

chronic fatigue syndrome

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If you suffer from fatigue, you have probably wondered at some time if you are suffering from Chronic Fatigue Syndrome (CFS). If you do have Chronic Fatigue Syndrome, yoga is one of the best therapies you can use to help you manage and improve your health. First of all, however, let's take a look at what CFS actually *is* as there has been much confusion in recent years about naming and defining this very serious and disabling condition.

Chronic Fatigue Syndrome is the name doctors use to define any unexplained tiredness or fatigue state that lasts longer than six months and which is not linked to exertion, or alleviated by rest. It is sometimes used as an umbrella term to describe the exhaustion suffered with illnesses such as untreated diabetes, HIV, Gulf War Syndrome, heart and lung disorders, cancer, fibromyalgia, depression, multiple sclerosis, post-polio syndrome or post-viral fatigue. More recently, the term CFS has also been used to describe a very extreme illness, which in the UK is referred to as myalgic encephalomyelitis or encephalopathy (ME). Myalgic encephalopathy means an abnormality of brain function, which also describes the various central nervous system abnormalities and cognitive problems associated with this illness. In the US, the term Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) is used to describe the same illness. In the next two chapters, I am referring to ME or CFIDS, but I will use the term CFS to avoid confusion.

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What is CFS?

Symptoms include:

- Extreme fatigue after minor mental or physical tasks. An acute reaction is often experienced even up to 72 hours after simple exertion that would seem normal and easy to healthy people. This is not made better by rest. Sufferers may take days or even weeks to recover.
- Muscle pain.
- Severe headaches.
- Malaise - a feeling of being 'poisoned'.
- Sensitivity to noise and light.
- Feeling too hot or cold - a problem with temperature control.
- Dizziness.
- Cognitive problems such as brain fog - difficulty in concentration, problems with memory and attention span.
- Problems to do with the nervous system, such as panic attacks.
- Disturbed sleep patterns.
- Digestive problems - gut dysbiosis.
- A pattern of relapse and remission - some days being able to do more than at other times.

These are just a few of the more common symptoms, but from this you can see that CFS is much more profound than mere 'tiredness', and most sufferers find it impossible to lead a normal life. This is why many people object to the term CFS, as the illness is clearly much more than just long-term fatigue. In a survey carried out by the UK charity Action for ME in 2001, 89 per cent of the 2,300-plus respondents had, at some time, either been bed-ridden or house-bound by their illness.

So, if you have CFS, you will certainly know about it. Most people with CFS find that any mental or physical exertion can produce severe symptoms. On some days you may feel well - you may even have good weeks. But whatever the case, if you have CFS, you will find it impossible to cope with your previous level of lifestyle. This can be very hard. The majority of those with CFS have to give up full-time work and severely curtail their social activities. For some people, even moving a limb or doing

a simple task such as having a bath or cooking a meal may seem like climbing a mountain. CFS is total physical and mental exhaustion - like a battery that has gone completely flat. Worse, you don't just feel very tired: you feel unwell for much of the time. CFS can affect anybody, from children through to the elderly, and both men and women of all social classes and ethnic groups. Various surveys in both the US and the UK show that up to 1 in 350 of the population may be affected by CFS. Some people with CFS make a full recovery in time; the majority stay the same, that is, follow a pattern of remission and relapse. A small minority gradually deteriorate.

CFS and Your Emotions

If you have CFS, you may find that you experience a kind of grief - a sense of loss for your old way of life and who you were before you got ill. You may experience shock, disbelief and, later on, anger. These are all normal emotions under the circumstances. The way to improve and to have some quality of life is to move forward and learn to come to terms with the illness. This is where yoga comes in, as yoga shows you how to accept what can't be changed and make the best of what you have. Because yoga is non-competitive, it teaches you not to 'push' but to listen to your body. When you are no longer using up energy fighting the illness but are able to accept that this is how you are for now and that you have to make the best of your restricted lifestyle, you may find that you start to get better. Your self-esteem will rise as you learn not to judge yourself by what you do, but by who you are. You will also be able to appreciate small things - such as a beautiful flower, a sunny day or just time when you are well enough to see a close friend.

