



MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

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MEA membership costs £18 a year for people living in the UK/BFPO.
For contact details, see foot of this page.



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Severe ME/CFS – helping you cope with it

INTRODUCTION

We know how very difficult life can be when you have severe ME/CFS. We understand that even the smallest activity like brushing your hair or having a bath can seem impossible at times. We appreciate that there are times when you will have trouble talking, remembering or making decisions and how emotional all this can feel for you.

We understand that you are severely limited in what you can say and do and are dependent largely or solely on others to help and care for you. We understand that many people with severe ME/CFS are unable to go out and that some of you are bedridden. It can be so hard when people cannot gain the understanding they need from their family, friends and, sometimes, from their GP.

In this booklet we talk about severe ME/CFS; the symptoms, some thoughts about management, how you can explain your illness to your family and carers – together with what help you may be able to get.

At The ME Association we receive many emails and telephone calls to our ME Connect helpline from people with severe ME/CFS. We have listened to you when you say:

- 'I just want to be normal,'
- 'ME has left me housebound,'
- 'I have no quality of life,'
- 'I've lost my social life,'



'I've lost my job',
'I'm not well enough to work',
and, so importantly, when you ask
'What help can I get?'

Please let us reassure you we are doing everything we can to try to help people and drive forward our research programmes. We know what a difficult and dreadful illness ME/CFS is.

For now, we'll try to answer some of your questions.

If you would like any more details about the leaflets or websites we mention in this leaflet, then please ring ME Connect and we shall try to help you all we can.

There will be times when you don't feel like talking. We'll understand if you are only on the phone for a few moments or if you need to end the call part way through.

We're also happy to respond to a short email or a line or two on Facebook.

WHAT IS SEVERE ME/CFS?

It is estimated that around 250,000 people in the UK suffer from ME/CFS and that about 25% of them have a severe form of the illness at some point in their lives.

This means they can spend long

periods housebound, wheelchair or bedbound.

Moderate to severe ME/CFS is best described by looking at the *ME/CFS Disability Rating Scale* – details of which we print on page 2.

WHAT ARE THE SYMPTOMS OF SEVERE ME/CFS?

Not everyone with severe ME/CFS has the same collection of symptoms. Nor do they have the same severity of individual symptoms. For some people with severe ME/CFS, pain is the most disabling symptom. For others, cognitive dysfunction is the most disabling symptom. And the pattern and nature of individual symptoms, which can vary from mild and moderate right through to severe, can often change over the course of time.

Below we have grouped together the main symptoms that are consistent with severe ME/CFS.

- Pain – which can affect muscles, joints and nerves – where it is called neuropathic pain.
- Activity-induced muscle fatigue – where even very minimal amounts of activity can produce what is called post-exertional malaise or post-exertional symptom exacerbation.
- Cognitive dysfunction – involving problems with short-term memory, concentration, attention span. This leads to difficulties with all kinds of normal mental functioning – computers, reading, writing and conversations.
- Inability to stand (orthostatic intolerance) for any length of time and may include light-headedness/dizziness and feeling faint or fainting.
- Muscle twitching (fasciculations) and spasms.
- Headaches – which may have a migrainous quality.
- Nausea.
- Fragmented sleep, restless legs syndrome, and sometimes a more severe disturbance of normal sleep rhythm pattern – all leading to non-restorative sleep.
- Sensitivity to noise (hyperacusis), bright lights (photophobia), perfumes, odours, chemicals, alcohol and some types of medication.

- Problems with temperature control including increased sensitivity to temperature extremes (cold hands and feet), sweating, feeling feverish
- Sensory problems including loss of sensation, abnormal sensations (paraesthesiae) and increased sensitivity to touch.
- Visual, swallowing and speech difficulties.
- Dietary limitations and food intolerance.
- Possible vitamin deficiency, especially vitamin D.
- Gastrointestinal problems including irritable bowel symptoms.

