FINE TRIAL

Patient Booklet

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Chronic Fatigue Syndrome:

What you need to know to get better

This booklet has been written with the help of patients who have made a full recovery from Chronic Fatigue Syndrome. Facts and information which were important to them in making this recovery have been included. The booklet includes the most up to date medical research available on Chronic Fatigue Syndrome from universities and hospitals around the world. It will take some time for you to read and understand how Chronic Fatigue Syndrome affects your body and the steps you can take to begin the road to recovery.

Some facts have been numbered for those who would like further details about the original work of the medical research involved. A reference list is attached.

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Part 1: Understanding Chronic Fatigue Syndrome

Part 2: The Treatment Plan for Your Recovery

1: What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome can be shortened to CFS.

It is sometimes called:

- Post- Viral Fatigue Syndrome,
- M.E or Myalgic Encephalomyelitis.

CFS patients complain of various intense and unpleasant symptoms:

- Overwhelming persistent fatigue unlike the feeling of normal tiredness
- Mental fatigue with poor mental performance, memory and concentration
- Muscle and sometimes joint pain
- Sleep difficulties resulting in waking unrefreshed
- Poor appetite with nausea at times
- Sore throat and swollen neck glands
- Headaches, dizziness and visual problems
- Feeling hot and cold, sweating excessively and inappropriately
- Low mood

But not all patients have all of these symptoms, and symptoms may come and go.

The symptoms can be very disabling, causing drastic changes in lifestyle with job, family and social relationships affected.

The symptoms are usually made worse by physical and mental exertion or stress.

The uncertainty of the illness and the feeling of being trapped can lead to feelings of frustration, anger and helplessness.

How does CFS start?

Sometimes CFS starts with a viral infection for example, glandular fever, 'flu, diarrhoea and vomiting. Complaints of aches, pains, tender stiff muscles, tiredness and temperatures make patients feel unwell. Rest is necessary at this stage.
People recover from viral infections at different rates.

Those with pressing commitments and responsibilities may not have the opportunity to rest and get back to full health.

Those who have a physically active lifestyle and those who don't like being ill, may not give themselves time to recover fully.

Some may expect to get back to a busy life too soon.

Sometimes CFS starts with a stressful life event for example, a major operation; bereavement; divorce; job loss; work, relationship and family problems.

The trigger factor for the condition may be different in different people. Some find that CFS starts suddenly while others are not able to pin point an obvious start.

What happens then?

When attempting your daily routine you may feel excessive tiredness and muscle aches. If the symptoms become overwhelming rest has to be taken because only rest relieves symptoms. However, rest only seems to relieve symptoms in the short term, because on becoming active again symptoms reappear.

A pattern develops of activity leading to symptoms and rest relieving symptoms.
If this continues some activities becomes limited or even avoided.

When the symptoms are persistent you may monitor and focus on them, becoming concerned about them and what they mean. The longer the duration of the illness the more difficult it can be to remember what it is like to feel well.

Feeling unwell, together with an inability to perform daily activities can lead to feelings of helplessness and loss of control.

What about those who do not rest?

It is more often active people who get CFS - those who achieve and do much in life. Because of their productive nature it is difficult and frustrating for such people to be inactive so they do not rest.

They battle against their symptoms, trying to carry on with life's activities by pushing

through the symptoms but are eventually overwhelmed by fatigue. Being on the point of collapse they have to rest and reduce activity for a time, as only this relieves the symptoms.

On good days some may push themselves to compensate for lost time or because they feel well. They then do too much activity for their reduced level of physical stamina, paying later when their symptoms return and they have to take rest.

A pattern develops of irregular activity, where life seesaws between doing too much activity and overwhelming fatigue that necessitates rest. This pattern of "boom and bust" is well recognised in some CFS patients.

Where does Chronic Fatigue Syndrome leave you?

If you have not had a definite diagnosis from your doctor explaining what is wrong, you are likely to feel uncertain or even frightened about your condition.
Because the symptoms are so real and disabling, the fear and uncertainty grows. Some of the questions that patients want answers to are:

- Is there a hidden disease in me that has not been picked up?
- Is the virus still present in my body?
- Has it left physical damage?
- Does activity harm my muscles or body?

Answering these questions and giving you the medical research information on CFS is essential for you to understand your condition.
Having an understanding of CFS will help you to see the purpose and necessity of the treatment enabling you to recover as others have done.

How to use this booklet

Many CFS patients are daunted by the size of this booklet.

You may want to skip through some chapters, just reading the summaries at the end of each section.

On the other hand, you may wish to read about the medical evidence in detail.

In each area of research, the numbers in brackets refer to medical publications listed in the reference section at the end of the booklet.

Many of these publications will be available at your nearest medical library.

In Part 1 we will help you to understand the changes that occur in your body with CFS and we will look at the medical research into:

- Muscles
- The effects of rest and reduced activity on the body
- Sleep disturbance
- The effects of anxiety on the body

In Part 2 we will use the information from Part 1 to construct the treatment plan.

2: Muscle Function in Chronic Fatigue Syndrome

In this chapter we will look at the changes that occur with CFS in the muscles as well as the effects that periods of rest and reduced activity have on the body.

Muscle research

Intensive research has been done on muscles of CFS patients. Research has shown:

1. Persistent viral infection does not play an ongoing part in the symptoms of CFS although, as we have seen, viral infections can trigger CFS.

Extensive investigations of body tissue samples have shown no evidence of persistent viral infection in CFS patients. Investigators originally convinced of a persistent viral infection in CFS have been unable to find any evidence of such an infection (1-4).

2. No evidence of other kinds of disease has been found in the muscles of CFS patients

Studies show no evidence of disease in the muscle tissue of CFS patients beyond that associated with normal wear and tear. This was also seen in healthy active people who did not have symptoms of muscle pain and fatigue. Therefore the changes of wear and tear are unrelated to the complaint of fatigue and muscle pain (5).

3. Muscle function or behaviour is normal in CFS.

The functioning or behaviour of muscles was studied before, during and after exercise in CFS patients and compared with a group of normal people. These studies were performed in two ways:(6;7).

- in cycle exercise tests where muscle function or behaviour depends on the motivation or voluntary effort of the individual
- with electrical stimulation of the muscles where muscle function is independent of the motivation or voluntary effort of the individual.

The Results showed:

- **the ability of muscles to generate force is normal in CFS patients.**
- **the ability of muscle to contract is normal in CFS patients.**
- **the long-term recovery of muscles in CFS patients was identical to normal people and complete by 24 hours following exhaustive exercise.**

However CFS patients complained of excessive fatigue, weakness or muscle discomfort afterwards.

For an explanation of this excessive fatigue, weakness and muscle pain after exercise read the next section on the physical effects of rest and reduced activity on the body.

4. Although no disease was found, a decrease in the number of cell mitochondria or 'powerhouses' and their enzyme activities have been found in the muscles of CFS patients (8;9). In order to understand what this means, we need to understand what mitochondria are:

Mitochondria are tiny parts of the cell that act as a powerhouse.
They are where energy is produced. Because there are fewer mitochondria in CFS patients, and because their enzymes are less active, less energy is produced. It is as if the muscle has a slightly flat battery.

Healthy people who were sedentary also had fewer mitochondria; however, inactive people can increase their muscle strength and endurance, by exercising. After several weeks they can exercise comfortably at higher exercise levels and for longer periods than before.

The exercise causes an increase in the number and activity of mitochondria in the cells, leading to improved power output and muscle metabolism (10;11).

If muscles are not used regularly, there are fewer mitochondria resulting in poor muscle metabolism.

Tests show that patients who ignored pain and discomfort and went on exercising in a controlled gradually increasing manner improved their mitochondrial function and so had less trouble with day to day physical activities.

5. Muscle strength decreases with rest in healthy people.

Muscle strength is maintained by frequent use of muscles.

In research studies healthy people who become inactive lose muscle strength by approximately 1% per day.

Those people who were physically fit before CFS, lose muscle strength quickly when they become less active. As muscle strength decreases through disuse, endurance also decreases.

In studies patients with CFS were physically weaker than sedentary controls and had a significantly reduced exercise capacity. Low exercise capacity was related to quadriceps muscle weakness and was reversed after graded exercise treatment.

Part of the function of muscles is to squeeze blood back to the heart.

As reduced activity leads to a reduction in muscle strength, tone and size, muscles cannot squeeze as much blood back to the heart.

Blood then pools in the calf muscles of the lower legs which may result in painful tingling and burning sensations in the feet and legs.

Less blood returning to the heart results in:

- less blood going to the brain leading to dizziness and collapse, patients may notice their vision is affected by dots or floaters.

- difficulty experienced when exercising.

Summary of Muscle Function

1. **No persistent viral infection or muscle disease has been found in CFS patients.**

2. **The muscles of CFS patients behave normally in tests.**

3. **Fewer, less active mitochondria are found in the muscles of CFS patients resulting in poor muscle metabolism with less energy. However, this seems to be a consequence of periods of rest and reduced levels of activity caused by CFS.**

4. **Muscle strength decreases with rest: this can result in dizziness, feeling faint and difficulty exercising.**

Taken together, this evidence indicates that muscle changes found in CFS patients are not the cause of the condition. Rather, they are consequences of rest and reduced activity levels caused by the condition.

II. The effects of periods of rest and reduced activity on the body

Patients with CFS find it difficult to maintain their previous level of physical activity. They may have to rest during or between activities and even reduce their activity level.

Over time, reduced activity and rest cause physical changes in muscles and the body. These changes cause physical sensations and symptoms. These symptoms are not in the mind.

The changes that occur in the body because of rest and reduced activity are not abnormal or unnatural. They are attempts by the body to make the best of its systems in unfavourable conditions.

Research has found that with reduced activity and rest the body becomes physically deconditioned or unfit leading to:

1. Changes in the cardio-vascular system

The blood contains the oxygen and nutrients that are vital for the body to function effectively. The heart is a muscle pump that sends blood to different parts of the body. Studies have been carried out on the effects of rest on healthy individuals

- **Within 24 to 48 hours of bed rest**, blood is redistributed from the extremities of the body to the central body compartment. In response, there is in a reduction in the volume of blood plasma (12). (Plasma is a clear liquid when separated from the rest of the blood. It forms the largest proportion of the blood.) The reduction in the volume of blood plasma results in a decrease in the amount of blood returning back to the heart. As a consequence, less blood goes to the brain contributing to dizziness on standing. This process also occurs with prolonged chair rest of 4 to 10 days (13).

- **After 8 days of bed rest**, there is a reduction in the total volume of red blood cells (12). As the red cells (which float in the plasma) carry oxygen to the organs of the body, including the muscles, there is a reduction in the oxygen carrying capacity of the blood which reduces exercise ability.
- **After 8 days of chair rest** there is a reduction in the capacity of the body to do physical aerobic work (13).
- **After 20 days of bed rest**, the volume of the heart is smaller by approximately 15% and it pumps out less blood to different regions of the body (14;15).
- **After 3 weeks of bed rest**, the heart rate increased by approximately half a beat per minute per day for each day of rest in healthy individuals (15). After the 3 weeks of rest their heart rate during a half hour walk was 40 beats per minute faster than before the 3 week rest period. When the heart beats faster it tires more quickly. These subjects needed from 5 to 10 weeks of exercise to return to their previous fitness level.

However, these changes are reversible: therapeutic exercise causes the heart to increase in size and the changes in blood volume and composition to return to normal, but it does take many weeks.

In CFS patients, no actual abnormalities or disease of the heart and lungs have been found (16).
However, there is evidence of muscle and cardiovascular deconditioning similar to that seen in resting healthy individuals including:

- a smaller heart size in some CFS patients (17)
- a reduced cardiac output (18)
- an increased heart rate at rest and during exercise (19)
- a reduced oxygen uptake (19)
- a reduced exercise capacity (19)

These physical changes are signs of deconditioning that:

- are associated with reduced physical activity levels
- result in difficulties when exercising including breathlessness, dizziness, excessive sweating, nausea and fatigue.

2. Following rest, there is a drop in blood pressure on standing up that causes dizziness.

Doctors call this type of difficulty ‘postural hypotension’. When we lie down for a rest, the heart no longer has to pump blood 'up hill' to the brain.
On standing, or when getting up out of a bed or bath, blood pools in the limbs due to gravity. Consequently, less blood returns to the heart. This results in less blood going to the brain causing dizziness and sometimes fainting.

This effect is made worse if:
- there is poor muscle tone in the lower limbs due to reduced activity levels
- the heart is less fit or deconditioned because it pumps out less blood.

The heart beats faster to provide an adequate supply of blood to the brain. This causes palpitations or pounding in the chest. Other unpleasant sensations include nausea, excessive sweating, dimness of vision, cold extremities and sometimes collapse.

In CFS patients, there is evidence of low blood pressure and increased heart rate on standing (20). This results in the unpleasant symptoms described above.

Rest does not have to be taken for a prolonged period for the effects of low blood pressure and increased heart rate to occur on standing. These effects were seen after only four days of chair rest in healthy individuals who experienced dizziness, nausea, vomiting and fainting (21).

3. Muscle inactivity during periods of rest results in poor muscle metabolism.

As we have already seen (see the section on muscle function above) reduced activity results in fewer and less active mitochondria in the muscle cells.
As the mitochondria produce energy in the muscle, the ability to perform work is reduced (8).

Fewer mitochondria may lead to production of lactic acid at low exercise levels which limits muscle performance and is often accompanied by muscle fatigue (8).
Increased levels of lactic acid have been reported in CFS patients (8;16).

4. Regulation of body temperature is affected by extended rest

Changes in blood flow to vital organs following rest results in feeling hot and cold, with excessive and inappropriate sweating at times. This has been observed in healthy people after 8-14 days of bed rest (12;22).

5. Visual problems can be caused by bed rest

Visual problems may occur due to a headward shift of bodily fluids after prolonged lying. This has been observed after 4-7 days of bed-rest in healthy people, as has an increased sensitivity to noise (12).

6. Calcium is removed from the bones during rest

Bones, which do not have to support the weight of the body or the pull of the muscles, lose calcium. Over time this leaves bones brittle (12;23).

7. Reduced activity and periods of rest cause reduced tolerance of activity or exercise

In tests, CFS patients felt themselves to be exercising at their full capacity because they felt very tired. However, clinical tests showed they were not exercising at their full power even though they felt they were (6;7). This increased feeling of effort on exercise has also been seen in healthy people who become less active: they experienced increased muscle fatigue as well as feelings of heaviness, clumsiness and muscle pain (24). In time, rest and periods of inactivity result in an increase in the feeling of fatigue when exercise is taken. Whilst rest relieves the symptoms of fatigue in the short term, in the long term the ability to be active is reduced as the body becomes unfit or deconditioned.

8. Periods of inactivity affect the nervous system

The nervous system is responsible for coordinating our muscles when we are active. Maintaining a high degree of coordination requires regular performance of an activity. After prolonged periods of inactivity, the nervous system is no longer able to do maintain speed and accuracy effectively: this causes unsteadiness and poor accuracy on carrying out precise movements (23).

9. Mental changes also follow periods of inactivity

Rest which no intellectual stimulation has a dulling effect on intellectual activity (23). Mental fatigue symptoms that occur after inactivity include poor attention, poor concentration, poor memory, word-finding difficulties, impaired problem solving and poor planning. Studies show it leads to a reduction of intellectual function and speed of perception (25).

Overall, the amount of inactivity needed to produce the above physical changes in the body does not have to be great. These changes have been seen in healthy people sitting in a chair for one week (13).

How is this research related to CFS?

Most patients with CFS are not bed or chair bound for prolonged periods. Most CFS patients are still active. However, over the months or years patients have had to reduce their physical activities in order to manage essential commitments and cope with symptoms. Unavoidably over time this has an add-on effect, leading to the muscle and cardiovascular deconditioning described in the above CFS research.

Although rest is the right treatment in the first stages of a viral infection or illness, once the body temperature is normal the virus has gone and a gradual return to normal activity levels is appropriate. When periods of rest and reduced activity continue to be taken they become harmful to the body' and perpetuate the symptoms of CFS.

What does the research mean to patients with CFS?

Fortunately, all of the changes listed above can be reversed by a therapeutic activity programme.

However, research shows that:

- It may take some considerable time to reverse the deconditioning effects of reduced activity.

Of significance to patients with CFS, the research shows that:

- Fit individuals who reduce activity reduce their physical working capacity and decondition to a much greater extent than those who already live sedentary lives (12;25;26).

- Active individuals require a longer period than do inactive subjects for heart size and exercise capacity to return to previous activity levels (25).

- In fact, the rate of physical deterioration caused by rest is more rapid than the rate of restoration once activity is restarted (27).

As most CFS patients have had reduced activity levels for at least six months there will be substantial physical de-conditioning of the body which can take some months to reverse.

Muscle pain

Why is there muscle pain after exercise, even when there is no muscle disease?

All of us have experienced muscle pain after unaccustomed exercise, for example, after the first session of exercise of a new season. This muscle pain is called **D**elayed **O**nset **M**uscle **S**oreness (DOMS).

Muscle pain after exercise can be prolonged and intense at times, especially for CFS patients who have had to reduce their levels of physical activity over time to manage their symptoms.

Muscles that are not used regularly become deconditioned or unfit.

When deconditioned muscles contract during activity uneven stresses are produced resulting in a feeling of weakness and instability (jelly-like wobbly legs) followed by delayed pain and discomfort (28;29).

The muscle pain experienced after exercise in CFS is a sign of muscle deconditioning.

Training eliminates muscle pain after exercise.

When athletes begin training at the start of the season, they expect painful and stiff muscles.

They know that the pain after exercise disappears, as they get fitter.

They see their muscle pain as a consequence of being out of condition and not a sign

of illness or disease.

Why can there be muscle pain at rest?

The muscles of the skeleton, including the muscles of the neck, back, abdomen, buttocks and thighs, are designed to work against gravity and allow us to maintain an erect posture.

