

# Chronic Fatigue Syndrome<sup>1</sup>

## What is Chronic Fatigue Syndrome?

Chronic Fatigue Syndrome is an illness in which people experience extreme fatigue and muscle pain from activity. As a result, they do much less than they used to do for a prolonged period. Even small things, such as making a telephone call, can leave them exhausted. All areas of life — work, relationships, interests and fun — are significantly effected. It is often known as 'ME'

## What causes Chronic Fatigue Syndrome?

There are different theories about what causes Chronic Fatigue Syndrome and few certainties. It is likely that a combination of factors is involved. Some factors make people prone to fatigue, others may trigger the problem and yet others keep it going. Here are some of the likely factors.

*What makes people prone to develop chronic fatigue syndrome?*

- *The pressures of life.* There is clear evidence from research that prolonged stress causes our immune system to work less well. This effects our mood (depressing it) and decreases our energy levels. Depressed mood leads to a depressed immune system and vice versa.
- *Life events.* For example, marriage, bereavement, changing job, moving house, break-up of a relationship. People who develop fatigue problems are more likely to experience major life events in the year prior to the problem developing
- *Lifestyle.* For example, working under pressure, being a single parent, being an athlete in training
- *Personality style.* People who are more inclined to set high standards for themselves and their performance, who have a tendency towards perfectionism, seem more likely to get fatigued.

*What triggers chronic fatigue problems?*

- *Viruses.* Physical illness, especially viral meningitis, glandular fever and Q fever, are frequently present at the beginning of chronic fatigue syndrome.
- *Crises.* Major life events are common prior to Chronic Fatigue Syndrome
- *Nothing.* Sometimes there is no obvious reason.

*What can keep fatigue going?*

There are several factors at play in recovery from illness. Some ways of handling the illness can make it worse or keep it going.

- *Too much rest.* Prolonged rest can be detrimental. A healthy individual who is forced into prolonged rest will lose 3% of muscle mass a day, becoming progressively weaker and more prone to illness
- *Too little rest.* Especially in the initial stages of chronic fatigue syndrome, people often struggle on through illness, resulting in them becoming more ill and fatigued. Eventually they 'crash'.
- *Disturbed sleep patterns.* A vicious cycle can develop. Fatigue leads to sleeping during the day, which reduces the quality of sleep at night, which in turn makes us more tired in the day and so on. How sleep problems are managed can make fatigue problems better or worse.
- *Avoiding activity.* Again, a vicious cycle can develop. Activity produces pain and exhaustion, so we avoid it. By avoiding it, we reduce our ability to do it.
- *Demoralisation and depression.* These feelings are commonly felt as there appears to be no hope and the sufferer feels they have little control over their condition. These feelings make an already bad situation worse.
- *The 'boom and bust' syndrome.* People may be overactive one day (perhaps going out to a special event or trying to 'catch up' with neglected responsibilities), leading to fatigue and long periods of rest to recover. This weakens the body still more. When they feel able to be active again, they again go beyond their now-reduced capacity.

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<sup>1</sup> Adapted from the patient management package by Mary Burgess, Dr Trudy Chalder, Dr Alicia Deale, Vincent Deary and Professor Simon Wessley, CFS Research Unit, GKT School of Medicine, London

## How is chronic fatigue syndrome treated?

There is no "cure", but various methods of rehabilitation have been shown to be helpful. These include cognitive behavioural therapy and cautious graded programmes of exercise. These treatments involve the sufferer in making activity consistent before gradually increasing physical activity and gradually reducing excessive sleep so that a planned and cautious return to usual activities is possible. The aim is for you to control your illness and not the other way around. The advice contained in this leaflet is based on these methods of treatment.

It is important to note that there is no specific medication that alone will cure fatigue. If the fatigue results *from* a physical or mental health problem, medication for these problems may reduce some of the underlying fatigue. Sometimes certain antidepressants have been found to be useful for some people.