As noted in the Chief Medical Officer's report into ME/CFS (section 4:2:1:2), some severely affected people with ME/CFS, usually a small minority, may experience serious neurological symptoms including double vision, blackouts, atypical convulsions/atypical seizures, loss of speech, and loss of swallowing. Extreme sensitivity to noise and light, muscle wasting and weight loss may also occur. Swallowing difficulties may necessitate nasogastric or percutaneous endoscopic gastrostomy (PEG) feeding.

With so many symptoms, it's not always easy knowing when a new symptom, or a change in the severity or characteristic of an existing symptom, is due to ME/CFS. When this occurs, it is important to speak to your doctor to make sure that it's not due to another medical problem that hasn't been recognised, especially something like low thyroid function (hypothyroidism) or type-2 diabetes – which have a number of symptoms that overlap with ME/CFS. Equally, it's important to note that a progressive deterioration of symptoms is not a normal finding in ME/CFS. So when this occurs, there should always be a thorough medical re-assessment.

ME/CFS DISABILITY RATING SCALE

VERY SEVERE

100% DISABLED:

Severe symptoms – often on a continual basis. Cognitive function (i.e. short-term memory, concentration, attention span) is likely to be very poor. Bedridden and incapable of living independently.

Requires a great deal of supervision and practical support – including aids such as a hoist or stair lift – with all aspects of personal care (i.e. feeding, dressing, washing) on a 24-hour basis.

90% DISABLED:

Severe symptoms, often including marked cognitive dysfunction, for much or all of the time. Bedridden and housebound for much or all of the time.

Has considerable difficulties with all aspects of personal care. Unable to plan or prepare meals. Requires practical support and supervision on a 24-hour basis.

SEVERE

80% DISABLED:

Moderate to severe symptoms for most or all of the time. Only able to carry out a very limited range of physical activities relating to personal care without help. Requires help with meal planning and preparation.

Frequently unable to leave the house and may be confined to a wheelchair when up, or spends much of the day in bed. Unable to concentrate for more than short periods of time. Usually requires daytime and night-time supervision.

70% DISABLED:

Moderate to severe symptoms for most or all of the time. Confined to the house for much or all of the time. Normally requires help with various aspects of personal care and meal planning and preparation, possibly on a 24-hour basis. Very limited mobility.

SYMPTOM MANAGEMENT: WHAT CAN BE DONE TO HELP?

Severe ME/CFS often involves a considerable number of symptoms – some of which can be alleviated by appropriate forms of management. These may involve a combination of simple self-help strategies and the use of both over-the-counter medicines and prescription-only drugs.

The MEA has information leaflets covering all the main symptoms found in ME/CFS – cold hands and feet, headaches, irritable bowel symptoms, orthostatic intolerance, pain, sleep disturbance, etc. These leaflets describe all the various self-help approaches to management,

drug options, non-drug options (e.g. a TENS machine for pain relief) and alternative approaches that may be worth trying (e.g. acupuncture for pain relief).

It is also worth having a look at the MEA Management Report: *Managing my M.E.* (available to download on the MEA website, or a paper copy from the MEA) which contains patient evidence from over 4,000 people with ME/CFS regarding which treatments help specific symptoms and which do not.

One very important addition to any management plan for people with severe ME/CFS is to check for vitamin D

deficiency. This is because people who are housebound, or largely housebound, and do not get outside, are at high risk of developing vitamin D deficiency.

There is also some evidence to show that vitamin D deficiency is more common in people with ME/CFS. There is a simple blood test that can check the level of vitamin D in the body. If the vitamin D level is low, it should be treated under medical supervision. For those at increased risk, the regular use of a vitamin D supplement should be discussed with your doctor or pharmacist.

PACING AND ENERGY MANAGEMENT: HOW DO I DEAL WITH VERY LIMITED PHYSICAL AND MENTAL ENERGY?

We talk about seeing your GP to help with your symptoms a little later. For now, let us look at pacing and energy management. These strategies will help you.

