

DRAFT: Patient Guide for adults

- 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 patients understand the nature of the illness, and what can be done to help and support them through it. A core principle is the building of a positive relationship with your GP.

This document is accompanied by a 'Scottish Good Practice Statement on Adults with ME-CFS' intended for GPs, and a detailed document entitled 'Scottish Good Practice Statement on ME-CFS'.

INTRODUCTION

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME-CFS) often starts with an infection, sometimes involving the chest or digestive system. It can also develop after an accident, operation, vaccination or exposure to 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 usual 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 (eg 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 specialized 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 creating the vicious cycle of ‘boom and bust’. Pacing organises your day into sustainable activity and regular rest to avoid this damaging pattern.

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 include a balanced mix of different sorts of 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 sometimes need to start at very low levels and should be manageable, even if you're not having a good day. To help you become aware of highs and lows of activity, keep a simple diary of all your current activities, and how they make you feel.

“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**. Once you have established a steady routine you can try to very gradually build up your activity in small steps. This process could take weeks rather than days and you need to approach any goal step by step, and flexibly. 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 eg programmes run by the Thistle Foundation, Multiple Sclerosis Society (Scotland), Arthritis Care and the Pain Association Scotland. These organizations offer general courses for people with any long term condition. Some specific courses may also be available as 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 and get in the way of recovery. 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.

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 may consider making adjustments to your lifestyle and also trying 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 approaches can help by reducing symptoms and making the experience of illness much less unpleasant in the short term. More importantly, they can maximise the chances of recovery and the rate at which it happens, as well as reducing the risk of setbacks and temporary increases in symptoms.

CHECKLIST

1. Learn to manage your energy and activity – physical, mental and emotional. Become an expert at managing your illness and stay in control.
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 stabilizing 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 25,000 people in Scotland have this illness.

CARERS, FAMILY AND FRIENDS

An illness like ME-CFS does not only affect yourself, 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.

LOOKING AHEAD

Early planning for changes in your circumstances (employment, education, family commitments) can be an important factor in your management of the illness.

FINANCE AND WELFARE BENEFITS

See Appendix.

There is a wealth of expertise, information and advice available – please see the Appendix for contact details of the national agencies and local support groups.

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Logos (Action for M.E., NHS Scotland and NHS Dumfries and Galloway?)

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APPENDIX

Useful Contacts

- **Action for M.E.**
Welfare Rights Line for people with ME. 0845 123 2380
- **Benefits and Work**
The Benefits and Work website contains plenty of information about benefits. Membership of £18.95 a year gives unlimited access to their guides for claimants and members forum.
www.benefitsandwork.co.uk
- **Centres for Inclusive Living** give information and advice on a wide range of issues including benefits and money eg. Grapevine and Lothian Centre of Inclusive Living.
- **Citizens Advice Bureau** www.cas.org.uk and www.adviceguide.org.uk or one of the main charities for advice on welfare benefits, employment rights, housing, transport issues etc. The local **Citizens Advice Bureau** may be able to help patients to fill in benefits forms. Also see the phonebook for the nearest bureau.
- **Department for Work and Pensions**
Benefit Enquiry Line for people with disabilities, plus downloadable factsheets from the website, which links to further information at Jobcentre Plus.
Tel: 0800 882 200, Mon-Fri 8.30am-6.30pm and Sat 9am-1pm.
www.dwp.gov.uk/esa
- **Disability Alliance:**
Free factsheets are available to download from their website. They also produce an annual guide called "Disability Rights Handbook (Disability Alliance)". The 34th edition is for the year April 2009-April 2010. There are separate publications on ESA (Employment and Support Allowance) and DLA (Disability Living Allowance). These guides can be ordered by telephoning 020 7247 8776 (please note that this is not an advice line) or through the website www.disabilityalliance.org
- **Jobcentre Plus**
How to claim and further information. www.jobcentreplus.gov.uk
- **Local authorities** often have benefits/money advice centres - see local phone directory.
- There are also **local welfare benefit advice organisations** and information is available from local support groups.

