?

The majority of people I see improve without resorting to anti-microbials by putting in place all the interventions to restore mitochondrial function and good anti-oxidant status. These include:

- stoneage diet
- nutritional supplements
- correcting mitochondrial dysfunction
- correcting anti-oxidant status
- sleep
- pacing
- detox regimes

However, Cheney has seen good results by treating CFS sufferers using artesunate. This is derived from the Chinese herb artemesia. It is of proven benefit in treating malaria. But, interestingly, it is active against a wide range of other infections including schistosomiasis, cytomegalovirus, hepatitis B, Human Herpes Virus simplex type 1, Human Herpes Virus type 6, hepatitis C, Epstein Barr virus, bovine viral diarrhea virus and probably others. Artemesins have also been shown to be effective against bacterial infections, yeast infections and also they have powerful anti-cancer activity. What is most remarkable is that side-effects are minimal and rare.

This begs the question as to how one drug can have such a broad spectrum of activity against so many different pathogens? The answer is that it has an effect on the redox state of the host ? it pushes it back to the right. It creates a terrain in which bugs cannot replicate! In a normal redox state mitochondria can work normally, energy levels are restored, the body warms up (many pathogens are markedly heat sensitive- that is why we run a fever to get rid of bugs) and the immune system has the energy to kill infection. BUT THIS WILL ONLY WORK IF ALL OTHER INTERVENTIONS ARE IN PLACE. Without normal mitochondrial function, normal antioxidant status, etc. artemesins cannot work!

Staphylococcus vaccine treatment of ME/CFS

Source: http://www.meassociation.org.uk/content/view/951
Article discovery: James Roberton

I am a medical doctor and associate professor working at the Karolinska University Hospital in Stockholm and a member of the committee of the Swedish Association for ME patients in Stockholm. However, I am also a patient with ME/chronic fatigue syndrome since 14 years and have been successfully treated with a vaccine against staphylococcus during the last 8 years.

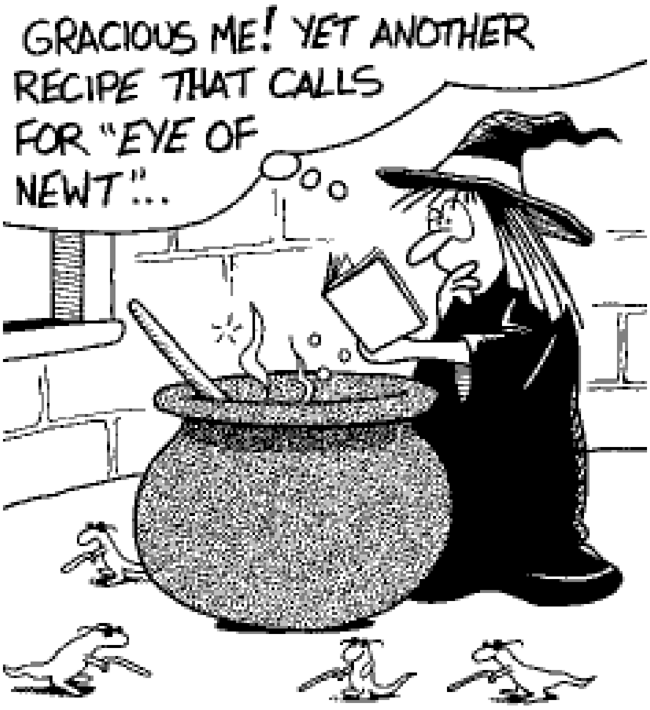
A Swedish research group has developed a treatment against ME/CFS that reduces symptoms significantly. In Sweden we have about one hundred and fifty patients with ME/CFS that have been successfully treated with a vaccine against staphylococcus. The vaccine has been given to us monthly during 5-10 years without any adverse effects. The treatment has made it possible for the majority of us to work and also to have energy left for our families, friends and even sports and outdoor life. The effectiveness of the vaccine has been proven in a double blind scientific study.

However the vaccine is not produced anymore and most of us have been forced back to illness life. We have thus come to an absurd situation where there exists a treatment of ME/CFS, which could dramatically reduce symptoms and make life much better for millions of people all over the world. It could also reduce the cost of health insurance and probably ***give a clever financier millions,*** but perhaps no further development will be done. As far as I can see this is the only possible treatment that could help us within a not too distant future.

We want to spread the information internationally about this treatment among patients, patient organizations and interested doctors as we hope that this could contribute to get a discussion going about how to get resources to develop the treatment. We need help to convince a vaccine manufacturer to start a new vaccine production that makes further research possible. We would also be pleased if someone has contacts or other ideas that could help to solve this problem.

Cartoons

Peter peter pumpkin eater



Police department halloween party

CFS/ME emotions and insights

Source (partial): Neil Perrett – newsletter editor
Quality control: Cathy Gould – secretary

This article contains some fairly in-depth information about emotions and CFS/ME. Young adults or those currently experiencing emotional issues maybe best reading this article at a time when they are feeling at their best and have others nearby to talk to.

A range of emotional issues are discussed so that those experiencing them may gain some useful insights. It does not follow, however, that CFS/ME sufferers will always encounter the range of problems discussed and, therefore, readers should not view the content of this article as expected problems.

