

## **Understanding Chronic Fatigue Syndrome**

### **South West London and Surrey Chronic Fatigue Service**

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#### **What is Chronic Fatigue Syndrome?**

Chronic fatigue syndrome (CFS) is an illness characterised by:

- Extreme fatigue
- Post exertional malaise
- Sleep disturbance and non-restorative sleep
- Swollen glands and/or sore throat
- Muscle and joint aches and pains
- Impaired concentration and memory
- Mood changes

It is possible to have other illnesses at the same time such as fibromyalgia, irritable bowel syndrome, gynaecological problems, diabetes, anxiety, depression etc.

#### **What causes Chronic Fatigue Syndrome?**

It is not fully understood why people develop CFS but there are some possible causes. These include:

- Persistent viral infection
- Immune disturbance of unknown cause
- Disturbance of the HPA (hypothalamic pituitary axis)
- Primary muscle/nerve disease
- Primary central nervous system disease
- Autonomic nervous system disease
- Neural hypersensitivity syndrome
- Prolonged and persistent stress

## **What are the physical effects of Chronic Fatigue Syndrome?**

The increased fatigue that people with CFS experience usually leads them to take prolonged rest. This prolonged rest has physical consequences. Medical investigations show that there is no disease cause for these physical symptoms, they occur as a direct result of inactivity and prolonged rest.

The physical effects include:

- Changes in muscle functioning resulting in pain and discomfort
- Changes in body temperature, for example hot flushes and night sweats
- Reduced calcium levels
- Reduced ability to exercise
- Deconditioning of heart and blood vessels
- Impairment of immune system leading to reduced ability to fight off viral infections
- Changes in body rhythms effecting secretion of hormones leading to problems with sleep, appetite and alertness
- Changes in the nervous system causing neural hypersensitivity leading to problems such as intolerance to sound and light
- Changes in mental function such as reduced concentration or impaired short term memory

## **Are stress and anxiety involved in Chronic Fatigue Syndrome?**

Having CFS may be very stressful, not only may a person be feeling unwell but they may also be dealing with other concerns related to their illness, such as financial worries caused by reducing or stopping work, or concerns about the effects their illness is having on their family.

Anxiety is a normal physical response to a stressful situation. When someone is anxious there is increased activity of the central nervous system causing higher levels of adrenaline in the blood stream. Physical symptoms result which include:

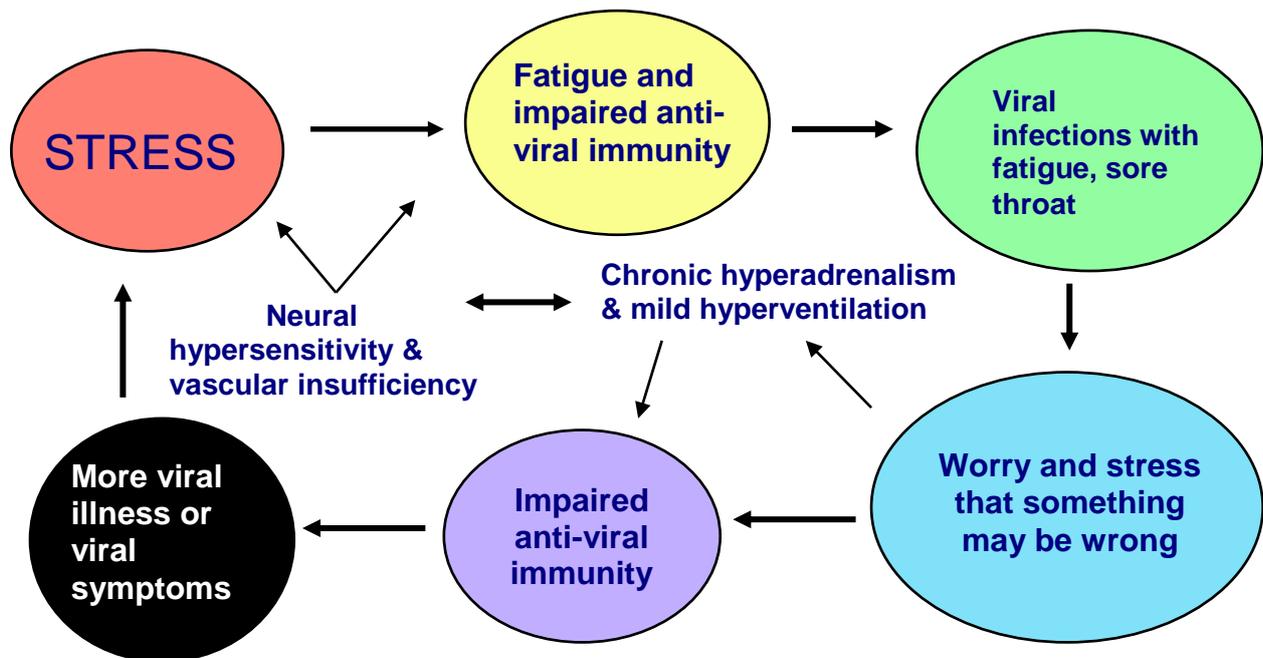
- Increased heart rate
- Breathlessness leading to light-headedness, dizziness, faintness, feeling unsteady, blurred vision, pins and needles, muscle spasms, sensitivity to light and noise etc.
- Alteration in blood flow
- Muscle tension