- You need to balance activity – which includes physical, mental and emotional activity – with appropriate periods of rest or relaxation.
- Find your baseline of activity and don't be surprised at how low it can be.
- Accept your limitations.
- Don't add 'just a bit more', you'll probably pay for it later.
- Listen to what your body is saying and obey its limits.
- Learn to say 'NO', don't worry about what you 'should' be doing.
- You will learn to recognise in advance when you require some rest, and not carry on for too long.
- When encouraged to keep going by well-meaning people, learn to trust your instincts and not give in.

- You can be exhausted by physical, mental and emotional things so take everything into consideration.

The ME Association has a leaflet on *Energy Management* which comes with a leaflet on Pacing.

WHAT EFFECT CAN SEVERE ME/CFS HAVE ON YOUR EMOTIONAL AND MENTAL HEALTH?

It is understandable that anyone with a long-term severe illness can feel emotional or anxious at times. Try to be positive, focus on your feelings and try not to dwell on practical problems more than necessary.

Talk a little with people and use a little humour where you can. Listening to others can be easier than talking sometimes.

As with any long term disabling illness, some people with ME/CFS will

become depressed, especially when there are additional problems relating to medical, family and social support, education or employment, finances and DWP benefits.

It's also important to distinguish clinical depression from just feeling fed up at times, which is a very understandable reaction to having ME/CFS.

Symptoms suggestive of clinical depression include loss of self-esteem, worthlessness, loss of interest in normal activities (anhedonia), loss of interest in personal appearance, tearfulness, suicidal thoughts and/or intentions.

If depression occurs, or seems possible, you must seek professional help from your GP to start with.

For some people, talking therapies or counselling will be worth trying. In other cases, a course of antidepressant medication may be necessary.

We have the following three leaflets covering all aspects of emotional and mental health:

Anxiety and Panic Attacks – Your Questions Answered.

Depression and Antidepressants.

Managing your Emotions in ME.

MAKE A REAL EFFORT TO GET YOUR GP ON YOUR SIDE

It can be difficult for a GP to completely understand how people suffering with severe ME/CFS feel. It may also be that you are unable to go out to visit a GP.

Do ask your GP if he or she would be willing to do occasional home visits. If this proves difficult, your GP may be willing to arrange telephone appointments.

Some GPs are now offering Skype appointments to housebound patients, and some are even beginning to communicate with patients by email.

Alternatively, it may be worth asking your local ME group (groups are listed on the ME Association website) if anyone knows of a GP who understands ME/CFS and will visit.

You could also ask if there is a specialist or occupational therapist who would be willing to visit.

Your GP can request our book *ME/CFS/PVFS: An exploration of the Key Clinical Issues* which has been written mainly for

the medical profession.

It may be helpful to your GP if you list your symptoms and describe how severe they are. On the centre pages of this leaflet, we have listed the main symptoms together with tick boxes for you to complete and pull out to give to your GP or other health professionals involved with your management. Rehearse what you want to say or take a reminder list with you. Taking someone with you to either talk for you and/or remember what is said can be helpful.

Ideally, people with severe ME/CFS should also be receiving on-going care and management from a specialised hospital-based multidisciplinary team involving doctors, occupational therapists, physiotherapists, dietitians, etc, as would happen with any other neurological illness.

Sadly, this is very unusual and many people with severe ME/CFS find

themselves with no meaningful medical support.

When it comes to hospital-based referral services for people with severe ME/CFS, there is a serious and unacceptable lack of facilities in relation to both out-patient facilities and in-patient beds, along with an almost complete lack of domiciliary (home visiting) services.

We do understand that some doctors don't have a great deal of knowledge about ME or don't fully believe in the illness. But this is no excuse for the very poor way in which many people with severe ME/CFS are currently being managed within the NHS.

The MEA takes the position that:

"People with ME/CFS deserve a medically-led service, with the authority to make a definitive diagnosis of ME.

"The service should be staffed by doctors and members of a multi-disciplinary team who can tolerate the severity of some cases and their own feelings of impotence when confronted with them, and not feel duty bound to try and 'cure' their patients.

"Currently, there is no curative treatment available. Patients accept this and it is often the doctors who find it difficult, and thereby fall into the trap of the 'Therapeutic Fallacy' whereby they are unable to accept the failure of their treatment regimes. This can lead to them rejecting their patients, or even worse, blaming the patient or their family for the failure of their treatment."