What Causes CFS?

The jury is still out on what CFS is. A few years ago, because nothing tangible could be seen under a microscope, some psychiatrists put forward the view that CFS was a psychological problem of 'learned helplessness' - that is, after an initial bout of illness, patients had 'learned' to be tired all the time. This was also referred to as a 'dysfunctional illness belief'. Unfortunately, this did a lot of damage and patients

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still suffer with the stigma of being labelled 'malingerers', 'lazy', or having a 'psychological illness that is all in the mind'. One author, Elaine Showalter, even wrote a book called *Hystories* in which she suggests that CFS is a cultural narrative expression of hysteria: a kind of modern social problem maintained by some doctors and support groups.

Luckily, we live in much more enlightened times and there is now hard scientific evidence that CFS has a physical origin. Nevertheless, because CFS is a chronic, disabling illness, some people may suffer with depression as a result of the restrictions and pain the illness places on their lives. Yoga, of course, sees us as 'whole' beings. In other words, mind, body and spirit are all linked, and whatever affects the mind or spirit will affect the body. The exercises given later help to address this 'holistic' approach to managing CFS.

It is generally agreed that CFS may be triggered by one or more of the following:

- A viral infection, such as flu, Epstein Barr or other virus, combined with not taking adequate rest to recover.
- A bacterial infection such as chlamydia, mycoplasma or helicobacter pylori.
- Exposure to environmental toxins such as organophosphates or mercury amalgams.
- An inoculation.
- Shock.
- Prolonged stress, combined with one of the factors above.

In 1998, the UK's Chief Medical Officer, Sir Kenneth Calman, said:

'I recognise Chronic Fatigue Syndrome is a real entity. It is distressing, debilitating, and affects a very large number of people.' This was then confirmed in January 2002 when, after a three year study, the UK's chief medical officer, Sir Liam Donaldson, published a report recognising ME/CFS as a 'real' and 'disabling' illness.

The World Health Organisation classifies CFS as a disease of the central nervous system. Current research indicates that CFS is initially a problem of the immune system and that for some reason - perhaps, for example, because of a virus,

combined with being run-down and under stress - parts of the immune system do not switch themselves back off again. In this way, the immune system is chronically activated - even if the initial virus has disappeared. There is some evidence of raised levels of cytokines and activated T lymphocytes (parts of the immune function) in some people. This episodic immune dysfunction is, in itself, very tiring. If this scenario continues, it eventually causes damage to the hypothalamic-pituitary-adrenal axis (HPA), part of your central nervous system (CNS). This affects nearly every function in the body. Your CNS is centred in your brain and spinal cord and is made up of millions of nerve cells, or neurons, which send messages around the body. The CNS controls bodily functions such as breathing, heartbeat and digestion, and all sensory perception such as pain, pleasure and the control of muscle movements. An example of this would be how the CNS affects our stress mechanism, or 'fight and flight' response, which we saw in Chapter 1. The autonomic part of your nervous system is needed to switch your stress response 'on' and 'off'. If it is not working properly, this may not happen.

Other symptoms such as fatigue, sleep disorders and poor temperature control are all consistent with hypothalamic dysfunction. The hypothalamus is in the brain, and you may remember that some of the yoga exercises, such as Alternate Nostril Breathing, can help to regulate its function.

Dr Andy Wright, who runs a CFS clinic and is an expert in chronobiology (the science of keeping in tune with our body's natural rhythms) says: 'Heart rate variability studies have shown that there is an excess of sympathetic over parasympathetic tone. This means that a constant biological stress message is present in the body.' Dr Wright is referring to research which shows that parts of the CNS are over-activated, which, in turn, causes those with CFS to become hyper-aroused to stimulation, which exhausts them very quickly.