Upon lying down this antigravity function of the muscles is no longer needed and the supine muscles which are unaccustomed to a supporting role take over. As a consequence, individuals who rested in bed for periods of 24-72 hours often complain of generalised muscle aches and tired feelings (25).

Such complaints are common in those CFS patients who take prolonged rest.

Summary of the Physical Effects of Rest and Reduced Activity

1. **Following periods of rest and reduced activity, the cardiovascular system becomes less fit or deconditioned resulting in symptoms including palpitations, sweating and nausea.**

2. **With reduced activity the physical capacity for exercise is reduced resulting in breathlessness and fatigue.**
   The less you do the less you are capable of doing.

3. **Rest and reduced activity lead to reduced muscle tone in the lower limbs, which results in less blood returning to the heart. This causes a drop in blood pressure on standing up and less blood goes to the brain, which causes unpleasant symptoms including dizziness and fatigue.**

4. **The decrease in muscle mitochondria or 'power houses' caused by reduced activity results in poor muscle metabolism and reduced muscle energy.**

5. **Prolonged rest can cause visual problems, sensitivity to noise, unsteadiness, dulling of mental powers and feeling hot and cold.**

6. **Reduced activity increases the feeling of fatigue when activity is taken. With rest and reduced activity the body tolerates less and less activity over time.**

7. **Fortunately, all of the changes listed above can be reversed by a therapeutic activity programme. However, it may take a considerable time to reverse the deconditioning.**

3: Sleep, the Body Clock and Chronic Fatigue Syndrome

Many patients with CFS complain of poor quality sleep.

Sleep is controlled by a 'biological clock' located in the hypothalamus of the brain.

This clock regulates many body rhythms which run on an approximate 24 hour cycle. These rhythms are called 'circadian rhythms'. They control vital functions such as:

- sleeping and waking
- feelings of tiredness and alertness
- intellectual performance
- memory
- appetite
- body temperature
- the production of hormones, for example, cortisol
- the activity of the immune system.

You will already be aware of the natural rhythms in the body. For example, feelings of hunger and the need to go to the toilet occur at a certain time each day. Most people feel more alert and perform better in the morning than in the middle of the night. These are all part of the natural rhythms of the body.

The biological clock is affected by the events of the day. The clock is reset each day by cues or signals, for example - going to bed and getting up times, meal times and performing daily routines.

The clock's time keeping can be disturbed if not reset by these 'cues' or signals of regular sleep and activity. This can occur in people who travel across time zones, work shifts or are ill or hospitalised. The disturbance to the biological clock when flying across time zones is called 'jet lag'.

- **If the regular cues are lost, disruption of the clock results in a slipping of the body rhythms.**

- **This means the normal intense night-time feelings of mental and physical tiredness can become shifted into the day making it difficult to cope with usual mental and physical tasks.**

- **The normal daytime rhythm may get shifted around to the night, causing some of us to feel alert, restless and unable to sleep.**

Slipping of the body rhythms results in:

- poor quality night sleep
- increasing fatigue during the day
- poor concentration
- forgetfulness
- low mood
- feeling unwell
- headaches
- muscle aches
- loss of appetite
- irregularities of bowel movement

As the symptoms of jet lag are so similar to those of CFS, circadian rhythms have been investigated in CFS patients.

There is evidence to suggest that CFS is associated with the biological clock losing control of the body rhythms (30).

It is thought that an infection or very stressful life event breaks the normal sleep-wake cycle and other daily routines needed to reset the biological clock. The biological clock then loses control over body rhythms which are disrupted resulting in the above mentioned severe physical and mental symptoms of CFS.

How can a virus affect the biological clock?

With some viral infections we feel unwell and are unable to perform our daily routines, needing to rest in the day.

Without the regular signals of daily routines needed to reset the biological clock (for example, sleeping and getting up at the same time, performing daily tasks and activities etc.) the biological clock starts to lose control over the body rhythms.

This results in the gradually slipping of the body rhythms, which are then no longer synchronised with the rest of the world.

How can stress affect the biological clock?

A stressful life event or an accumulation of persistent stresses can cause worry and arouse the nervous system of the body which leads to a disturbed sleep. If the stress persists the sleep pattern is disrupted with the following consequences:

- The regular sleep and wake cues are disrupted and no longer reset the clock which starts to lose control over body rhythms.

- The body rhythms are no longer synchronised with the rest of the world: intense fatigue can become a main symptom along with poor intellectual performance.
- This in turn can lead to worries about performance at home and work.
- In an attempt to recover and restore health, some people may rest or sleep in the day or early evening or at the weekend.
- Unfortunately, sleeping during the day actually makes the problem worse by causing further disruption to the body rhythms so increasing symptoms.
- More symptoms may lead to a reduced ability to perform demanding physical activities or exercise.
- Reducing activity will start the process of physical deconditioning, which itself will cause yet more intense symptoms.

Once the body rhythms are out of synchronisation, CFS symptoms are maintained.

Disturbance of the rhythm of cortisol production

Cortisol is a chemical hormone in the blood whose production is controlled by a circadian rhythm. Cortisol switches on our metabolism in the morning to prepare us for the physical and mental challenges of the day. Exercise and other stress cause an increase in the level of cortisol in the bloodstream.

There is research that shows some CFS patients have a lower level of cortisol (31).
This has also been found in:

- healthy individuals who have bed rested for more than three weeks (32) .
- healthy workers after five nights of shift work (33) .

No disease has been found and it is thought to be caused by disrupted sleep and social routine that occurs in these conditions.

The hormonal changes seen in CFS can be reversed by regulating disturbed sleep patters and gradually building a regular activity pattern (34).

Disturbance of the sleep–wake rhythm in CFS

Most CFS patients complain of poor quality sleep.
In sleep tests, CFS patients:

- had restless night sleep which added to their daytime fatigue when compared with a group of healthy volunteers.
- felt less refreshed on waking, lower in mood and more sleepy.
- held their muscles tense while sleeping and because of this, they had more muscle aches and felt weaker and stiffer the following day.

They spent more time in bed but slept less efficiently. Overall there were large fluctuations in the time they actually slept (35) .

In addition to having

- significantly more light sleep
- more movement times and awakenings

CFS patients had

- significantly less deep sleep than controls (36).

Physical activity and exercise promote deep sleep

As we have seen there is evidence of disturbed sleep and significantly less deep sleep in some patients with CFS (35;36).

Research shows that regular exercise:

- promotes deep sleep
- sleep is longer and more readily achieved (37)

Those who exercise regularly have more deep sleep than unfit subjects (38).
The beneficial effects of exercise on sleep seem to be short lived so to maintain improved quality of sleep, exercise has to be done regularly (39).

Summary of Sleep Research.

1. **The biological clock in the brain regulates important body rhythms, called circadian rhythms.**

2. **Daily cues or signals, for example, falling asleep and waking up times as well as activity, normally reset the biological clock.**

3. **Infection or a stressful life event can interfere with these daily cues so they are unable to reset the clock.**

4. **This can result in the biological clock losing control over the body rhythms.**

5. **The body rhythms slip resulting in daytime tiredness and night-time restlessness.**

6. **The slipping of circadian rhythms together with the effects of reduced activity on the body can cause a feeling of overwhelming tiredness during the day.**

7. **Research has shown that if healthy people have a disturbed night's sleep, they too complain of CFS symptoms, but these symptoms subside as the clock is reset with regular sleep and activity patterns.**

8. **The process is reversible. It is possible to reset the biological clock with regular sleep patterns, social routine and activity.**

4: Increased Nervous System Arousal & Adrenaline Production.

The nervous system is the vast network of nerve cells specialised to carry information to and from all parts of the body in order to bring about bodily activity.

The nervous system may be broadly divided into two parts:

- the central nervous system consisting of the brain and the spinal cord that process information and
- the peripheral nervous system - the nerves that conduct impulses to and from organs, muscle and tissues.

At times of physical and mental exertion or stress the nervous system is automatically aroused or 'switched on' and the powerful hormone adrenaline is produced. This prepares us for action and is known as the 'fight or flight' response.

In CFS the nervous system is frequently aroused in response to:

- overwhelming daytime fatigue
- physical deconditioning
- frustration with a limited lifestyle
- fear about the symptoms
- scepticism of others
- sense of helplessness
- anxiety and uncertainty about the future

Being in a stressful situation and having CFS can lead to a further increase in nervous system arousal and production of adrenaline.

The effects of nervous system arousal and adrenaline on the body

Nervous system arousal causes the body systems to work on **'maximum setting'**:

1. Increased heart rate

The heart beats faster to pump blood to the muscles ready for action.
Sometimes this is felt as **palpitations, pounding or tightness in the chest (40)**.
For some people this can be a frightening and distressing sensation, causing further anxiety, which results in further nervous system arousal and release of adrenaline so maintaining the unpleasant physical sensations (41).

In CFS, the heart is already deconditioned with a higher heart rate at rest, therefore, the further increase in heart rate during times of nervous system arousal can cause noticeable palpitations and increased fatigue.

2. Increase in blood pressure

During exertion there is an increase in blood pressure that gives vital organs and muscles a better blood supply. At other times when physical and mental stress is not

present, blood pressure on standing can be low (postural hypotension, see Chapter 2).

3. Breathlessness

This is a natural response to physical and mental exertion, stress or threat. Overbreathing occurs for the duration of the exertion and the lungs are filled with oxygen to prepare us for action.

If over-breathing continues it is called **hyperventilation**. Some patients do overbreathe with noticeable sighing and are not able to take a satisfying breath.

Effects of overbreathing on the body

1. The muscles of the chest wall can be over used causing **chest pain or discomfort** which is not related to a heart problem (42).

These sensations can be distressing and if interpreted as signs of an immediate catastrophe there is a further increase in nervous system arousal and adrenaline production which only increases unpleasant sensations. In some people this can lead to an attack of panic. Not all patients who overbreath realise they are doing so.

2. There is increased tension in the muscles of the head, neck and shoulders and pull on their attachments as they help raise the rib cage in rapid breathing. This results in **headaches, and localised stiffness and pain**.

3. The prolonged overuse and tensing of the delicate muscles of the neck in raising the heavy rib cage can cause **tightness or soreness of the throat**.

Increased nervous system arousal and adrenaline production also cause a reduction in the amount of saliva produced and this along with the excessive mouth breathing cause a **dry mouth and throat**, **difficulty with swallowing** and the sensation of a **lump in the throat**.

4. Overbreathing also causes a reduction in the amount of carbon dioxide in the blood. This upsets the delicate balance of chemicals in the blood causing tightening of the blood vessels, especially in the brain leading to unpleasant sensations such as: **light-headedness; faintness; feeling unsteady; clumsiness; blurred vision; dizziness; pins and needles, tingling or numbness** (sometimes one-sided) in the limbs or face, **cramp-like muscle spasms** in hands and feet, **increased sensitivity to light and noise**.

Feeling faint is misleading because overall blood pressure is high in stress. (You only faint when your blood pressure is very low).

Other abnormal sensations can occur including feelings of being **detached from oneself, feelings of unreality** and fear of loss of control, sanity or collapse.

4. Blood flow is altered

Blood is redirected to the muscles for action and relatively less goes to the skin and gut. Increased blood flow to some organs may cause discomfort, decreased blood flow can cause **pain** and sometimes **numbness or tingling** sensations (42). Sometimes patients may notice **flushing and temperature change** as blood is shunted around the body. Reduced blood flow to the skin can result in **pallor**; blood shunted away from the extremities, where it is not needed can cause **cold feet and hands**.

Bowel - Reduced blood flow to the bowel affects the passage of food and can result in symptoms of an irritable bowel, for example, **diarrhoea and/or constipation, abdominal distension discomfort**.

Stomach - Increased nervous system activity affects the tone of the stomach, the acid it produces and the control of the stomach opening. These can cause stomach upset including: **nausea, vomiting, reflux and pain behind the breast bone.**

5. Muscle tension

There is an increase in the tension in the muscles to prepare them for action.
This can cause **local aches, pains and fatigue**. In stressful situations discomfort is especially noticeable in the shoulders, neck, jaws and head. Sometimes **twitching, trembling** or even **shaking** of muscles, which are tensed for action, maybe noticed (41). Periods of prolonged exertion or intense stress which over tense muscles may be followed by a feeling of profound weakness and lethargy.

In CFS, the muscles are already deconditioned and predisposed to muscle ache**.** Consequently, the muscle tension associated with increased nervous arousal can intensify muscle pain.

However, physical activity does release the muscle tension produced by nervous system arousal and adrenaline.

6. Sweating

Increased sweating occurs to allow for heat loss causing clammy hands and feet.

7. Blurring of vision

Increased nerve activity affects the muscles of the iris in the eye causing dilation of the pupils, which lets in more light. The shape of the eye lens is altered to help improve side and distance vision. Together, these changes **increase visual sensations** that can be experienced as **visual disturbance**.

8. Sleep disturbance

Adrenaline is an arouser that disturbs sleep and can lead to **nightmares** and **emotional sweating**.

9. Concentration and memory

Individuals may experience problems with **concentration and memory.**

Facts to be aware of:

- Not everybody experiences all these sensations or side effects of nervous system arousal: some individuals may notice a particular pattern of sensations. At stressful times, however**, these physical sensations can be intense and more noticeable.** Because of this fact, it is possible to **misinterpret them as signs of a serious disease** (especially when you have no explanation of your condition). Fears that it could be a serious disease trigger further nervous system arousal and its sensations.

- In fact, these sensations are the signs of a normal bodily process that serves a protective function at times of mental and physical exertion.

- Then, because of a lack of information, these sensations are misinterpreted and seen as threatening signs of illness or even impending collapse, further anxiety is triggered. For some this can lead into a vicious circle that ends in a panic attack.

Nervous system arousal and adrenaline mimic 'flu-like illness'

During periods of **extreme or prolonged physical and mental exertion or stress** there is increased nervous system arousal and production of adrenaline.

In patients with CFS such arousal overworks the body's deconditioned systems. This cause overwhelming symptoms that can include:

- aches and pains,
- feeling hot and cold,
- sore throat.
- headache,
- chest tightness
- sweating,

These symptoms mimic the symptoms experienced with a flu-like illness.

Consequently, the individual may sometimes presume that they **'are coming down with a virus'** and may limit or avoid physical activities.

However, physical activity releases muscle tension, consequently, limiting activity can perpetuate the muscle tensing effects of nervous system arousal and pain, as well as leading to further deconditioning.

LOW MOOD

The situation that people with CFS find themselves in can be extremely difficult. It can cause feelings such as:

- loss of control over life,
- frustration,
- feeling disabled and helpless.

These and other feelings can lead to low mood for some people, and depression in others. **These are not signs of weakness, but a natural human response to stress**.

Low mood can lead to feeling tired which reduces the desire to be active, leading to reduced levels of activity. This in combination with the difficulty experienced when performing activity, due to the condition itself, results in even further physical deconditioning of the body. For those in whom depression limits activity so maintaining the condition and delaying recovery, medication can be helpful.

LIFE STRESSES

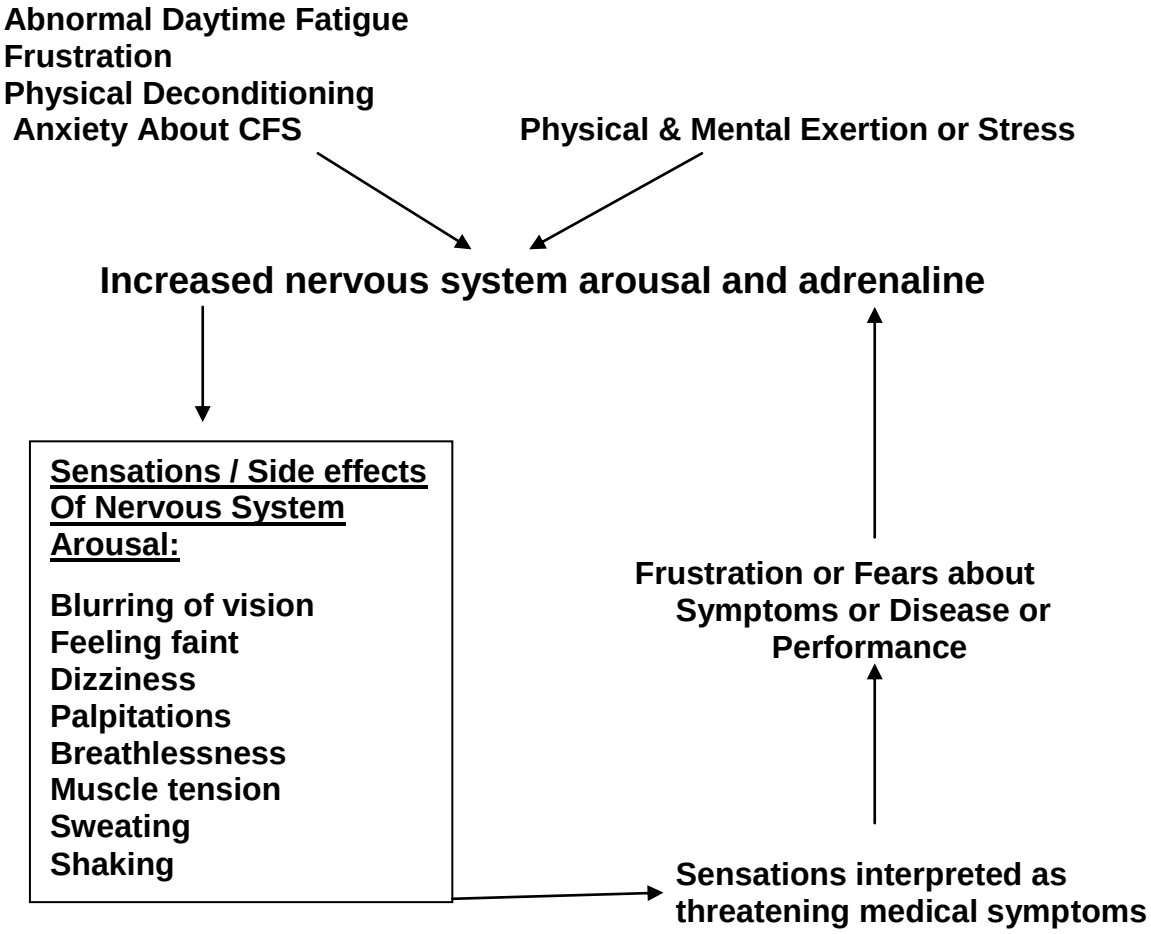
Many patients report major ongoing social stresses and difficulties. These include difficulties in employment, economic security and relationships. It is important to be aware that such difficulties can perpetuate the condition. They made lead to:

- Further increased nervous system arousal which acts on the deconditioned muscles and cardidovascular system making graded activity even more difficult to perform
- low mood leading to periods of inactivity which results in further physical deconditioning of the body,
- worry which disturbs the night sleep. If worry about problems persists it can perpetuate the disturbance of the body rhythms causing daytime fatigue.