Medications that claim to make you less tired can lead to addiction. That means, you have to use more and more of the drug for it to help you and when you stop using it your symptoms would be much worse. They are also harmful if taken during pregnancy or if used with alcohol and other drugs.

## Overcoming chronic fatigue syndrome

Although there is no certainty about the causes of CFS, there is much more known about what strategies bring about improvement. The following strategies work for many people, and have been tested in clinical trials. The three major strategies are:

- Spreading activity, exercise and rest evenly across the day and week - avoiding sudden changes
- Gradually increasing activity
- Gradually reducing any 'oversleeping' until you sleep between seven and a half hours and nine hours in every twenty four.

By gradually increasing activity, you will increase your body's ability to do more without fatigue and pain.

By gradually reducing oversleeping, you will increase the quality of the sleep you do take and will feel more energetic. This is because sleep is like food. Just as we can eat too much as well as eat too little, so also we can sleep too much as well as too little. Studies show that the amount of sleep our bodies need is between seven and a half hours and nine hours a night. More than this actually leads to feelings of daytime fatigue, impaired concentration, lack of energy and motivation. Then a vicious cycle can set in. Having these kinds of feelings during the day makes us think that yet more sleep is needed, which then lead to yet more fatigue and lack of energy.

However, it is very important to use these strategies slowly and carefully - starting first with a clear understanding of your current abilities and need for rest. Improvement is usually slow and occurs gradually over a long period. In the first few weeks, you will probably experience an increase in symptoms. If everything is done gradually, this should not be too painful and it should pass in a few weeks at most. **Enrol a friend, family member, counsellor, physiotherapist or other health care worker to help and support you.**

### 1. Record your current levels of activity and rest

Use the activity diary provided at the end of this leaflet to record when you are active, when resting and when sleeping. Record the type of activity - eg housework, reading, walking. Record the time you go to bed and the time you actually fall asleep. Do this as you go along during the day for a period of two weeks. Don't change anything during this time. Use different colour highlighters to code the periods of activity, rest and sleep, eg activity — colour red, rest — colour blue, sleep — colour yellow.

### 2. Establish a consistent pattern of activity and rest

To break the 'boom and bust' cycle, it is important not to overdo either activity or rest. The aim of this stage is simply to spread out your activity and rest evenly. Don't try to increase activity or decrease rest at this stage. To establish a consistent pattern of activity and rest:

*Study your diary sheets looking for patterns you might not have been aware of. For example,*

- Are certain times of day more difficult than others? People often get particularly tired in the afternoon between 2 and 5pm
  - Are there certain times of day when you are consistently more active, loading more into one part of the day and recovering in another?
  - Does your level of activity vary a lot from day to day? If you are very active on one day, are you more tired on the following days? Conversely, do you "save up" energy by resting in the days before an activity you know is going to be strenuous?
  - Do certain types of activity tire you more readily than others? Did you have to rest all Monday after relatives visited at the weekend? Did going for a walk exhaust you or pick you up?
  - How much of your activity is geared towards pleasure and how much towards responsibilities?
- Discuss what you find with your supporter - friend, family member or health worker

*Calculate how much activity, rest and sleep you currently need.* Add up the total number of hours of activity you have engaged in during the whole 14 days. Divide by 14 to get the average hours of activity per day. Compare your most active day to your most inactive one. How uneven is your pattern at the moment? Take a note of the kinds of activity you do - pleasure, work, exercise, social - and roughly how much time is devoted to each.

Now do exactly the same for rest. Add the total number of hours in the fortnight and divide by 14. Again, compare a good day to a bad day.

For sleep, calculate the total number of hours of day time sleep and the average per day. Do the same for night time sleep. Compare how much you are sleeping at night on average now with how much you used to sleep prior to illness. Also calculate your average getting up time and the average going to bed time.

Discuss what you find with your supporter - friend, family member or health worker

Plan your base line activity and rest level Use the information you have gathered to plan a consistent daily schedule that you think you can stick to even on a bad day. Remember, the main aim is consistency. Use the averages you have calculated above, but if you have any doubt about your ability to stick to them, set your targets lower. Improvement will come later. The only aim for now is to achieve a consistent pattern of activity and rest.

