

Scottish Good Practice Statement on ME-CFS

**Patient Guide: What someone should
know if they or their doctor think they
might have ME-CFS**

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Formally endorsed by the Royal College of General Practitioners (Scotland)
and the Scottish Neurosciences Council

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PATIENT GUIDE: WHAT SOMEONE SHOULD KNOW IF THEY OR THEIR DOCTOR THINK THEY MIGHT HAVE ME-CFS

PURPOSE

ME-CFS is a complex illness and the process of reaching a firm diagnosis can also be complex. This guide is intended to help adult patients understand the nature of the illness, and what can be done to help and support them through it. In the early stages of the illness it is difficult to predict how seriously any individual will be affected by the illness. A core principle is the building of a positive relationship with your GP.

This document is accompanied by a Quick Reference Clinical Guide intended for GPs, and a detailed document entitled *Scottish Good Practice Statement on ME-CFS*. All three documents are available at:

<http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners>

INTRODUCTION

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME-CFS) often starts with an infection, sometimes involving the chest or digestive system. It has been reported that it can also develop after an accident, operation or exposure to toxins or pesticides. It can develop gradually with no clear onset - people having previously been fit and well. Some people are severely ill right from the start. ME-CFS can affect all age groups.

Many cases of ME-CFS are triggered by a viral infection including glandular fever, viral hepatitis, and less commonly infection with bacteria or other organisms. Many of the infections which trigger ME-CFS seem to be ordinary flu-like infections, from which some people don't recover in the normal way.

The experience of ME-CFS varies greatly between individuals and over time. The severity of symptoms varies a great deal. Some people are mildly affected and are able to get back to work or study though they may have to cut back on everything else for a time. Others are more severely ill in as much as they are bedbound for periods and may need a lot of care and support. It is hoped that early diagnosis with good support and advice in the early stages should help to reduce the numbers of people who are severely affected. The needs of those more severely affected require specific guidance.

The typical reaction to over-activity is an increase in symptom severity, but with pacing yourself (including record keeping) this can be partly avoided. ME-CFS is a most unusual illness and may well be unlike any other illness you have experienced.

MAIN SYMPTOMS may include some but not necessarily all of:

- The most typical feature of the illness is exhaustion and malaise or feeling unwell following minimal physical or mental activity. This might not become fully apparent until 24-48 hours after the activity. This feature distinguishes the illness from other forms of chronic fatigue. Recovery may be prolonged – days, weeks or even months. Variability and fluctuation of symptoms is a second key sign.
- Pain, including muscles and nerve pain and/or pain in one or more joints without signs of swelling, redness or deformity.
- Problems with short term memory, concentration and attention span.
- Communication problems including a tendency to lose track of conversation in the middle of sentences, difficulty recalling words when speaking or writing and difficulty putting ideas into order.
- Constantly feeling unwell, with flu-like symptoms (e.g. sore throat, enlarged glands, joint pains) and being unusually sensitive to light, noise, smell etc.
- Being unusually sensitive to sleep disturbance, especially waking unrefreshed. The disturbance can include an inability to get to sleep, sleeping for long periods, perhaps 12-18 hours at a stretch, sleeping during the day while staying awake at night, and disturbing dreams.
- Problems with eye function and hearing including strange noises in the ear and increased sensitivity to sound.

OTHER SYMPTOMS

- Feelings of unsteadiness when walking or standing. Some people report feeling as though they are “walking on rubber”. Some experience faintness on standing up or standing still.
- Unpredictable emotional mood swings.
- Headaches of a new type, pattern or severity.
- Sensations of tingling or numbness or loss of sense of touch.
- Onset of drug and food intolerances including alcohol intolerance.
- Irritable bowel symptoms and nausea.
- Greater sensitivity to cold and heat.

DIAGNOSIS

The diagnosis has to be made from the typical pattern of symptoms, with the exclusion of other possible causes. Anyone suspected of having ME-CFS should be considered for a number of routine blood tests to identify other possible illnesses. More specialised investigations may be required if the diagnosis remains in doubt.

MANAGEMENT

Self Management

Success in learning to manage activity and rest is often referred to as pacing. People with ME-CFS find that their energy levels vary from day to day and it can be easy to do too much when having a better day. Unfortunately this can lead to a setback the next day or several days afterwards. Pacing organises your day into sustainable activity and regular rests. Increases in symptoms and flare-ups are common and it is important to be aware that they may well occur and to be prepared for them.

