

ME - WHAT GETS IN THE WAY OF GOOD MANAGEMENT

From **ME CONNECT**

Good management of M.E. can help people travel along the road to recovery and improve the quality of their lives. Of course it's one thing to know how to manage the condition, but quite another when it comes to putting that into practice. The help and support of family and friends is important.

It is helpful to look at the sorts of things that can get in the way of good management.

The three most common things are:

- Lack of acceptance of the condition.
- Poor skills in managing the illness.
- Other people's reactions to M.E.

LACK OF ACCEPTANCE OF THE CONDITION

Acceptance of the illness is a long process. Everyone goes through this process a little differently and at different speeds. It is therefore important to acknowledge that there is no 'right' way.



When people have not accepted that they are suffering from M.E, they tend to do two things:

- They fight against it, refuse to accept the limitations it imposes and try to do everything in the way they have always done.

This inevitably leads to problems, both physically and emotionally.

Physically they do too much and their symptoms get worse. They suffer the 'boom and bust' that is so common with M.E.

Emotionally there is anger, frustration, depression and despair, which are all very draining and upsetting.

- They search for the 'magic wand' or the 'miracle cure' that is going to take their illness away. This can lead to great disappointment, as well as empty pockets!

You, your family and friends can tell if you are not accepting your condition.

The signs are:

- Constant comparisons with how you used to be.
- Constant comparisons with others who don't have M.E.
- High demands on yourself.
- Unrealistic thinking about what you can do.

- Your thoughts and conversation contain 'should', 'must', 'have to' and 'ought'.

- You continue old behaviours even when these are not appropriate.

- Boom and bust of energy.

Your family and friends can help you in the process of acceptance.

No one can force you to accept your condition but having the support and encouragement of family and friends through the process can be very helpful.

They can:

- Hear your story and show understanding of it.
- Hear your comparisons with how you used to be, and how you are compared to others.
- Help you live within your limitations, and challenge your demands on yourself.
- Ask whether what you've been doing so far has been helpful to you.
- Help you look at your options. The choice is usually to stay as you are now or to tackle things differently.
- Use people you know, or have spoken to, as examples.
- Keep checking reality with you, when you make plans or talk about miracle cures.
- Encourage you and give you hope. Hope is really important in protecting people from depression. You need to hear the success stories of people who improve significantly. You can lead a far more normal life even if you don't quite return to being exactly the same as you were before.

■ Help you voice your fears for the future. Provide reassurance that it doesn't mean the end of things, but a different way of living for a while.

POOR SKILLS IN MANAGING YOUR ILLNESS

It is vitally important for people with M.E. to understand the basic rules of managing the illness, and then use these rules within their own lives.

Many people with M.E. used to be highly skilled at time management. Now instead of managing their time they need to manage their energy.

Energy can be compared to money in a bank account. People are used to making choices about how to spend their money because they only have a limited amount. It's the same with M.E. and energy. There's a limited amount and it's best to spend it wisely.

These basic ideas stand firm for anyone, and they involve the three P's:

Prioritising, Planning and Pacing.

PRIORITISING

People don't always think about what they want to spend their energy on. They tend to spend their energy on things that are not important, or on things that they think they ought to.

Think about the following:

- Could anyone else do this?
- What will happen if you don't do it?
- Will this matter six months from now if you don't do it?
- You need to put yourself first. Try to encourage yourself to be 'responsibly selfish'. Then you could start to feel better and more able to be unselfish.
- Never feel guilty that you are not doing enough. Remember you are ill, not lazy.
- If you can prioritise what is most important to you then you'll



deal with situations in the best way you can. This improves your confidence and self-esteem and you'll feel better.

PLANNING

Once you've prioritised what's important to you, a diary or planner can help.

Put some time on one side each week to look at the week that has passed, how it's been managed, and learn from this. Then look at the week ahead and plan things in.

This needs to become a habit that is maintained. It's easy to let these things go once you start to feel better, but then you may leave yourself open to relapse. It does help to write things down and regularly reflect on them.

PACING

If prioritising and planning have been achieved then pacing is fairly straightforward, though of course it's not easy. It is recognised that pacing is one of the main ingredients needed to recover from M.E.

The most important thing about pacing is that people need to stick to it more or less regardless of what's happening around them. Obviously there are some times when this is not possible but, unless there is a special reason, the rules of pacing need to be kept.