Chronic illnesses cause complex emotions. CFS/ME is no different. Many patients have an acute onset to their CFS/ME. They move suddenly from a situation of good health and full activity to a situation of pain, exhaustion and inability. Previous activities which gave identity and meaning to life are no longer possible. The prognosis is uncertain and patients do not know how long their illness will last. They don't even know if they will recover. In common with other chronic illness, feelings of frustration, isolation, loss of self esteem and even despair are part of the unwelcome package of emotions that have to be coped with.

In CFS/ME, the controversy over the nature of the illness can raise particular problems. It is difficult for both doctors and patients to deal with an illness where all tests and investigations give negative results. Patients often feel that they are battling against disbelief to communicate that they are exhausted or in pain and that that they are genuinely unable to carry out activities they were previously able to do without difficulty. The role of the doctor can become very perplexing in a situation which lacks the clarity of a clear diagnosis supported by abnormal test results. Doctors may fear that they are colluding with the patient if they accept that the patient is really ill. Yet where acceptance is withheld, patients can, and usually do, feel blamed for becoming ill.

Many patients report feeling isolated and stigmatised - as much by being unable to explain to others why they are ill, as from the restrictions imposed by the illness itself. Where the experience of an individual is not validated, this can leave a difficult vacuum where full expression of anger or loss or fear does not feel permissible. Powerful and painful feelings are not acknowledged as reasonable responses to the situation and are therefore not processed.

Many patients have commented on the value of being able to acknowledge feelings such as loss and anger at becoming ill and feel that their feelings were validated within a CFS/ME group. This simple validation does seem, for some patients, to have a profoundly therapeutic effect.

The mental fatigue associated with CFS/ME may also make effective emotional processing more difficult. Patients commonly report that mental fatigue (often described as 'brain fog') reduces their ability to analyse feelings and to connect emotions with events in a coherent pattern.

Source:
http://www.emotionalprocessing.org.uk/images/EP%20&%20Physical%20Health/chronic%20fatigue%20syndrome.htm

Kubler-Ross model (loss cycle)

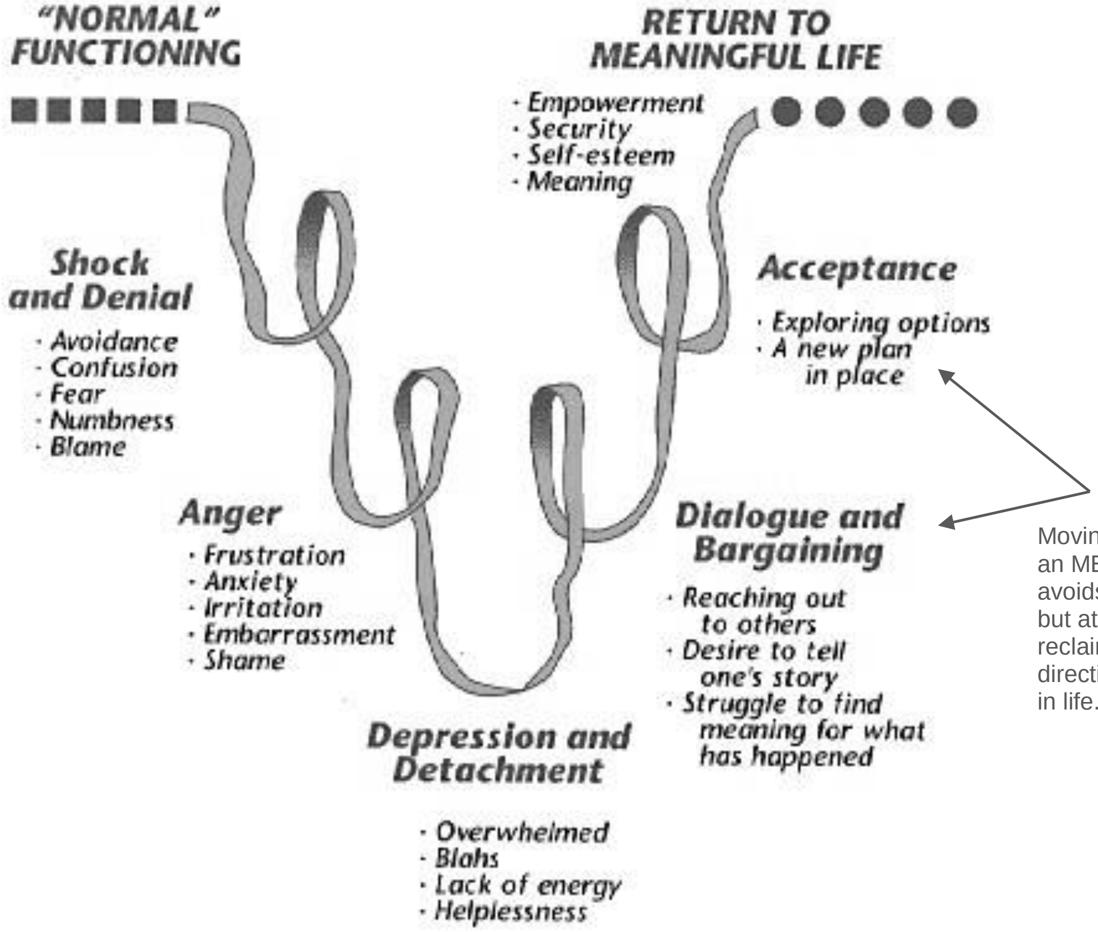
Although cognitive behaviour therapy (CBT) offers limited help for ME/CFS sufferers, one of the concepts typically covered is the Kubler-Ross model (a.k.a. loss cycle), which details a sequence of emotions that commonly occur in people experiencing some form of significant loss. ME/CFS sufferers are exposed to many types of significant loss, such as, ability, identity, direction, work, money and friends. Over time sufferers learn a new, ME compatible, lifestyle that attempts to reclaim some of these lost parts of life. On the loss cycle where this happens is called "dialogue and bargaining" and "acceptance".

