



Taming the gorilla

Experiences of people in Scotland
living and learning with M.E.



Revised April 2016

Foreword

Learning how to live well with M.E. takes time and energy. It is likely to be a bumpy and unique journey, as each of us experiences the condition differently.

This guide was devised based on workshops and conversations with 16 people, who between them have more than 100 years of combined experience of living with mild, moderate and severe M.E., and whose stories are woven throughout. All took part in Action for M.E.'s *Living and learning with M.E.* project in Scotland in 2016. The booklet's title is inspired by blogger Mary Hammonds' brilliant analogy comparing a disability to having a gorilla live in your house – see p 5 and 11.

This guide is written in a positive and practical light to support each of us to be as well as we can be, but it pulls no punches, and refers to some of the hurdles and low points you may experience.

I look upon those who participated in this project as “wise elders.” May the learning they have shared bring you some respite and hope that you – like them – can live a meaningful life with M.E. despite the challenges you face. May the guidance offered here contribute positively to the self-management of your illness.

Finally, I hope this guide will inspire you to share your story and your learning. If the making of this guide has taught me anything, it's that through sharing our experiences with one another that we feel less alone, more empowered, and better connected with one another. That may not be a cure, but it's surely a step toward a greater sense of well-being.

Michael Williams
Story Coach
Living and Learning with M.E.
www.michaelwilliamsstorycoaching.com

M.E. is different for everyone, so your experience may or may not be the same as those whose experience this booklet has been based on. Its content has been reviewed by Action for M.E.'s medical advisers Prof Julia Newton and Dr Gregor Purdie but does not constitute specific medical advice – please consult your own healthcare professional for support with symptom management or any other medical issue arising from M.E.

Contents

How to use this guide	4
What is M.E.?	5
Key things to remember	6
Section one: Thinking and talking about M.E.	
Coming to terms with your diagnosis	9
How we think about and talk about M.E.	10
Analogies for talking about M.E.	11
Relationships and support networks	12
Section two: practical self-management tips	
Pacing and balance	15
Diet and activity	17
Sleep and pain management	18
Non-pharmacological therapies	19
The medical profession	21
Employment	24
Welfare and social services	27
Section three: M.E. campaigns and taking action	29
Appendix I: Glossary of common M.E. terms	30
Appendix II: Examples of self-management tools	31
Appendix III: Useful resources and contacts	38
Acknowledgements and afterword	43

How to use this guide

This guide has been designed to help you to navigate your way through the maze of information available about M.E. It touches on the key areas of life affected by M.E. and provides signposts to further information from sources others have found helpful. Because it was produced by people living in Scotland, the organisations signposted to are mostly based there. But the experiences they have shared are likely to resonate with people affected by M.E., wherever they live.

For the newly diagnosed, it explains why how you think and talk about M.E. is important, and provides information on a wide range of tools and techniques that some people with M.E. find helpful to manage your condition. It also eases you into M.E. terminology with a glossary of terms and signposts to reliable sources of further information. For those who still struggle from time to time with managing this complex and variable condition – the ‘improvers’ – this guide may help you to find a different approach or a new self-management technique to try.

You may like to share the guide with friends, family and work colleagues, to help them to understand what a complex and challenging condition M.E. is to manage. Whilst the guide will be of most benefit to the newly diagnosed and to those with long term M.E. in the mild to moderate spectrum, carers and people who are severely affected by M.E. may also find some sections helpful.

The guide is split into three sections, which you can dip in and out of. We recommend that you start with section one which discusses how to come to terms with your diagnosis. It is important to understand and accept that a diagnosis of M.E. means life has to change, at least for a while, so that you can implement practical strategies to help you to build a stable platform and aid recovery.

Section two discusses management approaches that you can cherry pick from. While it's important to remember that what works for one person might not work for another, most people with M.E. tell us that pacing is essential for them.

Section three talks about how to be an ambassador for M.E. and different ways to support the fight to get M.E. universally recognised as a serious condition, worthy of respect, resources and investment.

What is M.E.?

Myalgic Encephalomyelitis (M.E.) is an illness with many names. Within the NHS it is commonly called Chronic Fatigue Syndrome (CFS or CFS/M.E.). Sometimes it is known as Myalgic Encephalopathy or diagnosed as Post Viral Fatigue Syndrome (PVFS).

People with M.E. experience severe, persistent fatigue associated with what's called post-exertional malaise (the body's inability to recover after expending even small amounts of energy; sometimes also called 'payback') and chronic pain. However, M.E. is also characterised by a range of additional symptoms including cognitive difficulties (also known as "brain fog"), digestive problems and hypersensitivity.

M.E. affects an estimated 250,000 people in the UK. There is much debate about its underlying cause, treatments and what does/doesn't work and at the time of writing there is still no drug therapy directed specifically at M.E. Current theories about the cause of M.E. include autoimmune deficiencies, viral infections, autonomic/ sympathetic/central nervous system dysfunction and genetic factors, amongst others.

Research (*Pheby and Saffron, 2009*) has found that early management of symptoms such as post-exertional malaise is the most important factor in how the condition progresses (ie. how severe M.E. becomes). So it's really important to learn as much as you can about how symptoms affect you, and what you can do to help manage them.

How this booklet got its name

"Acquiring a disability is a bit like getting home to find there's a gorilla in your house," says blogger Mary Hammonds, whose analogy was cited as those who took part in our *Living and learning with M.E.* project as a great way of helping others understand what it's like to live with M.E.