I once had my central nervous system tested on a machine called a 'Heart Rate Variable' monitor. The results showed that my CNS was, indeed, dysfunctional. Dr Ian Hyams, who also runs a CFS clinic, asked me to come back a week later to see if I could vary the reading, using yoga techniques. He was amazed when, after a period of deep meditation and relaxation, I showed a much more normal reading. In other words, yoga can help to calm and normalise your central nervous system,

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which, in turn, is going to have a profound and positive effect on your health.

Dr Derek Pheby, an epidemiologist and member of the UK Government's key Group of CFS/ME, says: 'Such changes have been demonstrated affecting, for example, the autonomic nervous system. Another significant change is in the hypothalamic-pituitary axis, the mechanism by which the brain controls the functioning of the pituitary gland and hence the endocrine system.' This then brings us to your hormone system. Your pituitary gland (part of the HPA axis) is often referred to as the master gland, as it controls all your endocrine functions, and this involves everything to do with your hormone production.

Your hormones are chemical messages, which travel via your bloodstream. They bring together all kinds of bodily mechanisms including your emotional responses. Various trials in America have shown, for example, that many of those with CFS put out either too high or too low levels of DHEA and cortisol, which are hormones produced by the adrenal glands. Research has shown that this constant biological stress causes adrenal fatigue. MR scans of the adrenal glands of those with CFS have shown that there is actually a reduction in adrenal gland size in some cases. You may remember from Chapter 1 the role that your adrenal glands play in dealing with stress. This explains why those with CFS can't deal with pressure very well without becoming ill.

In another example of endocrine dysfunction, some people with CFS may suffer with an underactive thyroid. Your thyroid produces hormones that convert your food into energy and help to convert oxygen into your cells. Your thyroid gland also affects your metabolism, fertility and body temperature. Other hormones, such as melatonin, which affects your body clock and sleep, may also be affected by endocrine dysfunction.

Yoga can help to normalise your hormone system, and many of the postures work to balance the various endocrine glands throughout the body. For example, the Shoulder Stand helps to stimulate the thyroid gland, and some of the backward bends can help to normalise your adrenal system.

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CFS, Poor Circulation and Oxidative Stress

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Yet more research using brain scans shows that CFS patients have a lack of blood-flow to the brain stem. This seriously affects brain function. Often, someone with CFS who is tired, or has overdone things, will become very pale and find it difficult to concentrate or find the right words. This indicates a lack of circulation to the brain. Blood is literally draining away from the head. All the inverted postures in this book will help to remedy this. This is a reason why I recommend that anyone with CFS does an inverted posture such as the Half Shoulder Stand every day. Generally, yoga will help with mental focus and problems such as 'brain fog' - one of the more distressing symptoms of CFS.

Some studies have shown that those with CFS have a reduced capacity to convert oxygen efficiently, which is a measure of aerobic fitness, or how well the body uses oxygen. Again, the yoga breathing exercises given in Chapter 4 will greatly improve your energy, by helping you to convert oxygen more effectively into your cells.

Finally, many experts believe that CFS is related to something called 'oxidative stress'. Professor Majid Ali, a leading researcher in New York, puts forward the thesis that all of the co-factors described in this illness (immune dysfunction, CNS and endocrine abnormalities etc.) contribute to a total burden of oxidative stress. Put simply, the implications of this are that you have too many free radicals in your body, which are then not eliminated properly, because those with CFS seem to have problems with detoxification. This, in turn, means poor oxygen transportation to your cells, poor oxidation in cells, the build up of acids in the body and blocked lymph glands. Your lymphatic system detoxifies your body by carrying waste products out of your system. However, it only moves with your circulation or with exercise. Dr Andy Wright explains: 'Further clogging of the lymphatic system, I feel, could be due to immune hyperactivity.' All the yoga postures work on stimulating the lymphatic system gently, which is why yoga is so effective in detoxifying your system.

To summarise then, if CFS is a disease of the immune system, central nervous system and endocrine functions which contribute to oxidative stress, you can perhaps see why yoga can have such a beneficial effect for those with ME or CFIDS.

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To Exercise or Not?