See the **ME Connect leaflet on Pacing** for people with M.E. which goes out with our Management File called **Energy Management in ME/CFS**.

Once pacing is under way and people start to improve it is easy

to forget about it, or try to move on too quickly. Spend that time every week looking at the week just gone, learning from it, and then looking at the week ahead. Remember, it is not possible to progress quickly with M.E.

Of course this life style can get frustrating and boring. Try to build into your weekly plan some activities that you really enjoy.

OTHER PEOPLE'S REACTIONS TO M.E.

A big problem for people with M.E. is that others don't know, and can't imagine, how you feel. There can be a lack of understanding and sometimes a lack of support.

The medical profession don't always fully understand the condition and it doesn't show up on any medical investigations. There remains, in some people's minds, this feeling of doubt that it's 'real.' But there has been an improvement over the past 15 years or so in this respect and now far more doctors accept M.E. as a real medical condition.

Long-term physical illnesses can have psychological effects at times. We all need to look at the whole person and not just one aspect of the illness and it is only with this sort of holistic approach that M.E. can be effectively managed.

■ As a person with M.E. you have to deal with your own feelings. The most frequently voiced emotion is guilt. People feel guilty that they are not at work or not doing enough in the house, for example.

It's important to compare these feelings with the reality. What are your capabilities and limitations and could you be doing anything differently?

■ If people are carrying around unhelpful emotions, like guilt, then often they interpret things other people say in an unhelpful way.

For example, someone telling you that you look well may be interpreted by you as meaning that they think you should be



back at work. But it may just have been that the person was trying to be pleasant and reassuring.

- People with M.E. are encouraged to explain to others how they feel in a very honest way. If you can do that and are not understood then you have done your best and can do no more. You cannot be held responsible for other people's thoughts and feelings.
- Problems can be seen as being weights to carry around. It can be useful to think about whose problem it is. Is it yours or the person commenting on the M.E.?
- You can help others understand by giving clear messages, saying the same thing in the same way until it is understood.
- People with M.E. often don't like to say no. You need to learn to do just that.

Once again it's about people learning to look after themselves.

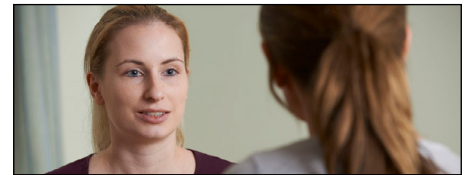
CONCLUSIONS

- To change any habit or routine is always hard – be it smoking, dieting or starting to manage M.E.
- However, going through this difficult process is not as hard as the option of remaining as you are.
- Good management of M.E. will, for most people, involve a change of behaviour, a change of lifestyle and a change of attitude.
- It is important to stress that this is not about giving in but rather about working with the resources of energy that are available.
- It is important to face situations and deal with them in the best way you can.

FURTHER READING

ME Connect has other leaflets that may help you:

- **Energy Management in ME/CFS** together with:
 - **Pacing for people with M.E.** (two leaflets for the price of one).
- Download available at <https://tinyurl.com/y4mdc4eb>
- **Managing your emotions in M.E.**
- Download available at <https://tinyurl.com/y2x3wyag>
- **Explaining M.E. to other people.**
- Download available at <https://tinyurl.com/y4fc583y>





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



Freephone
0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)

Saturday & Sunday
10am - 12 noon & 7pm - 9pm

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



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



VITAL SUPPORT
We are here to help you reach an informed decision.



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

We're here for you!



MEConnect@meassociation.org.uk



X.com/meassociation



facebook.com/meassociation



instagram.com/meassociation

meassociation.org.uk

MEA Membership:

From just £2 a month you can help support others affected by M.E. and will receive the excellent and exclusive ME Essential magazine delivered straight to your door.

Subscriptions are a vital part of our charity income and – together with donations – they allow us to help make the UK a better place for people with M.E.

Full Membership is available to all adults with ME/CFS, carers and anyone with an interest in the disease. Annual membership costs:

- £18.00 (UK residents and BFPO)
- £24.00 (Mainland Europe including Republic of Ireland)
- £30.00 (Rest of the World)

Each full member is entitled to vote at our Annual and Extraordinary General Meetings.

To become a member please visit <https://meassociation.org.uk/about-the-mea/membership>