The MEA continues to work towards educating all health professionals by providing written material and funding research into the illness.

HOW THE MAIN SYMPTOMS OF M.E. AFFECT ME

Tick the boxes that apply and show these pages to the people who are planning or providing your care or medical management

MY OVERALL STATE OF HEALTH AND DISABILITY

My percentage Rating Scale (see page 2) is around ____ %

or it fluctuates between ____% and ____%

Overall my level of ill health and disability is:

- IMPROVING
- FLUCTUATING
- STABLE
- DETERIORATING

MY SYMPTOMS

NO PROBLEM **MILD** MODERATE **SEVERE**

MOBILITY

Activity-induced muscle fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Post-exertional symptom exacerbation/malaise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems with balance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthostatic intolerance (problems with standing) and/or	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Postural orthostatic tachycardia syndrome (exaggerated rise in pulse rate on standing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle twitching and/or spasm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NEUROLOGICAL

Pain affecting nerves, muscles or joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive dysfunction (problems with memory, concentration, attention span)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Headaches (which may have a migrainous quality)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NO PROBLEM **MILD** MODERATE **SEVERE**

Disturbed thermoregulation
*(problems with control of
body temperature)*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Photophobia
(sensitivity to bright lights)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Hyperacusis
(sensitivity to loud noise)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Drug and chemical sensitivity
*(including drugs, odours
and perfumes)*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Sensory disturbances
*(including numbness
and 'pins and needles')*

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Eyesight problems
(eg blurring of vision)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Speech problems

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Seizures

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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GASTROINTESTINAL

Poor appetite and/or weight loss

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Problems with swallowing

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Nausea and/or vomiting

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Irritable bowel symptoms

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Food sensitivity or intolerances

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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OTHER

Sleep disturbance

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Vitamin D deficiency

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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**ANYTHING ELSE THAT
I NEED TO MENTION**

I HAVE CARERS TO HELP, BUT THEY DO NOT UNDERSTAND HOW ILL I AM. What can be done to help them understand the needs of people with severe ME/CFS?

ME/CFS is a poorly understood and varies in intensity among sufferers.

So it is important for your carers to understand how ill you are and the symptoms you have. You may like to complete a form to describe your symptoms and give this to your carer. We have put one in the middle of this leaflet to help you.

If your carer would like to know more about severe ME/CFS, then please ask them to contact our helpline ME Connect either by email or by telephone. The ME Association also has a leaflet for carers.

Social care is given to help people manage in their own homes. This could include help with:

- Cleaning
- Shopping

- Preparing meals
- Personal care

...contact your local Social Services to see what help may be available for you.

Many of you will have family members who are caring for you. It's hard for you here and we know you may feel like a burden to those around you, but be too tired and ill to do anything about it.

Try to get all the help available for both you and your carer so that you and your family can spend relaxing times together. Ask Social Services what they are able to offer and suggest that your family talk with a carer's charity – e.g. Carers UK – www.carersuk.org or contact Carers Direct (NHS Choices) – www.nhs.uk/carersdirect

WHAT AIDS, EQUIPMENT AND ADAPTATIONS MAY BE POSSIBLE TO HELP ME?

Many people with ME/CFS, especially those of you who are bedridden or have difficulty walking, need some aids to help them.

Social Services may be able to make small adaptations to your home, for example: hoists, bath seats, grab rails or ramps. Money or help may also be available for wheelchairs and other mobility aids. An occupational therapist can do an assessment to see what aids would be best for you, you can request this assessment from Social Services. We have a *To Whom It May Concern* letter on 'Disability Aids, Adaptations and Services' which you may like to give to Social Services or an occupational therapist. (*The letter is available from The ME Association – see Order Form on our website.*)

If you own your home and need larger adaptations like a downstairs bathroom, widening doors, or a stair lift, you can apply for a Disabled Facilities Grant from your local council.

If you do not own your home, then it is possible that the landlord can make some reasonable adjustments for you. They may be able to apply for finance to do this. The grant can be in the region of up to £30,000.