Kübler-Ross originally applied these stages to people suffering from terminal illness, and later to any form of catastrophic personal loss (job, income, freedom). This may also include significant life events such as the death of a loved one, divorce, drug addiction, or an infertility diagnosis. Kübler-Ross claimed these steps do not necessarily come in the order noted above, nor are all steps experienced by all patients, though she stated a person will always experience at least two. Often, people will experience several stages in a "roller coaster" effect - switching between two or more stages, returning to one or more several times before working through it.

Significantly, people experiencing the stages should not force the process. The grief process is highly personal and should not be rushed, nor lengthened, on the basis of an individual's imposed time frame or opinion. One should merely be aware that the stages will be worked through and the ultimate stage of "Acceptance" will be reached.

Source (partial)
http://en.wikipedia.org/wiki/Kübler-Ross_model

Kubler-Ross model diagram



Moving towards an ME lifestyle that avoids ME problems but attempts to reclaim meaning, direction and peace in life.

The way forward
So far this article has mentioned that:

- CFS/ME can cause a significant range and depth of emotions;
- talking to a CFS/ME group may help process emotions; and
- there is a typical pattern to emotions associated with loss that lead to stages of problem solving “dialogue & bargaining” and “acceptance”.

All of the above partially helps with the understanding of CFS/ME emotions, but is there a way to help a sufferer avoid having to go through all of the emotional processing in the first place? Given the complexity of the illness and how much it affects our interaction with normal life I have to say not completely, however, a lot of CFS/ME sufferers have spent years living through the Kubler-

Ross model to find their answers. Tell these answers to a sufferer while they are in the early stages of their illness, it might help them through the process. Below, under the heading ‘Insights’ I have attempted to provide some of these answers.

Aside from emotions being caused by encountering problems/loss due to the CFS/ME there is a second potential cause of emotions, physical changes in the body such as: neuro-chemical changes (e.g. low serotonin levels); and excessive adrenal levels.

Such changes may manifest as depression or anxiety at various levels of severity. Some sufferers experience an OCD type anxiety where they suffer from unwanted and intrusive thoughts that they can't seem to get out of their head. Such irrationality itself is scary, causing a catch 22 cycle. Examples include:

- constant, irrational worry about dirt, germs, or contamination;
- excessive concern with order, arrangement, or symmetry;
- fear that negative or aggressive thoughts or impulses will cause personal harm or harm to a loved one;
- excessive concern about accidentally or purposefully injuring another person; and
- feeling overly responsible for the safety of others.

If depression or anxiety is severe it is worth exploring the use of anti-depressants with your doctor. Cipralex, Cipramil and Lustral are examples. Also, discussing such issues with others in the same situation or a councillor/therapist is useful. There are answers to these situations that you can access that do work to solve the problem. It can be hard to imagine when in the middle of the emotions.

Insights

(a)Scared of not knowing what is happening to you

Hearing about someone having an illness and experiencing it are two very different things. CFS/ME can take us by surprise at how many symptoms there are, the severity of them and the impact it has on our lives. This is made far worse by doctors, friends and family also not knowing what the problem is – especially when standard blood tests show nothing wrong. Incidentally, there are a large number of articles that include involved tests showing significant malfunctions in the CFS/ME body.

Once you, or your doctor, have identified CFS/ME as your illness, it’s a start. Aside from reading about the illness one of the most powerful tools is to ***talk to others with the illness***. Often there is an instant rapport between CFS/ME sufferers because of the vast number and depth of symptoms and situations shared. Things you thought were so strange that you thought must be unique are actually shared with hundreds of thousands of other sufferers and that is just in the UK. There is a reclaimed sense of sanity and relief when we find others in the same situation as us.

(b)Scared of not being able to function and the future

I think that when our brain notices that we are not functioning properly (e.g. brain fog, short term memory loss, irrational anxieties, can’t read or follow the TV) it raises an alarm, a type of self-protection, in the form of anxiety that makes us worry about everything. So going to the shop can no longer be done mindlessly as normal, it requires analysing hundreds of things that could possibly go wrong. With the range of symptoms CFS/ME causes that can be a lot of things to analyse, which in turn causes brain fog. So just thinking of going to the shop can make you feel a lot worse.

Such inability to live normally makes us think that if we do not get rid of this illness what will become of our future….job, money, house, family. Thinking about solutions for the future causes a lot of stress. Stress being one of the worst things for intensifying symptoms.

One of the insights for dealing with CFS/ME is to ***avoid all stress like the plague***. That includes thinking about the future. Learn to create an environment and activities that offer a stress free (or as close as possible) lifestyle. By doing this it will, overtime, empower you to be able to cope with more intense events and/or more frequent events.

Pacing is one effective way to control stress. Pacing techniques include: keeping activity levels within a person's limits; taking regular rests; using routine; scheduling activity based on priorities; and timing activity for the best hours of the day. Other stress reduction approaches include: de-cluttering (for example, reorganizing the kitchen or discarding unused possessions); limiting exposure to media; limiting contact with some people; avoiding crowds; and making mental adjustments (such as letting go of unrealistic expectations).