The combined physical effects of anxiety and worry that automatically switch on nervous system arousal in combination with low mood can put an overwhelming burden on the body.

If stressful problems are perpetuating the symptoms of CFS, then treatment is unlikely to be as successful if these stresses are not dealt with and confronted.

Often just recognising what the main stresses are and accepting them, even if they may seem unsolvable, may be enough to move forward.


Abnormal Daytime Fatigue
Frustration
Physical Deconditioning
Anxiety About CFS
Physical & Mental Exertion or Stress
Increased nervous system arousal and adrenaline
Sensations / Side effects Of Nervous System Arousal:
Blurring of vision
Feeling faint
Dizziness
Palpitations
Breathlessness
Muscle tension
Sweating
Shaking
Frustration or Fears about Symptoms or Disease or Performance
Sensations interpreted as threatening medical symptoms

Summary of Increased Nervous System Arousal & Adrenaline

1. **In CFS, the physical changes in the body and their emotional and mental consequences arouse the nervous system in order to stimulate the mind and body.**

2. **Nervous system arousal causes the body systems to work on 'maximum setting' which causes many intense, unpleasant physical sensations:**

   - **palpitations**
   - **breathlessness**
   - **tingling**
   - **dizziness**
   - **feeling faint**
   - **numbness**
   - **visual problems**
   - **muscle shakiness**
   - **sweating**

3. **Misinterpreting physical sensations as signs of disease can trigger further anxiety and nervous system arousal. This leads to a worsening of symptoms.**

4. **In CFS, the cardiovascular system and the muscles are deconditioned. Consequently, arousal of these deconditioned systems can be followed by further feelings of weakness and exhaustion that adds to the fatigue and muscle aches of CFS.**

5: The Vicious Circle of Chronic Fatigue Syndrome
How do you get trapped in the vicious circle of CFS?

We now know that

- **with a virus** or **being ill** we reduce what we do - resting and sleeping more. The disruption of cues, such as sleep and waking times, daily routine and activities can lead to the biological clock losing control over body rhythms. This can result in daytime physical and mental fatigue, aches, and difficulty coping with physical and mental activities. If symptoms persist, certain activities are limited or even avoided to manage and relieve symptoms.

We now know that

- **very stressful events or an accumulation of problems** over time can lead to increased nervous system arousal and adrenaline production. This can cause increased fatigue, aches and pains, dizziness, visual disturbance **and can lead to a disturbed night sleep pattern that results in increased daytime fatigue**. In an attempt to cope and restore health the individual may rest or sleep in the day, evening or weekend. This can lead to disruption of the cues needed to reset the clock, which then can lose control over body rhythms. This results in daytime tiredness that can affect physical and mental activities leading to limiting activities and rest.

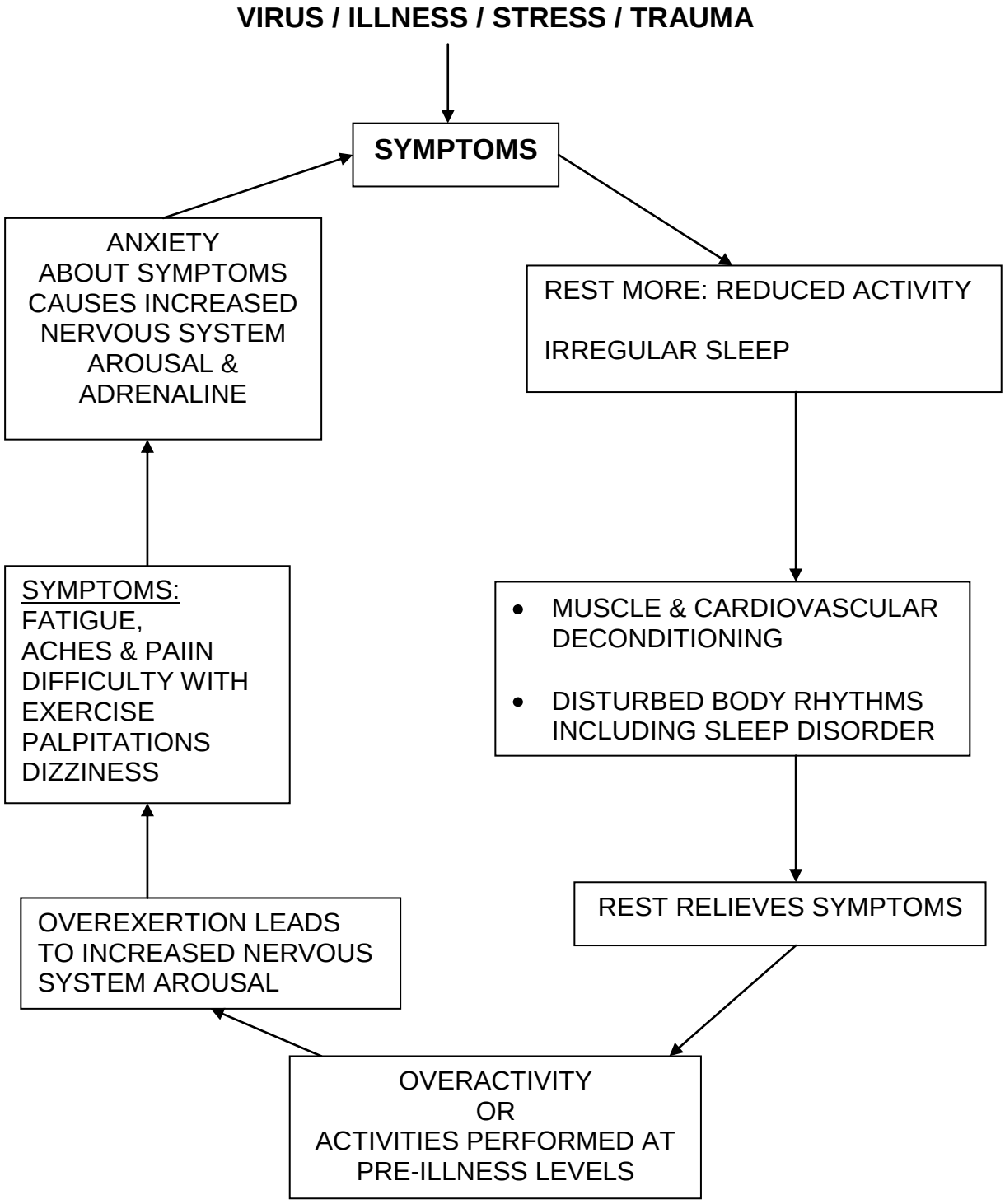
We now know that

- **over time, reduced activity and periods of rest lead to physical deconditioning** (unfitness) of the body. As a consequence of this, activity performed at pre-illness levels leads to physical symptoms. In order to relieve these symptoms and perhaps prevent further harm or restore health, rest is taken. This in turn maintains the condition and symptoms by leading to further deconditioning. **The less you do the less you are able to do**. Reducing exercise also reduces the quality of night time sleep. Fatigue can lead to daytime sleeping causing body rhythms to slip further, magnifying sleep problems and tiredness. The trigger factor has long since gone, but it has started a vicious circle into which you have unknowingly entered and its symptoms are controlling your life.

Together the slipping of the body rhythms, muscle and cardiovascular deconditioning result in the feeling of overwhelming tiredness and other symptoms of CFS.

At times the condition seems to be out of control. Fears, distress and frustration about symptoms and the underlying cause of the condition lead to increased nervous system activity and adrenaline production, with its physical sensations further fuelling the circle.

The Vicious Circle of CFS



Why doesn't everybody who has a virus get CFS?

Research shows that there are some other factors involved besides an infection or illness.

1. Activity and fitness before CFS

This is relevant to the development of CFS for two important reasons:

1. Physical deconditioning happens very quickly in active people

- the process begins within 24 hours of bed rest (21)
- after only four days of chair rest individuals experienced symptoms of deconditioning including dizziness and feeling faint
- after 8 days of chair rest there was a decreased exercise tolerance (13)

2. **Active individuals who rest, reduce their physical aerobic or working capacity to a much greater extent than those who already live an inactive life** (12;26;43).

Before becoming ill, CFS patients tend to be fit and active.

This is important because:

- Those who are fit expect to do their activities without undue symptoms.
- When fit active people rest for even the short periods of time described above, they start the process of physical deconditioning.
- This reduces their ability to exercise more than inactive people.
- Consequently, they notice the unpleasant symptoms of physical deconditioning more than those who are habitually inactive.

2. Commitments and Pressures

These are also important factors in the development of CFS. Individuals may be under pressure and expected to achieve previous activities and commitments.

- **External pressures**

Pressures and expectations from others to fulfil work, college or social commitments can result in a return to activities too soon before full recovery

- **Internal or personal pressure**

The individual can put pressure upon him or her self expecting to fulfil commitments and return to activities too soon before full recovery

3. Personality style

Personality style is also important. Patients with CFS often report the following qualities:

- being conscientious
- good listeners
- busy with many commitments
- hardworking
- having high standards
- a dislike of being ill

The combination of:

1. **activity and fitness before CFS**
2. **pressures**
3. **personality style**

can all be factors that contribute to the development of CFS at times of illness or persistent stress.

This may happen in the following way:

An illness or event that has resulted in **disturbed sleep, rest and reduced activity** can cause daytime fatigue and, over time, some degree of physical deconditioning and disturbance of the body rhythms.

Hardworking and conscientious individuals may be pressurised by others or themselves to return to previous commitments.

Returning to work or college or previous activities too soon before:

- **fully recovering from illness**
- **resynchronising body rhythms**
- **regaining full fitness**

will cause symptoms.

Pushing back to previous activities and commitments while still having symptoms can cause these symptoms to become even more intense with continuing symptoms, **work and activities are a greater effort** than usual. With increased effort there is **an increase in nervous system activity and adrenaline production**. This results in further unpleasant symptoms such as fatigue, dizziness and muscle aches.
Patients who are used to feeling fit may **worry about the cause of persisting symptoms**. Patients may feel **frustrated that the symptoms interfere with their ability to perform** usual tasks. **Worry and frustration automatically trigger increased nervous system arousal and adrenaline production**, that causes more intense physical symptoms.

The individual may at times be **overwhelmed by symptoms** and cope by resting or sleeping after daytime commitments or at the weekend to prepare for next week's duties. They may also limit usual activities and exercise. The disruption of sleep-wake and activity patterns results in a further slipping of the body rhythms and physical deconditioning.

On a good day attempting activities at pre-illness levels will be too much for the reduced level of physical stamina, which is the result of physical deconditioning. This will cause intense symptoms that are only relieved by rest, which causes further deconditioning.

A pattern of irregular activity sometimes called 'boom and bust' develops.

A combination of many factors are involved in the development of CFS which may include

- **illness**
- **busy lifestyle**
- **disturbed sleep patterns**
- **stressful events**
- **personality type**
- **irregular activity levels**

6: How Understanding CFS Can Help You Get Better

In the past you may have believed any of the following thoughts about your condition:

- If a virus triggered CFS and you have never been well since, you may believe that the virus is still present or has left your muscles damaged or diseased.
- If activity or exercise makes your symptoms worse, then you may limit or even avoid these as much as you can, as you may think they are harmful to your body.
- If you have past experiences of activity leading to relapses, these may reinforce your belief that activity is harmful.
- If your symptoms are persistent and overwhelming, making you feel ill, you may believe that you have a serious physical disease.
- If rest relieves your symptoms then you may think that rest is the answer.

Our thoughts and beliefs affect our behaviour.

Our behaviour affects the functioning of our body.

Is rest the answer?

In the short term it relieves symptoms but in the long term, rest and irregular periods of activity cause most of the disability.

For those who do rest:

Some people with CFS relieve their symptoms by resting most of the time. This prolonged inactivity leads to severe physical deconditioning. Consequently, any activity causes symptoms, and so in time such people become severely physically disabled.

For those who do not rest:

Others, however, do not rest.

In trying to overcome their condition they struggle on and at times do too much activity for their reduced level of physical stamina.

These periods are followed by overwhelming symptoms that are only relieved by rest.

Rest is taken until they feel restored when they become active again.
These people have the 'boom and bust' type of CFS. They only avoid or limit certain activities.

Some feel that, as most of the time they are not resting and are in fact active, the vicious circle of CFS does not necessarily apply to them.

If this is how you feel it may be helpful to look closely at the pattern of your activity.

Looking at the pattern of your activity

- If you are active for some days and then overwhelming symptoms necessitate rest and inactivity for a time afterwards, your body's physical systems are not being used to full capacity on a regular daily basis. Activity needs to be regular and paced for a fit body.

- In time, limiting activity, irregular activity and periods of inactivity result in partial physical deconditioning. In these circumstances the CFS symptoms experienced are not as severe as those experienced by CFS patients who have become more inactive, but are still present.

  Symptoms are not as severe simply because some level of activity has been maintained. But when the level of activity undertaken exceeds the reduced level of physical fitness of the body, the effects of physical deconditioning or being unfit, come into play with the associated symptoms. Too much activity is being done some days for the reduced level of physical fitness and too little on others.

- To correct this imbalance, activity should be done on **a regular daily basis** matching the body's level of physical fitness **and gradually increased.** In this way physical fitness and stamina gradually build up, and physical deconditioning is reversed.

- Maintenance of perfect health in humans needs a proper balance between exercise, rest and sleep, as well as time in an upright position. If the body is not worked as it was designed to be, then it runs down and is no longer in good working order.

Are the intense physical symptoms signs of persistent virus or serious hidden disease?

The medical research evidence shows:

- **no virus persists**
- **no signs of muscle disease**
- **no underlying serious disease.**

The medical evidence indicates that the intense physical symptoms are due to:

- **disturbance of body rhythms including a sleep disorder**
- **muscle and cardiovascular deconditioning**
- **increased nervous system arousal and adrenaline production**

Some important points

Fortunately, unlike other chronic conditions, it is possible to reverse the effects of muscle and cardiovascular deconditioning and resynchronise disturbed body rhythms.

Through understanding the changes that have occurred in your body based on the medical evidence in this booklet, you can reverse the process.

Instead of CFS controlling you, you can start to regain control of your body and your life.

The first step to recovery for some patients is accepting that they have a medical condition.

- Sometimes some **patients may doubt their condition** because not every body they meet believes in and understands CFS (including some doctors).

- Some patients put on a façade or **a front to hide their symptoms**, which can cause pressure to be placed up on them to perform as usual.

- Not everybody rests with CFS. Some **patients try to ignore their symptoms** and in doing so develop a 'boom and bust' activity pattern.

When patients find it **difficult to accept that they have a physically limiting medical condition they may tend to 'boom and bust'**. This results in some degree of physical deconditioning as well as increased nervous system activity and adrenaline production.

Both of **these perpetuate the symptoms of CFS**.

All the medical facts included in this booklet have led to a treatment designed to reverse physical deconditioning, resynchronise the body rhythms and deal with other factors which maybe helping to perpetuate the symptoms of CFS.

Part 2

The Treatment Plan for Your Recovery: How to Get Better

In the previous chapters we have attempted to give you an understanding of the underlying causes and factors that perpetuate CFS.
In the coming chapters we will look at how that understanding can be used as the basis for a logical and effective form of treatment.

For this treatment to be successful, determination and motivation are required.

But with an understanding of how you became trapped in the vicious circle of CFS, you will be able to see the logic of the prescribed treatment plan.
The treatment plan is divided into four main parts that deal with the fundamental problems of CFS. These are:

- Building **the right thoughts for your recovery** while looking at your situation and symptoms. This is necessary as unhelpful thoughts can put you off parts of the treatment programme and so delay or prevent recovery.

- **Designing your activity plan safely,** with the emphasis on starting activity at a level below your present level of physical fitness. In this way you can **still** do your daily routine without relapsing while build up your stamina steadily and safely.

- **Resetting your biological clock** by reorganising sleep habits and returning to a normal sleep pattern.

- **Learning to breathe properly** so you can make the best use of your body's physical resources. This will help in the recovery process. Relaxation can be used to help control the anxieties some people may have about their situation and the treatment programme.

It will take considerable time but the steady effort you put in will gradually be repaid in the form of sustained recovery. You will experience a snowballing effect as increasing fitness leads to increasing confidence in your ability. You will have conquered CFS by your own effort and you will be back in control of your body again.

7: The right thoughts for recovery

At times we all have thoughts which are unhelpful. In this chapter we will help you understand how some unhelpful ideas about CFS can affect behaviour and delay recovery.

Unhelpful thoughts in daily life

Everyone has thoughts that are unhelpful at times. For example:

- if you are anxious while talking to a group of people and you notice one of them looks out of the window you may think that you are boring that person. That thought can make you more anxious and affect the rest of your performance.

Unhelpful thoughts can affect your behaviour. For example:

- a man who became anxious at social events listened to others but avoided talking to avoid criticism or ridicule. His behaviour in avoiding conversation made it hard for others to include him in their conversations, which reinforced his belief that he is not an interesting person.