(For more information please read our leaflet *Disabled Facilities Grant*, which is available from the ME Association).

For disability aids have a look at the Lloyds Pharmacy shop – 'Betterlife' – www.betterlifehealthcare.com

Some disability aids are also listed on Amazon at www.amazon.co.uk Type 'Disability Aids' into the search box.

HOW DO I GET HELP FROM SOCIAL SERVICES?

Help to cope with everyday living may be available from your local authority Social Services department; you will find their telephone number in the phone book.

Social Services will tell you the kind of care and support which may be available for you and assess your needs. You can read more about the assessment process in our leaflet *Getting Help from Social Services*.

Payments for care and support may either be made directly by the department or the money given to you to arrange your own care.

Depending on your financial circumstances, you may have to contribute to the cost of your care.

In addition to our leaflet, you can read more at:

<https://www.gov.uk/careandsupport>

MY FAMILY AND FRIENDS DON'T UNDERSTAND JUST HOW ILL I AM. HOW CAN I EXPLAIN?

You, your family and your friends might like to read our leaflet *Explaining ME to other people*.

It may be that they don't understand ME/CFS but it is important that they understand how you feel, the symptoms

you have and what you are able to do and what you are not able to do.

Communicating your thoughts and feelings can be difficult at times. It can help to adapt what you are saying to the reactions of the listener.

ARE THERE ANY BENEFITS, GRANTS AND PERMITS THAT PEOPLE WITH SEVERE ME/CFS CAN APPLY FOR?

There are a number of state sickness and disability benefits and grants for which people with severe ME/CFS can apply.

EMPLOYMENT AND SUPPORT

ALLOWANCE (ESA) is for people who are unable to work.

PERSONAL INDEPENDENCE PAYMENT

(PIP) has replaced Disability Living Allowance (DLA) for all new applications. 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 have problems with mobility and/or care (i.e. washing, dressing, preparing food). 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 paid out to help with some of the costs 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 – see previous section on social care.

The MEA has information leaflets on all these benefits and grants as well as leaflets that give detailed guidance on how to fill in the application forms.

THE 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.

You can automatically qualify for a Blue Badge if one of the following applies:

- You receive the higher rate mobility component of DLA.
- You live in England and have been awarded 8 points or more in the 'moving around' activity of the PIP.
- You live in Scotland or Wales and have been awarded 8 points or more in the 'moving around' activity or 12 points in the 'planning and following journeys activity' of PIP.

The MEA has a leaflet covering Blue Badge applications and a *To Whom It May Concern* letter that can be used to support an application.

HAS ANY RESEARCH BEEN CARRIED OUT INTO PEOPLE WITH SEVERE ME/CFS?



Not surprisingly, there has been very little research into the cause or management of ME/CFS that has involved people with severe ME/CFS – mainly due to the way in which most hospitals and research units are not able to provide the necessary facilities and care for people at the severe end of the spectrum.

Our own Ramsay Research Fund has funded a study that looked at factors that may be involved in the development of severe ME/CFS.

And the ME Biobank at the Royal Free Hospital in London – which we fund – is collecting blood samples from people

with severe ME/CFS in their homes. This means that researchers who require blood samples and clinical details from people with severe ME/CFS will now be able to do so.

One recent study, from a research group at Newcastle University, has reported that people with ME/CFS who are housebound are significantly more impaired in relation to physical functioning, bodily pain, vitality, social functioning, fatigue, post-exertional malaise, sleep, pain, neurocognitive, autonomic, neuroendocrine (hormonal) and immune system function compared to people with ME/CFS who were not housebound. This is a paper that may be worth showing to a health professional if he/she is querying how disabling severe ME/CFS can be.

Reference: Prendergast T et al (2016). Housebound versus non housebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic Illness*, doi: 10.1177/1742395316644770.

Make a little time – just for yourself!

If you have just a small amount energy each day, it is lovely to do something you really enjoy.

We understand that for some people reading, using computers or watching television is not possible but for others they can manage just a short time.

