

A Self Help
Guide

Chronic Fatigue Syndrome (CFS/ME)



What is chronic fatigue syndrome?

Feeling tired is common. If you work long hours, have family problems and are suffering from stress – it is common to feel tired. This is not CFS/ME.

CFS/ME is defined as:

Severe disabling fatigue which lasts at least 6 months, made worse by minimal physical or mental exertion, and for which there is no adequate medical explanation.

Guidelines to diagnosing CFS/ME

- Severe tiredness/fatigue
- Definite time when it began
- Tiredness severe – affects physical and mental functioning
- Fatigue is present for 6 months or more – present 50% of the time

Other symptoms you may have

- Dizzy/lightheaded/problems with balance
- Muscle & joint pains/chest pains
- Inappropriately hot or cold
- Tummy pains/digestive problems/irritable bowel syndrome
- Increased sensitivity to light/noise/migraine
- Poor concentration/memory
- In women, worsening symptoms prior to periods

Once you have a diagnosis of CFS/ME the next step is acceptance.

Acceptance

This does not mean giving up. More the realistic acceptance that for the moment you are suffering from an illness which has no magic cure. Fighting your body is exhausting. Giving in and going to bed will weaken your body even more.

You can have CFS/ME and yet be healthy. Health has to do with acceptance, understanding and adaptation. Every person at some time will be sick, suffer loss or hurt and die. Health is not to do with avoiding these but accepting them and making sense of them.

How to adapt to CFS/ME

Balancing rest and activity

Many people with CFS/ME have good days and bad days, and often overdo things on a good day – this is a mistake.

PACING is the way to avoid this problem.

Alternating time-limited periods of physical and mental activity with good quality rest. Aim to stop before you are exhausted.

How to begin to pace:

1. For 2–3 weeks keep a record of your activities, time spent on them, your symptoms, feelings and mood.
2. Spot the patterns – remember the effects of getting tired often don't show up till the next day or day after.
3. Then structure your day with targets set and achieved. Start with small targets.
4. From your weekly record judge how long periods of activity should be. Increase gradually step by step as your fitness improves. Resist the temptation to overdo on a good day.

Relaxation

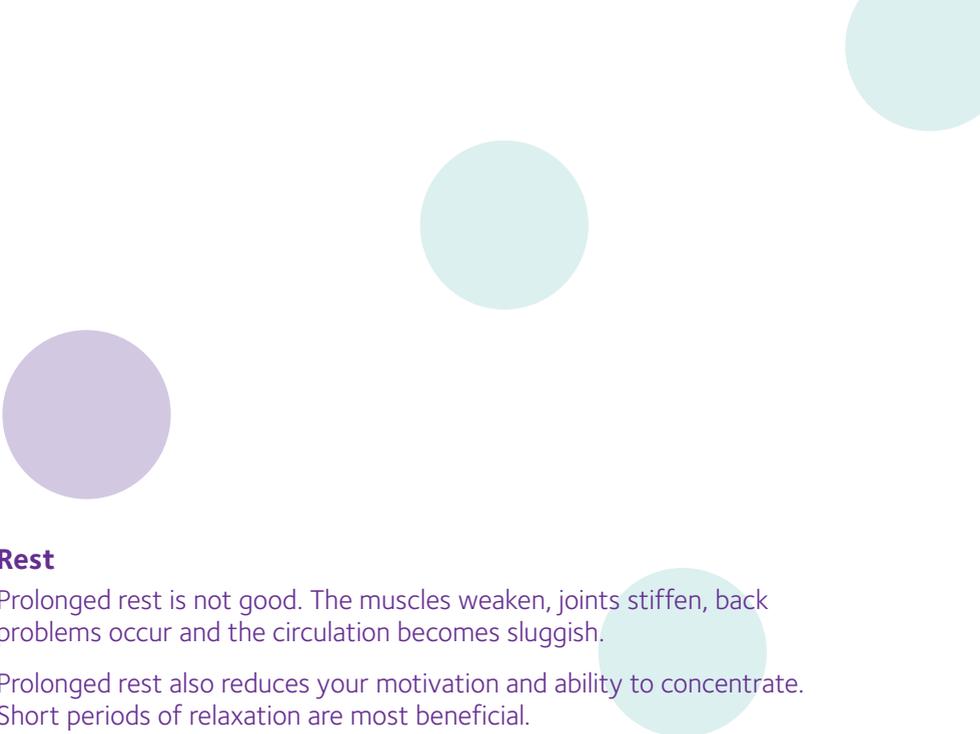
Relaxation is not just taking it easy or spacing out in front of the television. It means letting go of physical tension in muscles. Tensed muscles use energy, increasing your tiredness.