(c)OK, I can’t live normally but what DO I do

There are different degrees of ME ability and, of course, people are in different stages of life and have different resources (e.g. money, property, family) and problems beyond CFS/ME. For most, it seems that they are largely house-bound with limited trips/events out of the house when feeling brave or when they must. The following suggested activities have been written with this level of ME ability in mind.

Pacing & switching

Living by using techniques such as pacing & switching, in time, becomes second nature to an CFS/ME sufferer. When trying to live like a normal person, we experience many booms and busts in ability across a number of symptoms. We try to do normal activities only to be pulled down by a package of CFS/ME symptoms. We rest until some normality returns and then try to live normally again, with the same result. Pacing is a way of living by only using energy (mental and physical) evenly over time with regular breaks. By doing so, it stops us thrusting ourselves into the package of CFS/ME symptoms. It takes time to learn where the limits are and to know how to recognise symptoms starting but in time pacing leads to a better CFS/ME lifestyle.

Switching is where we make sure that we don’t do the same type of activity for too long. For example, spending all of your pacing allocation doing mental work (e.g. on the computer) may mean that your pacing allocation is shorter than if you had changed/switched at some point to doing some physical activities (e.g. tai-chi, cooking, tidying). Switching works on the premise that doing the same type of activity that uses the same system of the body will tire a CFS/ME person faster than if activities were varied by the systems of the body that are used. More information about pacing and switching is included in our Spring 2007 newsletter, which can be accessed in the members area of our website. (username= letme password= in)

Supplements

The next activity, that seems common with CFS/ME sufferers is learning about supplements that help fight some of the symptoms or secondary problems (infections/conditions that are caused by the CFS/ME but are not part of the ME itself). Identify the top 2 or 3 symptoms that are your main problem. It might be: lack of energy, insomnia and anxiety. Start to spend some time learning about supplements and things you can do to lessen these symptoms. The internet is a good source of information.

To deal with insomnia you might look at using melatonin. For anxiety you should stop having all caffeine and might look at 5HTP or anti-depressants. For energy you might look at NADH, CoQ10, D-ribose amongst others. To help clear up any opportunistic bacteria or viruses that are trying to thrive due to the immune system not working properly, you might look at garlic or grapefruit seed extract.

One of the key supplements for energy is magnesium. However, we absorb it through the skin better than through our digestive system, so one CFS/ME activity might be regularly having a bath with two handfuls of epsom salts (available from garden centres) in it. Be careful with the temperature of the bath because CFS/ME people don’t handle temperature very well and a bath that is too hot will probably make you feel very ill.

Our group offers a handout about ME supplements, if you would like a copy please ask by emailing rescue@f2s.com.

Meditation

I understand meditation to be calming the mind to the point where a single entity (e.g. thought, candle flame, sound) is the only focus of the mind. Initially a single entity might be difficult to achieve but minimising entities, perhaps to a few, is as effective. I understand that in concept, by meditating 'thought-energy' is freed up to be used elsewhere in the body (e.g. healing).

Meditation is perhaps thought of as a serious activity that is difficult to achieve. While that can be true, it is perhaps as true to say that we have all meditated naturally at some points throughout any year. It might be a mindless gaze at something beautiful or just pondering a single idea while deeply relaxed in the bath. The meditation I'm talking about in this article is simply achieving such states but deliberately. I found that to start, relaxing on the bed while listening to some meditative music was enough to achieve a basic level of meditation.

There are two reasons why meditation can be of serious help to a CFS/ME sufferer:

- countering stress; and
- slowing the pace of thoughts.

As mentioned in (b) earlier, one of the main antagonists of CFS/ME symptoms is stress. Instead of the stress rallying a heightened ability as intended, it feels as though it causes a number of the body's systems to partially crash resulting in symptoms such as a loss of both energy and concentration. Obviously, meditating is a relaxing exercise that avoids stress. The calming of the mind that meditation achieves can resonate throughout the day and after a time start to set a new calmer way of being in general.

One of the effects of CFS/ME seems to be a racing mind. I found myself only able to steer a torrent of thoughts. Many thoughts were coming, I had no choice in that, I was only able to steer the direction that the thoughts were going in. By contrast, by meditating I was able to approach thoughts as I wanted from a calm neutral. The more I meditated the more this neutral starting point became the norm.

Tai-chi, yoga or stretching

Obviously, CFS/ME pushes the sufferer in to a sedentary lifestyle. Exercise is likely to be impossible to do or be done at too high a price - long lasting punishing symptoms. Often just coping with symptoms (cognitive problems, malaise, pain) takes all our attention and leaves us in bed or sitting.

It is easy to find ourselves only moving to perform activities of necessity such as washing, cooking and shopping. I found that when walking to shop for food in the supermarket that the walking was almost foreign and awkward to do. Perhaps, my limited activity in the house had meant that the muscles in my legs were not even ready for normal outdoor walking.

Our situation means that exercise is limited, if not impossible/detrimental, but a life that is too sedentary causes further problems. Some daily or a few times each week stretching and movement such as that of tai-chi or yoga I think is important for supporting the basic functioning of our bodies, even when considering the limitations and/or consequences our CFS/ME causes.

(d) I'm angry or depressed about my situation

As mentioned earlier at the beginning of 'The way forward' depression and anxiety are a common reaction to the problems that CFS/ME causes. Aside from emotions caused by malfunctions in the body (e.g. neuro-chemical changes and excessive adrenal levels), emotions are a natural tool for problem solving that usually start when intellect alone fails to solve a problem. The function of anger is to get physical with something external to the body (e.g. force open a blocked door). In contrast, the function of depression is to focus on an internal problem such as a life decision or situation.