Activity doesn't just mean physical tasks; it also means mental exertion. This includes pastimes that you may think of as relaxing, such as talking to friends, reading, watching television or listening to music. It also includes hidden mental activity like emotion and worry. Pacing needs to be applied to all these activities and your day should, if possible, include a balanced mix of different sorts of activity. Consider switching activities, for example if brain activity is more tiring then move to a physical activity. Think of your available energy as a mobile phone battery. If you completely drain the battery you have to wait for it to recharge before you can use the phone again. If you use some of the battery and make regular top-ups, then your phone will always be ready for use. Managing your energy through planned periods of activity and rest will mean you are more likely to be able to do the activities you want to do.

If you restrict the amount of energy you expend on main activities compared to the energy you feel you could use, that should ensure stability plus allow you to sometimes take on additional activities. Before you can start to plan a pacing programme you need to recognise how much activity you can comfortably manage on a daily basis, without causing an increase in symptoms. This is called your baseline. Baselines should be manageable, even if you're not having a good day. Sometimes you will need to start at a very low level. This is usually lower than you would expect or hope. Many people do improve gradually as the body naturally recovers from illness. To help you become aware of highs and lows of activity, keep a simple diary when you are able to. The diary can record your levels of activity and is useful to show to health professionals and also is of value when applying for benefits.

"Before I learnt about pacing, the amount I did each day was very erratic. If I felt ok I had a tendency to overdo things, which would make me feel worse. Working out daily activity levels has brought things under control. By adding extra rest periods, I also occasionally 'save up' daily energy rations to use on a larger activity, like a trip out."

Planning your time is essential. You need to prioritise activities and tasks to include those that you have to do, but also those that you enjoy. It's important to develop awareness of how your body is coping, to sense if you are pushing yourself too hard, or if you have become wary of moving forward. You are the one who is most aware of your own energy levels and it is important to not be persuaded into undertaking activities (for example an outing with family or friends) that you know may well have unwelcome repercussions.

Self management programmes for patients are being developed which may be suitable for some people with ME-CFS e.g. programmes run by the Thistle Foundation, Multiple Sclerosis Society (Scotland), Arthritis Care and the Pain Association Scotland. These organisations offer general courses for people with any long term condition. Some specific courses may also be available at the Thistle Foundation. For further information on pacing, see Action for M.E.'s booklet: *Pacing: A guide for people with M.E.*

There are no drugs or treatments that can cure ME-CFS but medical research into the causes and a possible cure is being undertaken in Scotland and in many other countries. There are many approaches open to you and your doctor that could reduce your symptoms and help you manage them and give your body the best chance of recovery.

People with ME-CFS respond to treatment in different ways and what works for someone else may not be helpful for you, even though you share the same symptoms. It is important to adopt one approach or make one change at a time, to find out what works for you.

Managing symptoms

If left untreated, symptoms such as pain, sleep difficulties, faints/falls and mood problems can take over your life at some stage in your illness. Your doctor may be able to treat and prevent these symptoms by prescribing medication and perhaps suggesting changes in your lifestyle. Some people with ME-CFS appear to be more prone to side effects, therefore drugs may be started at lower doses than would normally be prescribed, to minimise side effects. Your doctor may need to try several medication options before finding one that can be helpful to you. As in other chronic conditions, medication may **not** work well.

CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) have been shown to be of benefit for some people but others have found them unhelpful. CBT and GET should only be delivered by suitably trained CBT and GET therapists with expertise in ME-CFS. Counselling may be of benefit to help you come to terms with and cope with the illness. Each different approach takes time to work, so be patient and don't expect results immediately. Through time, you will also discover tactics for yourself as you understand more about how ME-CFS is affecting your body.

Holistic approaches

As with any illness, supporting your body will give it the best chance of recovery. This may include eating a balanced diet, which is low in sugar and processed foods, with lots of fruit and vegetables, using meditation or relaxation techniques, and getting a balance between rest and exercise. Your diet may have suited you very well before you became unwell with ME-CFS but should be reviewed now. You will need to consider making adjustments to your lifestyle and also you may want to try complementary therapies. When making any decisions about lifestyle and therapies it may be helpful to take into account the recommendations of others who have benefitted from changes they have made or activities they have adopted. Please look at the Appendix to see where to obtain more information about these topics.