Relaxation exercise – sitting with the breath

1. Sit or lie in as comfortable a position as possible, keep your spine straight.
2. Close your eyes.
3. Be aware of your tummy as it rises and falls with each breath.
4. Keep your mind on the breath. When you are aware your mind has wandered off, gently bring your attention back to your tummy and breathe.
5. Practise this new skill 10 minutes twice daily e.g. on getting out of bed in morning and in evening before bed.
6. After relaxing take time to stretch before action.

Problems

Initially you will be more aware of pain. You may feel guilty “I am sitting doing nothing”. It will get easier and more enjoyable with practice.



Rest

Prolonged rest is not good. The muscles weaken, joints stiffen, back problems occur and the circulation becomes sluggish.

Prolonged rest also reduces your motivation and ability to concentrate. Short periods of relaxation are most beneficial.

Getting Fitter

Forget what you used to be able to do before you were ill. Concentrate on what suits your body now. You are in charge of the gradual increase in exercise. Plan exercises. Do not carry on till you feel too tired to continue.

Bending and stretching exercises

See figure 1 (*towards end of booklet*).

Start very gradually.

Hold each posture for count of 5. Keep breathing, do not hold your breath. Breathe out when you move from one posture to another. Never force your body into a posture. Leave that posture and gently try again tomorrow. Practice daily.

Walking

Short walk in the morning and one in the afternoon is better than one long walk. If you can only manage a few paces that is a good start. Get into a daily routine.

Swimming and cycling

Once your condition allows.

Remember to pace – start slowly, stop before you are too tired.

Posture

If you are tired you may be tempted to slouch. Think tall. Good posture is kinder to your body.

Sleep Hygiene

Have a calm routine before you go to bed.

Avoid alcohol and caffeine for at least 2 hours before bed. If you wake in the night, try to stay calm. Worrying about sleep is guaranteed to keep you awake. If you really can't sleep, get up, read, listen to music till you feel sleepy and only then go back to bed.

Re-establish a regular sleep pattern

Always rise at the same time each morning, even if you have slept badly. If tired during the day – try to rest and relax – not sleep. If you do need a daytime nap – make it at a regular time each day e.g. after lunch.

Sedatives/sleeping tablets

Best avoided as you can become dependant.

Low dose “antidepressant” drugs can be helpful. Not to help your mood – but to improve sleep and help with pain. Discuss with your doctor.



Eat balanced diet

Keep your diet and food as normal as possible. There is no evidence to date that vitamin or mineral supplements are helpful in CFS/ME.

Alcohol

Many people with CFS/ME find alcohol makes them worse.

Managing your mind

“I should be able to cope”

“I must fight this”

“I used to be so active – now I can do nothing”

“I wish it would just go away”

“I must rest to get better”

“I am useless – a failure”

“My family must be so fed up with me – I feel so guilty for being such a burden”

These kinds of thoughts are very common in people with CFS/ME. They are understandable but not helpful. If we dwell on these kinds of thoughts, we become low, anxious, frustrated and angry. These emotions are unhelpful and tiring.

How to deal with these unhelpful thoughts

Be aware of them.

Change them to more compassionate/encouraging thoughts. Stop making judgements about yourself. Be more patient with yourself.

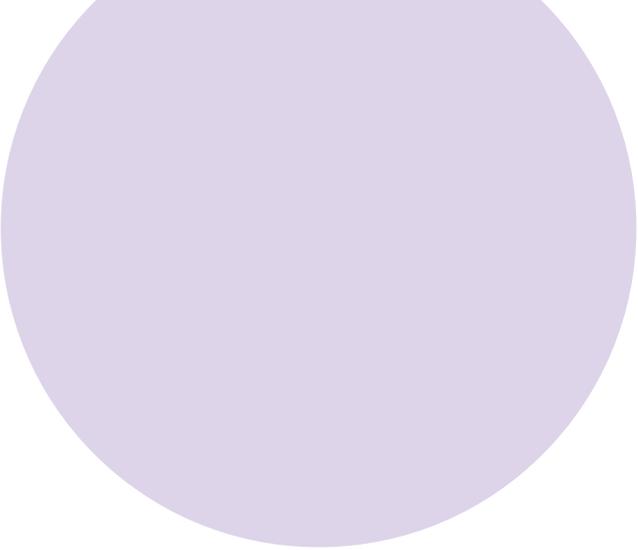
Think – how can I make things better today?

However severe your condition, there is more to your life than illness.

You are still a person of worth, you still have a contribution to make to your life and the lives of those you love.

You can take an interest in other things than illness. The more you concentrate on your illness, the worse you will feel.

Thinking and behaving in as normal a way as possible in the circumstances is going to make your life better.



Find the balance

Acceptance and Hope

People who get better with CFS/ME tell us that the real improvement started once they accepted what was happening to them.

“This is not what I wanted. I do not have to like it, but this is what is happening today – so how can I make the most of today.”

Thinking this way today – can lead to a more hopeful tomorrow.