Anger is rarely useful during CFS/ME as problems are not physical obstacles, however, anger can be relevant when used in a constrained and focused way at external problems such as disbelieving/un-supporting entities that maybe friends, family, doctors or the benefits system. Anger used constructively, can be said to support the concept that "the problem/error is yours". Whereas depression in contrast "ok, the problem/error is mine".

So, if experiencing anger, try to think if the situation is truly an external problem (i.e. someone else is making a problem/error that affects me). If it is then, try to express a conviction of your stance to the people/system involved, but in a non-emotional tone and calm way that will make what you have to say more effective.

The process of depression takes out of mind most all positives so that you can really focus on the negative problem to be solved. As such, if you ever want to pull up out of a depression mode, consciously force yourself to think about the positive truths about a situation that help to balance negative thoughts and put you back into a non-problem solving mode. Where depression becomes ineffective is where you leave the relevant problem to be solved and start moving through a large number of problems in your life in a cascade of thoughts. This is un-focussed problem solving. It's like trying to solve 50 maths equations at once. A key to constructive depression is focus only on the specific problem and once processed for a while come back to a non-problem solving mode.

If you find yourself stuck in a problem solving mode, anger or depression, then I strongly advise to talk to a doctor about anti-depressants and/or counselling/therapy. These support options will provide powerful help, irrespective or the problem being physical (e.g. neuro-chemical) or psychological (structure of thoughts, information).

(e) How do I improve my energy levels?

In sections (a) and (b) earlier, one of the measures for improving energy has already been mentioned…removing as much stress from your life as possible. Stress makes CFS/ME symptoms a lot worse, including energy levels. It is likely to take time to rearrange your life to avoid stress and indeed doing so may itself be stressful but minimising overall stress over time is always a good goal for an CFS/ME sufferer.

As well as stress, there are two other issues that really make CFS/ME symptoms worse, insomnia and doing too much. Possible solutions for insomnia are in the next section (f) and the main way of avoiding doing too much, "Pacing & switching" is discusses in Section (c).

OK, now that you have ***protected*** your energy levels by minimising your stress & insomnia, and are pacing/switching, you can now successfully try to ***increase*** your energy levels.

The body produces energy using various substances. By providing the body with a boost of some of the key substances it can help to improve energy levels. Key substances include: NADH; Co-Q10; magnesium; d-ribose and l-carnitine. Such supplements can be bought online via places such as Vitaminuk or Amazon, or in 'Holland and Barrett'. The doses that are stated on the packaging of the supplements are a good place to start. Please refer to Section (c) about magnesium baths. Our group offers a handout about ME supplements, if you would like a copy please ask by emailing rescue@f2s.com.

(f) I have sleep problems what do I do?

I think that insomnia is the worst antagonist for ME symptoms, even more so than stress. Even when we are not experiencing insomnia our sleep doesn't seem to be of a particularly good quality. For example, many report having excessive dreaming or waking as tired as when having gone to sleep. Some find their sleep pattern has shifted by a number of hours (e.g. sleep at 4am, waking at 12 noon), some find their sleep pattern constantly wants to shift to sleeping in the day and up all night, or constantly shifting by a number of hours each 24 hours.

Nytol can be a good sleep aid to try first. If that does not help then perhaps look into trying melatonin. If melatonin is not helpful, even up to 6mg per night, then it maybe time to explore sleeping tablets from the doctor. Sleeping tablets are addictive and often require an even increasing dose over time, so they are somewhat of a last resort.

Four, often very effective, tricks for getting to sleep are:

- mind dump;
- hot to cold;
- restart; and
- it will do.

Mind dump
There are many problems that can stop sleep. One of them is the mind being too active. Often, before sleep we might think over some of our life problems or think about important things that we must remember for the near future. If we get carried away then the activity of the mind can prevent sleep. One of the ways to clear the mind is to do a mind dump. A mind dump simply involves taking a pen and paper and writing down a list of all the thoughts or issues that enter your mind. Often, your mind will feel less active as you write your list. Also, you may feel more and more rested and sleepy. It maybe because your mind knows that it does not have to remember or solve the problems you have written down because they will be on the paper in the morning and ready to be mentally picked up for processing the next day.

Hot to cold
One biological way of making you sleepy is to make yourself hot (e.g. via a bath or shower) and then go to bed but opening up the windows so that cold air is reaching you. The quick change in body temperature from hot to cold causes sleepiness. I often lay on top of the duvet, then when I am cool and sleepy climb under the covers.

Restart
Sometimes when we experience insomnia, it is as if we are half asleep but not able to actually achieve sleep. I call this a failed sleep attempt. Sometimes, what is needed is another attempt. This is done by getting out of bed, putting on clothes again, going to a different room (probably the kitchen) and having some drink/food. After doing some normal life activities for a period of time (perhaps 20-30 minutes) then try to sleep again.

It will do
Often one of the problems with getting to sleep is the worry of not getting to sleep. As such, try to think that… even if I don't sleep and just lay here resting it will be as good as properly sleeping. By doing that it should remove worry of not sleeping.