The link between thinking, feeling and behaving

There is a link between thinking, feeling and behaving. Imagine you are alone in the house at night and hear the sound of milk bottles smashing.
If you had a **thought** such as:

- “It’s a burglar”, you may **feel** scared and panicky and would **behave** in a way that adds to the distress, for example, hiding under the covers or phoning the police.

However, if you had the alternative **thought**,

- 'It’s the cat!” you would not have **felt** afraid and **behaved** differently - gone back to sleep.

Our behaviour depends on how we think and feel.

Unhelpful thoughts can occur about CFS symptoms and the future.

If you have not been given a definite answer from your doctor about what is wrong with you, and not had an explanation for your symptoms, you probably feel worried and threatened by them.

That can lead to unhelpful and inaccurate thoughts about your symptoms and condition.

These unhelpful thoughts can influence your behaviour, with the result that you accidentally do things which maintain your condition or even make it worse.

- **Therefore your thoughts are of extreme importance to your recovery**.

At the start of treatment unhelpful thoughts can put you off difficult parts of treatment, especially gradually controlled activity, setting back your recovery.

If you can identify those thoughts you can look at the evidence for and against them and check they are based on accurate facts. You can see if they are helpful or harmful to your recovery.

At first it may be difficult to spot unhelpful thoughts because:

- you have lived with them for so long
- they may be upsetting so you do not always want to remember them
- they appear to be logical so you accept them.

Identifying unhelpful thoughts

Writing them down helps identify them.
Think of an occasion when your symptoms were very bad.
Write down what you were doing and a list of the symptoms. Try and remember the thoughts that went through your mind at the time.

Ask yourself how those thoughts influenced your feelings and behaviour.

- Were the thoughts helpful?
- Were they based on accurate information?
- Did they lead you to do something which could have slowed down your recovery?

Look at the evidence for and against your unhelpful thoughts.

Most of the time people only look at the evidence that supports their thoughts. To be fair to yourself you should look at all the information about the symptoms and the situation that caused the unhelpful thought, including facts and information against the thought.

If there is any evidence against your thought, see if this can be used to give an alternative thought.

On pages 44 and 45 there are some examples of some of the symptoms, unhelpful thoughts and alternative thoughts other CFS patients had before and during their recovery.

Recognising your unhelpful thoughts may make you feel uncomfortable especially if you feel you are having too many. Other CFS patients have felt like this at first. It just means you are identifying them more readily and once you can do that, you can start to check them for accuracy. After a time you begin to recognise them as helpful or unhelpful in which case you can start to reject them and use the helpful alternative explanations.

Some of these unhelpful thoughts may have been part of you for some time and they can be very strong. Therefore it will take time and determination to build alternatives, but it does become easier with practise.

Don't be afraid to challenge yourself.

What about those patients who have had past serious illness and operations?

For some patients the onset of their condition coincides with an unexpected severe physical illness or major operation. Such a traumatic, threatening event can be a devastating body shock, both physically and mentally. Coming to terms with a failure of ones body systems is very difficult and can take time. Those who have been healthy and fit prior to such an event may lose faith in their body's physical ability to function as before. Because of continuing ill health, they wonder whether their symptoms are due to the original problem or the sign of yet another serious medical disease. It can be very difficult in this situation to believe that there is nothing serious going on in the body. However, having been diagnosed as having CFS, it is advisable for such people to consider the following:

- the original problem has been dealt with
- further medical tests have shown nothing abnormal
- the body has a natural tendency to heal.

Reassurance

For some people anxiety about health can be related to such a traumatic medical history.
They seek frequent reassurance.
They request more and more medical tests to rule out possible disease.

If a sympathetic doctor performs yet more invasive medical investigations, that in its self can be viewed by the patient as confirmation that the doctor also believes there is something seriously wrong with them. This can confirm the patients' own fears about their health. However medical tests, verbal persuasion and reassurance only give a temporary reduction of the patient's anxiety. In the long term such actions can actually cause an increase in anxiety and preoccupation with health. In this situation it is advisable for the individual to look at all the facts:

- if all the investigations persistently come back negative,
- if reassurance given by medical investigation is only short lived,

the individual maybe falling into the trap of requesting more medical investigations to relieve their anxiety and not because they are medically required.

Anxiety and Panic

It will help if we first focus on the kinds of thoughts which occur when people are anxious and feeling panicky. As we said earlier, if you have not been given a definite answer from your doctor about what is wrong with you, and not had an explanation for your symptoms, you probably feel worried and frightened by them. This can lead to anxiety with further physical sensations.

You will remember from the chapter on increased nervous system arousal that when we feel worried and frightened there are automatic physical changes in the body - the nervous system is aroused and adrenaline is released into the blood stream which leads to the intense and unpleasant sensations of:

- breathlessness
- dizziness
- palpitations
- blurring of vision
- trembling
- feeling unreal
- tingling sensations.

If you are worried about certain sensations you scan your body for them. Once noticed, these sensations may be taken as further evidence of some serious physical disorder. This leads to a further increase in anxiety that triggers further nervous

system arousal and increased sensations. For some people being trapped in this vicious circle can lead to an attack of panic where they fear that:

- breathlessness will lead to stopping breathing.
- faintness will lead to collapse.
- palpitations are a heart attack.
- feeling shaky or having racing thoughts mean a loss of control over thinking and even sanity.

Interpreting or understanding the intense physical sensations of increased nervous system arousal and adrenaline in an unhelpful way, (thinking that they are more dangerous than they really are or that they are going to harm you in a catastrophic way) leads to panic. Without the unhelpful thought the panic attack would not occur.

Before some attacks people may have:

- been in an anxiety-making situation
- been excited or angry
- suddenly have got up from a sitting position (dizziness)
- been exercising (breathlessness, palpitations)
- been drinking stimulants such as coffee (palpitations)
- been in a particular phase in the menstrual cycle
- noticed a fleeting bizarre image.

Sometimes it's hard to tell the difference between the body sensations that trigger the attack and the sensations of the panic attack itself. In that case, it's difficult to pinpoint the cause of the attack. This can lead to the unhelpful thought that the attack has come out of the blue and is due to a serious physical disorder, which is not the case.

Here are some examples of unhelpful and alternative thoughts from people who had panic attacks. Included are the main body sensations they felt at the time and the unhelpful thought that automatically came into their head as a consequence. The unhelpful thoughts were misinterpretations of those sensations. They led to further anxiety that increased nervous system arousal, so maintaining the sensations or symptoms. After reading information about the physical effects of anxiety and nervous system arousal on the body, these people were able to build alternative, more appropriate thoughts, which are also listed.

Main body symptoms	Unhelpful thought	Alternative thought
Palpitations, breathlessness, chest tightness	I'm having a heart attack	It's just anxiety and overbreathing. I've had this feeling many times before and I did not die. It goes away when I distract myself and distraction wouldn't stop a heart attack.
Faintness, feeling unreal, breathlessness, dizziness	I'm going to collapse	No I'm not going to collapse. I know you need a drop in blood pressure to faint and when I'm anxious my pulse races and my blood pressure actually goes up. So, I'm less likely to faint when anxious than when not. I feel faint because more blood is going to my muscles and less to my brain which is a normal response when people feel they are in danger. With less blood to my brain there is less oxygen so that's why I feel faint. However this feeling doesn't mean I will faint because my overall blood pressure is up, not down.

Here are further examples of unhelpful thoughts and alternative thoughts of CFS patients before and during their recovery.

Main Body Symptoms	Unhelpful Thought	Alternative Thoughts
After gardening I had muscle pain, and fatigue	My muscles hurt because I've done too much. I must do less.	My muscles hurt because I haven't done this for a time. They need regular activity to build them up. If I do less now it will relieve my symptoms, but in the long run the less I do the less I will be capable of doing.
During and after a busy day I feel awful with tiredness, dizziness, aches and pains, sometimes even palpitations.	There must be something seriously wrong with me because I feel so bad when I try to do what other people do.	I feel tired and ache because I did too much. I became dizzy because my body is deconditioned and can not pump blood up to my brain quick enough. Sometimes when I feel these symptoms I become anxious about what they mean. I know anxiety triggers the nervous system and adrenaline, which cause further symptoms of further dizziness and palpitations. If I balance activity and rest by slowly and steadily increasing my activity and reducing rest, I will gradually feel better and stronger.
In bed still awake at 2am.	I won't be able to work properly tomorrow because I need a full eight hours sleep.	This is not true. If I look back on other days when I've had a sleepless night I can see that I still got things done. I just felt terrible, but I coped. If I start to reorganise my sleep pattern and build up my activity over time this will gradually improve.

MAIN BODY SYMPTOMS.	UNHELPFUL THOUGHTS.	ALTERNATIVE THOUGHTS.
After a few weeks of the activity plan. I feel fed up because I still feel tired with some muscle aches and dizziness.	I hardly feel any better and I'm really working at my activity and rest plan. I think it would be easier to pack it all in.	I know research has shown that with inactivity my body has got physically unfit very quickly: in fact quicker than I actually thought possible. I haven't done regular activity or exercise for sometime now because of my symptoms. Therefore, its logical that it will take time to build up my body again. Even so, looking in my diary I can see that I'm doing more than I did three weeks ago and it's all in a forward direction.
After exercise I feel like I am relapsing.	Look, it's happening again. Last time I tried to exercise I became really bad. Activity or exercise just makes it worse. I don't know anybody who has got better and I can't see a way out.	Last time I didn't get the right balance between activity and rest, not giving myself enough rest\relaxation periods. I thought I could do more than I was actually fit enough to do. Now I know that the key is to start activity at a level well below my present physical ability and gradually build up in a slow steady way. Resting hasn't made me better in the past and I don't know if I'll get better or worse doing a gradually controlled activity plan unless I try it. However, others **have** recovered in this way. Pain is normal if I exercise when I'm so unfit. But if I keep on exercising at the right level, I will build up stamina and fitness as an athlete does and pain will slowly disappear.

Summary of Alternative Thoughts.

1. **Everyone has unhelpful thoughts.**

2. **They are not always based on accurate facts and can be misleading.**

3. **Unhelpful thoughts can influence behaviour which then becomes unhelpful.**

4. **Unhelpful behaviour can maintain the problem.**

5. **Identifying unhelpful thoughts lets you check the evidence for and against them.**

6. **Based on your knowledge, from all the facts, you can ask yourself whether those thoughts helpful or harmful to your recovery?**

7. **You can ask yourself whether there is evidence against an unhelpful thought and you can you use the evidence to build alternative thoughts.**

8. **It will be difficult and uncomfortable at first to identify unhelpful thoughts. It becomes easier with practise.**

9. **Don't be afraid to challenge yourself. It can do no harm.**

8: Designing an activity plan - safely!

In this chapter we will help you to design a controlled, gradually increasing activity plan to help you move steadily forward out of the vicious circle of CFS and recover as others have. The activity plan used involves gradually building up exercise in addition to the usual daily activities that involve walking and standing.

Why the thought of any activity plan may turn you off!

- From your past experience you may be concerned that activity will lead to your condition becoming worse.
- You may have already tried activity plans before and struggled with them, getting nowhere or relapsing.
- You may not feel motivated to do an activity plan. Research has shown that prolonged inactivity increases the feeling of fatigue when exercise is taken. Therefore regular activity is an effort to perform (page 10, no 7).
- You may have daily commitments that need your limited energy.

When you do not feel like doing activity, when you are worried about its consequences and your ability to cope with other responsibilities, you may be apprehensive about starting regular activity.

Why is a regular gradually increasing activity plan so important for recovery?

We now know from the medical research:

- There is no persistent virus, no muscle disease or damage.
- There is no hidden disease.

However, there are physical changes in the body.

The muscles and cardiovascular system have become deconditioned. Irregular activity and periods of rest over months and years lead to the body becoming physically deconditioned or unfit. Muscles need regular exercise to work efficiently and without pain.

There is significantly less deep sleep. Regular exercise gives a deeper level of sleep improving its quality and resynchronising the body rhythms.

Activity or exercise cannot harm you. Instead, controlled gradually increasing exercise programmes have been used successfully to build up individuals who suffer from CFS (please see final chapter –Results of treatment trials for CFS).

The severity of CFS symptoms experienced depends on the amount of regular activity taken since the start of the CFS.

What is the safest level to start at?

The aim of the programme is to perform appropriate activities or exercises each day. The individual gradually increases the activity in a timed way, as they feel able.

In view of:

- the research facts about the severity of physical deconditioning,
- your apprehension,
- and the daily living activities that still have to be done,

It is very important to <u>start activity at a level which is well below your current level of ability</u>.

In that way:

- You can still manage daily tasks without doing too much activity and relapsing.
- You can build up a regular daily activity programme.
- You can still manage to do some level of activity even on a bad day.

Most CFS patients are more physically deconditioned or unfit than they think they are. To be diagnosed with CFS the disabling fatigue is severe enough to reduce for a period of at least six months, the average daily activity by at least 50%. The consequence of such reduced activity is physical deconditioning.

If you have had this condition for some time you may underestimate just how physically deconditioned you have become.

There is a pattern to CFS.

Doing too much activity for the level of your reduced physical stamina is followed by overwhelming symptoms necessitating rest.

A pattern of rest and irregular activity develops which, in time leads to further physical deconditioning and reduced physical stamina.

Therefore if you start activity at a level equal to or above your present physical stamina, you will find it virtually impossible to carry on with your activity plan and daily tasks and you will be overwhelmed by symptoms.

This situation leads to lack of trust in the activity plan which may then be shelved. And so the opportunity for recovery is set back or worse still, lost for those who lose all faith in it.

For this reason

It is best to start an activity at a level which you are capable of doing on a BAD DAY.

Pacing yourself as athletes do is essential for success.

Athletes at the start of the season do not expect to achieve full potential in the first days or weeks of training. They start building up fitness and stamina gradually, in a sustainable way over many weeks. They expect symptoms of deconditioning, seeing them as a sign of unfitness, not of physical disease. They know that as stamina and fitness increase muscle pain and fatigue will disappear.

Control is essential – increases in daily exercise or activities should be timed to avoid a 'boom and bust' pattern of activity which is associated with bad days. Controlled timed increases in exercise ensure sustained progress.

First impressions of an activity plan

At first you may notice **an increase in your physical symptoms**. On starting activity you may feel the symptoms of physical deconditioning: dizziness, breathlessness, sweating palpitations, fatigue and later, muscle aches.

Patient's thoughts about the symptoms are vitally important in recovery.

Those who do not fear the symptoms, understanding that they are the unavoidable signs of deconditioning have less nervous system arousal and adrenaline than those who do worry. With less nervous system arousal there is less muscle tension, consequently, exercises are easier to perform.

The increase in symptoms is only temporary.

Those who persevere at this difficult point notice that over time as they become fitter, the symptoms of physical deconditioning gradually lift.

As medical research and tests have shown, there is no hidden disease; therefore activity can do no harm when performed at a level matching your present fitness.

How long should symptoms last after exercise and when can I increase exercise times?

After your timed exercise, the symptoms of deconditioning (jelly-like, shaky sensations in the legs, pounding heart etc) should have subsided with ten minutes of rest. The individual may continue to rest further for up to 30 minutes at the start of the programme, which is reduced as weeks pass (please see the following section 'How long to rest for'?).

When symptoms have subsided with ten minutes of rest, the individual can increase

the time of exercise in the graded way suggested in the following sections on activities.

When symptoms subside after just a few minutes of rest, the body is fit enough to sustain that amount of exercise safely and a controlled, timed increase can be done.

When symptoms last longer than ten minutes it is an indication that the body is not yet able to tolerate that level of exercise and is being over worked. This may lead to increased symptoms and a relapse. Individuals may chose to reduce their exercise time to ensure symptoms have subsided with ten minutes of rest.

Regular rest is vital

Rest both before and after exercise is an important part of the treatment, especially in the early stages of recovery.

- **It allows the necessary time for the** metabolism of the muscles and the cardiovascular system to restore before the next activity**.**

- **Exercise causes an increase in nervous system activity and adrenaline production. Therefore after activity it is important to** rest to allow the body's physical systems to relax **– otherwise, continued adrenaline production will cause increased symptoms.**

Which position to rest in?

The human body is designed to lie flat for approximately eight or nine hours each night.

Lying down for long periods of time weakens the posture muscles of the neck, shoulders and back. This can cause back pain on sitting or standing**.**

Therefore, it is advisable to avoid lying down when resting.

For those who do lie down to rest, use an increasing number of cushions to prop up the upper body so that, over time, rest is taken in the sitting position.

Sitting propped up also helps with reconditioning or improving the fitness of the cardiovascular system**.**

How long to rest for?

After an activity **avoid resting for longer than 30 minutes**.
Sitting for longer will lead to blood pooling in limbs and body compartments causing more unpleasant symptoms on standing.

Therefore, even on a bad day, getting up regularly from rest and walking around the room even for a short period of time will:

- help to control symptoms
- start the process of reversing the muscle and cardiovascular deconditioning.

Break down household tasks into smaller amounts **taking a rest sooner than you feel necessary**. In this way, you will reduce the intensity of symptoms experienced over the day while being able to do more.

Following light activities that involve standing or gentle walking, you may only need ten or fifteen minutes of rest.

After your timed exercise, rest until the symptoms of deconditioning have subsided (shaky sensations in the legs, pounding heart, etc.). At the start of the programme, you may need 30 minutes of rest after your aerobic exercise. **As the weeks go by, your aim should be to reduce your rest time after activity** to 25 minutes, then 20 minutes and so on.

Over time as exercise and activity time increase, rest time decreases.

The goal is to gradually build up the exercise until the desired level of activity is reached and can be maintained.

Which exercise for recovery?

The type of exercise needed for recovery is aerobic exercise.

