

## DEALING WITH STRESS IN CHRONIC FATIGUE SYNDROME

Many people with Chronic Fatigue Syndrome are fearful of admitting or acknowledging that stress maybe a factor in their illness. There is that underlying worry that they may be labeled as suffering from a psychological illness, so denial seems easier. But we must acknowledge that stress is part of life and is a factor in every illness. A common cold will take longer to settle in times of stress and cancer suffers do better if stress issues are addressed. CFS is no different, and it is important to understand how stress maybe implicated and then deal with it accordingly.

Stress takes many forms. It maybe persisting emotional stress due to many and varied problems, it maybe a sudden unexpected event promoting an acute stress reaction, it maybe a physical stress whereby a person is just pushing the body too hard (eg sports training) or a surgical operation or accident. Any worry will create a stress reaction as will excitement and many pleasureable experiences. Thus we can experience, good stress – and we need a certain amount of that to make life interesting and exciting. Many people do in fact perform better when under a moderate amount of stress and performance can drop off if things are too easy. It's all a question of a balancing act. Enough stress to make life fun and challenging, but not so much that it produces adverse health effects.

We cannot separate mind and body, so that everything that happens to the body can have an effect on the mind – any illness creates anxiety, and everything that occurs in the mind can have an effect on the body – anxiety can create migraine headaches, bowel upset and many other symptoms.

There are however easily recognizable symptoms of an acute anxiety reaction: trembling, racing heart, rapid breathing, diarrhoea, nausea, dry mouth etc – symptoms I am sure we are all familiar with. If there is enough continuing anxiety, these symptoms can become more persistent and widespread – Sleep will be disturbed or shallow, and there will be loss of ability to deal with stress, irritability, depression and effects on healing and recovery. The body then seems to develop a habit of staying constantly overwrought. Coping ability decreases and the immune system is seriously affected. Depression becomes “part of life” too.

In CFS, we know that stress is implicated in development of the illness. Those that get this illness are genetically vulnerable, and if they are stressed mentally or physically at the time of a viral illness, (and any virus can be involved) this becomes a recipe for finally succumbing to this illness. The stress may of course not even be recognized as such – it can be the young athlete “overtraining”, someone just pushing really hard at work or study, a young mother coping with sleepless nights, a preceding accident or operation etc etc. Once a person has CFS, stress can have a major effect in prolongation of the illness, maybe due to poor sleep, aggravation of an already over reacting immune system (the cause of many of the symptoms) or just inability to recognise and deal with the ordinary day to day stresses. Many will cite major stress as a cause of relapse too. This may be sudden or of gradual build up and again can be physical or mental.

The physical stressors in CFS are fairly obvious and covered in another article. Overexercise, surgery, accidents, shiftwork, immunizations etc are all risk factors. Briefly the approach to dealing with this aspect encompasses avoidance of undue physical effort and avoiding a crash and burn approach to life, and resting up after times of physical crisis. Women particularly can experience major emotional ups and downs associated with the menstrual cycle, childbirth and menopause. The daily emotional stressors are often less obvious, but as soon as you start to think about them, the list can become extensive!

Life is full of everyday stressors, and those with CFS will experience them in the same way as everyone else. The impact of the stress may however be harder to manage and many with this illness report that they can no longer handle stress. It may really get them down or make them feel irritable and/or angry. Minor stress can feel as though it has mushroomed into something major leading to anxiety symptoms by day and inability to sleep properly at night. The illness is in itself extremely stressful as is any illness. We all hope and expect our bodies to be bullet proof and invincible, and when things go wrong, worry creeps into the equation of living.