Quite simply, if you have CFS and you attempt too high a level of activity, you will relapse. This can then make you avoid activity altogether, which will bring its own set of problems, such as muscle wastage - and yet more fatigue, because your body needs some activity to convert your food into energy. The subject of exercise is very controversial for those who have CFS. In most cases, prolonged aerobic exertion will push you into a relapse ('aerobic' means an activity that raises your heart rate). In a paper demonstrating the organic basis for CFS, Dr Andy Wright says: 'Giving general advice to simply increase aerobic exercises incrementally often makes people worse. Exercise capacity is reduced. This is partly secondary to an inability to achieve maximal predicted heart rate. This is thought to be due to autonomic dysfunction.'

Dr Cheney, who is Professor of Medicine and Chair of the Nutrition Department at Capitol University, Washington, and one of the leading experts of CFS in America, explains that the aerobic system in CFS is injured and that aerobic exercise past a certain point can dramatically worsen CFS. In the UK, many of the hospitals that treated those with CFS in the 1990s used programmes called 'graded' exercises, where patients were forced to do a bit more physical exercise every day, no matter how ill they felt. This was based on the idea that people with CFS had 'unhelpful illness beliefs' about what they could or couldn't do. Under this regime, many relapsed. Today the view is that people with CFS should combine rest with gentle activity on the days when they feel well enough. Perhaps if I explain my own story, you can see how yoga can be effective in fulfilling the so-called 'activity' criteria.

In 1992 I was hospitalised with severe CFS. Part of my treatment was graded exercise. My experience of this was mixed. On the one hand, it helped me to get physically stronger and develop muscle strength, which meant that I could walk again. On the other, on days when I exercised, I simply had no energy left for anything else and sometimes I felt much worse. I was lucky; I worked with an understanding physiotherapist who didn't push me. If I relapsed, I was allowed to bed-rest until I felt stronger. Physiotherapists who are not flexible in this are at risk of pushing their patients into further ill health. When I came out of hospital, I joined a remedial yoga class, which was brilliant because it allowed me to work within my own boundaries. Nobody ever pushed me to do more, and if I was too ill

to attend a class, I could usually do a few stretches at home. This then helped my health to steadily improve.

My personal view is that those of us with CFS need to attempt some kind of activity within our boundaries, but the old-fashioned view of rigid graded exercises is unhelpful. Graded exercise programmes only work if they are flexible and take account of the individual's fluctuations. Graded exercises can be harmful for some if the practitioner has not recognised the physical limitation of CFS and assumes the illness is due to deconditioning because of 'illness beliefs'. Practitioners should always listen to their patients, rather than pushing them to the point at which they 'crash'. I think a quote from Dr Mason Brown, who has recovered from CFS himself, sums up the situation on graded exercises quite well: 'Being scientifically logical, would any doctor treat a patient with angina of their heart with only graded exercise...? No. Then, why in ME with recurrent decreased brain and pituitary circulation, treat it with only graded exercise...? It is illogical.' Dr Brown goes on to explain that exercise has to be appropriate to the patient's health and paced with rest.

In a report carried out by Action for ME and the ME Association, out of over 1,000 people questioned with severe CFS, 50 per cent said that graded exercise made them worse, and only 34 per cent said it made them better. (The rest said it made no difference.) The conclusions of the survey were that, for some, complete rest is helpful, but this can include relaxation (such as the Pose of Complete Rest), as opposed to bed-rest. However, excessive rest can also be harmful, simply because muscles become deconditioned. Short walks, breathing exercises and gentle yoga are recommended by the charity for those who are well enough - but the most important feature in coping with, or overcoming, CFS is in pacing your activities. In the survey, almost all had tried pacing their activities and 90 per cent reported that this had helped them.