Aerobic exercise is exercise where your breathing rate increases and your heart rate increases to deliver oxygen to the muscles to allow them to work efficiently.

Aerobic exercise will:

- **reverse physical deconditioning, improving fitness and stamina**
- **improve the quality of your night sleep**

At the start of aerobic exercise training, individuals may notice breathlessness, pounding in the chest, sweating, dizziness. In time, the exercise can be done for longer periods without undue breathlessness.

The exercise activities you chose will depend on the severity of your condition.

When you wish to start a gently increasing aerobic activity, the activity should be:

- realistic and enjoyable
- performed several times a day
- performed every day - good days and bad - otherwise the benefits of the activity already gained by your body (and hard effort!) will be lost.

- **Doing exercises frequently that are paced over the day (for a controlled time) is of greater reconditioning benefit for the cardiovascular system and muscles because they are frequently stimulated**.

There is no other medicine that can be taken to build up your body's systems and muscles, other than controlled graduated activity - but it does work.

Which activity for you?

The following suggested activities are of varying physical intensity to do in the early stages of recovery. You may wish to **choose a selection of gentle and aerobic activities** to perform that is spread over the day.

- standing sessions
- stair exercises
- dancing
- jogging
- walking sessions
- exercise bike sessions
- marching

You will need to tailor your exercise programme to suit your own individual needs. This will depend up on many factors including your level of deconditioning and your daily living commitments.

Some patients increase exercise at faster rates and do more sessions than others depending up on their individual circumstances.

Many patients are already standing and walking as part of their present routine; but they are often limited in the length of time that they can perform these actions.

If you wish to increase your stamina to be able to do these or any other activities for longer periods, you will need to increase the timing of these activities in a controlled way.

For those with a very severe CFS problem

Targets can be set to match the level of disability for example for those who spend most of the time lying flat:

- Propping yourself up with pillows for short periods of time (five minutes in a two hour period) and gradually increasing the length of time.
- Circling your feet or hands every couple of hours starting with two repetitions and gradually increase the number of repetitions.
- Squeezing a stress ball or body scrub sponge every couple of hours starting with five times and gradually increasing the number of repetitions.

- Raising your arms with the eventual aim of lifting them above your head. Doing this two or three times a day and gradually increasing the number of arm raises.
- Dangling your legs over the side of the bed or sofa every couple of hours, starting with five seconds and gradually increasing the length of time.
- Using the bathroom unaided.
- Spending a few seconds sitting on the side of the bed, then, when you can, standing upright for one or two seconds. Gradually increase the length of these sitting and standing sessions.
- Getting out of bed and sitting on a chair for increasing lengths of time.
- Gradually increase walking time by starting with two paces away from the bed and two paces back. Over time this can be gradually increased and then timed in seconds. As you improve you can take your walk around the house.

Remember, that if you have been used to lying flat for most of the time, when you start raising your head above your heart, which is deconditioned, you can expect to experience dizziness, nausea and palpitations. Also, when you start sitting or standing the muscles of posture including those of the head, neck, shoulders, mid and lower back are deconditioned. Consequently, you can expect to experience generalized muscle aches and tiredness.

As you increase the length of time that you sit up the heart and the muscles will become stronger and fitter and these symptoms will start to subside.

Remember to avoid overwhelming symptoms:

- Start at a level that is right for you and build up gradually
- Pace the above activities over the day with rest periods between each session.

Walking

This is a gentle way of gradually building up fitness. Some patients may chose to do a graduated walk once or twice each day. This can be the first step for those who have been house bound. Some may wish to take a partner until feeling sufficiently confident. Try to walk at a normal speed. Balance can be lost when walking very slowly.

To start, time the amount of walking that you can do safely without causing symptoms at the time or afterwards.

For example, inside the house, if you can only walk for 10 seconds, then you may wish to do this around your house on two or three occasions spread throughout the day.

- The next day do 15 seconds for each session
- The third day do 20 seconds per session

- Carry on increasing by 5 seconds daily until you feel confident enough to increase by 10 seconds daily.

Some patients start by walking outside the house: walking out from their door for 15 seconds and back for 15 seconds. The following day they may walk 20 seconds out and 20 seconds back. The next day 25 seconds out and back. Once patients feel confident with a 10 second daily increase, they can increase by 20 seconds daily, then 30 seconds and so on.

For those who feel able to do more than this, and wish to start at a higher level of activity, please remember:

The aim is to begin activity well below your present level of physical fitness so that you can still do your other daily tasks.

Pacing yourself is vital to success. Walking time soon builds up and gradually you will start gaining physical benefit from it. **A slow steady sustainable increase is the aim.**

Standing

Standing requires a fit heart. On standing the blood pools in the calf muscles because of gravity. With walking, the lower limb muscles act as pumps, squeezing blood back to the heart. With standing, however, the muscle pumps of the lower limbs are idle allowing blood to pool in our lower extremities.

This means that there is less blood returning to the heart and going on to the brain which causes sensations of dizziness and feeling faint.
In reponse the heart beats faster to circulate blood which causes palpitations.

As there is reduced muscle strength and the heart is deconditioned in CFS:

- **Standing is hard work but a very valuable exercise to build up**

The starting level of standing depends on the degree of deconditioning.
Severely affected patients may start standing by holding on to a chair for 5 seconds. Other patients may start at 15 seconds. This may done several times spread over the day. It can be increased by several seconds each session or day depending on symptoms and degree of deconditioning.

Some patients **select those household activities that involve standing and increase their duration** in a controlled timed manner.

An exercise bike

This has proved to be the **most reliable and popular method of aerobic exercise** in the early months of recovery. Its advantages are:

- **you** are in control
- it can be done at home without relying on transport, without worries of becoming exhausted while being out and unable to get home
- it can be done in all weathers
- it is partly weight bearing, consequently it is less demanding on a body that is physically deconditioned
- after the first few weeks it has the added advantage of making you out of breath which further stimulates your cardiovascular system.

A suggested safe level to start at:

- The first week start with 5 revolutions or pedals in the morning and repeated in the afternoon. (It may not seem much **but** it will not cause relapse)
- Increase to 7 revolutions the next day, am and pm
- Increase to 10 pedals the next day, am and pm
- Increase to 12 pedals the next day, am and pm.
- Carry on increasing by 2 or 3 pedals daily, am and pm for the first week.
- **In the second week**, increase by 5 pedals a session. When 55 pedals is reached, time how long it takes on a watch. Work from that time adding on a 5 second increase each day for the rest of the second week.
  For example: if 55 pedals takes 1 minute, then cycle for 1minute 5 seconds. The next session cycle for 1.10, then 1.15 the following session and so on.
- The third week increase by 5 seconds per session.
- The fourth week increase by 7 seconds per session
- The fifth week increase by 10 seconds per session
- The sixth week increase by 15 seconds per session
- Carry on increasing steadily.

Aerobic exercise reaches the depths of physical deconditioning.

After some days of you may notice an increase in the symptoms of physical deconditioning (jelly-like, shaky sensations in the legs, pounding heart, breathlessness, sweating and fatigue). This is because your body is not yet used to such regular activity. But with perseverance you will become fitter, reversing the physical deconditioning in your body.

Although it will take a considerable length of time for your body to recondition, which is why the duration of the programme is between one and two years as that happens, the symptoms will subside.

Tension can be added to the exercise bike when patients are doing 20 to 25 minutes

or over. Some bikes allow the arms to be worked in a rowing action. This can be started when patients have achieved more than five minutes on the bike. Again, build up in a graded manner.

A combination of exercises gets recovery underway

Although the exercise bike is beneficial in reconditioning the heart, lungs and muscles, it is only partially weight-bearing. Consequently, additional full weight-bearing exercises, which will complete the reconditioning process, need to be added to the programme for full recovery.

It is important to be aware that frequent stimulation of the cardiovascular system with both partial and full weight bearing timed exercise is most effective in reconditioning the body. Consquently, in addition to their two daily exercise bike sessions, some patients chose to do full weight bearing activity sessions. These can include:

- Walking and standing, which we have already outlined
- Stair exercises
- March, dance or jog

The full weight bearing exercises: stairs, dancing, marching and jogging are more demanding on the deconditioned body than the exercise bike which is partially weight bearing. Therefore, they are harder to perform and it will take longer to build up exercise times compared with the bike. It is advisable to spread the sessions over the day: **follow each session with a rest**.

Again, these or any other further sessions are **started at a very low level of intensity and duration**.

Stair exercises

Climbing stairs is a regular part of normal life. Therefore doing stair exercises prepares you for after recovery. Stair exercises are of great benefit, they are an instant workout for the cardiovascular system and working different sets of muscles. However, these exercises are not recommended for patients who have had previous problems with their knees or backs.

- Start with climbing just one stair (not the flight) in the morning, lunchtime and one in the afternoon
- increase to 2 stairs the next day if possible
- increase to 3 stairs the next day if possible and so on.

This can be an extra activity on top of your chosen aerobic sessions. Starting at such a low level and building up slowly means your body can adapt to extra activities without jeopardizing your progress or your main activity plan.

Dancing or Marching

This can be performed in the house beginning at a low level of intensity with one session in the morning and one of the afternoon. The arms can be worked too.

- Start at five seconds and increase by 2 or 3 seconds per day.

Or Jogging

Some patients choose to jog on the spot or around the house or garden. Jogging quickly loads the deconditioned systems of the body with full body weight. Consequently, it is very demanding and if performed at a level greater than the body's reduced stamina level it will cause a relapse. It is vitally important to start jogging at a very low level.

- Start at 5 seconds and only increase by 2 or 3 seconds per day as able.

Patients report that in comparison to the other exercises they do, **it is harder to increase jogging time – so beware!**

Medicines for other illnesses are taken several times a day. Steadily increasing activity which is the medicine for physical deconditioning, is no different. If missed, as with other medicines, there is no improvement.

Structuring Your Day

You may feel that doing your daily tasks are enough.
Adding an activity to your day is just too much and could set you back.
For this reason, **we emphasise that you should start an activity or exercise at a level well below your physical ability.**

Then, you can still do your daily routine without doing too much activity and relapsing.

Controlling daily activities controls the level of symptoms.

Those CFS patients who have recovered found this was the best way of coping with an activity programme.
At the start of a programme, trying to fit in daily tasks with social activities and the daily exercise programme can lead to an overwhelming increase in symptoms. Controlling those daily activities controls the levels of symptoms. Recovered patients found it useful to structure their day, pacing and controlling activity, rest or relaxation time.

Patients who recovered made the following suggestions:

- Get up at a set time in the morning (remembering that 8 – 9 sleep hours is advisable)
- Plan your day before getting up.
- Prioritise tasks as necessary.

- Decide when essential tasks need to be done.
- Spread aerobic exercise sessions over the day.
- Follow each exercise session with a period of restful relaxation in a chair. (Practising relaxation and breathing exercises will physically benefit recovery – see next chapter)
- Balance rest, activity and exercise throughout the day.
- Break down household activities into small amounts.
- Try not to over compensate by resting too much on a bad day (doing a gentle walk outside can help reduce symptoms).

How much aerobic exercise and for how many months?

The number of aerobic exercise sessions depends on the circumstances of each individual patient. **For those who do four aerobic sessions spread over each day**:

- **the aim is to achieve four 15 minute paced sessions**.

Following that, two sessions of differing exercise are built up to 30 minutes.

Once sleep begins to improve and patients wake feeling refreshed, one exercise session can be dropped. The other exercise session should be maintained until the individual feels fully recovered and at the desired level of physical fitness.

When patients can do exercise for substantial periods of time, for example, 30 minutes on the exercise bike, they may chose to do other types of activity to increase their aerobic exercise abilities, for example swimming.

Swimming is very effective in building up cardiovascular stamina. However, at first it is advisable to start with short frequent sessions, for example, 15 minutes, if possible several times a week. In these early pool sessions, walking forwards and backwards is an effective exercise; **frequent rests** are recommended between these short walks to prevent over tiring. Over the weeks and months, a gradual build up of the number of widths and then lengths of the pool (taking frequent rests) is advised.

Home aerobic videotape. Those who build up substantial time dancing or marching may choose to do a home aerobic videotape. Again, at first it is advisable to start these different activities at a reduced level and gradually build up stamina. When you feel confident you may wish to attend classes for aerobics, dancing or gym work.

After recovery from CFS, 30 minutes of enjoyable physical activity of moderate intensity, for example, cycling, swimming, brisk walking, gardening, **is recommended as routine for a minimum of three times a week**. This ensures that all the benefits of regular exercise help to maintain health.

Increasing general activities

Any household activity however small (washing up some cups, tidying up) can be built into your daily routine with the appropriate period of rest taken afterwards.

The aerobic exercises will build up your physical stamina; however, increasing general activities at the same time is an important part of recovery and they too should be increased in a controlled paced manner. As recovery continues the periods of rest between graded exercise and activities can be reduced.

Be warned – Progress is slow!

The medical evidence shows that with rest:

- the body deconditions more rapidly that it reconditions once regular activity is started.

As most CFS patients have had reduced activity levels for at least six months there will be substantial physical deconditioning which can take a considerable length of time to reverse. **This is why the duration of the programme is between one and two years**.

Sometimes patients are not always aware of the severity of their physical deconditioning until they start the graded exercises. This is because they have put in place strategies to manage or avoid their symptoms. For example, they may make a pile of articles at the bottom of the stairs in order to avoid frequent trips upstairs that could cause more symptoms. The early weeks of the graded exercise programme can be very difficult as each patient learns the extent of their physical deconditioning.

Progress at first is very slow and can be frustrating.

When individuals:

- are frustrated or disappointed with progress
- expect more from their deconditioned body that it can perform

there is an automatic triggering of the nervous system and adrenaline in order to improve the performance of the muscles and the cardiovascular system. However, the muscles and the cardiovascular system are deconditioned; the nervous system arousal of these deconditioned systems causes increased symptoms including muscle tension, palpitations and breathlessness.

Consequently:

- exercises becomes even more difficult to perform
- the rate of recovery becomes even slower

It does take time to recover

Even though progress maybe slow at first, as you carry on working steadily at each part of your treatment plan you will gradually feel an improvement.
It will need determination on your part, but you will find symptoms lift and you recover.

An activity diary acts as a record of your progress

If you have a record of activity to look back at, you can see how much you have achieved and progressed even though you may still be fatigued in the early stages. Compare how you are now with how you were six months ago.
Close friends will probably notice an improvement before you.

At the end of this booklet are daily activity diaries for you to record those activities which you aim to gradually increase and your achievements.

Focus on your achievements not on your symptoms or limitations.

Symptoms and limitations are temporary.

Focusing on symptoms or limitations can cause distress or frustration. This will increase nervous system activity and adrenaline production which increases symptoms and therefore hinders exercise and recovery.

As you perservere with exercise:

- **symptoms will subside**
- **your achievements will grow**
- **your confidence will increase**

and as a result

- **there will be less nervous system arousal and adrenaline**

What to do on a bad day

Unfortunately, bad days will happen.

Bad days happen around the time of **increased physical activity or mental stress**, for example, increasing exercises too quickly for the level of deconditioning, overdoing housework or gardening, attending hospitals or social events such as parties or weddings. Also, increased mental effort or stress, for example dealing with benefit claims, work issues, relationship problems or long/difficult phone calls.

An **increase in physical or mental exertion** will increase nervous system arousal and adrenaline production leading to **overwhelming symptoms** and bad days.

If you compensate for these symptoms by taking rest and not doing any of your previous set exercises you will slow down the process of reconditioning the body, which you will have already started with your exercises.

You will stay longer in the vicious circle of CFS and your recovery will be delayed. In order to recover you have to be prepared to break out of that vicious circle.

Whenever you choose to take that step, you must be prepared for an increase in symptoms.

Getting your body used to regular activity after rest or irregular activity is never going to be easy. This is because the effects of physical deconditioning in the body can be severe and in order to reverse them, motivation and great effort are needed.

The key to successful recovery is:

- **if possible on a bad day try to do the same amount of exercise as the day before but no more.**

It will be a struggle but you will not harm yourself.

If, however, it is not possible to do the same amount, reduce the amount of exercise in the way outlined in the next section ‘What to do when setbacks happen’.
Those who have recovered experienced bad days with increased symptoms, but by working through their thoughts about those symptoms in their mind, using their understanding of physical deconditioning and rationalising their thoughts, they managed to overcome their symptoms and the fears. There is an explanation of how they did this in the section on 'The Right Thoughts for Recovery'.

- **After a bad day start to increase on the next good day**.

In time, **as patients pace their activities, breaking them up with rest over the day**, there is a decrease in the frequency of bad days.

Designing an Activity Plan for Mental Fatigue

Mental fatigue symptoms such as poor attention, poor concentration and poor memory improve once recovery from physical fatigue has started to take place. The recovery from mental fatigue takes place more slowly lagging behind the recovery from physical fatigue by a number of weeks. Sometimes mental fatigue symptoms do not improve as much as we hope. A programme of gradually increased activity scheduling can be helpful such as programmes that have been used successfully after mild brain injury. The presence of mental fatigue in CFS does not indicate that you have had any brain damage. But this work shows that, even when people have had mild brain injury, they can make a recovery from mental fatigue (44).

The same principles apply to an activity plan for mental fatigue as for physical fatigue:

1. **Plan you day balancing essential tasks, physical activity, mental activity with periods of regular rest or relaxation.**
2. **Choose a mental activity to do at least twice per day.**
3. **Start at a level well below your level pf mental ability.**
4. **In a controlled, gradual way increase the activity on good days.**
5. **On bad days try to do what you did the day before.**
6. **Your symptoms may increase at first but this is only temporary.**
7. **Don't do too much when you feel good and too little when you feel bad.**
8. **Try to keep to your plan – stick to your mental and physical activity and rest times or else you lose the balance between them and then control of your symptoms.**
9. **Slowly and gradually increase your mental activity as you reduce rest and relaxation.**
10. **A variety of different activities improve mental fatigue more efficiently than the same activity repeated over and over again.**
11. **Ultimately you should aim to do 30 minutes of such mental activity in one go, once a day.**

Your effort in working steadily on each part of treatment will take time and patience to produce results but it will be rewarded.