"There are three major approaches to the gorilla in your house," Mary continues. "One is to ignore it and hope it goes away. This is unlikely to work. A 300 lb gorilla will sleep where he likes, and if that's on top of you, it will have an effect on you."

To read about the other two approaches, and the rest of Mary's blog, visit www.tinyurl.com/gorillainyourhouse

Key things to remember

Some people do recover from M.E., often partially and in some cases fully. There isn't yet clear evidence about who is likely to recover or why. People who have recovered give different reasons, though common themes are:

- stepping back from their busy pre-M.E. lives and taking actions, including resting, to stabilise their condition
- listening to their bodies
- understanding their major symptom triggers
- being resilient to set-backs
- finding patience to take very gradual steps towards recovery when able to do so.

Everyone's experience of M.E. is individual. Even the basic pattern of the illness varies, with some experiencing a sudden onset of symptoms following an infection or accident while others develop the condition gradually over several years. Some people's condition is relatively constant while others experience cycles of remittance and relapse.

There is growing evidence from experts in the field of M.E. that a number of sub-groups exist within M.E. This most probably explains why people with M.E. differ in terms of their illness experience and the course their illness follows over time.

Accept the situation you are in

“Take the illness seriously, acknowledge that life needs to change significantly, hopefully for the short term.”

This doesn't mean you have to resign yourself to never recovering or give up on life – far from it! However, you can't will yourself better or drive M.E. away by ignoring it and trying to continue as you were before.

People with M.E. who helped put this booklet together said that M.E. is a bit like a knot in that the more you pull on it or fight it, the tighter it gets. In this situation, it's more productive to give yourself some slack to think about how best to untangle what you can, and manage life with the illness so you get the most out of it. This kind of strategic thinking and acting, driven by you as the 'expert' in your condition, is what we mean by 'self-management.'

GPs and other health professionals still have a role to play and responsibilities for your health and wellbeing. Self-management is not an alternative to medical care. Ideally, the two should complement each other, with your experiences and priorities being listened to and respected by professionals.

When health professionals talk about treating M.E., they are referring to symptom management and patient care, not a cure – there is not yet a pharmacological cure for M.E. In practice, at the time of writing, there are limited treatment options available for M.E.

There is also still some disagreement and confusion among professionals about how to manage the condition. This means that people with M.E. often have to be particularly self-reliant. Part of your self-management strategy may include thinking about how to build relationships and get the most out of the contact you have with your GP and/or other health professionals.

Be kind to yourself

Rather than beating yourself up over all the things you can't do, recognise the day-to-day achievements and positive contributions you make despite your illness. They may seem small compared to what you did before M.E., but for you, in your current state, they are equally – perhaps even more – impressive.

“Let go of ‘shoulds’ and ‘musts’ and feelings of responsibility which creep in as energy returns [following a crash].”

Learning to manage your condition effectively is an ongoing learning process. Identify where you are making the same mistakes repeatedly (eg. running for that bus, climbing stairs instead of taking the lift) and try to do things differently, but don't be too hard on yourself. It is human to slip-up sometimes – keep working away at improving and share your learning. As your self-management strategies become established, your confidence about what you can do (and your limits) will increase.

“Recognise your ‘fluster’ point and give yourself a break. Rest often, drop your standards and make time for a nurturing activity every day.”

Section one: Thinking and talking about M.E.

Coming to terms with your diagnosis

Having a thorough understanding of M.E., knowing yourself and choosing how to relate to 'your' M.E. and how to express it to others helps you to manage the condition, rather than to be managed by it.

Coming to terms with a diagnosis of M.E. may require a shift in how you think about illness, disability and dependency. It may mean learning to see the world differently in terms of your own expectations and to accept that it is ok not to meet other people's expectations.

"I was addicted to my former life and it took me a long time to realise that I had to make a transition to a new life."

Being ill, especially long-term, can be perceived as a sign of weakness. In our culture, we are expected to "fight" or "battle" illness. Leading the same pre-M.E. lifestyle is unsustainable for many of us but learning to let go of your 'normal' life can present significant challenges. Stepping back and working with the condition rather than trying to beat it means that you are taking control, even though it may not feel like you have an option at the time.

"I have a better quality of life through managing M.E., even though it isn't the life or quality that I want or thought I would have."

The sooner you are able to let go of the areas of your life which are causing you the most difficulty, the more likely it is that you will be able to pick them up again at some level once your condition stabilises or improves. Allow yourself to enjoy small things that you are able to do.

"You can start the process of letting go with a blank piece of paper. Completely rethink everything in your life. I felt dead when I received my diagnosis, which felt like the death of an old persona. I had to find new reasons to live and to recognise that I had done the best I could for as long as I could."

How we think about and talk about M.E.

M.E. often receives a bad press. Time and again we come up against language that tells us “it’s all in the mind’ or that ‘everyone gets tired.” Do you internalise such stories and comments? Do you regard yourself as a victim, survivor, or hero?

Living and learning with M.E. project participants talked about how the language we use to communicate with people around us about our condition, and the way we tell that story, is important. Remember that you will not always feel the way you do now, and that there is more to you than your symptoms or health condition. You are the author of your own story.

Think about times when you have really managed to get across your message.

