



ME CONNECT

We're here to help

August 2019

JUST DIAGNOSED? We are here to help

INTRODUCTION

This leaflet has been written especially to help those of you who have just been diagnosed. You may have so many questions to ask and be finding it hard to understand what the illness is and how to get help. We try, in this booklet,

to answer as many of your questions as we can.

Our information and support line, ME Connect, has a lot of information to give. Do give us a call on 0844 576 5326. We can also listen and talk through with you the difficulties you have.

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The ME Association has over 70 leaflets and booklets covering all aspects of management including DWP benefits, employment and education.

ORDERING FROM US

If you would like to order any of these leaflets, here are your options:

- Download the items from our website – www.meassociation.org.uk/shop/
- Download the 8-page Order Form from our website, print it off, fill it in and post it to our office, together with your cheque. You will find the form close to the top right hand corner on our website landing page.
- Phone the office on 01280 818 968 and pay by debit or credit card. Please phone on weekdays only between 9.30am and 3.30pm.
- Phone our ME Connect helpline on 0844 576 5326 and ask for an information pack to be posted out to you. This will contain an Order Form.

WHAT IS ME/CFS?

ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) is a complex multisystem illness that affects the brain and muscle function and, in some cases, other body systems as well.

It can cause prolonged ill health and disability.

There are uncertainties about the cause of ME/CFS but research has demonstrated abnormalities involving the brain, muscle, immune and endocrine (hormone-producing) systems.

ME/CFS is characterised by brain and muscle symptoms that are often made worse by minimal physical or mental exertion. We often call this post-exertional malaise.

Together with constantly feeling unwell with 'flu-like symptoms, people with ME/CFS are likely to have some of the following symptoms:



by **DR CHARLES SHEPHERD**,
medical adviser, The ME Association

- Muscle and nerve pain
- Sleep disturbance and unrefreshing sleep
- Concentration and memory problems
- Problems with balance (feeling unsteady) and staying in an upright position (orthostatic intolerance)

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WHAT IS ME/CFS?

- Headaches
- Sensitivities and intolerances to some foods, drugs and alcohol
- Problems with body temperature control (thermoregulation)

The severity and range of symptoms varies from person to person.

ME/CFS is a fluctuating medical condition. Symptoms can vary throughout the day and from day to day, from week to week and from month to month. Symptoms can also vary suddenly where a person's health can deteriorate quite rapidly leading to complete exhaustion.

ME/CFS is classified by the World Health Organisation as a neurological disease.

A diagnosis of ME/CFS does mean that your life will change but – with medical help, symptom management and self-management – you will hopefully become more stable and be able to work towards improved health.

With good medical and self-management many people do improve.

We have several leaflets which will help you; perhaps you may like to start with our combined leaflet on *Energy Management and Pacing* and then have a look at the leaflets which will give you more information about the symptoms you have.

You will find a list of leaflets on The ME Association website: www.meassociation.org.uk/shop/

MANAGING YOUR ME and GETTING MEDICAL HELP

Try to accept that you are not well, learn about the illness and try to get the most out of the help that is offered to you.

Part of managing your illness means forgetting the words 'should' and 'must'. Most of all learn to recognise why you need to rest.

It will be hard to accept that there are things you can no longer do; you will simply need to let these go for the time being.



There will, of course, be other new and less energetic things you can do and hopefully enjoy. New hobbies, perhaps, which will take less energy and can easily be put to one side when you feel tired.

Firstly, it is important to form a good relationship with your GP and to get the best medical help you can with your symptoms.

If your GP would like to know more about ME/CFS, The ME Association would be happy to send the surgery a copy of our book *ME/CFS/PVFS: An Exploration of the Key Clinical Issues*. This has been written specifically for the medical profession.

Most people with ME/CFS can be managed by their general practitioner and members of a primary care health team. But if you or your GP feel it would be a good idea to refer you to a medical specialist or a hospital-based ME/CFS clinic, The ME Association has a list of NHS Specialist Services on our website at www.meassociation.org.uk/nhsspecialistservices/

Our leaflet *How to deal with your doctor* may also help: www.meassociation.org.uk/shop/medical-management-leaflets/how-to-deal-with-your-doctor/

At the moment there is no drug treatment that can successfully treat or cure ME/CFS but there are a number of

drugs which can help to provide relief from some of the key symptoms – in particular pain, sleep disturbance, irritable bowel and (where this occurs) depression.