Which mental activities should I do?

Mental activities need to engage the person's attention and concentration, involve some degree of planning and memory. They should be things that the person enjoys and can be done at the person's own pace.

Examples including jigsaw puzzles, other types of puzzle or games including some card games and chess, computer games or problem solving tasks. Light reading can improve concentration but may not help much with problem solving tasks. Tasks involving memorising lots of facts are usually too demanding to start with but can be worked towards.

As you improve you should try different types of mental activity because each one makes different demands on you in terms of your attention, memory, concentration, problem solving and planning.

If you have work or a pastime you plan to do or a course of study you want to pursue you can make the tasks more and more like the ones that you will be doing in the future. Please do not start with these tasks because they are usually complex and too demanding on you mental energy for you to make enough progress.

How much should I do and for how long?
Mental activity tasks usually require some time for you to get used to the task. A reasonable starting point is 5 to 10 minutes repeated twice per day.

The activities are built up gradually at a rate of 1-2 minutes per week twice per day depending on your overall fatigue symptoms, not just your symptoms of mental fatigue**.**

Most people reach 30 minutes per day by 2 months and the aim is to reach 30 minutes per day in a single mental activity at one go repeated 3 times per day (preferably 3 different types of mental activity for 30 minutes in each day).

What to do when setbacks or relapses happen

Most patients experience several setbacks during recovery. They are to be expected. They can occur when:

- you do too much activity because its a good day
- a stressful event occurs
- something unexpected occurs and you have to do activity other than your regular activity programme
- you catch a cold or other infection

When they do happen, don't be too frustrated, if possible try to do the same amount of activity as the day before but no more. Start to increase on the next good day.

Remember excessive levels of physical activity and mental stress can cause intense nervous system activity and adrenaline production causing flu-like symptoms that mimic a virus.

If, however, you do catch a cold or an infection with a temperature (checked on a thermometer) you may wish to reduce your exercise level. It is advisable to avoid lying down to rest or sleeping in the day. Gentle pottering around the house at regular intervals will do no harm and will prevent a return to deconditioning.

When your temperature returns to normal the infection has left the body so it is safe to **start your activity again but at a reduced amount**.

Restarting exercise after a cold or setback.
Start your activity at a reduced amount

For example:

- if you cycled for 3 minutes before your setback, start at 15 seconds and increase by 15 seconds a session until you reach 3 minutes and then increase in the usual controlled graduations.

- if you cycled for 10 minutes before your setback, start at 2 minutes and increase by a minute a session until you reach 10 minutes and then increase in the usual controlled graduations.

Restart your other activities: marching/dancing/jogging; stairs; walk, at a reduced level and expect to take several days to build back up to the exercise times you peformed before the setback.
Symptoms may increase again causing fear of relapse, but remember **these are the symptoms of physical deconditioning**, nothing else.
You will not relapse to any great extent because of stamina built up during the regular activity performed before the setback.
But it is **important** to resume your activity plan as soon as possible so as to move forward again.

A warning from those who recover!

Patients, who have recovered using a gradually increasing activity programme, say that the early weeks are the most difficult.

Many felt they had been generally active during the time they had CFS and in consequence did not realise just how physically unfit they had become.

As a result they pitched their activity level too high for their reduced level of physical stamina and after a few days felt overwhelming symptoms.

They then had to reduce the level of activity to a level that allowed them to cope with essential daily tasks as well as the chosen activity to avoid overwhelming symptoms.

It is common for CFS patients to feel that they have been active whilst battling through their condition, and in fact many have.

They actually have been **too active for their reduced level of physical stamina**.
A result of that over activity is overwhelming symptoms which in turn necessitate rest.
Over time rest and periods of inactivity, even though irregular and infrequent, have caused the running down or deconditioning of the body's physical systems.

Recognising this pattern in your own behaviour is one of the steps on the road to recovery. Once you are aware of this pitfall you can control your activity plan tightly so avoiding mini relapses.

With this in mind, the emphasis is therefore on starting regular activity in a small way in combination with your daily living tasks.

Even so, for some people:
- symptoms may increase
- progress seems very slow.

Anxiety also can play its part in these first stressful weeks, triggering increased nervous system activity and adrenaline production causing more unpleasant symptoms in addition to those of physical deconditioning. So Beware!

It can be disheartening and so easy to want to give up on the activity programme. But from the research we now know that:

- **giving up on activity will only lead further into CFS with its disabling symptoms**.
- those who persevere in a controlled gradually increasing way do not harm themselves, but start to feel the physical benefit of exercise.
  Symptoms do start to lift.

Beware of doing uncontrolled activity!

As you start to feel improvement in yourself

- it can be easy to fall into the trap of doing too much, resulting in a return of your symptoms.

This is a sign that you have not yet fully reconditioned your muscles and cardiovascular system and recovered.

To ensure full recovery avoid bursts of uncontrolled activity and gradually build up exercise until the desired level of activity is reached and maintained.

As you improve those around you may expect you to do more too soon.

People who struggle with controlled activity programmes often have tried to increase by too much on good days.

They pay for it later when they have to rest in order to recover.
This **boom and bust pattern of activity perpetuates the vicious circle of CFS**.

If you:

- control the amount of activity that you do
- increase in a gradual manner in proportion to your physical stamina,

you will avoid mini relapses.

Instead of CFS controlling you, you will learn to control it and therefore regain control of your life.

The benefits of exercise.

1. Exercise produces **endorphins.** They improve mood, give feelings of well-being, pain relief (45) and help sleep. This has been noticed by people who take regular exercise.
2. **Exercise produces cortisol** which boosts the body's metabolism.
3. **Exercise has been shown to improve mood.**
   In regular exercisers strenuous exercise increases positive mood and relieves negative mood (46). Even in those who do not exercise regularly but did mild walking an improvement in mood was observed (47).
4. **Exercising regularly reduces anxiety and protects against it.**
   Exercise has been shown to reduce anxiety in research studies (48;49).
   Therapeutic exercise should consist of regular, light or self-selected exercise, 30 min several times a week. This is adequate for reducing anxiety, depression and for physical benefit. It seems that a certain amount of physical activity is biologically necessary to keep anxiety at normal levels (50).
5. **Exercising regularly relieves depression and protects against it** (49).
   People who exercise regularly are less depressed than inactive people (51).
   When regular exercisers were denied exercise they suffered depression, anxiety and had feelings of being unable to cope (52).
   Regular exercise improves self-esteem and positive feelings about oneself.
6. **Exercise has a toughening-up effect on the body**.
   Research has shown that repeating one form of stress helps people to withstand other forms of stress. Exercise by its nature is stressful and exercise increases one's ability to withstand stress in every day life (53). In a group of business executives who were chosen because of their stressful lifestyle, those who exercised the most suffered the least illness (54). Physical fitness and exercise protect against the harmful physical effects of psychological stress. Psychological stress affects blood pressure and heart rate and leads to the development of cardiovascular heart disease (55). However, in those who take regular exercise the effects of stress on the cardiovascular system is reduced. Research has shown that physically active men and women have less chance of developing high blood pressure (56) and dying of coronary heart disease (57) . After regular exercise there was a drop in the blood pressure of people who had a mild blood pressure problem (58).
7. **Exercise is known to promote deep sleep**.
   Those who exercise regularly have more deep sleep than unfit individuals. They sleep longer and sleep is more readily achieved (37).
8. **Exercise is associated with better mental functioning.**
   Studies have shown physical fitness and exercise has a beneficial effect on memory and concentration (59).

Summary of Activity Plan.

1. **Plan your day balancing essential tasks, activity and rest or relaxation. Keeping an activity diary helps you to keep to your target activities.**

2. **Do something little and often.**

3. **Choose an aerobic activity to do at least twice a day.**

4. **Start at a level well below your present level of physical ability.**

5. **In a controlled, gradual way increase this activity on good days. (Timing the increases in activity avoids boom and bust activity patterns)**

6. **On bad days, if possible, try to do what you did the day before. This is the key to a successful recovery. Do not increase your activity until the next good day.**

7. **Your symptoms may increase at first but this is only temporary.**

8. **Don't do too much when you feel good and too little when you feel bad.**

9. **Try to keep to your plan - stick to your activity and rest times or else you lose the balance between them and then control of your symptoms.**

10. **Slowly and gradually increase your activity as you reduce rest.**

11. **Ultimately you should aim to do 30 minutes of such activity in one go, once a day. It will take time and patience, but your effort in working steadily at each part of the treatment will be rewarded.**

9: How to reset your biological clock

In this chapter we will explain how to reset your biological clock by re-organising your sleep habits. If you follow the advice in this chapter the body rhythms, which have been thrown out of synchronisation by your condition, will gradually return to normal. As they do so, the symptoms associated with disorganised body rhythms will subside.

Why cues or signals are so important in resetting the biological clock

From research we know that the biological clock in the brain controls body rhythms which in turn control vital body functions, such as:

- the sleep-wake cycle
- intellectual performance;
- memory:
- feelings of alertness and tiredness

In healthy individuals, the biological clock is reset each day by cues or signals such as:

- sleeping and getting up,
- performing daily routines and activity.

Cues can be disturbed by shift-work, jet lag, infection, illness or stress. If continued, these conditions cause the gradual lengthening of the body rhythms, which become out of synchronisation with the rest of the world. This results in worsening symptoms that include poor-quality sleep, increasing fatigue during the normal daily active phase, poor intellectual performance, and low mood.

Therefore disruption of regular cues plays a central part in the desynchronisation of body rhythms. To reset the clock and body rhythms, cues need to be re-established at normal times. In order to do this, reorganisation of sleep habits is necessary.

Why some sleep habits make the problem worse.

CFS patients often feel that the excessive tiredness they experience during in the day necessitates rest. Sometimes there can be an overwhelming desire to sleep which proves impossible to fight. Yet we now know some important facts from research. Sleeping in the day magnifies the problem of CFS for these reasons:

- **It sends another disruptive signal to the biological clock, throwing body rhythms further out of synchronisation.**

- **Deep sleep taken during the day reduces night time deep sleep, with the result of feeling unrefreshed in the morning.**

- **Sleeping or resting in the day means the body is inactive, therefore adding to overall body physical deconditioning.**

How to create a quality sleep pattern

It will take time to reorganise sleep habits and reset the clock, but it is possible. The reward is quality sleep. The two main ways to achieve this are by:

- re-establishing cues
- dropping unhelpful sleeping habits.

We will divide the day, looking at how to re-establish cues and check any sleeping habits that are maintaining the symptoms of CFS.

In the morning

Build regular cues into your morning routine such as:

- routinely using an alarm clock.
- exposure to bright light has been found useful in relieving the symptoms of jet lag (where the biological clock is also out of time). Therefore when your alarm goes off either put a light on or draw back your curtains.
- getting up at the same time every morning, no matter what time you have fallen asleep the previous night.

Sleeping late in the morning results in poor quality sleep the next night. You may have already noticed that you can be in bed for 12 hours or more and still feel tired.

Increasing the amount of time you spend in bed in order to 'feel better' actually magnifies your problem.

For some, getting up at the same time every morning may seem impossible to achieve at first. However, it is possible with planning and determination to reduce the time spent lying-in.

- If, because of how tired you feel, you spend time lying-in, try to get up an hour earlier the first week.
- Each following week make your getting up time an hour earlier, so eventually you are getting up at a relatively early time.

Most adults need between 7 and 8 hours sleep each night with less as they get older.

- Resting in bed for longer than this means your body is physically inactive so adding to your overall body deconditioning or unfitness.

Therefore staying in bed for too long helps maintain the symptoms of CFS.

At first, these new sleeping habits will make you feel more tired, but that will change as your clock starts to reset itself. You can not harm yourself with this approach. It will take time and persistence coping with these new habits, but gradually you will have a deeper, more refreshing sleep.

In the day

Sleeping or cat napping in the day

- **reduces the amount of deep sleep** you have at night.
- throws your **body rhythms further out of synchronisation**.
- means the body is inactive **further contributing to physical unfitness**.

Therefore try not to nap.

Take your mind off the urge to sleep by either:

- talking to a friend or relative
- doing a task
- doing gentle exercise
- going for a gentle walk in the fresh air.

Such gentle and controlled activities cause arousal of the nervous system and production of adrenaline. **This helps to keep us alert and prevents sleep**.

It can take a time to break this habit but with your determination it is possible.

If you are in the habit of going to bed and sleeping in the day, you can help break this habit by reducing the time spent in bed each week by an hour.

Structuring your day with a plan makes sure that there is sufficient time for rest or relaxation (but not to sleep). In addition, physical and social activities performed at about the same time each day provide cues which help to reset your clock.

In the evening

Get into a relaxed bed time routine.
We know from Chapter 4 (Increased nervous system arousal and adrenaline) that when you are worried, excited or stressed, adrenaline is released into your bloodstream. This causes an increase in heart rate (maybe noticed as palpitations), and an increased rate of breathing (feeling breathless).

Adrenaline also makes you wide awake and alert and therefore prevents sleep.

Sleep occurs in a tired mind and body when there is no adrenaline activating body systems.

With this fact in mind it is wise to **do a slow winding down process before going to bed of a night:**

- Avoid going over unsolved or unsolvable problems in your mind. If something is troubling you and there is nothing you can do about it, try writing it down before you go to bed and then tell yourself to deal with it in the morning.
- Avoid worrying about not sleeping because this causes further symptoms of adrenaline and arousal. Nobody has ever died from lack of sleep. Eventually you will sleep once your mind switches off. Lack of sleep only affects your mood not your performance.
- **Avoid disturbing phone calls or conversations before going to bed.** Long calls that require attention will increase nervous system activity and adrenaline.
- **Avoid vigorous exercise just before going to bed**. Do your graduated activity programme during the day and late afternoon or early evening.
- Gradually building up your activity or exercise plan in the day, will send you to bed with **the feeling of normal healthy physical tiredness associated with exercise**, rather than that overwhelming tiredness associated with CFS.

As we have discussed in the Chapter 2, daytime rest causes increased feelings of fatigue. By developing your steadily increasing activity plan you will gradually overcome this feeling of excessive fatigue, replacing it with the normal healthy variety. **An extra benefit of regular exercise is that it promotes deeper, more refreshing sleep**.

Avoid stimulants like caffeine in tea, coffee, chocolate and cocoa. Decaffeinated beverages are preferable.

Watching amusing or soothing TV, light reading, listening to a relaxation tape or music before bed, can help unwind you. As these become part of a regular routine they act as cues to help reset your clock.

Going to bed at the same time every night is another cue to help reset your biological clock, reordering and strengthening body rhythms, teaching your body to fall asleep. Aim not to go to bed before ten o'clock each night.

In the night

Relaxing

If you don't fall asleep, don't worry. Lying completely relaxed will rest you just as well as sleep. Practise any relaxation routine you may have learnt as long as it does not include strong tension movements which would cause arousal.

You can do some gentle breathing exercises. With your hand on your tummy take in a small, comfortable, unforced breath, feeling your tummy move your hand up. Then let

it go, taking a little longer over the outward breath, thinking **Relax** as you do so. Try to pause for a moment before you breathe in again.

Finish with pleasant mental and rhythmic images: for example, imagine you are lying on a warm beach, feeling very sleepy. Watch the waves rolling in and hear them swishing down, again and again.

For those who can not do relaxation exercises, don't worry. Get up and go to another room to do something you find relaxing for example, some light reading. Return to bed when you start to feel sleepy. Repeat this as many times as you feel you have to; it is important to remember that bed is for sleeping, not worrying. For the first few nights you might find that you sleep very little; don't worry about that, it's just a sign that you are breaking out of the old, bad habits before establishing new ones.

If you have a bad night, resist the temptation to sleep the next day - it will make it harder to go to sleep the following night and deprive you of quality sleep.

Keep your bed for night sleep only, then it will become associated with sleep.

- Breaking and dropping bad sleeping habits can be very difficult, especially when there is a feeling of overwhelming tiredness.
- It requires determination and motivation, but patients who have recovered from CFS have found that it is possible to break such unhelpful habits.
- It is in the first weeks that it is most difficult - when you still feel tired and you may not feel the improvement as quickly as expected. Do remember, it will take some time to reset your clock and build a regular, refreshing sleep pattern again.

But it is possible, as those who have recovered found.

Anti Depressant therapy

You may have been prescribed anti depressant tablets for example, Dothiepin, Prozac. These are some times given, not because you are clinically depressed (though some CFS patients maybe depressed as a reaction to their condition), but because they help to restore a normal sleep pattern. They help extend the periods of deep restful sleep and make people feel more refreshed when they wake. They need to be taken for some weeks before their full benefit is felt and then need to be taken for some months to consolidate their effects. They are not addictive so there are no problems with dependency. Not all patients need anti depressants. They are not a 'cure', but they may have a role in the case of some patients.

Summary of how to reset your biological clock

1. **Set your alarm to wake you in the morning.**

2. **Turn on your light when you wake.**

3. **Get up at the same time every morning no matter what time you fell asleep the previous night.**

4. **Gradually reduce your lie-ins so your getting up time becomes earlier.**

5. **Avoid sleeping or napping in the day; when sleepy in the day do a gentle walk or exercise.**

6. **Go to bed at the same time every night.**

7. **Get into a relaxed regular bed-time routine.**

8. **If you don't fall asleep, don't worry. Practise your breathing and relaxation exercises or else get up, go to another room and do something you find relaxing. Return to bed when you feel sleepy. Remember bed is for sleeping not worrying.**

9. **Keep your bed for night time sleep only.**

10. **Most adults need between 7 and 8 hours sleep each night, no longer. Staying in bed for several hours more perpetuates the physical deconditioning and CFS.**

11. **Regular graduated activity helps to give deep sleep. Those who exercise regularly have more deep sleep on days with exercise than those without it.**

12. **At first you may feel more tired but this will change as your clock starts to reset itself as you re-establish cues and improve your sleeping habits.**

10: How breathing properly can help you relax

In this chapter we help you understand how to use your lungs fully when breathing so to get maximum physical benefit for your recovery. Learning to breath correctly will have the added advantage of helping you to become more relaxed.