Further Resources

1. CFS/ME/PVFS An exploration of the key clinical issues, Dr Charles Shepherd and Dr Abhijit Chaudhuri for the ME Association, October 2009
2. Living with CFS/ME – leaflet produced by Dumfries and Galloway M.E. Network. February 2009
3. Pacing for people with M.E., Action for M.E. 2010
4. All about 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. Better Recovery from Viral Illnesses, Dr Darrel Ho-Yen, (2008) Dodona Books, ISBN 0-9511090-7-3
8. Myalgic Encephalomyelitis/chronic fatigue syndrome, Carruthers et al; Journal of Chronic Fatigue Syndrome, January 2003 (Canadian Consensus Document: rating scales section).

National charities

- Action for M.E.
Booklets including Pacing for people with M.E., plus factsheets, volunteer supportline, welfare rights helpline.
Tel: lo-call 0845 123 2380
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

Local support groups

- ME and You Aberdeen
Gregor McAbery
Tel: 01224 581162
E-mail: Gregor.mcabery@mac.com
www.meandyouaberdeen.co.uk
- Cathcart ME Group
John McKnight
Tel: 0141 632 2486
E-mail: peter.cathcartmegroup@ntlworld.com
- ME East Kilbride [MEEK] Group
Margaret Williams
E-mail: margaret.williams@icscotland.net
- Dumfries & Galloway ME Network
Norma and Denis Turner
Tel: 01576 204129
E-mail: dennor@btinternet.com
www.dgme.co.uk
- Edinburgh M.E. Self-Help Group (edmesh)
Membership Enquiries to: 0845 625 2025 or email: membership@edmesh.org.uk
E-mail: convenor@edmesh.org.uk
www.edmesh.org.uk
- ELMESH (East Lothian ME Self Help)
Dr Marilyn McNeill
Tel: 01620 880651
E-mail: Marilyn@rowansdrem.plus.com
- Falkirk ME Self Help Group
Neil Swinnerton

- Tel: 01506 842599
E-mail: Neil@swinnerton.net
- ME Support Fife
Catherine Lewis
Tel: 01334 653202
E-mail: Catherine@claremont-cupar.freereserve.co.uk
 - Glasgow West
Ewan Dale
Tel: 0141 332 8115
E-mail: ewandale@yahoo.co.uk
 - Glasgow CFS/ME Meet-up Group
Anna Wood
Tel: 01419452682
E-mail: anna.k.wood@talktalk.net
www.meetup.com/glasgow-me
 - Inverness ME / Fibromyalgia/CFS Support Group
Brenda Fraser
Tel: 01463 238533
E-mail: Glenesk.brenda@yahoo.com
 - Lanarkshire ME Support Group
Jane Giakoumakis
Tel: 01698 817114
E-mail: janeyannis@talktalk.net
 - Oban
Adrian A Lauder
Tel: 01631 720262
E-mail: adrian.lauder@gmail.com
 - Paisley & District ME Support Group
Theresa Bates
Tel: 0141 561 3426
E-mail: Theresa@mepaisley.co.uk
 - Perth ME Group
E Moncrieff
E-mail: e.mon@tiscali.co.uk
 - MESKYE (Isle of Skye)
Mike Wotton
Tel: 01470 592369
 - ME Support (Stirling)
Alexandra Russell
Tel: 01786 816478

Other useful organisations

- Neurological Alliance of Scotland
Tel: 07540 643545
www.scottishneurological.org.uk
- Long Term Conditions Alliance Scotland
Tel: 0141 404 0231
www.ltcas.org.uk
- Carers Scotland

www.carerscotland.org

0141 445 3070

- Citizens Advice Scotland

www.cas.org.uk

- Thistle Foundation

Tel: 0131 661 3366

www.thistle.org.uk

- Children in Scotland

www.childreninscotland.org.uk

Enquire helpline for advice on educational support needs.

Tel: 0845 1232303 E-mail: info@enquire.org.uk

- Princess Royal Trust for Carers

www.carers.org

Tel: 0141 221 5066

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