Finally, if you have tried everything and you just can't sleep, then don't and go with the flow a bit. By that I mean sleep when the CFS/ME wants you to sleep (e.g. 7am to 4pm). Fighting against problematic sleep can be stressful. As such, it maybe best not to constantly fight the pattern of sleep the CFS/ME is trying for. If you have to maintain a job, then working with your doctor to find sleeping tablets might be your only option. But if you're not in that situation, perhaps trying to reset your sleep to normal hours once a month is appropriate. Resetting sleep can be done most effectively (albeit very uncomfortably) by forcing yourself to stay awake until appropriate sleeping hours (e.g. 10pm). Apparently sleep clinics are inclined to correct sleep by forcing the patient to stay awake during appropriate waking hours, rather then trying to force sleep at appropriate sleeping hours.

(g) I have anxiety what do I do?

There seem to be several different causes of anxiety in a CFS/ME sufferer:

- one of the emotions of processing loss as explained in the Kubler-Ross model;
- neuro-chemical changes such as low serotonin levels; and
- the anxiety experienced as a direct result of experiencing symptoms.

Earlier information about the above, in order, is included in sections Kubler-Ross model (page 7), the way forward (page 8); and insights a and b (page 9). However, here I will try to list a number of ideas that help combat anxiety.

- Stop having any caffeine (e.g. tea, coffee, coca-cola, hot chocolate)
- Take some essential fatty acid supplements (e.g. VegEPA)
- Avoid stress as much as possible
- Talk to other ME sufferers about your illness and situation
- Pacing and switching so that you are not pushing yourself into symptoms
- Get a doctor that understands ME and who can support you
- Consider anti-depressants with your doctor (which also relieve anxiety)
- Consider talking to a councillor/therapist about your anxiety and exploring coping strategies
- Minimise cigarettes and alcohol
- Identify and do activities that are within ME limits that help keep your mind engaged with something constructive (e.g. tai chi, meditation, research CFS/ME online, finding new music online, cooking something new)

(h)I have sensory overload

Most people with CFS and FM are sensitive to noise, light and crowds, and to sensory input coming from more than one source at the same time. A helpful response is to limit sensory information to one type at a time, for example, talking without any background noise. It may also mean socializing with only one or a small number of people, rather than in large groups, and visiting restaurants and other public places in off-peak hours.

Frequently, my CFS/ME has meant that I have not been able to drive. In better times, when driving has been possible I have found a sensory overload from the visual input of driving, experienced as if trying to look at a bright light during a headache/migraine. Wearing sunglasses while driving reduced the visual input to more manageable levels. Of course, never drive if your ability is significantly compromised and if wearing sunglasses ensure that there is enough daylight to be able to see properly.

Source (partial)
http://www.cfidsselfhelp.org/library/coping-with-impacts-cfs-and-fm-0

Conclusion

CFS/ME is a complicated illness that involves many bodily systems (e.g. neurological, immune and endocrine). Some symptoms vary, others are constant. The range of symptoms are wide and their intensity serious. Typically, a sufferer rarely has the ability to leave the house with any confidence of function and must learn a new way of life. All of which occurs with the vast majority of the public and a significant percentage of the medical profession considering CFS/ME to be simply a matter or tiredness or psychological issue.

Often people will see a CFS/ME sufferer walking, talking and behaving normally. They do not realise that it’s taken days or weeks of resting to get to that point, and that it will take days or weeks to fully recover from this peak of activity that they witness.

It is not surprising then that during this illness a CFS/ME sufferer will have to deal with serious emotions as they struggle to learn about their illness and the new way of life that they are forced to turn to.

Although there is no current cure for CFS/ME, there are insights, supplements and treatments that can help to lessen some of the symptoms. Learning about such help comes from scientific research found on the internet, experience of others going through the same thing and your own experience of what works for you. I hope that something of the information included in this article will help.

Reflexology

Reflexology is a type of bodywork that focuses on relieving stress and tension in the body through the hands and feet. There are reflexes in the hands and feet that correspond to glands, organs and other parts of the body. A Reflexology Therapist can detect imbalance within the body by palpating the hands and feet. By massaging and pressing specific landmarks they can stimulate and send energy to the unbalanced areas of the body.

Benefits of reflexology

Reflexology has short and long term benefits. Immediately after a session of reflexology relaxation and a release of stress and tension are apparent benefits. More long term benefits have been reported as reduced pain from migraines, constipation, neck and back problems, reduced PMS symptoms, increased circulation and an improved immune system.

Reflexology and CFS/ME

It is important to note that reflexology is not used to treat particular illnesses, infections or diseases but is instead geared towards relieving stress and tension that has built up in the body. It is believed that the body can relax and heal itself better if tension is reduced. It is the belief of most practitioners of reflexology that a great deal of health conditions can be traced back to an overload of tension in the body. Reflexology is a discipline of natural healing that aims to release much of this pent up energy in the human body and to promote self-healing. It helps to improve the way the digestive system works, aids in proper circulation of the blood and helps to get rid of harmful toxins that build up in the body over time.

CFS/ME cannot specifically be treated with reflexology, however, it can work to improve a sufferer’s overall level of health and for that reason it is a form of natural therapy that is highly recommended for CFS/ME patients. Reflexology is an excellent stress reliever and is also known to be a good way to increase a person’s ability to sleep through the night.