Dr Rosaleen Isles
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With acknowledgements to Frankie Campling and Michael Sharpe for information from Chronic Fatigue Syndrome – the facts and Richard Smith, Editor BMJ from article in Dec 2002 edition.

Fig 1. Bending and stretching exercises

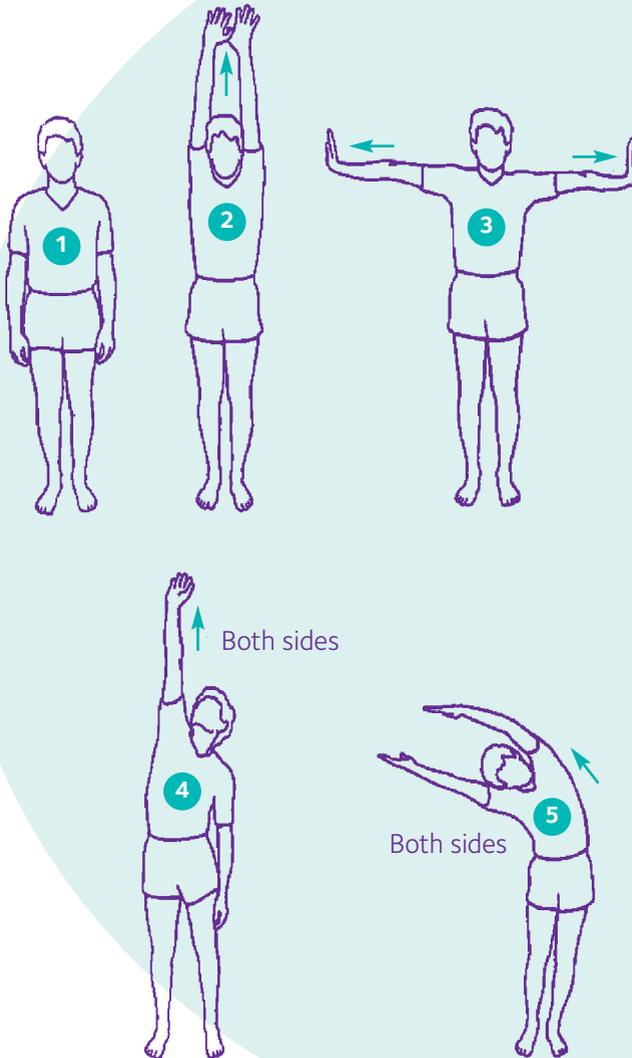
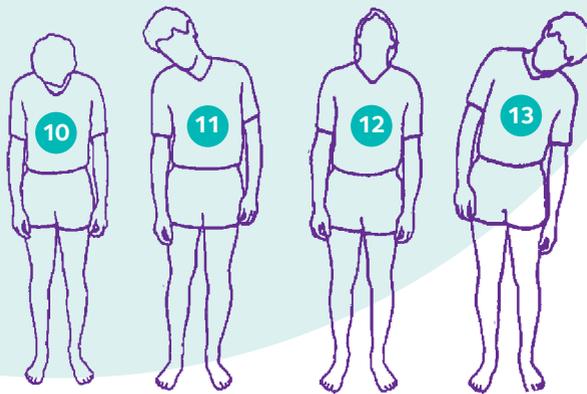
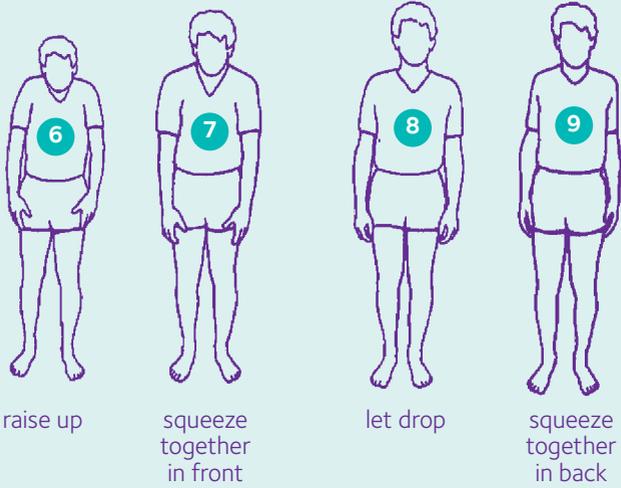


Fig 2. Shoulder rolls; do in forward then backward directions



Neck rolls: do in one direction, then the other

Fig 3.