Action for ME advises against embarking upon graded exercises where increases in activity are imposed with no regard to the patient's reaction. Instead, they recommend that you rest in the acute stage of your illness, then experiment with the level of activity (physical and mental) that you can manage, without causing a relapse, then gradually increase this only if you don't feel any worse. The more

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why yoga works for CFS

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With any chronic illness such as CFS, it is important to maintain some mobility, if at all possible, as this can create energy and stop muscle and joint atrophy. I hope I have convinced you by now of the value of practising yoga if you have CFS. It is an activity you can do at home, which costs you nothing, and which you can practise entirely within your own limits. Also, as we have seen, CFS is a disease affecting immune, CNS, endocrine, circulation and detoxification functions. Yoga helps to normalise and regulate all of these systems. We have also seen that aerobic exercise may be harmful for CFS sufferers. However, according to Professor Cheney, the anaerobic pathway is largely intact with CFS. That means that gentle stretching, such as in yoga, can maintain muscle tone and strength and improve the elimination of toxins - without provoking a relapse. Yoga postures are of great benefit because, as well as keeping your whole system going, they also create a proper exchange of oxygen with other gases in your blood, so that your cells can burn up the food you have eaten and convert it into energy

In particular, yoga helps CFS because it:

- helps to calm the central nervous system, especially through the relaxation exercises;
- uses meditation, relaxation and visualisation exercises, which help the brain to go into an Alpha state, where brain waves slow down. This is deeply healing and an antidote to the 'fight and flight' mechanism;
- reduces stress in many ways;
- increases mental focus and helps with 'foggy head' and cognitive problems;

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- helps to transport oxygen more efficiently to the cells, thereby giving you much more energy - the breathing exercises are particularly good for this;
- counteracts any problems caused by hyperventilation by teaching correct breathing control;
- helps normalise endocrine function - the postures are particularly good for this;
- helps to detoxify the system by gently stimulating your lymphatic mechanism;
- generally improves your lungs and circulation system;
- strengthens organs, bones, joints, muscles and spinal cord;
- improves digestion - irritable bowel syndrome and allergies are often common problems in CFS;
- gives you more energy, rather than using it up like normal cardiovascular exercise;
- offers the benefits of exercise, but in a gentle way that won't trigger a relapse;
- works on your chakras, or energy centres;
- may introduce you to the spiritual philosophy, giving a more positive meaning to your life.

The beauty of yoga is that you can practise it at any level - without ever overdoing it - as one of the principles of yoga is listening to your body and keeping within your limits. So, if you have severe CFS, you can do breathing and relaxation exercises - and maybe, on a good day, some gentle stretches. Whatever you do however, you need to listen to your body and be aware of your limits. It's the law of diminishing returns - you reach a point at which you gain maximum benefit from yoga. Push yourself any further and you could trigger a relapse. You have to decide what that point is, and never be tempted to cross it.

Remember to Pace Yourself

When considering any form of exercise, the idea of 'limit setting' or pacing yourself, as we saw in the last chapter, is probably the most important thing you can do. Professor Cheney says about activity in general: 'Find the boundaries of what you can do and then stay within them. Both trying to do too much, and doing too little are counter-productive. People with CFS are very susceptible to the push-crash phenomena and you need to stay within certain boundaries. To the extent you do

that, you will tend to do better.' In other words, yoga will make you better, providing you don't over-do things.

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Listen to Your Body and Set Your Limits

So, remember - you can do yoga postures at your own rate, according to your level of health. There is *no* competition, so you don't have to push yourself into relapse. The first step is learning to listen to your body so that you can take note of how you feel and pace yourself on that particular day. Work out your own yoga programme, using the guide below. You may start with just breathing, stretching or meditation. Always do less than you think you can do. For example, if you feel well enough to do 20 minutes of yoga postures, do only 10 minutes - and if you think you can do 10, just do five. Five minutes a day is better than no minutes and is a base on which to build. Aim to work slowly, to add perhaps an extra posture every month. Don't be tempted to do too much on a good day. If you are having a bad day, or a relapse, or are very ill, then just practise the relaxation and breathing exercises. People with CFS tend to be perfectionists - we want to be the best. But think of your yoga practice as learning that you don't need to think like this any more. Your best is what you can manage, and no more. As long as you build up your muscle tolerance slowly, set yourself small, achievable goals, pace yourself, keep to your limits and are patient, you will find that gentle yoga helps tremendously. The road back to good health will be long and slow - but yoga will take you in the right direction.