Make a plan for each day with the help of your supporter — friend, family member or health worker. The plan needs to include:

- a regular getting up time. This should be based on the average getting up time you calculated above. It must be a time you think you will realistically be able to manage on most days
- your average daily amount of rest and activity spread evenly across the day. For example, if you are currently being active most of the morning and resting most of the afternoon, your plan will involve more rest in the morning and more activity in the afternoon. Make any changes gradually over time and not all on one day.
- No more than an hour's rest at a time and no longer period of activity than your average tolerance. Break up prolonged activity with rest periods and rest with activity. For example, if you currently rest for 5 hours a day, break it into 5 periods of 1 hour each. If you currently do housework for an hour in the morning, break it into 2 half hours or 4 quarter hours and spread it evenly throughout the day.
- A balance of pleasurable and necessary tasks each day.

As an example, here is a list of what the initial daily plan of someone who had previously been resting most of the day might look like:

- 1 Get up at 10 am
- 2 Do 15 minutes of housework four times a day
- 3 Read for 10 minutes twice daily
- 4 Garden for 10 minutes in the morning
- 5 Walk for 10 minutes in the afternoon
- 6 Phone a friend for 10 minutes
- 7 Rest for 3/4 hour every hour.

Remember this stage is initially difficult. Do not move on until you can keep to your schedule consistently.

### 3. Set goals for where you want to be

This step involves setting some medium and long term goals, which you will then gradually work towards. Ask yourself: "What areas of my life and activities have I let go due to illness, but would like to do again?" and "What would I like to do that I cannot do now?" Write down everything that comes to mind.

Now break down your list into specific areas. Set one or two targets for each area below:

- **Work** eg you may wish to return to work you did formerly or to go back part time or to train to do something different or do voluntary work
- **Home life** eg you may wish to do some DIY or gardening
- **Social life** eg you may wish to be able to go to the cinema or out for a meal
- **Private leisure activities** eg hobbies, reading, playing music
- **Significant relationships** eg spend more time with your partner, children or close friends
- **Exercise** eg to walk briskly for half an hour a day
- **Sleep** eg to eliminate all day time sleep or to reduce night time sleep to nine hours a night.

Your targets should be realistic. For example, if you have not worked for ten years, choose a target such as doing two days voluntary work a week or starting an evening class, rather than the target of working full time. Similarly in relationships, if you are currently single and wish to be in a relationship, choose a target such as being able to go out to social situations where you can meet people. Your targets should feel achievable, given a degree of improvement.

Now make your targets specific. You may find it helpful to talk this over with your friend or helper. For each target, say:

- *what the activity is*, eg voluntary work, reading, going to the cinema
- *how often* you would like to be able to do it, eg twice a week, once a month
- *how long* you would like to be able to do it for, eg for an hour, for a whole morning.

Next, rate your targets using the following scale:

Doing this activity now, for this length of time, this often would be...

0 = no problem, 1 = usually possible, 2 = possible, 3 = not so easy, 4 = cause me discomfort, 5 = wouldn't try often, 6 = could only do it occasionally, 7 = would be really difficult, 8 = impossible

This will allow you to see which targets you are nearer to achieving and which you will need to break down into more small steps.

Make your targets varied. Plan for work and pleasure. Don't make all your targets very ambitious. Plan some that you feel you could reach sooner. This will give you a sense of progress. Plan for fun as well.

Finally, break your targets into easy stages, beginning with an initial stage that you feel that you will be able to do now. The next stage should feel like it would be achievable once you have reached the initial stage. Here are some examples:

#### **Example one:**

Final target: to go out to the cinema with a friend once a fortnight.

Where you are now: You may not be going out at all at the moment, and find even socialising at home difficult.