- What was the difference compared with other less successful attempts?
- Were there things about the way you communicated or what you said that made the difference? For example:
 - Did you focus more on your feelings or on practicalities?
 - Do you think your message came across to listeners as mainly positive or negative? Did that make any difference to their response?
 - Did you say something that particularly captured the interest of the person/s you were speaking to?
 - Did you use any examples or analogies that listeners strongly related to?
 - Did you tell your story straight or use humour?
 - Was it an interactive conversation or more of a monologue?
 - Were there any reactions from listeners that you adapted to while you were communicating with them?
 - How did you feel while you were communicating?

M.E. is a neurological condition. But as with other illness, there is a psychological and emotional impact that comes as the result of managing such challenging symptoms.

The way we think about ourselves is as important as the stories we tell others. Gaining confidence in your own understanding of your condition and ability to communicate about it will help you to deal with unhelpful reactions from others.

Learning to notice your thoughts and the language you use can help to shift perspective, feel more in control, and break out of unhelpful patterns that most people (with or without M.E.) experience from time-to-time, and especially when we are under stress.

"We are hard wired into thinking a certain way – need to re-wire our thoughts so that we can see that getting out of bed and shaved is a great achievement."

If this is a significant area of difficulty you may benefit from a talking therapy that suits your personality and style or a mindfulness practice. Some people shy away from such approaches, concerned that using them suggests their illness is psychological. People who understand M.E. will not make this assumption. The same therapies are used by people with MS or cancer.

Psychological therapies are not for everybody, but some people do find that as part of a holistic approach, talking therapies can be a useful support to help them manage their condition. Don't be afraid to take control and ask for what you need, or to try a different therapy or therapist if the first is not helpful.

You will find some 'patient perspective' films in which people with M.E. talk about their experiences of living with the condition on the Action for M.E. website. You will also find short films portraying life with M.E. from self-help groups across Scotland, made as part of Action for M.E.'s 2014 digital story telling project.

Analogies for talking about M.E.

The spoon theory was authored by Christine Miserandino, an award-winning US writer, blogger, public speaker and lupus patient advocate. You may see other people with chronic conditions calling themselves "spoonies" – this is why. You can read the spoon theory on Christine's website www.butyoudontlooksick.com

Blogger Mary Hammonds compares having a disability or long-term condition with having a gorilla living in your house. You can read it at www.tinyurl.com/gorillainyourhouse

Relationships and support networks

It is important to be able to talk about your feelings. Think carefully about your audience and who to trust with your feelings – who is most likely to understand and be supportive?

“I gave in to expectations, despite thinking it wasn’t the right thing to do, and it was damaging. That’s when we need those around us to validate the condition and to encourage us to do only what our bodies are capable of doing at that time.”

Self-management is greatly enhanced if people close to you can support you. The people who know you well can play an important role in helping you to pace effectively, with timely reminders and support in communicating your needs and limitations to others. Open communication is vital and honesty is important, though it is not always easy to achieve.

You may find that you edit your story if it seems too difficult, upsetting or uncomfortable to hear and this can leave you feeling alone and alienated. Or you may feel hurt and misunderstood if support is not there, or you are not believed.

Even for naturally optimistic people, it can be difficult to remain positive all the time when living with M.E. Feeling down or vulnerable at times is a natural response to the challenges of living with your condition. However, some people do develop depression on top of their M.E. Don’t put off asking for help if you need it, rather than struggling on alone.

Talking therapies are not for everybody, but some people do find that, as part of a holistic approach, they can be a useful support to help them manage their condition. Don’t be afraid to take control and ask for what you need, or to try a different therapy or therapist if the first is not helpful.

Relationships can be strained by the illness and being on the receiving end of care may leave you feeling vulnerable and in a dependent position. Partners may begin to see you as a patient rather than a partner.

“Support from my partner has been invaluable. I would have left had the roles been reversed.”

While some partners may view themselves as carers, many couples only use this term to the outside world (eg. when completing forms for welfare benefits), and feel that it is important to remember that they are still ‘partners’ first and foremost.

“The real heroes are the carers. They give their time and effort but get little social support and no medals.”

Partners and carers often experience isolation and stress alongside the person with M.E. and may be unaware of sources of advice and support, including welfare benefit entitlements. Local carers centres can be good sources of information and support and provide opportunities to link-up in person with other carers: contact Carers Scotland (see p 38) for details.

“It’s a lonely condition which isolates us.”

Isolation increases for many people with M.E., as their capacity to socialise is reduced. Getting out to social events becomes difficult and, when you do get out, being able to keep up with conversations, especially when in a group, can be hard.

“Often it’s our nearest and dearest who are completely blind, who don’t get it.”

"Home can become a prison – you need to find ways of getting out and engaging with life."

If you are not receiving the understanding, support or advice that you need from those closest to you, interacting with other people who have M.E. may be helpful. Even if you are well supported, connecting with M.E. groups either online or meeting face-to-face can give you access to a massive wealth of experience, knowledge and strength. Joining support groups and online communities which understand your limitations can help to reduce isolation. This may also relieve pressure on partners or friends who are compensating for your loss of other social outlets.

"I don't get tired of talking about M.E. as I don't get to do it much. Most people aren't interested – it feels good to connect with others who understand."

Those who contributed to this booklet sometimes found that M.E. groups can be too negative, especially when group members become focused on discussing symptoms and "moans." Some health professionals discourage people with M.E. from attending patient-led support groups for this reason and/or because they think support groups reinforce unhelpful beliefs about the condition.