In a perfect situation, a healthy relaxed person breathes without thinking about it, gently, calmly, and low down in the lungs. The abdomen swells slightly and the lower ribs expand a little. The outward breath is slightly longer than the inward breath, with a tiny pause after breathing out. The body takes in as much oxygen as it needs and breathes out some carbon dioxide. Between 12 - 15 breaths are taken each minute.

When **anybody** physically exerts him or her self, or is worried or stressed, breathing automatically becomes more rapid and higher in the chest. This is called hyperventilation and is a normal reaction to a physically or mentally stressful situation when a lot of oxygen is needed quickly. In this situation overbreathing serves a useful protective function.

However, with present day stressful life styles, continuous overbreathing can sometimes become a habit. The individual may not realise they are overbreathing.

Overbreathing is in fact an inefficient way of breathing for everyday living because, as the rate and depth of breathing is increased, more carbon dioxide is breathed out. This leads to a reduction in the amount of carbon dioxide in the blood which upsets the delicate balance of chemicals in the blood. This results in the following physical sensations:

- dizziness
- faintness
- visual problems
- tingling of hands and feet
- chest pain
- difficulty in breathing
- feeling unable to take a satisfying breath
- uncontrolable cramp - like muscle spasms.

Breathing fast in the upper part of the chest on a daily basis can increase general feelings of restlessness and unease during the day. It leads to a build up of tension in the neck and shoulder muscles.

When overbreathing becomes a habit it feels normal to the individual, who may be unaware that it is occurring. For such people trying to breath correctly feels uncomfortable and difficult at first.

Experiencing this difficulty can cause concern which triggers increased nervous system activity and adrenaline production leading to further overbreathing. However, it is possible to re-learn how to breathe efficiently.

Why do some CFS patients overbreathe?

CFS patients may be frustrated by their condition or worried about their symptoms or their future. This triggers the nervous system and adrenaline which causes overbreathing and increased muscle tension especially of the neck and shoulder muscles. This in turn may lead to raised tense shoulder and neck muscles that prevent:

- the normal breathing movements of the chest wall
- the diaphragm working efficiently.

The **diaphragm** is the muscular partition that separates the chest from the abdominal cavity. The diaphragm pushes the lungs up and down like a pump, encouraging airflow. Normally 80% of the work of breathing is done by the diaphragm.

Tense raised shoulder muscles prevent the diaphragm moving up and down as it should.

The diaphragm flattens making it less efficient and the upper chest muscles take over.

Breathing is then done in the top part of the lungs. This form of breathing is not efficient because:

- only a small part of the lungs are used
- the muscles of the upper chest require more energy than the diaphragm to do the same job.

Those CFS patients who do breathe like this are generally unaware that they do so. Even if you do not breathe in this way, it is of value to learn the most efficient type of breathing called **Diaphragmatic Breathing**. This type of breathing can be used to relax people in stressful situations, but to be able to do it, individuals first have to be aware of breathing at different levels of their lungs.

Breathing is done at three levels in the lungs:

- Top (sometimes called 'Apical') breathing
- Lower rib (or 'Lateral Costal') breathing
- Abdominal or Diaphragmatic breathing

To be aware of the different types of breathing, find a suitably quiet room which is at a comfortable temperature. Sit comfortably in an upright position in an armchair with

your head and back supported. Let your shoulders drop. It may help to close your eyes. It is important to relax when practising your breathing.

Top or Apical breathing.

- Move your hands to the very top of your chest.
- Breathe gently twice, causing your hands to lift.
- You may be able to feel tightness there.
- Now try to drop your shoulders.
- Sigh out to empty your lungs then take in a breath.
- Keep your hand on top of your chest and monitor it, trying all the time to relax and drop your shoulders.

Once you are aware of breathing with the top part of your lungs you can gradually learn how to bring your breathing further down into your chest. This can be difficult at first and will take practice.

Lower Rib or Lateral Costal breathing.

- When you feel ready, try to drop your breathing further into your chest.
- Relax and drop your shoulders.
- Turn your hands inwards, putting your knuckles on either side of your chest wall above your waist (lower rib area).
- Sigh out, then in your own time, breath in and out gently, so you can feel the chest wall moving in and out. This makes for more efficient respiration as more lung volume is used.

When you are aware of breathing in the lower rib area, the final step is learning to breathe from your diaphragm which is the muscle partition that separates the chest cavity from the abdominal cavity. The diaphragm pushes your lungs up and down. Diaphragmatic breathing is the most efficient form of breathing for your body. It uses all the lung volume.

Diaphragmatic breathing.

- Place a hand below your rib cage on your abdomen.
- Breathe out gently
- Now breath in, taking the air down as far as you can into your lungs.
- The aim is to feel your hand move and see your abdomen rise up as you breath in and fall as you breath out gently.
- Focus more on the outward breath and think **RELAX** as you let it go. Make your outward breath longer than your inward breath.
- Let all the air escape from your lungs through your mouth, but don't use any force to do this.

- After each breath out have a pause for 1-2 seconds before breathing in again.
- Don't attempt to push your abdominal muscles out and in - concentrate on drawing the breath deep down into your chest as far as your diaphragm.

While practising these breathing exercises you may feel you are not taking enough air inside you. This is normal as your body is readjusting to the new normal levels of carbon dioxide.

Begin by practising slow gentle breathing from the abdomen, for periods of one or two minutes several times daily. Progress this to 5 and then 10 minutes. Ultimately, this is how you should be breathing all the time.

It may take quite a lot of practise to master this way of breathing. **Remember** that this type of breathing is normal, and fast irregular breathing is just a bad habit.

Once you have mastered controlling your breathing in the sitting position, try using it when walking. Start with a few steps. The aim is to control your breathing when walking, talking, eating and dressing. Don't forget it is quite natural to be breathless during strenuous exercise.

Panic Attacks

In panic attacks breathing tends to become quicker and shallower until the chest is full and the breath is held.

Some people misunderstand the intense physical sensations felt during a panic attack and think that they are a sign of impending collapse or loss of control. Their fears trigger further sensations of nervous system arousal which fuels the attack.

How to control panic attacks:

- Offering yourself alternative responses to the unhelpful thoughts about the intense sensations will help you to become panic free (see Chapter on The right thoughts for recovery).
- Learning to control and bring your breathing gently down into your chest during a panic attack will help you to calm yourself.

The benefits of diaphragmatic breathing

Practising diaphragmatic breathing at home regularly will:

- help you breathe more efficiently. This will be of great physical benefit in your recovery (overbreathing is associated with more fatigue)
- reduce feelings of restlessness
- reduce the tension in your muscles (especially neck and shoulders).

Muscle tension uses up energy. Therefore extra tension is a drain on valuable energy reserves. Learning to breathe and relax helps you to feel more energetic and emotionally in control. Once you have mastered diaphragmatic breathing turn your breathing exercise session into a relaxation session.

Learning to breath correctly and learning to relax are related.

Relaxing is different to just resting. It is as important to your recovery as is activity.
All of us should learn how to relax properly.
Relaxation is important not only for CFS patients, but anybody who has a busy or stressful lifestyle. You may find relaxation tapes from record and health shops useful.

Many relaxation tapes include muscle tensing exercises. In the first stage of learning relaxation, groups of body muscles are systematically tensed and then relaxed. By alternating the tension and relaxation of muscles you can:

- tell the difference between being in a state of tension and relaxation (at times this can be difficult).
- be more aware of the parts of the body that are particularly tense.

Practise your relaxation twice a day for 30 minutes.
This can be done after your chosen activity programme in the morning and the afternoon.
Relaxation is a very important way of recharging your physical and mental batteries.

Please remember: Once you are practised in the first stage of relaxation, omit the muscle-tensing exercises if you have been using these. You can then do your relaxation exercises or tapes before bed time when they can help you unwind, lowering your level of arousal. Remember to avoid the tensing exercises before bed, as that will arouse you, keeping you awake.

A Relaxation routine.

When using your relaxation techniques in normal situations, it is best to sit in a comfortable chair taking the same position as you did when practising your breathing exercises.

- **Focus your mind on your breathing.**
- **Really feel yourself breathing - easy, relaxed, comfortable.**
- **Focus your mind on the amount of air that you are breathing in, and slowly letting out.**
- **Think RELAX when breathing out. Try to make your breath out longer than your breath in.**
- **Try and make every breath slow and steady, gentle and relaxed.**
- **If thoughts come into your mind, don't deal with them now. Remember for later. Release them so that they drift away and you can relax again.**

- **Feel time slowing down.**
- **Imagine yourself at the top of a staircase with ten stairs down to total relaxation at the bottom.**
- **Each time you take a step down you feel yourself becoming more relaxed and peaceful.**
- **Count yourself down each step, sinking deeper into relaxation with each step.**
- **Imagine you have reached a place that is warm, where you really feel comfortable and can relax.**
- **Begin to let go of all the physical tension in your body.**

Using your imagination

Some people find it helpful to imagine that there are peaceful, relaxing waves just above their heads, either warm and soothing waves, or cooling and refreshing.

See if this works for you. As you relax, imagine the waves:

- coming over your eyebrows, relaxing the top and sides of your head.
- feel them wash over your eyes, soothing and bathing them.
- feel them flow over your face, and the back of your head, down to your chin, your mouth teeth and gums.
- let them flow down your neck and shoulders, so that your shoulders drop and feel loose.
- let the waves of relaxation flow through your arms, your elbows, forearms, wrists and hands, all the way to the ends of your fingertips.

See if you can:

- feel the waves down your back and your spine, flowing into every muscle.
- let your back go loose and relaxed.
- let the waves flow to your chest and heart, down into your lungs, making it even easier for you to breathe.

Finally,

- feel the waves flow down into your stomach, and your body into your thighs.
- let the waves flow into your knees and calf muscles and into your feet.
- feel every part of your body and every muscle being soothed by these calming waves.
- imagine that each breath you breathe in, is cleansing your body.
- imagine that with each breathe out, you are releasing all the stress that was in your body.

Gradually learn the benefits of relaxation

This is your time to just breathe and relax, deeper and deeper with every slow breath out. You should now feel totally relaxed and calm. There is no limit to how relaxed you can be.

When you have spent a comfortable time feeling relaxed, bring yourself out of relaxation by slowly counting to five, and with each count become gradually more and more aware of your surroundings. You will now feel calm and ready to cope with anything that you have to do.

You will probably find it quite hard to relax at first because of the concerns and worries that go with your condition.

That is understandable.

It is not always easy to do, and like anything else that is worth learning, it does take practise. With practise you will find that controlling other thoughts and distractions that stop you from relaxing becomes less difficult. Relaxing becomes easier.

Soon after starting these daily relaxation sessions you will feel the benefits of relaxation and a positive effect on the quality of your life.

Summary of how breathing properly can help you relax

1. **Many people with and without CFS don't breathe correctly.**

2. **When stressed we tend to overbreathe. This is a normal protective function of our body.**

3. **If we have a stressful life style, continuous overbreathing can become a bad habit.**

4. **People who overbreathe use the top part of their lungs and do not always realise that they are overbreathing.**

5. **Breathing should be from the diaphragm.**

6. **Diaphragmatic breathing is the most efficient form of breathing for your body, as it uses all your lung volume.**

7. **On the outward breath of your diaphragmatic breathing think RELAX as you let it go. This turns your breathing exercises into a relaxation routine.**

8. **Relaxation should be a part of your day if you have a busy or stressful life style.**

9. **Make use of relaxation to recharge your physical and mental batteries.**

11: Final Steps on the Road to Recovery

In this chapter we will help you to use your understanding of CFS as a solid base from which to re-enter life.

The Signs of Success

As you see yourself able to do more and more, you re-establish faith in your body's ability to be physically active. Even though at first progress is only little and slow, it snowballs due to your continued activity plan.
Your confidence steadily grows in your overall ability to cope and perform as you see your self improve. However, you may still be apprehensive. **But it is good to be cautious** for this is a sound, protective brake, preventing you from doing too much at first.

Reviewing the Situation.

Once you experience the snowballing improvements in your well-being and are well on the road to recovery, it is advisable to think about your experience of CFS.
Understanding CFS is the main weapon against it, enabling recovery.
If you allow yourself to reflect on your experience, your understanding of CFS will grow and strengthen your recovery.

Consider the following:

- how CFS started for you,
- the facts the treatment plan are based on and why it worked for you,
- what the pitfalls and traps were in that recovery process.

Look at how you lived your life before and during CFS. This is an important part of the treatment plan. By doing this you can learn about yourself and your lifestyle.

The combination of:

- the understanding of CFS you have gained through treatment
- and an insight into your personal lifestyle

will benefit you, preventing any relapses.

Before CFS

Many patients report that they were:

active people
with many commitments
having high achievement standards
some having perfectionist tendencies

If you expect 100% of yourself all of the time then

You will spend more energy than those with lower expectations

There will be increased arousal of the nervous system and adrenaline production which causes fatigue, aches, headache, dizziness, palpitations and sore throat.

There is less tolerance of tiredness

The result is a person who will continue to push themselves

High expectations can make you feel like a failure no matter what you do.

If you do not reach your own expectations you can view your effort as a failure.

The constant expectation to be perfect becomes a chronic source of stress when that individual feels to meet his or her high standard.

Perfectionists and those with very high standards often miss out on fun, relaxation and satisfaction.

Ways of coping with perfectionism

Make a list of the advantages and disadvantages of trying to be perfect.

Increase your awareness of the all-or-nothing way of thinking. For example, viewing everything as good-bad, success-failure.

Be realistic about what you can do. Don't expect too much.

Learn how to deal with criticism. Learn to acknowledge your mistakes and assert your right to make mistakes.

During and after recovery

Personality and lifestyle affect the body's level of nervous system arousal and adrenaline. It is for these reasons you must be aware that even when you are fully better:

- The greater the number of commitments you take on
- The higher the standard of performance you expect
- The longer the duration of the commitments

The more your nervous system will be aroused which inevitably leads to symptoms including fatigue, headaches, aches and dizziness.

- Fear of symptoms
- Misinterpreting symptoms as signs of relapse or disease
- Monitoring symptoms
- Frustration with symptoms and limitations

Causes further nervous system arousal with further symptoms that can delay or prevent complete recovery.

By controlling the number of commitments and the standard of performance you can control the level of activity of the nervous system and adrenaline production. In this way you control symptoms.

After CFS

The mind and the body build up the ability to cope with mental and physical commitments by gradual repeated exposure to:

- Social contact
- Study
- Work
- Exercise

Remember, for the first months such activities will cause increased nervous system arousal resulting in symptoms including fatigue. Because recovering patients experienced such symptoms when they were ill with CFS, they may fear relapse in recovery. This can be avoided by:

- Gradually building up demanding, stressful commitments
- Pacing these activities with relaxation
- Doing regular aerobic exercise that maintains deep sleep and physical stamina
- When you feel tired after demanding activities such as work, avoid sleeping in the daytime and early evening. Do some gentle enjoyable exercise.

It is necessary to project your recovery: assert your right to health. As others see you improve more may be expected from you.

Try to take a step back from giving your 'all' to others or to work.

Save something for yourself.
Recovery and life to be enjoyed.
Your recovery has been a great achievement, hard earned on your part, requiring effort, determination and motivation.
Now is the time to reap its benefits.
Make a point of doing something pleasurable and relaxing each day as well as your activity.

Returning to work - Safely!

Those who recover have found that

- physical stamina builds up first
- the quality of sleep improves
- followed by improvement in mental performance
- and the last piece of the jigsaw to fall into place is the ability to cope once again with stress in daily life.

With this in mind break yourself gradually and gently into commitments.

Some patients find that doing either

- part-time adult education courses (for example, basic or refresher computer courses)
- voluntary work for example working in a charity shop for one or two sessions a week) help build up confidence.

Returning to work, school or college is best achieved by starting part time and gradually increasing.
It is advisable to discuss this possibility with the employer or college.
It will take a few months to build up your mental stamina level.
Some find going back for three mornings on alternate days for a few hours a safe way to make the transition.

Expect to be Tired on Returning to Work or Commitments

Work or commitments inevitably involve some degree of demand and stress that automatically arouse the nervous system and produce adrenaline.

When individuals are not yet used to regular commitments and stresses, there can be

increased levels of nervous system arousal for longer periods, which works the physical systems of the body and so causes fatigue, palpitations and muscles aches.

When individuals return to work or commitments **before they are fully fit** and have fully reversed the physical deconditioning their deconditioned muscles and cardiovascular system will be more vulnerable to the effects of adrenaline that include increased muscle tension and increased heart rate.

Consequently, these individuals can feel intense fatigue, muscle ache, palpitations, dizziness, sore throat and headache. Therefore, avoid returning to work before you are fully fit.

Stress in any form makes you tired after the event. The main way to build up your resistance to stress is by experiencing it regularly. But as the weeks pass, you will cope better with the stresses of your job and life, as others have. Eventually you will be able to live your life feeling confident in your ability to cope and perform without worrying about the consequences of your activities.

However, do remember, that everyone, even those who are fit and healthy, get tired at times! It is a fact of life.

When you do return to work, wherever that is, and you experience this tiredness, remember to:

- check for any unhelpful thoughts about fatigue
- rationalise your situation
- look at your progress
- build alternative responses
- **maintain your daily activity and relaxation**

It will take time, patience and your understanding of the condition to make a full recovery.

Beware of symptom watching

Most healthy people sometimes feel sensations or symptoms during a day, however they do not always take these as a sign of serious disease or impending collapse.