The steps could be broken down as follows:

1. Talk to a friend on the phone for 15 minutes daily
2. Have a friend visit for 30 minutes once a week
3. Visit a friend for 30 minutes once a week
4. Go out somewhere with a friend once a week for 30 minutes
5. Go out somewhere with a friend once a week for an hour
6. Go out somewhere with a friend once a week for two hours
7. Go to the cinema with a friend.

**Example two:**

Final target: to be able to do voluntary work for two mornings a week.

This can be broken down into steps as follows:

1. Make a list of the sort of voluntary work you would like to do
2. Telephone your local Volunteer Bureau or Council for Voluntary Organisations to find out what is available in your area. (Telephone numbers are in the telephone directory or local library reference section.)
3. Make a visit to the Volunteer Bureau to discuss the best match between what is available and your skills and abilities.
4. Arrange an informal visit to the organisation you plan to work for.
5. Arrange to work for 1 hour 1 day a week.
6. Gradually increase the time you work for. Say do 2 hours after 2 weeks; 2 hours for 2 days after 4 weeks; 3 hours for 2 days after 6 weeks.

**Example three:**

Final target: to take a brisk walk for half an hour a day

Where you are now: You may be resting most of the day and walking only as necessary around the house.

This can be broken down into steps as follows:

1. Walk to the corner of the road and back (5 minutes) every day. Stick to this routine until it feels easier to maintain it.
2. Increase the duration of the walk by one or two minutes. Again, keep this up until you can achieve it fairly consistently.
3. Increase the duration of the walk by one or two minutes again.
4. Continue increasing the duration of the walk until you are walking for half an hour a day.

Plan as many steps as you think it might take. There is no rush. Better to go too slowly at first, than go too quickly and knock yourself back. The next section will help you incorporate your targets into your daily activity.

**4. Incorporate your targets into your daily routine – gradually increase your activity and reduce rest**

First make sure that you are comfortable with your current consistent level of activity. This means that on most days for most of the time you are able to stick to the schedule you worked out at section 2 above. If this is not the case, do not proceed. Go back to sections one and two, decreasing your initial targets if necessary.

Set aside planning time. Set aside half an hour to an hour each fortnight to evaluate how the last two weeks have gone and to plan what you will do for the next two weeks. Make this a regular appointment with yourself that you keep. Involve your helper also if possible.

Look at the targets that you have broken down into steps in section 3 above. Pick at least two targets that you would like to work on first. The initial steps of these two targets must be ones that you feel you could cope with introducing into your routine over the next couple of weeks. The new steps you introduce could be increases in an activity you are already doing, eg walking for 10 minutes rather than 5 minutes twice a day; or it could be a completely new activity, eg doing some gardening or swimming. If it is a completely new activity, where you have no way of knowing how much you can do without 'overdoing it', it is important that you start cautiously.

Remember to vary your targets. Schedule some work and some pleasure.

Review your progress every two weeks with your helper. When you feel you can now cope comfortably with the new level of activity, choose two more new steps to introduce. This may take you two weeks or it may take longer. The key is gradual, achievable change, sustained until you feel it get easier. However, don't wait to feel lots better before you increase. Remember, particularly in

the early stages of treatment, symptoms will persist. The main measure of success at this stage is being able to do more without feeling worse. Fatigue and other symptoms will only go as you gradually begin to feel the effects of an overall increase in activity, consistently maintained. This can take weeks or months. Don't be impatient. Take pleasure in what you can do now that you couldn't a few weeks ago.