Anxiety, depression and other mood problems

Looking after your mental health is vital to your improvement, so it is important to seek medical help if low mood or anxiety becomes an issue for you. Remember that anxiety, mood swings, or depression can occur in any long term illness and are not the cause of your ME-CFS.

PROGNOSIS/OUTCOME

People with ME-CFS vary enormously in their experience of the illness and also how long their symptoms last. Many people make good progress – some quite quickly – while others can remain ill for a number of years. People often find that they don't completely get back to the way they felt before they became ill, but with adjustment they can still lead fulfilling lives. Treatment can help some patients reduce their symptoms and make the experience of illness less unpleasant.

CHECKLIST

1. Learn to manage your energy and activity – physical, mental and emotional. Become an expert at managing your illness.
2. Deal with the major symptoms that can take over your life such as pain, sleep disturbance and low mood. Uncontrolled symptoms can get in the way of recovery. Your doctor can help you to manage these with medication. Other strategies can also be helpful, such as pacing your activities, relaxation techniques and complementary therapies.
3. Establish a relationship with your GP. This can take time but the partnership between you and your GP can be crucial to stabilising your illness and enabling recovery.
4. Remember that people do recover from M.E. Learn to accept your illness and recovery is more likely to follow in time.
5. You are not alone. An estimated 20,000 people in Scotland have this illness.

CARERS, FAMILY AND FRIENDS

An illness like ME-CFS does not only affect you, it will also affect family and friends. The condition can be distressing for the individual suffering from the illness and those around them. It is important to recognise that this can be a difficult time for those caring for you as well as for yourself and to share with them your plans for managing your condition. It is important that you support each other and talk about what is happening to your lives and also consider what changes are occurring in any intimate relationships.

EMPLOYMENT AND EDUCATION

You may need time off work or away from studies and may need to adjust to the prolonged nature of recovery. A phased return to work or studies may be of benefit though this will depend on the severity of your illness and should be negotiated carefully. Employers and schools may need advice about how to manage this appropriately. You may be entitled to benefits, such as Employment and Support Allowance and/or Disability Living Allowance.

Further Resources

1. Living with CFS/ME – leaflet produced by Dumfries and Galloway M.E. Network. February 2009
2. Pacing for people with M.E., Action for M.E. 2010
3. All about M.E., Action for M.E. 2010
4. Your Child and M.E., Action for M.E. 2010
5. Action for M.E. has a series of articles by medical professionals and others, together with a number of factsheets, available to download free from its website: www.afme.org.uk
6. The ME Association's publications list is available online at www.meassociation.org.uk
7. Ho-Yen D. *Better Recovery from Viral Illnesses*, Dodona Books, 2008, ISBN 0-9511090-7-3

National charities

- Action for M.E.
Booklets including Pacing for people with M.E., plus factsheets, volunteer support line, welfare rights helpline.
Tel: volunteer helpline lo-call 0845 123 2314
www.afme.org.uk
- ME Association
Factsheets and volunteer helpline.
Tel: 0844 576 5326
www.meassociation.org.uk
- Association of Young People with ME (AYME)
For children and young people up to 25
Tel: 08451 23 23 89
www.ayme.org.uk
- 25% Group
For people who are severely affected
Tel: 01292 318611
www.25megroup.org
- Young ME Sufferers Trust (Tymes Trust)
Tel: 0845 003 9002
www.tymestrust.org

In addition to these national charities there is a wide network of local support groups for ME-CFS. Contact details of the local support groups are listed in the *Scottish Good Practice Statement on ME-CFS*, which also contains details of welfare benefits, social care and emotional support. It is available, along with further copies of this patient guide at:
<http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners>

National helplines

NHS 24: Provides self care advice for people in Scotland and urgent care assistance/ clinical advice when GP surgeries are closed. Tel: 08454 24 24 24. www.nhs24.com

NHS Inform: Provides a coordinated source of quality assured health information for the public in Scotland. Tel: 0800 22 44 88. www.nhsinform.co.uk

Care Information Scotland: Provides a confidential information phoneline service for any individual who is seeking information about community care for older people.
Tel: 08456 001 001. www.CareInfoScotland.co.uk



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