It is quite important that you have a hobby, which can be put down on a table or a computer programme you can log out of as soon as you start to feel tired. Some people with severe ME/CFS try to find new interests which only need minimal energy.

If you are able to keep up a little with your friends either with very short visits, brief telephone calls or on the Internet, this can help those feelings of isolation.

We have asked people with severe ME what they enjoy doing, here are some of their responses:

- A simple Sudoku
- Talking Books
- Researching ancestors online (easily saved information and logging out)
- A few stitches of sewing or knitting
- Catching up with friends just for short sessions on Facebook, Twitter or Skype
- Simple card making
- Colouring in – there are now many adult colouring books on the market
- Keeping in touch with friends by writing a few words on a pretty notelet
- Having a bird box or feeder just outside your window to watch the birds
- Some gentle music

If you are able to use a computer for just a little while then there may be adaptations you can make to help. Have a look at this website for some ideas:

<https://mcmw.abilitynet.org.uk/>



You may like to ring or email our helpline if you have any other questions. Alternatively, you may find that one of our leaflets will help you.

The ME Association produces over 90 leaflets and booklets.

You will find an Order Form on the website or you can order from the MEA Shop – again on the website.

Alternatively, we can post you an Order Form, or you can call the MEA office, if you are unable to use a computer.

MEA Free Literature section
<https://meassociation.org.uk/fdwc>

It can help to talk

If you can't use a computer or read much, ring our helpline on 0808 801 0484. We'll tell you more about the leaflets and, where possible, look stuff up for you on a website. You may just want to talk about how you are feeling.

ME Connect is here to listen, understand and help you through the day. If you need to keep the call short, we will understand. You may prefer to email meconnect@meassociation.org.uk or post on our Facebook. Here you may be able to do just a few words at a time.

and enjoy...

Try to achieve a little something each day – an extra movement, an extra step, an extra task. Do something small which you will enjoy.

WHERE CAN I OBTAIN FURTHER INFORMATION AND SUPPORT?

Local ME Groups

Help with local information. There's a list of local groups on our website at:

<https://tinyurl.com/yy2wk3j>

Click on the county you are interested in. If you cannot go online, phone ME Connect and one of our volunteers will look it up. Some groups may be able to talk on the phone and some may visit.

Local Volunteer Bureau

If you can get out but have no transport, ask your bureau for help. The number will be online or in the phone book. They can also help with shopping, befriending, gardening and DIY.

Local Pharmacist

Ask if the pharmacist can deliver your medications. They can also be a good 'first port of call' if you want to check on the side effects of your medication or run out of prescribed medication.

Dental Care

Most dentists will treat people with special needs. But some people with severe ME/CFS will not be able to get to the surgery. If this is so, the dentist

should refer the patient to a more specialised dental service. Ask what is needed for a referral and if it is right for you. More information on the NHS website at:

<https://tinyurl.com/p8gwwml>

Eye Care

Some opticians make home visits – e.g. The Outside Clinic:

www.outsideclinic.co.uk

Specsavers:

www.specsavers.co.uk/home-eye-tests

Benefits Information

Carers UK:

<http://www.carersuk.org>

Tel: 0808 808 7777

Citizens Advice:

www.adviceguide.org.uk

(click on benefits)

Disability Rights UK:

www.disabilityrightsuk.org

Tel: 0207 250 8181

Turn2us – General benefits information and information on grants :

www.turn2us.org.uk

Helpline: 0808 802 2000

DIAL gives disability information and advice. Visit: <https://www.dialuk.info>

MEA leaflets

Sleep disturbance and restless legs syndrome

Energy Management (includes a leaflet on Pacing)

Explaining ME to other people

Benefits leaflets covering ESA, PIP, Universal Credit, Carer's Allowance, etc

ME and my Carer

Counselling – your questions answered

Books

ME/CFS/PVFS: An Exploration of the Key Clinical Issues (written mainly for doctors).