- Visual disturbances
- Sweating
- Sleep disturbance
- Changes in mental functioning such as irritability, forgetfulness, restlessness and rumination

## What is the relationship between fatigue, stress and worry, the immune system and the autonomic nervous system?

- Stress, depression and persistent anxiety are able to reduce the effectiveness of the immune system which is required to contain or keep in check previously acquired chronic viruses
- Those with CFS may enter a cycle of stress and worry leading to an increase in their adrenaline levels. The increase in adrenaline can impact on the sensory perception of the nervous system leading to sensory stimulation being interpreted at a higher than normal level. This is referred to as **neural hypersensitivity**.
- The situation is compounded by mild hyperventilation arising from the stress, worry and increased adrenalin levels.
- Examples of neural hypersensitivity include:
  - severe pain and tenderness of the legs following a brief walk
  - exposure to normal light or 'white noise' may feel as though one has been gazing into the sun or been listening to amplified noise
- This neural hypersensitivity can precipitate increased fatigue, headaches or irritability further increasing stress and worry
- This increase in stress and worry impacts negatively on cellular immune function which can lead to re-activation of a viral infection. In turn this may cause a sore throat and swollen lymph nodes/glands or the original symptoms such as nausea, vomiting, diarrhoea as well as worsening of fatigue and flu-like symptoms. This may cause fears about a serious illness that causes further stress and impaired cellular immune function
- This cycle then repeats itself leaving a person feeling both physically unwell and mentally fatigued as symptoms continue to worsen. **This cycle needs to be broken**

The diagram below represents the relationship between stress, fatigue and the autonomic nervous system.



Note that the cycle is capable of being blocked at several points.

In particular measures to reduce stress levels are important. These will reduce adrenaline hypersecretion and hyperventilation as well as restoring immune function. Eliminating negative thinking appears especially capable of restoring normal endocrine and immune function. Anti-viral drugs may reduce in some patients' symptoms of fever, fatigue and aching and block the cycle. Other drugs may stimulate normalisation of the disturbed immune pathways.

**Reminder:** the important functions of the immune system in terms of combating severe infections are totally normal and there are unlikely to be signs of immunodeficiency in patients with CFS.

### How can Chronic Fatigue Syndrome be managed?

As there is no magic wand cure for CFS, management of symptoms is aimed at breaking the virus, stress, fatigue and autonomic nervous system cycle; to aid recovery and improve one's quality of life. However, making changes is initially challenging but should help you to improve your overall quality of life in the longer term. Making changes is a bit like getting a new pair of slippers, they may not be comfortable at first, but over time the more you wear them the more comfortable they become. Making changes and forming new habits can be uncomfortable but eventually they can become second nature just like the old ones.