Some of the particular issues relating to CFS are: the long delay before diagnosis is made; lack of real firm diagnosis or diagnostic test; lack of understanding by those around you, and this may include health professionals; fear of a more serious life threatening illness; loss of job, money, prestige and confidence; reliance on others, who may not always be sympathetic; trying to maintain a normal life while coping with the illness; loss of friends and difficulty maintaining relationships; inability to fulfill normal everyday tasks; no defined time frame for the illness; depressing/distressing stories from other people etc. Most people who get CFS have previously been busy high achievers, who have performed efficiently and reliably – suddenly this ability is lost, and a growing sense of worthlessness may develop. Inevitably as you read this, you will realise that this huge load of stress very soon leads to depression with feelings of helplessness, loss of motivation and loss of enjoyment in everyday things. Many patients deny depression, but I feel they would be seriously abnormal if they were not depressed from time to time through this illness. Physically very active people have often relied on exercise to overcome stress, suddenly this is no longer an option for them, so their frustration escalates.

In dealing with stress the first essential is to acknowledge and recognize that stress does have a major impact on our lives, particularly in illness, when coping skills diminish. Identifying the stressors is the first step in stress management. Sometimes making a list can be helpful as writing things down has been shown to positively assist in relieving stress and sorting out priorities. Prioritising and breaking the issues into smaller fragments is a useful way of beginning to see light at the end of the tunnel. Some things will be easy to deal with, and straightaway if you can see that some minor change is possible, it does prove that even the bigger issues may become manageable. There will be things that can be dealt with rightaway, others that today seem impossible, so can be put on hold, and those that you realise are unimportant anyway, from which you can walk away.

Time should be set aside for discussion and sharing of stress issues. The old saying “a worry shared is a worry halved” is so very true. Just talking things through with another person, be it your nearest and dearest or a professional counsellor can give a feeling of enormous relief, and sometimes you begin to wonder why you actually worried about something! If you are alone, talking to yourself in a mirror (and smiling at yourself) may seem crazy, but it works. Sometimes a lot can be achieved by talking to a pet or into a recorder. Pets are wonderful as they do not argue back, provide company and warmth and make you feel really needed. Many people say they just wouldn't get up in the morning if it wasn't for the fact that the cat needed feeding.

Having acknowledged that stress has a major impact in life and health, finding a strategy to facilitate relaxation is essential. Exercise and more active pursuits may no longer be applicable, and coming to terms with this is often hard. Learning to relax properly certainly enhances our quality of life, health and wellbeing. Many people say “I just haven't time to do all this” – in reality a short spell of regular relaxation can help relieve fatigue and make you so much more efficient that you find you can actually fit far more into the day. There are many forms of relaxation and it really is a matter of finding what suits a particular individual as we are all very different. It is no good taking on board something that just does not appeal, as you will never keep it up. These approaches do not always give instant relief and much practice maybe needed to achieve success.

One of the simplest forms of relaxation is just lying back listening to music and letting go all the muscles, while breathing quietly and easily. Music has been shown to be very powerful in creating a particular state of mind. Slow rhythmic music can help promote relaxed feelings, while rousing choruses can promote feelings of energy. Good breathing technique has a very positive effect, and many with CFS do hyperventilate intermittently or have very shallow breathing much of the time. This in itself leads to feelings of anxiety and exhaustion. Many people relax by gradually letting go of all the muscles and feeling the tension flow away. Some will have learnt to do this by first tightening a muscle group, and then letting go – this is not the best approach in CFS as the muscle tightening may lead to pain and exhaustion – best to just let go and not use up energy unnecessarily. A physiotherapist can often help with breathing techniques and progressive muscle relaxation. Gentle massage and warmth can also be added into the equation. Sometimes just reading a good book, playing a musical instrument, painting a picture or losing oneself in an absorbing hobby can be a great release.

Creative visualization, self hypnosis, meditation and prayer are all associated with feeling of mental peace and this is due to creation of alpha rhythm in the brain and endorphin release. These quieter approaches are particularly useful at times of extreme physical exhaustion or pain, when more active approaches maybe inappropriate. Learning these gentle brain pathways to feelings of calm may take time, but are well worth exploring. Doing these exercises of the mind at bedtime enhances quality of sleep too. Many people find that by stilling the mind, problem solving becomes easier and creativity increases. Yoga, Tai Chi and Pilates are all associated with a combination of good breathing, mental calm and gentle exercise. The important thing is not to be too ambitious and expect to be able to twist the knee behind the head or even keep up with a regular class. As with other exercise, pacing carefully is important.