Living with ME (by Dr Charles Shepherd)

Fighting Fatigue (Edited by Sue

Pemberton and Catherine Perry)

Severe ME/CFS: A Guide to Living (by

Emily Collingridge - buy from www.severeme.info)

ME Connect helpline

Tel: 0808 801 0484

Email: admin@meassociation.org.uk

Facing down her M.E.

HANNAH RADENKOVA wrote this piece for the *Daily Telegraph* after yet some more promising biomedical research hit the headlines.



On hearing the news that Chronic Fatigue Syndrome (CFS) is finally being recognised by doctors as a 'real' illness, my first desire was to run around shouting 'I told you so!' at the top of my voice.

Having suffered with CFS (also known as Myalgic Encephalomyelitis (or ME) for four years, I was obviously too sick to do that, but I did allow myself a tiny, non-tiring fist pump at the fact there is now some acknowledgement that this sickness is more than just 'yuppie flu.'

Researchers found that those with the syndrome, which causes extreme tiredness that isn't allayed by rest, had a specific chemical signature in their blood – similar to that of hibernating animals.

That comparison made me laugh, because my CFS certainly makes me feel like a bear with a sore head. What's

less amusing is that, for the most part, simply surviving and existing forms the majority of my life.

The new research also gave me a huge feeling of relief. Finally, I thought to myself, we might be believed and people might start to understand us more. It's so, so tiring constantly having to try and explain or prove to people that what we have is a real, physical disease, yet being told that it's all in your head.

Because, despite evidence to suggest otherwise, you're always fearful that people aren't going to believe you're ill. If you've ever been on the receiving end of the stigma CFS comes with, you never, ever forget it.

I had been working as a freelance illustrator as well as part-time in retail to support study for my Master's degree when I got sick, and my working hours averaged around 75 hours a week. It rankles when people suggest CFS isn't a real illness, and that those who suffer from it are just malingerers or attention seekers, because I know very well that's not true. I worked so hard for my life, I loved it, and it got taken away from me. My life now? It's not what those doubters would think.

I'm 29 and I live with my retired parents, who are my carers. For the last two years, I've been completely housebound. I can't work, watch TV, or listen to the radio, and I'm only able to see one of my friends once a month, for around half an hour.

I get pains, and brain fog, and so many other symptoms, along with

the constant, relentless exhaustion. Two thirds of my day is spent resting in silence, focusing on my breathing, and relaxing my muscles as much as possible, so that I can function for the other third.

Hibernation is a pretty apt term.

Every little pleasure and activity I've managed to fit into my routine I have



The doll that stands in for Hannah at family events

fought tooth and nail for by using this resting regime, eating well (thanks to my parents, who prepare all my food), and waiting, little by little, for my energy levels to improve.

I tried therapy, and putting 'mind over matter', but not treating my CFS as a physical illness is what ultimately led me to become housebound, and it's only through treating it as such that I've seen any improvement at all.

Every tiny activity has consequences now – even writing this – but over time I've come to terms with that, and found ways to be involved in the world without being physically present.

I write a blog to keep my friends updated and give advice to fellow sufferers and their families, and I even made a tiny version of myself in doll form to go to events like weddings and birthdays in my stead.

It's a difficult life, but I'm still fighting, and it's always fantastic when any evidence is uncovered to support the physical effects of CFS.

For now, being able to say 'I told you so' is one of the few small pleasures I have.





MANAGEMENT FILE

by DR CHARLES SHEPHERD, our medical adviser

This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine .
MEA membership costs £18 a year for people living in the UK/BFPO.
For contact details, see foot of this page.



January 2020

NUTRITIONAL ASSESSMENT IN ME/CFS

ARE SOME PEOPLE WITH M.E. AT RISK OF BECOMING MALNOURISHED?

There is a great deal of positive discussion on ME/CFS internet forums about the benefits of unproven special diets, restrictive and exclusion diets, and dietary supplements.

At the same time, very little attention is being paid to the dangers of cutting out or reducing the intake of specific food groups such as dairy or wheat. And people with more severe ME may have significant problems in obtaining groceries, preparing meals, and even eating a full meal.

All of this could be having an adverse effect on their overall health. So do we need to start looking at diet and nutritional status in ME from both a clinical and research point of view?