"When a GP says don't join a support group as there will be mass psychosis and it will make you worse, nothing is further from the truth. Would a doctor give that advice to someone with MS or cancer?"

Don't be put off trying local support (or 'self-help') groups if you think you could benefit from going to one or would like to help support others. As with most things, it's important to work out what is right for you and this may change over time. Groups may also change with new members or different types of social setting, so don't put too much emphasis on one-off experiences.

Section two: practical self-management tips

Pacing and balance

Pacing is a methodical approach to balancing activity and rest, with the aim of bringing about more stability in your symptoms. It's a common self-management practice for people with M.E.

"Say 'I could,' not 'I should.'"

While the practice is individual for each person, the basic approach is to start by establishing a personal baseline and work from there. You must be the one to determine what you can accomplish, and learn to accept limitations when they arise.

"One is often tempted to add in that little bit extra to see if you can 'get away with it' only to find out that there is always payback."

In this fast-paced world of task-focused action and busyness, starting with what the body is capable of taking on may seem unnatural, but this is essential.

"It's important to know yourself and your limits, to be able to say 'no' and to trust your instincts."

You have to listen to what the body is saying and only do what the body is able to take on that day, regardless of what you may like to be doing or think you 'should' be doing.

"Give yourself more time to accomplish tasks like getting to the bus. Avoid situations where you might end up rushing – stay in the slow lane."

Living and learning with M.E. project participants agreed that, with time and practice, you will learn how to listen to your body, understand when dips in energy are coming, and when the body or mind requires rest. This is challenging and progress is likely to be erratic, not least because with M.E., symptoms are so variable and identifying triggers and a baseline can be overwhelming to start with.

"It's hard not to give in, especially when friends and family are encouraging you to do more."

Bear in mind that emotional aspects can be as draining as physical aspects and mental fatigue needs to be considered as well. You may find it helpful to attend a course on how to manage living with a long-term condition, or to receive one to one specialist support where this is available, perhaps from a nurse or occupational therapist trained in working with people with M.E. Outside of the NHS, organisations including the Thistle Foundation, Multiple Sclerosis Society (Scotland), Arthritis Care Scotland and the Pain Association Scotland run general courses for people with any long term condition that may be suitable for people with M.E.

"Take your time, and don't expect perfection! You will experience red flag moments – times when you dip or experience a setback. Trust that you will, through trial and error, find a balance that works for you."

There are many tools that can help you to discover how to pace yourself in a way that leads to stability and progress, or at least helps you to avoid what's known as 'boom and bust' and to better understand your triggers. Tools that the 16 people with M.E. who contributed to this booklet have found useful can be found in Appendix II.

Diet and activity

Eating healthily is important, and many people with M.E. opt for natural (ie. unprocessed) foods and avoid (or reduce) sugar, caffeine and alcohol. Eating simple, light meals is less taxing on the digestive system and may help to avoid an increase in weight as life becomes more sedentary.

Some who took part in our *Living and learning with M.E.* project people feel that changing their diet has helped their digestive and immune systems. For example, some found juicing an easy way to improve their vitamin intake (though please remember that the NHS Eatwell Guide recommends that, given their sugar content, fruit juice and/or smoothies should be limited to no more than a combined total of 150ml per day). Others take nutritional supplements or explore holistic and alternative approaches.

However doing this without expert support can be problematic. If digestive problems have a significant impact on your health, discuss your symptoms with your GP who can give advice on treatment and refer you to a gastroenterologist if required.

Many people were physically active before getting M.E., and find it hard to give up exercise. Strenuous exercise is not recommended for people with M.E., but it may be possible for some to undertake gentle activities, at a pace set by them.

For example, some people with M.E. have found gentle stretching is beneficial, and can be done even whilst lying in bed. Arthritis UK have produced a useful guide to gentle exercise including stretching (see p 38).

It is important for your wellbeing as well as physical health to keep as mobile as you safely can. Some people with M.E. have found electric bicycles very helpful in enabling them to go out independently and in the fresh air.

Try to maximise your exposure to sunlight (with protection against sunburn and sunglasses if you need them: some people with M.E. find they are sensitive to bright light.) Sunlight is the best source of vitamin D, which can become deficient when you spend a lot of time indoors, causing additional health problems. Vitamin D levels can also be boosted through your diet by eating oily fish (eg. salmon, sardines, mackerel), eggs or fortified spreads or cereals.

Sleep and pain management

There are a number of options for relieving pain, including medication in the form of tablets or patches, and you can work with your GP to optimise your pain management. If required, your GP can refer you to a pain management clinic. You can also speak to him or her about pain management courses available on the NHS in your area. There are aspects of these courses that can be helpful for some people with M.E. and it would be valuable to discuss this with your GP.

Prescription drugs for sleep management can be useful as can prescriptions that calm the body down when it is “tired but wired.” However, relying solely on medication brings its own challenges. Some people do not tolerate the medication well while others find the drugs work better when combined with lifestyle practices or that lifestyle changes alone are enough.

You might be prescribed an antidepressant at a very low dose to help manage pain and/or sleep, but this does not mean you have not been believed or dismissed as depressed (these drugs don't work as antidepressants at low doses).