Using a biopsychosocial model of care provides a framework which addresses all aspects of one's life to promote lasting change.

This is achieved through implementing a range of techniques and strategies which include:

1. Cognitive behavioural therapy
2. Deep relaxation/Mindfulness
3. Pacing and grading activity

4. Graded exercise therapy
5. Medications

## What is the Biopsychosocial model?

**'Biopsychosocial'** is a term we use to understand the various factors that affect people with CFS/ME. As you will have experienced, your CFS/ME causes many different symptoms and influences many different parts of your life.

For example, when you have CFS/ME you are:

- physically unwell and have several **biological** symptoms – fatigue and pain
- you may feel less like your normal self and more unhappy – **psychological**
- you may not feel able to see friends as much – **social**

Whatever is happening to your body **physically** (e.g. fatigue, pain, dizziness) is also having a knock-on effect **psychologically** (changes in the way you feel and behave) and **socially** (changes in activity, working life, seeing friends). It is important to understand how CFS/ME affects these aspects of your life (not just the physical symptoms) in order to help you improve the quality of your life.

### 1. What is Cognitive Behavioural Therapy (CBT)?

**'CBT'** is a model used to help explain the interactions between our cognitions or thoughts, our behaviour and our feelings and physical states.

CBT has been used as an aid to help in management of other conditions such as chronic pain, cardiac rehabilitation, diabetes, and cancer as well as anxiety, depression and phobias.

Looking at thoughts and feelings does not mean that CFS is a psychological problem or that it is 'all in your head'.

Sometimes it can be difficult to distinguish our thoughts from our feelings. A simple rule of thumb is that you can usually sum up a **feeling** in **one word**, whereas a **thought** usually takes a **few words**.

Some **feelings** associated with CFS might include:

- Fear
- Anxiety
- Depression
- Frustration
- Anger

If this is how you are **feeling**, how does it affect your **thinking**?

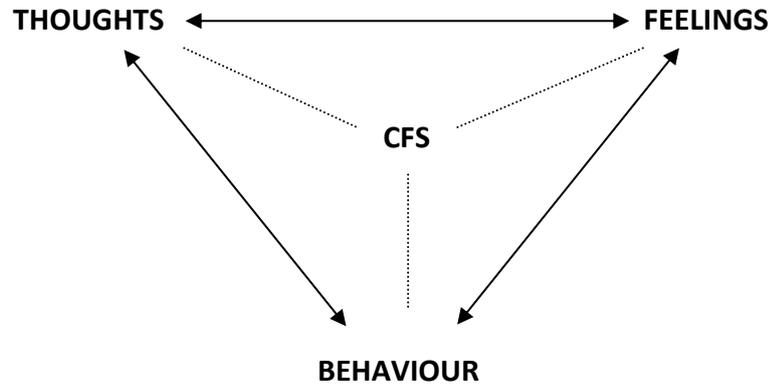
- Under estimating control
- Personalisation
- Catastrophising or getting things out of proportion
- Self-blame/blaming others

If you are **thinking** these things, how do you **feel**?

Does this have any effect on your behaviour - what you do?

Do all these things affect your CFS?

The diagram below represents the CBT model and CFS



Being able to explore ones thoughts, feelings, behaviour and physical state provides a means for making and maintaining changes for recovery.

## 2. Why is deep relaxation important?

People with CFS often have a state of mental hyperactivity that makes sleeping difficult and also impairs their concentration and short term memory. This means that they are unable to truly relax and in consequence they suffer a heavy and draining demand on their mental and physical energy.

Interestingly, this persistent neural hyperactivity may explain the phenomenon of ‘crowding’ and ‘brain fog’ that many patients with CFS suffer in crowded or busy situations.

For these reasons it is important for those with CFS to practice some form of deep relaxation therapy daily. This can be done using guided relaxation, mindfulness, meditation, yoga or self-hypnosis,.

An easy and economical way to get started with deep relaxation is to purchase one of the widely available relaxation CD’s that use techniques such as breathing exercises, visualisation and muscular relaxation exercises to help learn to relax.