If you have mild or moderate CFS, you may be able to do more, perhaps even join a class. A word of warning - do find the right teacher. Iyengar or Ashtanga yoga, for example, will be too dynamic for most people with CFS and could put you off yoga for life! All the yoga in this book is based on classical yoga. I would, however, advise you not to join an ordinary yoga class until you have made considerable progress in your recovery; it is too easy to overdo things and relapse. Either join a remedial class or follow the postures in this book that you feel well enough to do at home. Angela Stevens (see Useful Addresses) has a list of yoga teachers who specialise in teaching CFS sufferers in the UK.

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How to Approach Your Yoga Practice

- Set yourself a programme of rest and activity times throughout the day. Include in this one gentle session of yoga, according to your level of health.
- Remember that mental activities count as well as physical ones.
- When your energy levels are good, take advantage of this, but do *not* push yourself beyond your limits.
- Find your baseline - how much yoga you can do - and don't cross this for several weeks, until you are confident in adding a few more stretches.
- On a good day, do not be tempted to do too much. Remember, CFS fluctuates, so don't go mad! Pacing is about discovering your limitations and learning how much you can do, without triggering a relapse.
- Remember - yoga is not just about doing physical postures. Relaxation, breathing exercises, visualisations and meditation are all part of yoga, so on a day when you feel physically drained, you can still do some yoga practice.

You need to learn to tune yourself in - to be aware of the difference between a 'healthy' tiredness and the 'unhealthy', poisoned feeling you get after too much activity, or if you have pushed yourself too far. Listen to your body. Remember that a relapse from overdoing things can occur up to three days after activity. Also, please remember that we are all individuals. I am not with you, and even if I were, I am not in your head, so to speak, so I can't understand your particular health restrictions. Only you can work this out for yourself, so you need to be very clear in how much activity you do. To help you, I am going to describe Professor Findley's parameters of CFS, so that you can decide which category you fit into, and then be guided by how much yoga you do according to that.

The Different Levels of CFS

Professor Findley, a neurologist, who runs an ME clinic in the UK, categorises ME (his term for CFS) into the following:

Mild ME - Sufferers are mobile and can take care of themselves, doing light domestic tasks. They may be able to work, but to do so, will have stopped all leisure and social activities, often using the weekend to rest.

Moderate ME - These are people who have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs during the day. They usually cannot work and require rest periods, often sleeping in the afternoon. Sleep quality in general is poor.

Severe ME - This group can only carry out minimal tasks such as brushing teeth. They have severe cognitive difficulties and will be wheelchair bound. They are usually unable to leave the house and will have severe after-effects from any effort.

Very Severe ME - Sufferers are not mobile, cannot carry out any task for themselves and are in bed for most of the time. They cannot tolerate noise or bright light.

Clearly then, ME or CFS affects all of us in different ways - from those who can have a reasonable quality of life, through to those who are completely disabled and crippled by this illness.

In the following sections, I am going to use Professor Findley's categories and recommend a yoga programme for each one. From this, you can select the yoga routine that you think will work best for you, but please bear in mind your own individual response and fluctuations - and always start by doing less than you think you can do before you build up. Also, you can 'pick and mix' from the different categories, depending on how your health varies. What you will find, over a period of time, is that if you can practise a little bit of yoga every day, then your health will start to improve and you will have much more energy. Remember to always start and finish with a five-minute relaxation posture, such as the Pose of Complete Rest.

Mild CFS

If you haven't done any yoga before, you may like to try the postures listed under Moderate CFS first, to see how you react. You may also like to try the yoga DVD I have made with another teacher to go with this book (see Useful Addresses). If you are fine with these, then an excellent programme to try is called 'The Rishikesh Sequence', a classical set of gentle postures that provide a complete workout. I have modified this for those of you who have not done yoga before, to make it

slightly easier. For example, I have replaced the Full Shoulder Stand with the Half Shoulder Stand, the Pose of Tranquillity has replaced the Plough and the Cobra takes the place of the Sphinx.

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