A healthy sleep routine may help you to get at least some good-quality sleep. Sleep management advice usually includes:

- avoiding caffeine in the afternoon/evening
- following a wind down routine before bed
- going to bed at the same time each night
- avoiding daytime naps
- getting up for a while and doing something boring if you can't sleep, rather than lying in bed trying to make yourself sleep.

It may be possible to get a referral to a sleep specialist (through your GP) if sleeping is a major area of difficulty for you.

Non-pharmacological therapies

In the absence of an effective pharmaceutical cure for M.E., many people with the condition have tried a range of different approaches to help with managing their symptoms.

Approaches that some of the people with M.E. who contributed to this booklet have found helpful are listed below. As different people have tried different approaches with variable results, we have tried to provide a balanced summary of those discussed in the *Living and learning with M.E.* project groups. Not all are readily available and most of them cost in terms of money, time, and/or energy so do treat these as ideas to consider, rather than recommendations.

No-one can be certain whether or how a person might benefit from a treatment and people with M.E. differ, sometimes greatly, in their response. Action for M.E. advises people to examine with scepticism any treatment, therapy or other approach which claims to offer a cure, has not been subject to research published in peer-reviewed journals and requires the payment of large sums of money.

Some people with M.E. find complementary (also known as holistic or alternative) therapies such as acupuncture, aromatherapy, massage, reflexology or reiki) useful as part of their individual self-management plan. Good quality published evidence can vary considerably for each therapy, so it's important to find out as much as you can if considering such an approach.

Professionally delivered talking therapies (including counselling or cognitive behavioural therapy) have been used to help people to come to terms with the significant and difficult life changes that can arise from living with M.E.

Some people with M.E. have reported that they also find self-help books useful; those suggested by project participants can be found on p 30.

Approaches you can try yourself

Journaling or other forms of writing can be a useful way to express emotions and how you are feeling about living with M.E. Sometimes it's helpful to get feelings off your chest, even if you burn what you've written afterwards. However, sometimes it's good to have a record of how far you've come.

"If you experience cognitive difficulties, start with a few words or as much as you can manage."

The 16 people with M.E. who contributed to this booklet suggested that hobbies or creative activity (such as gentle gardening, bird watching, arts and crafts, adult colouring books, playing a musical instrument) can be soothing, fulfilling and/or meditative pastimes. Simple pleasures such as sharing a joke, spending time in natural surroundings or watching birds at a feeder can all be good for your wellbeing. Listening to music can be used to sooth or uplift, though you may find that any additional noise is too taxing on your nervous system at times.

"Have ready-made craft packs/tools at hand for days when you are mentally tired but your hands could be doing something."

Positive affirmations, mantras, meditation or spiritual reading can be helpful for some in reframing their outlook on life and increasing self-confidence.

"Meditation can take you away from beating yourself up over being 'lazy.'"

Some find that mindfulness, meditation or relaxation techniques can help relax both body and mind.

"I find that putting myself into a meditative state at least gives me some quality rest when I am exhausted but can't sleep."

The medical profession

“When you receive a diagnosis of M.E. your GP may want you to find your own way with the condition.”

Experiences with health practitioners, and most notably GPs, vary from supportive to demoralising. It may be helpful to think about the type of relationship you currently have with your GP/health professional and about the type of relationship you would ideally like to establish. Is there anything you can do to improve this relationship?

Relationships with GPs/health consultants can be categorised into four basic types (this is a simplification but it may help you to think about your own relationship with your GP).

- 1 Subordinate, where the GP holds all the power and the patient has a passive role following the GP's instructions or prescription.
- 2 Structured, where the GP still holds most of the power but the patient has some say in which treatments to follow.
- 3 Collaborative, where both the patient and the GP have an equal say.
- 4 Autonomous, where the patient is largely left in charge in self-management, with little or no involvement from the GP.

Most people aspire to a collaborative relationship (type 3) with their GP (or other health professional) where the doctor works with them to understand what is wrong and to agree upon the best way forward. Unfortunately, this option is not available to some people.

Autonomous relationships (type 4) with the patient in charge of self-management can be good at one level, but is not empowering when patients feel they have been left to their own devices or abandoned by their GP.

People with M.E. often describe being regarded as a “heart sink” patient (ie. one who causes their doctor's heart to sink when they come in the room because the doctor doesn't know how to help them). It can be hard for doctors who want to help, but don't know what they can do for you – especially with a condition like M.E. where there is currently no pharmacological cure. Your GP still has responsibility for your healthcare, but sometimes understanding their perspective can help you to get more out of the relationship.

Although some people with M.E. do suffer from depression and/or anxiety that GPs can help with, it can be very frustrating for people with M.E. to experience being misdiagnosed with depression or anxiety disorders. Sometimes people feel they have to accept what is offered or swallow poor advice, not to improve their health but in order to build a positive relationship with their GP and to be seen as a willing patient. Of course, this shouldn't happen.

"The doctor must be right [...] I've failed [...] Do I really have M.E.?"

It is a good idea to stay visible to your GP and remind them that you still have M.E. if necessary. You may need their support for employment issues or welfare benefit claims and they are your gateway to any referrals that you may need.

Action for M.E. publishes a guide for GPs in Scotland that your health professional may find helpful to refer to (see p 39).

Key UK guidelines (ie. the National Institute for Health and Care Excellence guideline on M.E. and the Scottish Good Practice Statement on M.E.) highlight that shared-decision making and a supportive, empathic and collaborative relationship are essential for people with M.E. and the healthcare professional supporting them.