Sources
http://generalhealthinfo.wordpress.com/2008/08/18/what-is-reflexology/
http://www.thehealthguide.org/chronic-fatigue-syndrome/reflexology-and-cfs/

Further information about the credibility of reflexology and how it works

Please refer to the following internet link. Apologies for those without internet access but the information was too extensive to include here.

http://www.universalreflex.com/article.php/20040309175204417

Reflexology
for ME/CFS patients

£15 per session
Contact Debbie Burgess
Mob: 07876 710288
dcmburgess@googlemail.com

Debbie is one of our members based in Godalming.

Switch off, switch on

By Robert Matthews

Source: www.thenational.ae/article/20090705/OPINION/707049916/1036
Article discovery: James Roberton
* Last Updated: July 4. 2009 4:30PM GMT

Two British scientists are treating rheumatoid arthritis and multiple sclerosis by destroying patients' B-cells and starting over with fresh ones.

We’ve all done it. Faced with some malfunctioning gadget or computer, we pull the plug on it, switch it back on – and find it works perfectly again. Known to the cognoscenti as the “hard reboot”, it’s a trick used more often in desperation than insight. Now it’s emerging as a promising new approach to treating some notoriously debilitating medical conditions. Recent clinical trials have shown that “rebooting” our disease-fighting immune system can dramatically improve the condition of patients with multiple sclerosis and rheumatoid arthritis. And according to a study published last week, it may even bring relief to patients suffering from the enigmatic condition Chronic Fatigue Syndrome, affecting millions worldwide.

There is a growing sense of excitement about the rebooting technique. But behind it lies an inspiring story of how a pair of scientists overcame indifference to convince the medical community of the merits of what is now called B-cell Depletion Therapy (BCDT).

B-cells are a type of white blood cell which randomly churn out so-called antibodies, many of which prove useful in destroying disease-causing pathogens. Yet, like every defence system, mistakes sometimes happen – and innocent bystanders end up being targeted. During the late 1990s, two medical researchers at University College London began to wonder if this “friendly fire” might hold the key to the debilitating disease rheumatoid arthritis (RA).

Affecting about one in 100 people worldwide, RA can strike anyone literally overnight, their immune system suddenly attacking their joints. The condition is excruciatingly painful, and for years there seemed no hope of a cure. Until recently, the prime culprit was held to be T-cells: white blood cells that play a key role in the disease-fighting immune system. Yet despite intensive study, no one could explain how or why T-cells should produce a lifelong ailment such as RA. Most tellingly of all, therapies targeting T-cells failed to benefit patients.

This prompted Professor Jonathan Edwards and Dr Geraldine Cambridge at UCL to ponder the possibility than B-cells might be to blame. Their idea was based on the fact some B-cells are known to make antibodies which inadvertently seek out and destroy healthy tissue. Normally, these would be destroyed by the B-cells themselves. But what if some of the antibodies by chance possessed the means to evade their own destruction – and go on to attack the joints?

That led Prof Edwards and Dr Cambridge to a radical new approach to treating RA: “rebooting” the immune system by destroying all the B-cells, and then starting over with fresh ones.

Fortunately, a compound capable of targeting just B-cells had just become available: rituximab, a so-called monoclonal antibody which homes in on specific targets like a heat-seeking missile. This could destroy all the B-cells, leaving patients to develop a whole new set free of the renegade variety that attack joints.

That at least was the theory, and with the standard T-cell theory not getting anywhere, the team thought it was worth bringing to the attention of other researchers. They soon found that new ideas aren’t always welcome in science – even if the old ones aren’t working.

Their academic papers were rejected by journals as “obviously” wrong – on the grounds that they focused on B-cells, not T-cells.

They were not helped by a lack of experimental evidence. Yet the pair found themselves in a chicken-and-egg scenario: only if they already had evidence from clinical trials could they persuade funding bodies to pay for more clinical trials.

The pair managed to publish their idea in a medical journal, only to be met with silence. Determined to make their case, they set up a small but demanding test, using rituximab to treat five patients with severe RA. The results were impressive: once their B-cell systems had been “rebooted”, their condition improved dramatically. Yet attempts to publish the results in journals were rebuffed on the grounds that the study involved too few patients.

So the pair tried again, cobbling together enough money to treat 20 patients. Again, the results were impressive, with all but two of the patients showing dramatic improvements. It made no difference: the medical community remained utterly unimpressed.

Frustrated by the lack of interest, Prof Edwards and Dr Cambridge decided some media coverage might help. When the reports of their success with 20 patients emerged, they found themselves vilified by fellow academics as hype-mongers.

Whatever the rights or wrongs of their decision to approach the media, it certainly boosted awareness of the B-cell depletion theory. In 2000, just six people had turned up to hear a lecture about the theory; a few months later, the media coverage led to 3,000 packing a lecture hall to hear what it was all about.

The coverage also helped win funding for a substantial clinical trial involving more than 160 patients. By 2002, the results were in: when combined with a standard therapy for RA, rituximab proved three times more effective than the standard therapy alone. In 2006, the B-cell depletion therapy (BCDT) was approved by regulators in the US and Europe for use alongside the standard therapy.

Despite this vindication, the two researchers have not rested on their laurels. Since the late 1990s, they have suggested that BCDT might help in treating another disease linked to a malfunctioning immune system: multiple sclerosis.

Last year, a study of more than 100 patients showed that BCDT could halve their relapse risk. The UCL team has also shown that the technique brings benefits to patients with the auto-immune disease, lupus.

Now a team of researchers in Norway is claiming the therapy could help treat Chronic Fatigue Syndrome, sometimes called myalgic encephalomyelitis (ME). Characterised by mental and physical exhaustion, with muscle and joint pain, this enigmatic condition has no accepted cause.