### **5. For People Who Do Too Much**

Another less common pattern in Chronic Fatigue Syndrome, is doing too much. This pattern occurs in people who are still working, or looking after children or just find it hard to rest, despite extreme exhaustion. Typically they will fall into a pattern where they work very hard, and then 'crash out' for long periods of time, maybe at the evenings and/or weekends. Increasingly energy is devoted only to what they 'have to do', and enjoyment gradually seeps away. If this is the case for you, you should follow the steps outlined above but consider the following factors when you set your targets:

1. Schedule rest into work time. People often work until they drop, until their body *has* to stop. However, if people take a break before they get too tired.... *they don't get too tired*. Take a coffee break, take a lunch break, don't work at the screen for more than an hour without a ten minute break... it's all common sense, but for good reasons
2. Schedule activity into rest time. People who are still working often think they don't have the energy to do anything else. However the cycle of work, crashing-out, work, crashing-out is in itself exhausting. Beginning to gradually incorporate some enjoyable activity into free time — a social visit, some gentle exercise — will, in the long run, give you more energy. Build up gradually as outlined above.
3. Do you feel guilty about not being busy? This is a not uncommon feeling in people who do a lot. They think they should be busy, that doing nothing is wrong. Exhaustion becomes the only legitimate reason for resting. Having a look at your own feelings around taking it a bit easier. The best way to do this is to do it — take it easy and see what comes up. Practise resting more until it feels comfortable.

### **6. Overcoming sleep problems**

Most people with chronic fatigue syndrome have sleep problems. These are of two main kinds:

- The quality of night time sleep is poor. People have difficulty in getting to sleep and often wake up throughout the night. As a result, they feel so exhausted, they often fall asleep or take naps during the day.
- Oversleeping. As discussed above, sleeping more than about nine hours in twenty four leads to feelings of daytime fatigue, impaired concentration, lack of energy and motivation.

#### **To reduce oversleeping**

Use the methods outlined in sections 1–4 above. Start by establishing a consistent pattern every day, then reduce and eliminate daytime sleep. Replace daytime sleep with good quality rest time or with gentle activity. Resting is superior to sleep, as it is much harder to get going again after the body has been in a deep sleep. (Deep sleep sets in after about one hour.) Once you are no longer sleeping during the day, set targets to gradually reduce night time sleep. Again, follow the same method: establish a consistent pattern within your current capacity and then, when you can maintain that pattern comfortably most of the time, reduce your sleeping time gradually, eg by getting up at a slightly earlier time every two weeks

#### **Example:**

Target: to eliminate day time sleeping

Where you are now: You are sleeping on average for two hours during the day.

The steps could be broken down as follows:

1. Take your sleep at a fixed time every day for a fixed time - that is, if you sleep for less than two hours one day, you must not increase the sleep period on the next day. Stick to this routine until it begins to feel easier to maintain it.
2. Reduce the sleep period by 15 minutes. Replace with rest.

3. Reduce the sleep period again 15 minutes. Replace with rest.
4. Continue reducing until you are sleeping for an hour and resting for an hour. Then split the sleep-rest period into two sessions of one hour each, one of sleep, one of rest, one in the morning and one in the afternoon. Stick to this until you can achieve it fairly consistently.
5. Reduce the sleep period by 15 minutes. Replace with rest.
6. Continue reducing the sleep period until you are no longer sleeping during the day.

### **To improve the quality of your night time sleep, try the following strategies:**

- Use your bed only for sleeping (and sex) and not for any other activity. Look at your activity and rest diary and see if there is a difference between the time you usually go to bed and the time you actually fall asleep. If so, go to bed much nearer your going to sleep time. If you are in the habit of resting, watching TV or reading in bed before sleep, do these in another room or, if this is not possible, in an other place in your bedroom. Only go to bed, when you are feeling sleepy. If you are not asleep within half an hour at most, get out of bed. Go somewhere else and do something relaxing - eg listening to music or reading. Go back to bed when you feel sleepy again. Repeat this as often as necessary during the evening — and also in the night, if you wake then.
- Wind down in the hour prior to sleep with a bath, music, reading
- Develop a 'getting ready for bed' routine, eg locking up, brushing teeth
- Don't exercise too near bedtime.
- Don't eat a large amount of food or drink close to bedtime.
- Don't take tea, coffee or nicotine (or reduce the latter) within four to six hours before bedtime.
- Don't drink more than a couple of units of alcohol near to bedtime.
- Don't do anything mentally or emotionally strenuous near to bed time, eg work, argue.
- Make sure your bed is comfortable and the bedroom is not too hot or cold.
- Get up at the same time each morning and change into day clothes. This will signal to your body that you are in a different mode, even if you still feel tired.