How you present yourself – how you tell your story or get across your messages – at an appointment can help to establish common ground and open the pathway to more constructive dialogue. Some things you may find helpful to consider before attending an appointment are:

- choosing a smaller number of specific symptoms to speak to the doctor about
- speaking to a trusted friend or family member about what you want to say to the doctor before going to your appointment; ask the listener for feedback and to point out things you may have overlooked.
- taking a list of the points you want to make to your appointment (some GPs won't accept lists from you but you can still use them as reminders to yourself)
- bringing someone with you to the appointment who can talk on your behalf or take notes to help you to remember what was said
- finding out about any services other people with M.E. in your area have accessed and, if you feel any of these might help you, asking your GP for a referral
- becoming an 'expert patient' and informing yourself about different management and symptom treatment options. A good GP should be open to discussing sensible suggestions and having one or two pieces of useful, well-evidenced information highlighted to them.

Don't blame yourself if your doctor says he or she can't help you. Try suggesting solutions, but if all else fails, perhaps you need to look for another doctor who is better informed or more helpful. People often have the misunderstanding that they have to stay with the same GP in the practice when it doesn't matter which one they see, so you are free to try out others at the same surgery.

Employment

Many people with M.E. find that working the same amount of hours or working as intensely as they did prior to having M.E. is no longer possible. You may have to reduce your hours at work, consider a different career if work becomes too demanding, or even give up work altogether to focus on recovery and/or stabilisation of your M.E. symptoms.

“There are days when I just can’t grasp the work, which I can do on other days with no problem, but my cognitive ability just goes and I have to go home.”

For some people, managing the best possible exit from their current employment is a key part of their management strategy. For others, it may be finding suitable employment. Some people with mild to moderate M.E. are able to find and sustain a suitable level of the right kind of work for them.

Consider not just the job itself but how you travel to and from work. Is there a less energy consuming way of getting there? Could someone give you a lift? Could you work from home some (or all) of the time? An Access to Work grant can pay for practical support.

“They made sure I had HR support, a quality return to work schedule and helped me to stick to my hours and not take on too much.”

Support and understanding from work colleagues, including team members and line managers, can help you to sustain your job. Being able to communicate openly with your employer is important, and being able to negotiate a mutually agreed return to work schedule (if you have been off sick) can make a difference. Having control over which tasks you do when can also be very helpful, as can delegation of certain tasks. Other examples include:

- being able to schedule energy-intensive meeting or tasks that require a high level of concentration at times when you have most energy
- asking a colleague to stand in for you in a meeting, take notes for you or help with manual tasks such as moving furniture.

“Returning to work too early is very often damaging.”

If you are off sick, trying to build up your activity level so that you can return to work can be a difficult and challenging period. Many people with M.E. push too hard and their condition worsens.

"I was expected to be back to my normal routine within two weeks of getting back to work, despite having been off ill with M.E. for four months."

You may find that although colleagues are sympathetic, a lack of understanding about the condition means that you are expected to be able to return to normal duties more quickly than you are able to manage.

Taking ownership of the condition, knowing your limits and setting realistic goals is important. Establishing a shared view with a supportive healthcare professional can be very helpful in negotiations with your employer around what is safe and achievable

Employers have a duty to follow the Equality Act 2010 and to make reasonable adjustments to try to retain you as an employee. These might include:

- allowing you to work more flexibly
- changing your hours
- providing you with a quiet rest space
- providing you with equipment such as a perch stool or trolley
- arranging for a colleague to do lifting, carrying or stretching tasks that fall within your work remit.

If this is not being put into practice in your workplace, seek advice from ACAS, Jobcentre Plus or your local Citizen's Advice Bureau (see page 40). Action for M.E. also publishes booklets with guidance and information for employers and employees.

"I need to show a little more restraint in how much I take on."

Some people have found that work takes up such a disproportionate amount of energy that there is little left over for socialising and other activities. This has encouraged them to explore different ways of making a living, perhaps working part-time, from home or in a less challenging position.

Managing a best exit from their current employment may provide the best opportunity for recovery. For some, this may mean ill-health retirement. For others, a return to work may be possible again in the future. It's important to identify barriers you face, but also some possible solutions so that you can be confident about what to ask for.

"The workplace starts to feel like a different world [...] I miss being a workaholic."

Some people with M.E. who would like to get back into work try volunteering activities where they have a high degree of flexibility about how much they take on. This allows them to experiment with different approaches to see what works for them and may also provide opportunities to gain new or upgraded skills and increase their confidence. For those who are no longer able to work, learning to fill the gap can be challenging and it is important to find new ways to fill your time meaningfully.

Welfare and social services

You may find that you need financial (eg. welfare benefits) or practical (eg. home help) support from the state because of your health condition.

“There is a gap between law and justice and we are often treated harshly.”

There are a number of benefits to which you may be entitled. Do not be put off making legitimate claims. Having access to welfare benefits or social service support may make the difference between you being able to live independently or factor in enough rest to be able to stabilise your symptoms. Do be prepared to have to persevere to access the welfare and social support you need under the current system and take full advantage of the free expert advice and support that is available to help you.

Assessments can feel impersonal and it can be difficult to be honest about how severely the illness affects you when you are used to down-playing its impact and trying to get on with life as best you can. You need to put this reluctance aside and be well prepared to spell out exactly how affected you are by your M.E. on normal and bad days.