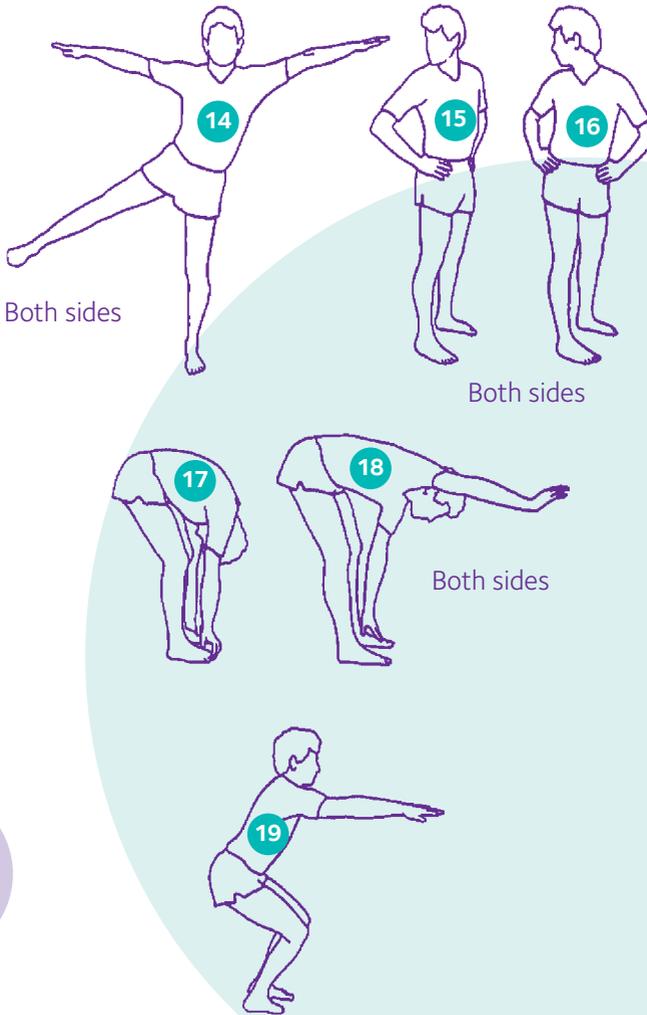
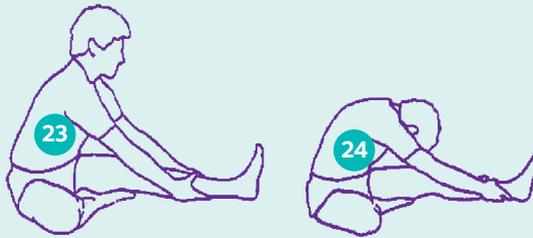
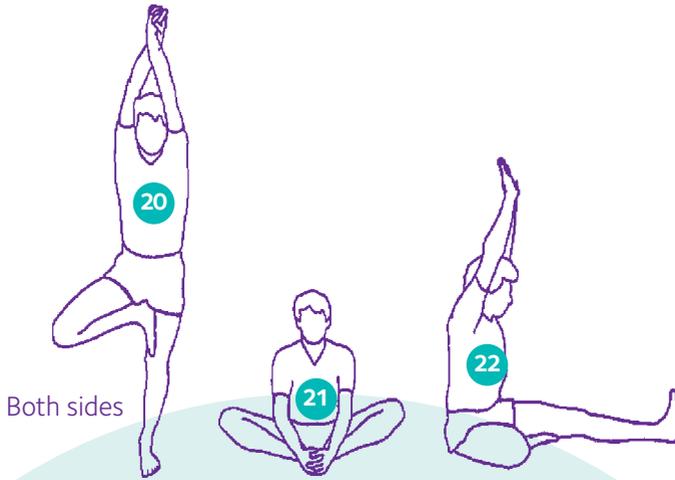


Fig 4.



Repeat 22 to 24 on other side



Sources of help

The ME Association

Stanhope House, High Street, Stanford le Hope, Essex, SS17 0HA.

Tel: (01375) 642466 or (01375) 361013.

Web site: www.meassociation.org.uk

– Provides information, support and advice.

ME Association, Scotland

110a Maxwell Avenue, Westerton, Bearsden, Glasgow, G61 1HU.

Tel: (0141) 943 1440.

The National ME Centre and Centre for Fatigue Syndromes

Disablement Services Centre, Harold Wood Hospital, Harold Wood, Romford, Essex, RM3 0BE.

Tel: (01708) 378050.

– Information packs, general advice, support, self-help groups and treatment programmes.

www.kcl.ac.uk/projects/cfs/patients/

– For useful self help for chronic fatigue/ME.

Useful books

Chronic Fatigue Syndrome the Facts

Frankie Campling & Michael Sharpe, Oxford Medical Publications 2000

ISBN 0-19-263049-0.

Somebody Help ME – Self help guide for young sufferers

Jill Moss, Sunbow Books, 1995

ISBN 0-9525-783-01.

Coping with Chronic Fatigue.

Chalder, T. Sheldon Press.1995

ISBN 0859696855.

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Version 1



Lothian – Psychological Interventions Network



West Lothian
Council



Midlothian



East Lothian
Council