## Why are breathing exercises recommended in Chronic Fatigue Syndrome?

- It is thought that some people with Chronic Fatigue Syndrome may be burdened by hypocapnia – reduced levels of blood carbon dioxide.
- This can be unnoticeable to an individual. Even minor degrees of over breathing can, over a period of time, lead to a significant reduction in the level of carbon dioxide in your blood. This causes an alteration in the level of ionized calcium in the blood as well as other important substances.

- Low levels of carbon dioxide can lead to a constriction of several important blood vessels. This is especially important in the case of the central nervous system. It is possible that constriction of blood vessels may contribute to a sensation of being remote from the environment as well as tiredness, pins and needles in the hands and feet and an increase in pain levels.
- Controlling the rate of breathing and correcting the low carbon dioxide level could therefore be an important part of the therapy used in the management of Chronic Fatigue Syndrome.

The control of breathing has been found helpful by several of our patients with severe Chronic Fatigue Syndrome where, in addition to relieving the tiredness, it has helped to reduce muscle aching and spasms and contributed to an improvement in concentration and stamina

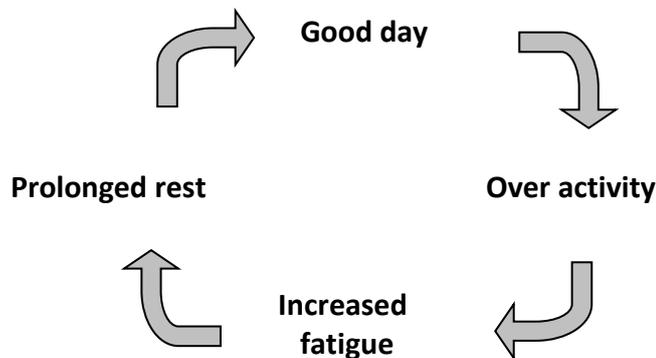
### 3. Why is pacing and grading activity important?

Pacing and grading activity can help those with CFS break the **Activity Cycle**.

Often people with CFS/ME describe having varying amounts of energy from one day to another or even within the same day. A lack of control of this energy may be experienced with an inability to decide whether or not to attempt an activity. This lack of energy may lead people to attempt to do too much on a 'good' day and much less on a 'bad' day. After a period of rest, feelings of frustration and despair often follow this. This is referred to as the **boom and bust cycle** or **activity cycling**. This can interfere with improving energy levels and contribute to maintaining fatigue.

Pacing and grading activity can help those with CFS to do the same amount of activity each day so breaking the boom and bust cycle.

A diagram illustrating the activity cycle



### 4. What is Graded Exercise Therapy?

We know that for some individuals with CFS in the early stages of their illness they experienced prolonged periods of inactivity and there are others for whom their level of physical activity has decreased significantly over time. This can lead to general loss of strength and stamina, weight gain, joint pain and impaired function known as 'deconditioning'.

Graded exercise is a systematic programme of exercise designed to overcome the effects of deconditioning. An individual programme of graded exercise is usually devised by a physiotherapist or occupational therapist and once established can be continued on your own at home.

## **5. Are medicines useful in Chronic Fatigue Syndrome?**

There is no cure for CFS but sometimes medicines may be used to help relieve symptoms or aid recovery.

Due to the nature of CFS and the multiple sensitivities some individuals' experience, many people with CFS are intolerant to any drug therapy leaving no alternative but lifestyle management.

To date the only research based evidence supported by NICE (National Institute for Health Care Excellence) for the management of CFS is graded exercise therapy and cognitive behavioural therapy.

Of those patients who are able to tolerate medication and have shown improvement, the effect is not always long lasting.

Benefit with medication is usually seen within the first four to eight weeks. If there is no benefit within this period it is unlikely that the therapy is going to work.

### **What medicines are used in Chronic Fatigue Syndrome?**

Different medicines are used depending on the symptom being treated. We would encourage your GP to access the British Association for CFS/ME: Therapy and Symptom Management in CFS/ME

[www.bacme.info](http://www.bacme.info)

## Getting Started - Managing Your CFS/ME.

### South West London and Surrey Chronic Fatigue Service

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Following a diagnosis of Chronic Fatigue Syndrome (CFS/ME), people often describe experiencing a number of mixed feelings. These may include feeling relieved that their symptoms are finally validated and at the same time feeling anxious, or angry, or sad in relation to learning to live with a chronic condition.