The process of form-filling and attending assessment interviews is cognitively and physically draining. Focusing on the negatives of the condition and feeling judged can also take a great toll emotionally, and puts many people off applying for benefits to which they are entitled. The fluctuating nature of M.E. is not always understood or acknowledged by assessors so you will need to clearly communicate the impact of specific symptoms.

Seek expert support and advice early on in the process and be prepared from the outset to appeal decisions which you feel are unfair. A very high number of claims are successful on appeal. Don't be afraid to request either an extension if you need it to complete paperwork or a home assessment for welfare benefits if you are too unwell to travel to an assessment centre. If you are applying for social care, you will be assessed at home: contact your local authority to find out more.

Some assessments (and appeal tribunal hearings) can be quite long, so be prepared to say when you are about to reach your limit and ask for a break if required. It can be helpful to mentally prepare yourself in advance to interrupt proceedings and get the message across as the very time when you need to express it is the time when your cognitive and communication skills will be most challenged.

"I show no outward signs that I have stopped functioning to those who don't know me well, though people close to me can see the change. I can be asked a question and know the answer but can't express it."

Action for M.E.'s Welfare Advice and Support Service offers expert, confidential advice – see p 40 for details.

Section three: M.E. campaigns and taking action

People with M.E. need and deserve more specialist and more consistent NHS services, better treatment by welfare benefit providers, more biomedical research and fairer media coverage.

“Let’s remember that M.E. is classified as a neurological condition [...] MS brain fatigue is accepted, why not with M.E.?”

There remains much debate over how to clinically define M.E. and more research is urgently needed in order to further understanding of the condition.

Media coverage that portrays M.E. in an unfavourable light, with misleading and damaging headlines in papers and news items, feeds the myth that M.E. is ‘all in the mind’ or that it is not a serious illness. Such views can pervade the systems there to support us, meaning for instance, that it is not unusual to find medical professionals and benefit assessors unsupportive or misinformed.

We can work together to convey the real implications of living with M.E. to highlight the need for increased resources. Some people get a lot personally out of contributing to M.E. campaigns, raising awareness about the condition or supporting other people with M.E., and also give a lot to others.

You may feel you don’t have the time, energy or skills required to contribute, but little acts can make a difference! Living with M.E., and its fluctuating nature, means that you probably don’t have the capacity to commit to energy-intensive campaigning activities, but people contribute in many different ways including innovative fund raising, sharing information on Facebook, reaching out a hand of support or simply telling your story as best you can when you can. Campaigns and actions are gathering strength around the world, while local groups and charities are supporting people across the UK.

If you feel up to it, there are plenty of ways that you can get involved locally, nationally or even internationally when the time is right. Action for M.E.’s campaign toolkits have been produced with this in mind. We have also included some of the most popular campaigning and information websites in Appendix III. Collectively and individually, each of us can make a contribution.

Appendix I: Glossary of common M.E. terms

Baseline – finding a consistent level of activity which can be carried out –usually – daily that does not lead to worsening symptoms.

Biomedical – using biological science in medical research.

Boom and bust – when your energy/ability levels are erratic from day to day, usually caused by ‘doing too much’ or exceeding your pacing regime (see ‘pacing’, ‘payback’ and ‘tired but wired’).

Brain fog – Term commonly used by people with M.E. to describe the characteristic inability to concentrate or process information, reduced capacity to remember or recall basic information associated with the condition.

Carer – anyone who cares, unpaid, for a friend or family member who due to illness, cannot cope without their support.

CBT – Cognitive Behavioural Therapy is defined by NHS Choices as “a talking therapy that can help you manage your problems by changing the way you think and behave.”

Cognitive difficulties – see brain fog.

DLA – Disability Living Allowance. A welfare benefit that is being systematically replaced by the new benefit, PIP.

DWP – Department for Work and Pensions – a UK Government department that is responsible (at the time of writing) for employment and welfare benefits.

ESA – Employment Support Allowance, a welfare benefit.

Insomnia – The condition of not being able to sleep normally over a period of time.

LTC – long term condition.

Meditative state – The act of giving your attention to only one thing; it is used to aid the body and mind and to change how you think about things.

Mindfulness – This is the practice of being aware of your body, mind and feelings in the present moment.

Neurochemistry – science of the nervous system.

Neurological – a disorder of the body’s nervous system.

Pacing – planning activity and rest each day so that you avoid or reduce peaks and troughs (see ‘boom and bust’, ‘payback’ and ‘pacing’).

Payback – delayed fatigue and/or increase in symptoms experienced when you have exceeded your daily energy/activity limit (often associated with ‘boom and bust’)

PEM – post-exertional malaise. A period of intense exhaustion that can typically take up to 48 hours to kick in following physical, emotional or mental activities.

PENE – Post-exertion Neuroimmune Exhaustion. Similar to PEM, used to describe symptoms provoked or made worse by physical or mental exertion.

PIP – Personal Independence Payment, a welfare benefit.

PVFS – Post Viral Fatigue Syndrome. An alternative name for M.E. that is sometimes used in the UK when development of the condition is linked to a viral infection.

SEID – Systemic Exertion Intolerance Disease. An alternative name for M.E. proposed in the United States in 2015.

Self-management – decisions and behaviours that patients with chronic illness engage in that affect their health.

