

Myalgic Encephalomyelitis (M.E.) is a debilitating disease affecting both the central nervous and immune systems.

Symptoms can include incapacitating pain, often constant intractable headache, sore throat and recurrent flu-like illnesses, also

- impaired cognitive functions, chronic fatigue, and exhaustion often made worse by exercise.
- It varies in severity and can be life threatening.
- There is no cure, only management.
- It is severely debilitating, can affect anyone, and can last for years.
- It affects the lives of all the family, including carers.
- M.E. still carries a stigma. In the past it has been the subject of ridicule and has been given ridiculous names.
- People with M.E. require both help and understanding.
- The purpose of this "Carer's Guide" is to help you, the carer, to give basic guidance on coping with the illness.
- If you have access to the internet, or even if you do not, you can access the following carers' site via your local library which may offer free internet access.

<http://brightfield.org.uk/living/index.html> is a website that offers help and guidance to people who live with others who have long term illnesses, whether they be parents, relatives or friends. There are many articles on the topic of how friends and relatives of chronically ill people can adjust to their situation and deal with day-to-day problems.

The Young ME Sufferers' Trust PO Box 4347, Stock, Ingatestone CM4 9TE Tel 01245 401080 is a national organisation which supports young people with ME and their families. Services are free up to age 26; they also have a telephone helpline and provide training days for professionals. Website www.tymestrust.org

The 25% ME Group 4 Douglas Court, Beach Road, Troon, Ayrshire Tel/Fax 01292 318611. This is an independent group set up to help severe ME Sufferers, and their carers, and to help break the isolation ME brings to their lives. Website www.25megroup.org.

BRAME Blue Ribbon for the Awareness of ME 30 Winmer Avenue, Winterton on Sea, Great Yarmouth, Norfolk, NR19 4BA. Tel 01493 393717. A group set up to highlight ME as a serious illness and the consequences of living with it. Website: www.brame.org

The CFS Research Foundation 2 The Briars, Sarrat, Rickmansworth Herts WD3 6AU Tel 01923 268641 is a registered research charity which concentrates entirely on research into the physical aspects of ME/CFS. Website: www.cfsresearchfoundation.org.uk

MERGE The Gateway, North Methven Street, Perth PH1 5PP UK. Tel/Fax: 01738 451234. This commissions and funds research into the causes, consequences and treatment of ME. Website: www.mererearch.org.uk



Leger-ME:

*Supporting Myalgic Encephalopathy or Encephalomyelitis (ME),
Chronic Fatigue Syndrome (CFS),
Post Viral Fatigue Syndrome (PVFS),*

An ME/CFS Carers Guide

by Carer member

Trevor. Wainwright

A practical guide to caring for people with M.E. based on my experience. This is a strategy arrived at through trial, error, frustration and patience. What I have learnt has been by listening to the experience of others in the same situation, who have looked after sufferers among their own families and friends.

The cardinal rule is, believe in their illness

Try to remember how you yourself felt when you had an illness and remember that they feel 100 times worse, and that there seems to be no end to that feeling and pain. Lots of patience and understanding are required. Try the best psychological treatment; simply say "okay I believe you, now how can I help you?"

Love and support at all times

Remember they know how they feel at any given moment, help them get through the illness as best you can. It's very difficult for the carer to cope but even worse for the person suffering from ME. It doesn't just affect them, it affects the whole family, you have to change your life to fit in with the illness.

You may want to give them a cuddle, they may not want it. However upsetting for you, you must accept that sometimes they want to be left alone. Let them come to you, always be ready. Remember, ME is a serious physical illness, and a sufferer's physical and mental states can change very quickly but they are still the same person underneath.

Encourage, but do not force them to talk about the illness and how they feel, but take care not to over burden them with your interest. At all times try to keep your sense of humour, it can keep you going through many bad and frustrating times.

Learn all you can about the illness

G.P.s are busy people. Many do not have the expertise or the time to deal with M.E. Ask to be referred to a regional clinic (e.g. Leeds or Sheffield). Sadly most of the NHS support is based on management and coping strategies.

If there are different doctors in the practice find one that is understanding of the illness. If not, move to another practice. Remember they are there to serve you. Certain private doctors may provide a better service.

Visit your local library, they have many books on the illness. If not, ask and they will order them for you. They will also have internet access, a source of much useful information, but beware, there is no guarantee of the accuracy of this..

Join internet discussion lists and chat groups. Listen to others' experiences and suggestions, but do not force their experiences on the sufferer. The illness is as individual as they are.

Support Groups, either local or national, can be useful for information. Contact them, make the first step, if you think they can help, use them, if not try another. Remember many groups are run by sufferers themselves.

Treatment issues.

Listen to the sufferer, as they in turn must listen to their own body. Treatment is a lottery, and what works for some, may not for others, so the only realistic option is try it and see. Do not be put off trying alternative therapy. Give it a try-if it makes you worse or there is no improvement you can always stop it. Some mental health strategies have not been found as helpful as some practitioners would hope. Family support and belief is often better, far better. Remember that as a Carer you may be the sufferer's only friend. Be prepared for social isolation.

Education

By law, children have to be educated, but do not have to attend school. LEAs must provide suitable education to match the needs of the pupil which may be home tuition. The doctor or paediatrician can help to secure this but you may need to be persistent.

Further Information

What is described in this leaflet is not exhaustive. You are not alone, there are many others. At all times remember though, it is the sufferer's wishes that are paramount. Do not force, but encourage, do not drive, but lead, do not demand, but ask. You can give much to a sufferer, and always remember, the best you can give is Support and Love.