There is often a lot of information to take in at this stage. Most of the information we share on the management of CFS/ME is covered in our comprehensive website [www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome](http://www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome).

This handout has specifically been designed to help you know what you can do to get started in managing your CFS/ME symptoms and includes information on:

- Activity Management
- Sleep Management
- Implementing Rest and Relaxation
- Breathing exercises

### Activity Management

CFS/ME symptoms often fluctuate which can have a direct impact on what you feel you can do in your day. It is common for people to report that they find themselves doing more on their 'good days' which increases their risk of post exertional malaise often resulting in being able to do little or rest for long periods to recover. This activity pattern is called 'boom and bust'.

Some people with chronic fatigue no longer have good days and end up being able to manage low levels of activity only with long rest periods. Avoiding or reducing what you do as a way of controlling your symptoms often may help in the short term; however, it can prevent you from longer term gains of energy improvement. Prolonged rest can produce weakness and loss of strength (deconditioning) and fatigue. It can also result in a reduction of activity, feelings of demoralization, loss of control and a very restricted life.

- The first important goal is to establish a consistent level of activity across the week.
- Doing too much or too little are both problematic with the management of CFS/ME.
- An activity diary is a useful way to help you to record the time you spend in activity, rest and sleep each day over the course of two weeks.

**(See Completing Activity, Rest & Sleep Diary information pack).**

You can use this information to calculate your baseline (or an average) of how much activity you can do on a good and a bad day (that causes less suffering related to your fatigue).

This may result in you:

1. Reducing your activity in the first instance
2. Learning how to pace your activity with small chunks of activity followed by rest breaks

### 3. Using a graded/incremental approach to increase your activity.

The diaries can also help you aim to establish consistency with your rest and sleep at night. (See the rest and sleep sections in this handout). Another way to establish a consistent activity level is by using a step counter.

Once you have successfully stabilised your activity (which may take several weeks), you can then start to gradually increase your activity. An incremental approach is recommended where every 2-3 weeks, you can increase your activity by no more than 10-20%. If you experience a bad day with your CFS/ME, it is recommended to remain at your activity level (with an increase in rest breaks) and delay any planned incremental increase.

**Remember to try to include a pleasurable or meaningful activity daily.**

## Sleep

### Sleep Management

Difficulty with sleep, e.g. unrefreshing sleep, is common for people with CFS/ME. Often people think that if they are tired they need sleep, but fatigue in CFS/ME is not improved by sleep.

The quality of sleep is likely to have a significant impact on fatigue levels during the day. Here are a few key tips for improving your quality of sleep:

- Establishing a regular sleep pattern is very important so try to wake up and go to bed at the same time (within an hour) to synchronise your body clock.
- Have a wind down period prior to going to bed to help cue your body it is time to sleep, e.g. stop work at least 30 minutes before going to bed and do something non-stressful, e.g. read, have a bath, listen to music, listen to a relaxation CD.
- Try to use your bedroom only for sleep. Activities such as reading, eating, watching T.V., and talking about problems are likely to make you associate bed with wakefulness and alertness which may interfere with you getting to sleep.
- Avoid cat napping during the day as this can lead to over sleeping or not being able to sleep at night.
- Make your sleeping environment conducive to sleep. Minimise noise and light, bedroom temperature should be cool, take a light bedtime snack such as a warm glass of milk or a banana, avoid stimulants like caffeine after 4pm, or write down any worry thoughts before you go to sleep.

Resolving sleep problems takes time and requires effort. Try one thing at a time and whilst your sleep routine may never be perfect, any improvement in your sleep routine can be beneficial and can lead to an improvement in CFS/ME symptoms.