SO WHAT'S THE ANSWER?

This is a very important question. The whole issue of nutritional assessment in people with ME/CFS, along with the risk of malnutrition in those with more severe ME/CFS, is something that I will be raising during the preparation of the new NICE guideline on ME/CFS.

As this is such an important and neglected topic, I have prepared a fairly detailed reply.

Firstly, it's worth noting that malnutrition is surprisingly common among people with chronic long-term medical conditions. And having any form of malnutrition has an



important adverse effect on health. This includes decreased immune system function, decreased muscle strength, delayed wound healing and an increased risk of falls.

It will also cause a further reduction in energy levels and exacerbate cognitive problems – both of which are very relevant in ME/CFS.

So a proper nutritional assessment – which includes both food and fluid intake – should form part of the medical assessment and on-going care of everyone, especially those with moderate or severe ME/CFS. And it must involve a dietitian, preferably one who has experience of seeing people with ME/CFS.

The assessment should take account of all the factors that increase the risk of malnutrition in vulnerable groups of people with long-term medical conditions.

Physical factors include the presence of nausea and/or loss of appetite, swallowing difficulties and bowel symptoms that may affect both digestion and absorption of food.

Psychological factors can include depression – if this occurs – and its effect on appetite. Social factors involve the ability to obtain food and prepare meals.

The assessment should record the person's normal daily intake of food and fluid in terms of total calories, carbohydrates, proteins, fats, sugars, vitamins and minerals and micronutrients.

For example, although fruit and vegetables are very healthy they contain very few calories. And while dairy has become a 'bad food' in the eyes of some it is an important source of calories, protein and calcium. Fluid intake should be in the region of five or more cups per day of water, juice, coffee, tea, etc.

Physical signs of possible malnutrition should also be noted. These include loss of hair, changes in facial features – including prominent cheek bones and sunken eyes, a red swollen tongue – which may add to swallowing problems, loss of skin elasticity when pinched, brittle nails and muscle wasting.

Finally, the assessment should include the use of what is called a validated screening tool such as the five-step **Malnutrition Universal Screening Tool (MUST)** and/or the **Mini Nutritional Assessment (MNA)**.

These tools are designed to record and monitor a person's BMI (body mass index – the ratio of height to weight which identifies people who are overweight, normal weight or underweight) along with any recent weight loss.

The scoring system identifies people who are at high, medium or low risk of

malnutrition. And it's worth noting that people who are overweight or obese can also become malnourished if they are not having a healthy diet.

A blood test to check for Vitamin D status is also important in anyone who is housebound and whose skin is not being exposed to sunlight, which is how most Vitamin D is produced in the body

If a person has evidence of malnutrition, or is identified as being at risk of developing malnutrition, a nutritional care programme should be organised and supervised by a dietitian. This will include specific dietary advice about calorie intake, all the different food groups, along with vitamins, minerals and micronutrients.

It could also involve the use of oral nutritional supplements – which can be prescribed on the NHS if necessary. These come in the form of powders and

flavoured drinks and can be used to increase the intake of specific food groups and calories, or to help with food intake where there are swallowing difficulties in people with severe ME/CFS.

◆ Please let us know if you have had a proper nutritional assessment which identified a nutritional problem and what sort of care plan was arranged as a result

NUTRITIONAL ASSESSMENT SCREENING TOOLS:

MUST/Malnutrition Universal Screening

<https://tinyurl.com/ycr3gyhn>

MNA/Mini Nutritional Assessment:

<https://tinyurl.com/voutlw7>

THE ME ASSOCIATION



ME CONNECT

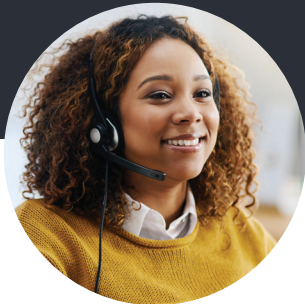
The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect



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We are here to listen, validate and empathise with any issues you might be facing.



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We provide a safe, confidential and understanding environment where you can be heard and understood.

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