Having felt physical symptoms for the duration of CFS, which can be a long time, there is a tendency for some people to be more sensitive to physical sensations and symptoms during recovery.

These symptoms are inevitable. They are caused by a combination of:

- **increasing physical exercise that works a deconditioned heart and muscles.** It can that take several months or more to recondition the body. During this time symptoms can be experienced; however, the patient is able to achieve more for the same symptoms. The time taken to recondition the body depends on how often, how long for and which type of exercise is performed (see Chapter 8 – Designing your activity plan).

- **increasing mental activities**, for example, social activities. Remember this can be a stressful, demanding time and you do not have control over the body's natural anxiety process. Therefore at times, stressful events cause an increase in nervous system arousal and adrenaline production. This can cause increased symptoms and disturb night time sleep.

Thinking about recurring sensations or symptoms can cause frustration or worry which can automatically trigger the anxiety process and more symptoms.

Inaccurate, misleading thoughts and fears about symptoms can hold you back and delay your recovery or make it only partially complete. Check such thoughts for accuracy and where necessary build alternative accurate responses. Otherwise these could hold you back, delaying your recovery.

Opportunities for Change!

Being unwell gives you the time to think about your life. As you are getting better you feel it is possible once again to make plans for the future. If you have lost or had to give up your job due to CFS, this can be the opportunity to think of making changes in your life and chosen job. This requires you to be practical and realistic.

During the recovery you have learnt a lot about yourself and now is the time to put this to good effect. You are aware of your strengths and your weaknesses.

To have overcome CFS on your own requires great mental fortitude and this is one of the many strengths you will have discovered about yourself.
Learn to build on your strengths, but also accept your weaknesses which we all have.

Your outlook on life will have changed.

Many people learn so much about themselves that they go on to find different sorts of employment, career or life activities which are more in keeping with their personality.

In this way you can change what you may have felt as being the lowest point in your life, into the spring- board to a more fulfilling future.

Final important points to remember

- **Pacing yourself is still as vital as ever**. Those who struggle with recovery don't balance activity and relaxation. You cannot afford to break these rules.
- Follow a regular 8 hour night-only sleep pattern.
- Do 30 minutes of exercise three times a week (such as swimming, cycling or brisk walking).
- Keep up the momentum of your improvement by entering into life's daily activities in a paced manner.
- Learn to enjoy life again.
- Learn to socialise again.

Know your limits – have boundaries beyond which you are not prepared to be pushed!

There may be patients who, at the present time, may not have control over some of the stressful factors that triggered or perpetuate CFS. Stressful factors, for example, those living in difficult circumstances will keep the nervous system in a state of arousal with adrenaline being produced. This will tire the muscles and cardiovascular system making the exercise programme even more difficult to perform. However, with the knowledge of how to recover from CFS they too can move forward when the time is right. People who are struggling to cope with commitments like work can find it hard to do the programme and may need a time out.

Can I relapse when I am better?

This is one of the greatest fears of all CFS patients.

If you can fully understand what factors lead to CFS:

- virus
- illness
- work pressure
- stressful life events
- multiple commitments / responsibilities
- trauma

and which factors perpetuate it:

- irregular activity and rest
- lying-in bed
- sleeping or cat napping in the day
- unhelpful thoughts about symptoms
- frustration
- worry and fears
- symptom watching
- commitments that increase nervous system arousal

you cannot relapse because you now know how to combat it.

You understand what happened to your body during CFS and why a controlled graduated activity plan and regular night-only sleep pattern was necessary.

You will know what to do in future during times of great stress or serious physical illness, when you may feel symptoms similar to those of CFS.

Your understanding of CFS is your ultimate weapon against it and prevents any possibility of relapse.

Research trials: Treatment of CFS

There is a growing body of evidence that shows graded exercise can produce substantial improvements in physical activity levels and fatigue. Patients in the following trials of treatment that involved graded exercise for CFS obtained good outcomes.

1. **Butler, S., Chalder, T., Ron, M., Wessely, S (1991)** Cognitive behaviour therapy in chronic fatigue syndrome.Journal of Neurology, Neurosurgery,and Psychiatry, 54,153-8.

2. **Sharpe, M., Simkin, S., Surawy, C., Hackmann, A., Klimes, I., Peto, T., Warrell, D., Seagroatt, V (1996)** Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial. British Medical Journal,Vol.312, 22-6.

3. **Deale, A., Chalder, T., Marks, I., Wessley, S. (1997)** Cognitive behavior therapy for chronic fatigue syndrome: A randomized controlled trial. American Journal of Psychiatry, Vol.154,3,408-414.Am J Psychiatr;154;408-414.

4. **Fulcher, K., White, P. (1997)** Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome. British Medical Journal Vol.314, 1647-1652.

5. **Wearden,A., Morriss, R., Mullis, R., Strickland, P., Pearson, D., Appleby, L., Campbell ., Morris, J. (1998)** Randomised, double-blind, placebo-controlled treatment of fluoxetine and graded exercise for chronic fatigue syndrome. British Journal of Psychiatry, Vol.172, 485-96.

6. **Deale, A., Husain, K., Chalder, T., Wessely, S. (2001)** Long-term outcome of cognitive behaviour therapy versus relaxation therapy for chronic fatigue syndrome: A five year follow-up study. American Journal of Psychiatry vol.158,12,2038:42.

7. **Powell P, Bentall R, Edwards R, Nye F (2001)** Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome. British Medical Journal, Vol.322, 387-390

8. **Powell,P., Bentall, R., Nye, F., Edwards, R. (2004)** Patient education to encourage graded exercise in chronic fatigue syndrome: 2 year follow-up of randomised controlled trial. British Journal of Psychiatry, Vol.184, 142-146.

9. **Wallman, K.E., Morton, A.R., Goodman, C., Grove, R., Guilfoyle, A.M. (2004)** Randomised controlled trial of graded exercise in chronic fatigue syndrome. Med.J.Australia 180(9): 444-8.

This booklet was part of the randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome (Powell et al. 2001)

About this trial

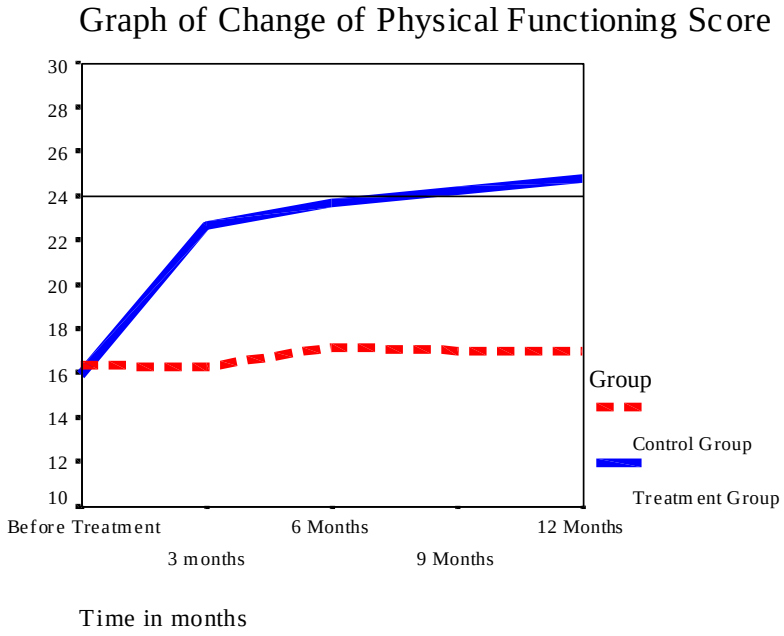
148 patients with CFS took part. 34 patients were allocated to the control group and received no further treatment. 114 patients received the active educational intervention treatment.

Each patient was given a verbal explanation of their condition based on the medical evidence of disturbed body systems: this was supported by the educational booklet. An individualised graded exercise programme was designed with each patient. Some patients received regular follow up contact sessions by telephone or face-to-face over four months. In all, 21 patients dropped out of the trial: 2 from the control group and 19 from educational intervention treatment.

Results

All patients who joined the trial were entered into the statistical analysis, including those who dropped out of treatment in which case they were given their last score received.

The results are shown in the form of a graph.
Physical functioning means the ability to be active.



Physical functioning means the ability to be active.

The numbers on the vertical line represent the physical functioning scores on a scale of 10 to 30, where 10 indicates severe limitation in all physical activities and 30 indicates no limitation in physical activities. Higher scores close to 30 indicates the ability to do strenuous physical exercise.

The fine solid black horizontal reference line indicates the normal daily physical functioning score of 25 for the UK general population.
A measure for good outcome for patients was a score of 25 or more, or an increase of 10 or more on this physical functioning scale.

In the first year:
Before treatment both active and control groups were very impaired but after 12 months from the start of treatment there is a marked difference between the groups.
Those in the active educational intervention group who did graded aerobic exercise (shown by the thicker solid black line) could do significantly more physical activity than those in the control group. This shows the benefits of this educational treatment.
At 12 months, 69% of patients achieved a good outcome in physical functioning compared with 6% of patients in the control group.
Significant improvements were seen in fatigue, sleep and mood. If only those patients who completed treatment were included in the results, 81% of patients achieved a good outcome at one year.

Patients' views at one year
84% of patients who completed active treatment rated themselves as 'much better' or 'very much better' compared with 13% of patients in the control group. One patients in active treatment rated himself as 'a little worse', while six reported 'no change'.

In the second year:
At 24 months, 60% of the active treatment patients had maintained a good outcome. 78% of these patients who had completed active treatment rated themselves as 'much better' or 'very much better'.
47% of control patients who crossed over into active treatment achieved a good outcome and 68% reported being 'very much better' or 'much better'.

12: Diary Sheets

The following pages are record sheets that you may wish to complete.
Patients who recovered from CFS using this treatment booklet have suggested these sheets.

Thought diary:
Some patients found the following sheet helpful in dealing with worrying thoughts about symptoms or other problems. We know such thoughts can delay recovery. For those of you who do experience such feelings, an explanation of how to use this sheet in helping your recovery is given in Chapter 7.

Sleep and pacing diary:
There are three pages which can be used to keep a record of you sleep, activity and rest patterns. Those patients who have a severely disrupted sleep pattern, for example, spending a long time lying in bed in the morning or afternoon, or sleeping in the day can find these sheets helpful in trying to regulate their sleep pattern (for advice see Chapter 9).

Patients may choose to fill in:

- getting up time
- bed time
- number of hours in the day that they are active
- number of hours in the day that they rested

It also allows a check to be kept on sleep where it is taken in the day.
These sheets can also be helpful to spot 'boom and bust' activity patterns.

The sheets monitor all 18 weeks of the programme. After that patients may have developed their own routine and not feel they need to complete diary sheets. If you are severely affected by CFS you may find that you wish to keep a record after that time.

Activity diary:
The final sheets comprise an activity diary. **Patients do find it useful to have a record of their achievements**, especially if they suffer setbacks while on the programme. We do advise keeping a record of the duration of the exercises that you have chosen over and above your usual daily activities, for example: bike, dance, jog, stand, walk.

We would advise against keeping a record of your symptoms even though they are intense and unpleasant at times. Monitoring and recording symptoms causes increased arousal or activity of the nervous system and increased adrenaline production. This can cause further symptoms which can delay recovery.

Situation and Main Body Symptoms	Unhelpful thought	Alternative thought

Problems and achievements of the week

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First week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Second week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Third week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Fourth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						

Fifth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Six week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Seventh week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Eighth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						

Ninth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Tenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Eleventh week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Twelfth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Thirteenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Fourteenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						

Fifteenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Sixteenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Seventeenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						
Eighteenth week						
	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Getting up time (am)						
Evening bed time (pm)						
Time spend active during day						
Time spent resting during day						
Time spent sleeping during day						

Activity Diary

Day 1 – Date:	Activity	Time spent

Day 2 – Date:	Activity	Time spent

Day 3– Date:	Activity	Time spent

Day 4 – Date:	Activity	Time spent

Day 5– Date:	Activity	Time spent

Day 6 – Date:	Activity	Time spent

Day 7– Date:	Activity	Time spent

Achievements of my first week:

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Day 8 – Date:	Activity	Time spent

Day 9 – Date:	Activity	Time spent

Day 10– Date:	Activity	Time spent

Day 11 – Date:	Activity	Time spent

Day 12– Date:	Activity	Time spent

Day 13 – Date:	Activity	Time spent

Day 14– Date:	Activity	Time spent

Achievements of my second week:

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Day 15 – Date:	Activity	Time spent

Day 16 – Date:	Activity	Time spent

Day 17– Date:	Activity	Time spent

Day 18 – Date:	Activity	Time spent

Day 19– Date:	Activity	Time spent

Day 20 – Date:	Activity	Time spent

Day 21– Date:	Activity	Time spent

Achievements of my third week:

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Day 22 – Date:	Activity	Time spent

Day 23 – Date:	Activity	Time spent

Day 24– Date:	Activity	Time spent

Day 25 – Date:	Activity	Time spent

Day 26– Date:	Activity	Time spent

Day 27 – Date:	Activity	Time spent

Day 28– Date:	Activity	Time spent

Achievements of my fourth week:

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Day 29 – Date:	Activity	Time spent

Day 30 – Date:	Activity	Time spent

Day 31 - Date:	Activity	Time spent

Day 32 – Date:	Activity	Time spent

Day 33– Date:	Activity	Time spent

Day 34 – Date:	Activity	Time spent

Day 35– Date:	Activity	Time spent

Achievements of my fifth week:

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Day 36 – Date:	Activity	Time spent

Day 37– Date:	Activity	Time spent

Day 38– Date:	Activity	Time spent

Day 39 – Date:	Activity	Time spent

Day 40– Date: Activity	Time spent

Day 41 – Date: Activity	Time spent

Day 42– Date: Activity	Time spent

Achievements of my sixth week:

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Day 43 – Date:	Activity	Time spent

Day 44 – Date:	Activity	Time spent

Day 45– Date:	Activity	Time spent

Day 46 – Date:	Activity	Time spent

Day 47– Date: Activity	Time spent

Day 48 – Date: Activity	Time spent

Day 49– Date: Activity	Time spent

Achievements of my seventh week:

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Day 50 – Date:	Activity	Time spent

Day 51 – Date:	Activity	Time spent

Day 52– Date:	Activity	Time spent

Day 53 – Date:	Activity	Time spent

Day 54– Date:	Activity	Time spent

Day 55 – Date:	Activity	Time spent

Day 56– Date:	Activity	Time spent

Achievements of my eighth week:

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Day 57 – Date:	Activity	Time spent

Day 58 – Date:	Activity	Time spent

Day 59 - Date:	Activity	Time spent

Day 60 – Date:	Activity	Time spent

Day 61– Date:	Activity	Time spent

Day 62 – Date:	Activity	Time spent

Day 63– Date:	Activity	Time spent

Achievements of my ninth week:

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Day 64 – Date:	Activity	Time spent

Day 65– Date:	Activity	Time spent

Day 66 – Date:	Activity	Time spent

Day 67 – Date:	Activity	Time spent

Day 68– Date: Activity	Time spent

Day 69 – Date: Activity	Time spent

Day 70– Date: Activity	Time spent

Achievements of my tenth week:

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Day 71 – Date:	Activity	Time spent

Day 72 – Date:	Activity	Time spent

Day 73– Date:	Activity	Time spent

Day 74 – Date:	Activity	Time spent

Day 75– Date: Activity	Time spent

Day 76 – Date: Activity	Time spent

Day 77– Date: Activity	Time spent

Achievements of my eleventh week:

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Day 78 – Date:	Activity	Time spent

Day 79 – Date:	Activity	Time spent

Day 80– Date:	Activity	Time spent

Day 81 – Date:	Activity	Time spent

Day 82– Date: Activity	Time spent

Day 83 – Date: Activity	Time spent

Day 84– Date: Activity	Time spent

Achievements of my twelfth week:

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Day 85 – Date:	Activity	Time spent

Day 86 – Date:	Activity	Time spent

Day 87– Date:	Activity	Time spent

Day 88 – Date:	Activity	Time spent

Day 89– Date:	Activity	Time spent

Day 90 – Date:	Activity	Time spent

Day 91– Date:	Activity	Time spent

Achievements of my thirteenth week:

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Day 92 – Date:	Activity	Time spent

Day 93 – Date:	Activity	Time spent

Day 94– Date:	Activity	Time spent

Day 95 – Date:	Activity	Time spent

Day 96– Date: Activity	Time spent

Day 97 – Date: Activity	Time spent

Day 98– Date: Activity	Time spent

Achievements of my fourteenth week:

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Day 99 – Date:	Activity	Time spent

Day 100 – Date:	Activity	Time spent

Day 101– Date:	Activity	Time spent

Day 102 – Date:	Activity	Time spent

Day 103– Date: Activity	Time spent

Day 104 – Date: Activity	Time spent

Day 105– Date: Activity	Time spent

Achievements of my fifteenth week:

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Day 106 – Date:	Activity	Time spent

Day 107 – Date:	Activity	Time spent

Day 108– Date:	Activity	Time spent

Day 109 – Date:	Activity	Time spent

Day 110– Date: Activity	Time spent

Day 111 – Date: Activity	Time spent

Day 112– Date: Activity	Time spent

Achievements of my sixteenth week:

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Day 113 – Date:	Activity	Time spent

Day 114 – Date:	Activity	Time spent

Day 115 - Date:	Activity	Time spent

Day 116 – Date:	Activity	Time spent

Day 117– Date: Activity	Time spent

Day 118 – Date: Activity	Time spent

Day 119– Date: Activity	Time spent

Achievements of my seventeenth week:

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Day 120 – Date:	Activity	Time spent

Day 121– Date:	Activity	Time spent

Day 122– Date:	Activity	Time spent

Day 123 – Date:	Activity	Time spent

Day 124– Date: Activity	Time spent

Day 125 – Date: Activity	Time spent

Day 126– Date: Activity	Time spent

Achievements of my eighteenth week:

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