The MEA has leaflets on most of the ME symptoms, have a look at the order form on the home page of our website. There's a little picture to click on near the top right-hand corner.

It is important to look after yourself and strike the right balance between activity and rest. Here you need to take account of the stage of your illness, the severity of your illness and to what extent your symptoms fluctuate day by day.

Over the following pages we talk about pacing. Both research and listening to people with ME/CFS have shown how important and helpful pacing can be.

You may wonder if a change of diet or taking supplements may help. We do not specifically recommend these but a sensible, well balanced diet will help together with keeping the body well hydrated with water.

The ME Association has leaflets on diet, have a look at the order form on our website.

DR CHARLES SHEPHERD, medical adviser to The ME Association and HILARY BRIARS, manager, ME Connect helpline.

SOME HINTS TO HELP YOU COPE Communicating your thoughts and feelings to family and friends

- Focus more on your feelings when talking to family and friends rather than practical problems
- Try to be positive not negative
- Use a bit of humour to get your point across
- Adapt what you're saying according to the reactions of the listener
- Try not to let your conversation turn

into a monologue

Communicating with your doctor

- Choose only a few of your symptoms to describe when talking with the doctor
- Rehearse what you want to say, and get useful feedback from someone
- Use a reminder list
- Encourage someone to come with you to an appointment so that they can talk for you and remember what is said

A few thoughts about Partners/Carers

- You feel as if you might be a burden to those around you, but you are too tired and ill to do anything about it
- You feel vulnerable and dependent on those around you
- Partners should be partners, not only carers
- Remember that carers experience the trials and stress and isolation of the illness too

PACING AND ENERGY MANAGEMENT

PACING is the balance we all strike between activity and rest.

ACTIVITY can be physical, emotional or mental.

BASELINE You are aiming to gain stability in the way you feel. Find your baseline of activity by dropping your activity and increasing your resting until every day is the same and you have control. Keeping a pacing diary for a week (see next page) can be helpful but it is better to learn by listening to your body and being honest about what you can cope with.

ACTIVITY

- When doing any activity, remember the fatigue sometimes appears after a delay.
- Recognise the feeling of "doing too much" e.g. tired, stressed or anxious.
- Never fight your illness; stop the activity when your body tells you to.
- All activities need to be done in manageable chunks, with short rests at intervals.

REST

- Give yourself permission to rest and not feel guilty.
- Complete rest is when there is no outside stimulation.
- Reading or watching the television is more active rest.
- Have mini rests between chunks of every activity.

- It is possible to overdo resting, particularly when you are fearful of doing too much.

REVIEW YOUR PRIORITIES

- Do not feel guilty. Remember you are ill; put yourself and your health first.
- Is the activity needed? Can you put it off? Learn to say no and learn to ask for help.
- Include things purely for your enjoyment.

PROBLEMS

- If new symptoms are allowed to continue, they may stop you pacing successfully. Any new symptom needs to be reported to your doctor.
- Always have a reserve of energy so that any unexpected demands can be met.

SET BACKS Pacing is a skill and you might misjudge things. Drop your activity levels, and don't increase activity until you feel stable again. Learn from the experience.

ENJOY YOUR LIFE!

You must accept that you are ill, but nevertheless everyone needs some enjoyment. Your plan for the day should contain some activities only for you. They should be a priority.

**SUE MAYES, Retired
Physiotherapist and Lead
Volunteer with ME Connect**



- Two for the price of one – the MEA's leaflet on *Energy Management in MECFS* also contains an introduction to the technique of pacing. The leaflet can be purchased online here: <https://tinyurl.com/y6a79ycct>

PACING DIARY

This chart can be used to give you an idea of how much energy you are using throughout each day. You will have an idea of the tiring parts of the day, and a view of the week.

PACING DIARY

DATE	SLEEP	6-7	7-8	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	11pm	TOTAL	
MONDAY																				
TUESDAY																				
WEDNESDAY																				
THURSDAY																				
FRIDAY																				
SATURDAY																				
SUNDAY																				

ACTIVITY SCORES

0-1 SLEEP

2-3 REST

4-7 LOW LEVEL ACTIVITY

8-10 HIGH LEVEL ACTIVITY

Put your activity score into the boxes.