## Implementing Rest and Relaxation.

Rest is an important aspect of pacing activity. We can say that we are resting when there is minimal brain and body activity and when we are “re-charging”. Relaxation is a form of rest. All activities require some level of energy. Activities such as watching television and reading are still quite demanding in terms of energy use although are less demanding than going out shopping or doing housework. Sleep is not as

effective for rest as relaxation. People often have poor quality sleep, may be moving around or dreaming and therefore using up energy.

- Taking short regular frequent rest breaks throughout your entire day can help sustain your energy across your day.
- Rest is about reducing stimulation both mentally and physically. – Quiet time.
- You can rest sitting up or lying down. Try not to rest on the bed you sleep on as you are more likely to fall asleep.
- Have a go at implementing short frequent regular rest breaks throughout your day. (i.e. 5 – 10 mins) dispersed between activity.
- Try to be proactive with your rest breaks; don't wait until you have run out of energy.

Relaxation is an ideal form of rest as it enables the body to re-charge and to gain back some energy. As well as providing effective rest, relaxation helps in the management of anxiety by decreasing muscle tension and stressful thoughts. It can also help reduce adrenaline levels and therefore reduce the likelihood of hyperadrenalinism (raised adrenaline) which results in symptoms such as brain fog, mental crowding, impaired attention and therefore memory, fatigue and general symptoms of adrenaline such as pounding heart, pins and needles, temperature fluctuations.

Relaxation helps with fatigue and improving the sleep patterns as well as preventing 'sensory overload'. Relaxation is an important tool in helping people with pain control. Incorporating regular rest and relaxation breaks into your daily routine assists with pacing activities, helps restore energy and enables you to feel more in control of managing your symptoms.

- Daily – set a manageable goal. E.g. 10 minutes a day.
- Try to schedule a relaxation break earlier in the day; this may reduce likelihood of falling asleep.
- Avoid undertaking directly after meal times or using your bed (sleep space) as you are more likely to fall asleep.
- If you are likely to fall asleep – set an alarm.
- Trial various techniques to find the style that will suit you and will be easier maintain, e.g. breathing exercises, visualisation, progressive muscular relaxation. Guided relaxation in the form of "You Tube", smart phone apps or CDs may be helpful.
- Be comfortable – warm environment, consider a supported sitting or a lying position.
- Remember, relaxation is not watching TV, reading, listening to music.

People differ in the techniques that they find useful so it can be worth trying several. Relaxation is a skill and takes time and practice, so it is important to persist with it. The more opportunity you have to practice, the more benefit you will notice. Lying positions give a great deal more rest than sitting positions. Remember that rest is giving the brain minimal information from the body or from the mind. When you sit your balance reactions are constantly sending information to the brain. When you lie down the amount of information is greatly reduced. Remember also that closing your eyes reduces the amount of information being sent to the brain.

**Getting Started with Relaxation** - This is a good way to start any relaxation: Find a comfortable position; this may be lying down or simply sitting in a chair. Gently close your eyes and allow yourself to be still – still in your mind and still in your body. Wait a couple of minutes. Focus lightly on your breathing. Don't try and control it in any way, just be aware of its rhythm as you breathe in and out. In your own time, take a deeper breath in, hold for just a moment and breath out. On each out breath, try to let go of any tension. Allow your breathing to return to its normal pattern

## Progressive Muscle Relaxation

This exercise involves the systematic tensing and releasing of all the major muscle groups in the body. As well as allowing you to relax, this can help you become more aware of the sensation of tension in your own body. Starting at your toes and working right through the body one muscle group at a time, up to your head and face, gently tense, hold for a second focusing on this tension and then release, noticing the difference and how this feels as any tension flows out.

Remember to tense the muscles only moderately and stop immediately if you feel any discomfort.

## Mindfulness

Minds are busy and tend to wander and this can be particularly apparent once you stop other activity. This will happen as you relax and it is important to be aware of this and not give yourself a hard time when this happens, but just notice it and bring your mind back to your breathing or to the technique that you are using. If this is a particular problem for you, you may wish to try techniques that engage your mind such as visualisation or guided imagery.