Many researchers have suspected a link with the immune system – a possibility now tentatively backed by researchers at Haukeland University Hospital, Norway. In the current issue of the online journal BioMed Central- Neurology, the team reports treating three CFS patients with BCDT, and observing marked improvements.

With so few patients, it’s hardly definitive proof of a cure. Yet it is just the situation Prof Edwards and Dr Cambridge found themselves in a decade ago. CFS sufferers must be hoping medical researchers are not about to repeat history by rejecting these intriguing findings out of hand – despite not having any better ideas themselves.

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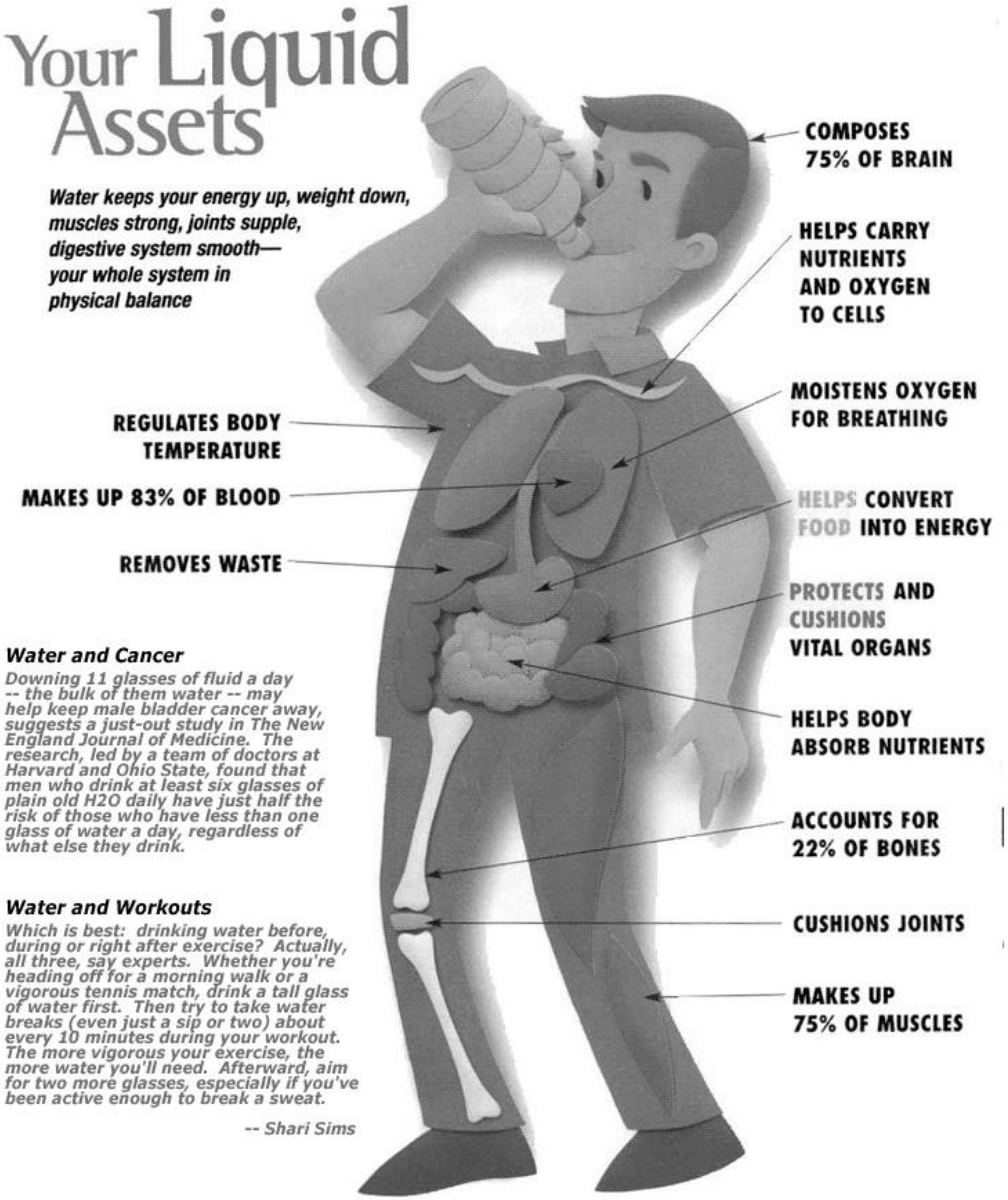
A reminder to drink water



Your Liquid Assets

Water keeps your energy up, weight down, muscles strong, joints supple, digestive system smooth—your whole system in physical balance

Water and Cancer

Downing 11 glasses of fluid a day -- the bulk of them water -- may help keep male bladder cancer away, suggests a just-out study in The New England Journal of Medicine. The research, led by a team of doctors at Harvard and Ohio State, found that men who drink at least six glasses of plain old H2O daily have just half the risk of those who have less than one glass of water a day, regardless of what else they drink.

Water and Workouts

Which is best: drinking water before, during or right after exercise? Actually, all three, say experts. Whether you're heading off for a morning walk or a vigorous tennis match, drink a tall glass of water first. Then try to take water breaks (even just a sip or two) about every 10 minutes during your workout. The more vigorous your exercise, the more water you'll need. Afterward, aim for two more glasses, especially if you've been active enough to break a sweat.

-- Shari Sims