Add them up at the end of each day.

BENEFITS

Benefits, grants and permits that people with severe ME/CFS can apply for:

There are a number of state (DWP) sickness and disability benefits and government grants that people with ME/CFS may be able to apply for.

Employment and Support Allowance (ESA) is the DWP benefit for people who are unable to work.

Personal Independence Payment (PIP) has replaced Disability Living Allowance (DLA) for all new applications and people currently claiming DLA are being progressively assessed to see if they are eligible for this new benefit.

PIP provides financial help to people who are having problems with mobility and/or care (i.e. washing, dressing, preparing food) and each component can be paid at a higher or lower rate. PIP can be paid to people who are still able to work.

Carer's Allowance is a benefit to help with some of the costs that are incurred when someone requires a significant amount of care from another person.

Disabled Facilities Grant is a grant that can be used to help to pay for aids and adaptations in the home.

The MEA has information leaflets covering all these benefits and grants as well as leaflets that provide detailed

guidance on how to fill in the complex application forms. We can even update you on the development of **Universal Credit**.

Blue (parking) Badge is very useful if you are not confined to the house and able to get out in a car, even if this is just occasionally. Having a Blue Badge allows the car you are in to park in restricted areas. The scheme is for drivers and passengers – you do not have to drive the car to apply.

We have a leaflet on the Blue Badge Scheme which comes together with a supportive evidence letter.



Employment and Education - If you are still in work, or studying at school, college or university, you will need to stay in touch with your employer or your educational institution.

The ME Association has a booklet covering all aspects of employment and occupational health – *Employment issues and ME/CFS*.

We also have a leaflet that can be given to an educational institute which explains how students with ME/CFS may need to have modifications made to their timetables and exams.

There is also new leaflet covering all aspects of ME/CFS and university life.

In relation to employment and education, it is important to note that ME/CFS is an illness that is covered by the Disability Discrimination Act and the 2010 Equality Act.

MANAGING YOUR EMOTIONS

It is very common that people with ME/CFS can feel down, emotional or anxious.

This is very understandable as you can be faced with not only feeling very unwell, but also changes in lifestyle, relationships, activities, work and domestic responsibilities.

This is especially common in the early stages of the illness or diagnosis as people can feel that there is a lot of uncertainty regarding their health and future. Feeling emotional about such big changes in life is normal at this difficult time.

If you feel it would help to talk about these feelings with someone who understands, our telephone helpline, ME Connect, is always happy to talk with you if you are feeling emotional or, simply, if you are just having a bad day.

For some people, these feelings of anxiety and low mood are more persistent and they can experience depression. This is when people start to notice that their emotions are having an impact upon their daily lives.

People might notice that they feel down, hopeless or anxious on most days for a lot of the day. They decide whether to do things based upon how they feel emotionally rather than physically.

Depression can affect people's appetites, sleep, motivation, enjoyment in activities, energy levels and self-esteem. It can also cause people to withdraw from social activities and things they would normally enjoy.

If you have noticed these symptoms, then please see your GP as they will be able to discuss treatments that may help including antidepressants, counselling or a combination of both.

Some people also notice that they feel more anxious, with symptoms such as palpitations, nausea and butterflies in the stomach, headaches, muscle tension, needing to go to the toilet,



and a dry mouth. They may experience changes in the way that they think about things, expecting the worst thing to happen, predicting the future, only seeing the negative and worrying about little things.

As with depression, if you have noticed these symptoms please see your GP who can help.

Here are some things you can try which might help you to manage your emotions:

- Relaxation or mindfulness. There are many online videos and phone apps for these.
- Find something you enjoy which is within your energy limits.
- Talk to a friend, family member or helpline about how you're feeling.
- Write down good things that happen and things you're grateful for.
- Be kind to yourself and understand it takes time to adjust. There is no right or wrong way to feel when you have a chronic illness and everyone experiences it differently.