## Visualisation

Start with the getting started exercise above. Now imagine yourself in a favourite calm and peaceful place. This may be real or imagined. Try to use all your senses, focusing on sight, touch, smell and sound to engage in every detail of your chosen place.

If you find this exercise difficult to practice by yourself, you might try using a “Guided Imagery” relaxation on “You Tube”, smart phone apps or CDs.

## Counting

Once again, begin with the getting started exercise. In your own time, then count from 1-20 and back down again from 20-1. When you have finished, do the same again – counting to 20 and back – this time counting only on the OUT breath.

You may do this as many times as you wish.

Don't worry if you lose count, or become distracted, just continue where you left off, or start again. You may also make this exercise as long or as short as you wish by changing the number that you count up to (for example 10 or 100).

## Noises

Start as before.

Allow yourself to follow the sensation of your breathing and, with your eyes closed, focus your attention on all the sounds that you can hear **outside** the room. How many can you hear? Acknowledge them and just allow each one to come and go naturally. Continue this for a few minutes.

Now bring your attention closer to home – listen to any sounds **within the 4 walls** of the building you are in. Listen carefully. Continue this for a few minutes.

Concentrate your attention even closer to home and once again follow the pattern of your breathing. Maybe you can even hear the **sound of your own breath**. Continue this for a few minutes.

Allow your eyes to open while listening to **all** the sounds you can hear.

Lying positions give a great deal more rest than sitting positions. Remember that rest is giving the brain minimal information from the body or from the mind. When you sit, your balance reactions are constantly sending information to the brain. When you lie down, the amount of information is greatly reduced. Remember also that closing your eyes reduces the amount of information being sent to the brain.

## **Breathing Exercises**

### **Importance of Controlling Breathing in People with CFS**

It is clear that even minor degrees of over breathing can over a period of time lead to a significant reduction in the plasma carbon dioxide level. This causes alteration in the level of ionic calcium and other important electrolytes. Additionally there is evidence which confirm low circulating carbon dioxide levels promote constriction of several important blood vessels. This is especially important in the case of the central nervous system where it is quite possible that regional blood flow abnormalities may be arising from this abnormality.

In turn these changes may contribute to a sensation of being remote from the environment as well as tiredness, pins and needles in the hands and feet and an accentuation of any painful stimuli. Controlling the rate of breathing and correcting the low carbon dioxide level (hypocapnia) would therefore be an important part of the therapy used in the management of CFS.

Interestingly the control of breathing has been found helpful by several of our patients with severe CFS where in addition to relieving the tiredness, it has helped to reduce muscle aching and spasms and contributed to an improvement in the concentration and stamina.

There are 2 main types of breathing: **Chest** breathing and **Diaphragmatic** breathing.

We tend to use **chest** breathing during exercise and in situations when we are tense or stressed. **Diaphragmatic** breathing is much slower and more calming. This is the best type of breathing for relaxation and also has the advantage of giving our internal organs a gentle massage which helps keep them healthy.

**Spend a few minutes practicing some Diaphragmatic breathing as outlined below.**

Sitting comfortably, with your shoulders relaxed, place one hand on your upper chest and the other on your stomach, just below your rib cage. As you breathe in through your nose and out through your mouth, notice which hand rises first – the one on your chest or the one on your stomach. This will indicate whether you are breathing from the chest or from the diaphragm.

Focus now on breathing only from the diaphragm. As you inhale, allow the stomach to rise. As you exhale gently, feel your stomach flatten. There should be little or no movement in the chest. Allow yourself a little time to get into a regular rhythm. When you are confident that you are continuing to breathe from the diaphragm, you might want to close your eyes.

Continue the breathing exercise for a few minutes.

Using the guidance it is recommended that the breathing exercises are done daily for 3 months and if helpful can be continued long term.

### **Word Breath**

Think of a word that makes you think of feeling calm. For example: *Peace, Sea, River* or the name of *somebody important* to you or a *place that you like*. Begin with the “**Getting Started**” exercise outlined in the relaxation section. Now allow yourself to breathe quite naturally, say this calm word to yourself on every out breath.

Repeat this as many times as you need to.