There are many stress management techniques and good books, tapes and CDs promoted and you can learn a lot from them, but much of stress management relies on acknowledgement and common sense. We have probably all learnt over time that exercise and having fun can help, there are comfort foods (chocolate!) and some people have of course resorted to alcohol or drugs. Alcohol can help make you feel relaxed and confident initially, but it soon catches up with you if the drinking is more than minimal. Sleep deficit and hangovers are the immediate risks, but binge drinking can certainly cause a relapse in CFS or prevent recovery. Similarly with recreational drugs, the aftermath can be devastating. Even coffee can make a CFS sufferer feel unwell, aggravate sleep and make you feel anxious by causing the heart to race. Withdrawal effects from drugs, including caffeine, can be nasty.

You may have heard of Cognitive Behavioural Therapy (CBT) as a form of treatment for CFS. Research does indicate that it is helpful, but I am sure it is helpful in every disease, and probably a lot of GPs practice CBT much of the time anyway. It really involves changing the way we think and using positive words rather than negative, and gaining understanding and insight into the illness in order to manage it better. Dealing with stress is all part of this as is looking at what you can do rather than what you cannot. There are a number of good CBT practitioners in NZ but always check the credentials thoroughly. Other therapies involving “mind” techniques are frequently advertised such as Reverse Therapy, Mickel Therapy, Lightning Process etc. These therapies are advertised relying on patient testimonials rather than research, but there is no firm research to prove their worth.

Stress is always harder to cope with if you are always alone and we all need a good support network of friends and family. Having any illness does of course restrict social interaction – sometimes you just don't have enough energy to cope with people or going out and often others back off as they do not know how to handle illness or a different you. An illness such as CFS certainly helps sort out your real friends and allies. Overall most studies into chronic illness find those with a long term supportive partner fare best. Company, sharing, love, sex and support are all part of the formula for success in life. And it works both ways. Your partner has been under awful strain too throughout this CFS journey, and you can help him/her as well. An illness such as CFS can be isolating and many relationships do fail, and joining a support group or network of people with similar interests gives you a new outlook on life. Nowadays the internet is also opening many doors for those stuck at home. Broadening horizons, opening the mind and using your energy wisely makes life more interesting allowing less time for stress to intervene.

Finally we need to look at drugs that maybe important and useful to help you cope better with stress and anxiety. Sometimes the anxiety or depression is so great, the person just cannot manage to see a way through. Panic attacks may occur too. This gives a sense of overwhelming and often frightening anxiety. Medical intervention may take the form of counselling, psychotherapy or medication. Your doctor maybe skilled in these areas, and if not you may be referred to a psychologist, psychiatrist or counsellor. Medication may mean quite simply a few days on an anti-anxiety agent (such as lorazepam, oxazepam or clonazepam). This can be a band aid approach breaking the anxiety/stress cycle. For most with CFS, looking at sleep is important, as sleep is rarely refreshing, and medication such as a very low dose tricyclic (amitriptyline, doxepin etc) or melatonin is usually needed. These drugs are non-addictive but do not necessarily work quickly and often the addition of a relaxant sleeping pill (zopiclone, halcion) is required in the first couple of weeks. Treatment of depression is essential, as if untreated it will inevitably hinder progress. Most modern antidepressants, such as fluoxetine, paroxetine and citalopram work efficiently, often in small doses and side effects are minimal once you are settled and the body has adapted to the new regime. For those with persistent anxiety and a lot of pain, ongoing use of clonazepam coupled with good pain relief works well. The important message is not to be afraid of medication, for although there are some useful herbal alternatives (lavender, St Johns wort, 5HTP) there has been good research looking at the use of drugs in CFS, focusing on need for small doses and things that are likely to work properly for the condition.

Remember to smile at yourself in the mirror every day – creasing the face into a smile actually makes you feel happier and having a good belly laugh releases endorphins, so essential for a sense of wellbeing. My grandmother had an old saying embroidered in cross stitch on her wall, and I feel it is very apt:

**“Laugh and the world laughs with you. Sigh and the world is grey”**