These leaflets from The ME Association may help you:

Anxiety and Panic Attacks: Your Questions Answered (No Panic Helpline number: 0844 967 4848) Counselling – Your Questions Answered

Depression and Anti-Depressants and other forms of treatment

Stress - and how to handle it

Melanie Knowles, Therapist and ME Connect Volunteer



EXPLAINING ME TO OTHER PEOPLE

It is hard to explain an invisible illness like ME/CFS to other people especially when you may look quite well. Perhaps it may be easiest to tell family and friends the name of the illness and the two or three main symptoms you have.

Here it would help if you explained what you are able to do and what you are not able to do. Explain as well that, sometimes, using even a minimal amount of energy can make you feel quite ill.

Simple explanations are best.

If your family and friends would like to read a little about ME/CFS we would suggest our leaflet *ME/CFS: your questions answered*. As well as explaining ME/CFS, the leaflet also discusses what makes the illness so different from other possible causes of chronic fatigue.

Alternatively, if you think that watching a short video would be easier or more help then please have a look at the video *If Only* on the home page of our website www.meassociation.org.uk. The video only lasts for three minutes 22 seconds.

Our booklet *Explaining ME to other people* will give you some ideas to help you explain your illness to others. This booklet also has a list of symptoms; you can tick the ones that apply to you to show other people, including your GP or other health professional.

Some people find Christine Miserandino's *Spoon Theory* can help friends and family to understand that people with ME/CFS only have a limited amount of energy.

Here spoons represent energy.

For example, we may have five spoons of energy but 10 tasks we want to do or others want us to do. Thus, we have to explain our limitations.

For more information on the spoon theory have a look at Christine's website: <https://tinyurl.com/hsp4vr7>



Christine Miserandino – author of the 'Spoon Theory'

Some people may say to you that they don't believe in ME/CFS or that it is a psychological illness. Explain that it is a neurological illness and is listed as such by the World Health Organisation.

Alternatively, it may be easier just to say that you have a debilitating neurological illness and then explain what you can and can't do together with what help and support you need.

GETTING THE HELP YOU NEED

Accept all the help which is offered to you and ask for any other help you need. Here are some examples of organisations that may be able to help you. If you have other questions about the help you need, please ring our helpline, ME Connect, and we'll try to find some information for you.

Social Services

If you find it difficult to manage at home, it may be possible for Social Services to provide some help for you. You will find their details online or their telephone number in your local phone book. You will need an assessment before help can be provided. We have more information in our leaflet *Getting help from Social Services*.

Local Groups

Perhaps you may like to talk to others who have ME and live near you.

The ME Association has a list of independent local groups on their website. You can find it by clicking on 'Support' in the top navigation bar and then 'Local Support Groups'.

Having the support of others can help with your own self-management.

Local Volunteer Bureau

Where a person is able to leave home but has no transport, they can contact their local volunteer bureau who may be able to put them in touch with a local charity that can help.

You will find the phone number for your local volunteer bureau either online or in local telephone directories.

Volunteers may also be able to help with:

- Shopping
- Befriending
- Gardening and DIY

Local Pharmacist

Local pharmacists may be able to deliver any medication people need, just ask.

Pharmacists can also be a good 'first port of call' to ask about the side effects of medication or where a person runs out of prescribed medication.

Citizens Advice

Your local CAB may be able to help you with benefits, work, debt, housing, some aspects of law, consumer rights etc.

You will find their telephone number in your local telephone directory or visit www.citizensadvice.org.uk

Remember – Look after yourself, explain briefly to people that you are not well enough to do some of the things you used to do and accept all the help you can.

Hilary Briars
Manager, ME Connect



Our quarterly membership magazine.

For details about how to see it regularly, please phone 01280 818 968 during office hours or email:

admin@meassociation.org.uk

ME CONNECT We're here to help



Do you need to talk?

ME Connect is the telephone and email helpline service of the ME Association. It provides information and support for people with ME and those who live with or care for them.

ME Connect provides a safe and understanding environment for people with ME so that they know they are being heard and understood.

ME Connect is a member of the Helplines Partnership which promotes high standards.

CALL 0344 576 5326

10am-12noon
2pm-4pm, 7pm-9pm
every day of the year

Email: meconnect@meassociation.org.uk



Calls cost the same as other standard landline numbers (starting 01 or 02).
If you have a call package for your landline or mobile phone then calls will normally come out of your inclusive minutes.