Finish by taking three deeper breaths, allowing your-self to feel more awake with each of these three breaths.

### **Elephant Breath**

Take a breath in to the count of saying the word **Elephant** to yourself **twice**. Hold your breath to the count of **one Elephant** and then breath out to the count of **three Elephants**. Repeat this as many times as you wish.

## Additional Resources

### South West London and Surrey Chronic Fatigue Service

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#### Books

- Charles Shepherd and Abhijit Chaudhuri (2018) ME/CFS/PVFS An Exploration of Key Clinical Issues. The ME Association.
- David Burns (1999) The Feeling Good Handbook. Penguin.
- Mary Burgess with Trudie Chalder (2009) Overcoming Chronic Fatigue: A Self-help Guide Using Cognitive Behavioural Techniques. Robinson.
- W. Collinge (1994) Recovering from M.E.: A guide to self-empowerment. Souvenir Press.
- Gillian Butler & Tony Hope (2018). Manage Your Mind. The Mental Fitness Guide (3rd Edition). Oxford University Press.
- Dennis Greenberger & Christine A. Padesky. (2015). Mind Over Mood. Change How You Feel By Changing The Way That You Think 2<sup>nd</sup> Edition. The Guildford Press.
- Jon Kabat-Zinn (2013) Full Catastrophe Living: How to Cope with Stress, Pain and Illness Using Mindfulness Meditation. Piatkus.
- S. Milstrey Wells (2000) A Delicate Balance: Living successfully with Chronic Illness. Da Capo Press.

#### Websites

- **EPSOM & ST. HELIER UNIVERSITY HOSPITALS NHS TRUST**  
[www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome](http://www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome)
- **NICE (The National Institute for Health and Care Excellence) guidelines** – Chronic Fatigue Syndrome (currently under review)  
[www.nice.org.uk/guidance/conditions-and-diseases/chronic-fatigue-syndrome](http://www.nice.org.uk/guidance/conditions-and-diseases/chronic-fatigue-syndrome)
- **BACME – British Association for CFS/ME**  
[www.bacme.info](http://www.bacme.info)
- **The ME Association**  
Tel: 0844 576 5326  
[www.meassociation.org.uk](http://www.meassociation.org.uk)  
[admin@meassociation.org.uk](mailto:admin@meassociation.org.uk)

- **ACTION FOR ME- Patient support organisation**  
<http://www.afme.org.uk/>  
 work related information  
<http://www.actionforme.org.uk/professionals/employers-and-managers>  
 To access your local groups go to the main website and search local services using your postcode.
- **Direct Gov Website:**  
 Provides information under the disabled persons link: on employment, benefits, education, transport, housing, rights and obligations, leisure and travel.  
<http://www.direct.gov.uk/en/DisabledPeople/index.htm>

## Local Support Groups

There are a number of support groups that can be found via social media.

### Popin Club – support group for people with Fibromyalgia, Fatigue and Chronic pain conditions

No 2, 11<sup>th</sup> Avenue,

Holly Lodge,

Lower Kingswood,

KT20 6SL

Tel: 0844 887 2579 (local rates)

[www.fmcppopinclub.wordpress.com](http://www.fmcppopinclub.wordpress.com)

### Richmond and Kingston ME group

[www.richmondandkingstonmegroup.org](http://www.richmondandkingstonmegroup.org)

[randkmegroup@yahoo.co.uk](mailto:randkmegroup@yahoo.co.uk)

### Surrey ME/CFS and Fibromyalgia Support Group

[www.facebook.com/surreymegroup](http://www.facebook.com/surreymegroup)

### Redhill ME Support Group

[hilarygrinyer@aol.com](mailto:hilarygrinyer@aol.com)

Tel: 01737 761776

## Psychological Therapy

For help with depression and anxiety you can self-refer to your local IAPT (Improving Access to Psychological Therapies) or ask your GP for details.

## Mindfulness

There are a number of applications available for smart phones/tablets or guidance videos via “YouTube”

Headspace

Calm

Insight timer

Mindfulness

Breathe

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