### **Dealing with worries and problems**

Worries often go through our heads, when we are falling asleep. This can make us more anxious and makes it even harder to go to sleep. If this is the case for you, then set aside some worry time in the early evening, when you decide to focus on what's come up during the day and anticipate what's coming up in the future. Choose the main issue, sit down with a problem solving sheet (your health worker can provide you with one) and go through the following steps:

1. Say exactly what the problem (or goal) is.
2. List 5 or 6 possible solutions to the problem — write down any ideas that occur to you, not merely the 'good' ideas.
3. Evaluate the good and bad points of each idea in turn.
4. Choose the solution that best fits your needs and is achievable — the one you are going to try.
5. Plan exactly the steps you will take to put the solution into action. Decide on the first step.
6. Stick to this plan - implement it. Review your efforts in your next worry time. How did it work? Praise all efforts. If unsuccessful, start again.

Now, when it comes to bedtime and worries arise, tell yourself that you have the matter in hand. If new worries arise or new angles on old ones, tell yourself that you will deal with that tomorrow in your official worry time.

Your health worker can give you more information about problem solving techniques.

## Slow breathing for relaxation (a special technique)

Feeling physically or mentally tense can interfere with sleep. Learning ways to relax can help sleep problems. There are many types of relaxation techniques. This is one of them.

- breathe in to a count of 3 seconds.
  - when you get to 3, slowly breathe out to a count of 3
  - repeat this exercise for 5 minutes
  - when you are doing it last time say the word 'relax' to yourself as you breathe out
    - breathe in using your abdomen (not your chest) and through your nose
    - practise 10-15 minutes, at night in a comfortable chair
    - keep in mind that benefits of relaxation will not occur unless you practise
- Your health worker can give you more information about relaxation methods and more information about getting a good night's sleep.

## 7. Dealing with negative thinking

Chronic Fatigue Syndrome is a very confusing condition. There are a lot of conflicting views as to what is going on and what makes it better or worse. Sufferers often feel that they have no control over the situation. Any attempt to change things, to do more for example, may lead to an increase in symptoms, which the sufferer may believe means that they are doing themselves permanent damage. Feelings of hopelessness are common and these feelings then make it much harder for the sufferer to keep up the strategies described in sections 1-5, which will eventually lead to improvement. Negative thinking can lead to feelings of hopelessness and slow down recovery. If this is true of you, ask your health worker for the leaflet on overcoming negative thinking, which outlines ways of challenging and overcoming such thinking. You are likely to need help from a friend, counsellor or other health worker.

## 8. Sources of further information

*Chronic Fatigue Syndrome: the Facts* by Mike Sharp and Frankie Campling. OUP, 2000, for more severe symptoms

*Coping with Chronic Fatigue* by Trudy Chalder, 1995, for mild to moderate symptoms

Institute of Psychiatry's website (<http://www.smd.kcl.ac.uk/kcsmd/cfs/cfstitle.htm>), which contains more information about Chronic Fatigue Syndrome and aids to self-management.

## Finally

- Doing the exercises when you feel tired is difficult
- It might be useful to work through them with a trusted friend or family member.
- If you need extra help you can always talk to your doctor, counsellor or other health worker.

## You can overcome chronic fatigue syndrome

Reformatted from original obtained from:

<http://www.bradfordvts.co.uk/ONLINERESOURCES/WFB.PHP?subdir=13.%20MENTAL%20HEALTH&sortby=name>

**DAILY ACTIVITY AND REST DIARY**

Day							
Slept for (hours)							
Awake at (time)							
8-9							
9-10							
10-11							
11-12							
12-1							
1-2							
2-3							
3-4							
4-5							
5-6							
6-7							
7-8							
8-9							
9-10							
10-12							
Asleep at							