Tired but wired – when you’re exhausted but can’t rest/relax or sleep. Warning! This might ‘feel’ like energy/recovery, but if it appears quite suddenly and is accompanied by an unsettled feeling your body may be going into overdrive, and you need to rest.

Trigger – levels of activity and situations which cause symptoms to flare-up.

Tunnel vision – when you keep going even though you have gone beyond the point of being able to cope, everything else gets blocked out and asking for help is beyond you.

Appendix II: Examples of self-management tools

Traffic lights

This offers a simple way to track your capacity to help you to understand what you are capable of doing on any given day so that you don't overdo it. The tool uses positive language and focuses on what you can do rather than what you can't do, using a simple red, amber and green light approach.

Over a period of a few weeks, you note roughly what you are or are not able to do, and key symptoms, under green (as good as it gets), amber (struggling but managing) and red (experiencing significant problems).

Here's an example from a member of the Fife M.E. support group who kindly shared their own, personalised approach to traffic lights:

- Green 1: As good as I get. Able to have full days out (carefully).
- Green 2: feeling ok, half days, visits to garden centre etc.
- Amber 1: staying in, but can do DIY, bit of housework, potter in the garden.
- Amber 2: Staying in. Can get up but only light housework, hobbies. Lots of rest and TV.
- Red 1: Get up but on bed. Visitors. Watching TV, listening to music.
- Red 2: Bedbound, gentle music, lights low, all senses run down. No visitors.

"For example, I was Red 1 until yesterday. I am now Amber 2. Even if I feel better I will force myself to stay Amber 2 until Monday, then Amber 1 for a week. Then I'm green and will start enjoying the odd day out."

You may find it helpful to sketch out your own set of traffic lights, using activities that fit with your level of illness and lifestyle.

Phone battery analogy



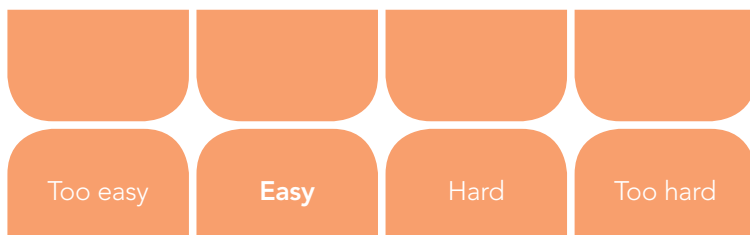
To understand pacing it can help to think of your available energy as being like a mobile phone battery. If you completely drain the battery you have to wait to recharge it before you can use the phone again.

If you use some of the battery and make regular top ups, then your phone will always be ready for use. The phone battery analogy can also be useful for explain the impact of M.E. to other people.

If we imagine that everybody is powered by batteries, a person with M.E. has a faulty battery that very quickly drains of power and is very slow to recharge. An M.E. battery therefore needs constant recharging (ie. rest) to be able to function.

Keith's TEEHTH

TEEHTH stands for "too easy, easy, hard, too hard." NHS Fife M.E./CFS specialist nurse, Keith Anderson, uses this analogy to help with pacing.



Keith says everything you do can be broken up into bite-sized chunks and categorised as too easy, easy, hard or too hard (what fits where will vary from person-to-person and may fluctuate with your condition).

With pacing, everything you do should be in the "easy" box. If activities are hard, this means you are taking on too much. Don't bite off more than you can chew or you will risk choking. But activities shouldn't be too easy either (that would be like eating a meal, one grain of rice at a time) – remember to step-up your activities when you are able to do so without ill effect.

As a rule of thumb, aim to do 70% of what you feel you can manage. That may be a bit too easy on a good day, but will be harder on a bad day.

Preparation, activity, recovery (PAR)

Keith Anderson also uses PAR to help people with planning. This approach can be helpful when dealing with hard activities that you can't avoid or are very important to you. As an example, imagine the activity is a holiday.

Preparation involves asking yourself key questions:

- What do I need?
- Who's involved / who could help me?
- What do I need to do?

Activity involves thinking about the intensity of the activities you take on.

- How much can/should you do yourself?
- What can other people help with?
- What are the risks?

Recovery involves thinking about the things you need to do to support your recovery from a hard (energy-intensive) activity.

- Can you cancel other activities to make space or re-organise your timetable?
- Can you schedule in rest times?
- Is there medication that can help you?
- Can you delegate other activities to friends or family?

Tracker tools

Tracker or symptom tracker apps for your smart phone or tablet can help you to make sense of what is going on in your life. You can input data on particular areas which you can then explore through pie charts or graphs for quick feedback. They can be used to help with pacing, identifying triggers and monitoring activity or symptoms.

Below are two examples, which we liked the look of (but have yet to try ourselves):

The M.E./CFS Diary app (www.mecfsdiary.com) aims to help you to keep tabs on your activity/rest levels. One of the testimonials says: "Personalisable and relevant, Unlike a paper diary, I have never forgotten to complete this one. I email myself the results and have a log to show my doctors. The baseline is interesting as I tend to overestimate how much I can do then crash – this app calculates it for you and helps you avoid the push-crash of M.E./CFS."

The M.E./CFS Assistant app (www.me-cfs.org) is free (though there is a charge for 'premium features'). It can provide simple or complex monitoring on a computer or a mobile device, and says "Every so often the ME/CFS Assistant mobile app will prompt you to rate the severity of your most problematic symptoms. You control which symptoms you are asked about and how often. Also, you can easily record instances of secondary symptoms only when they occur."

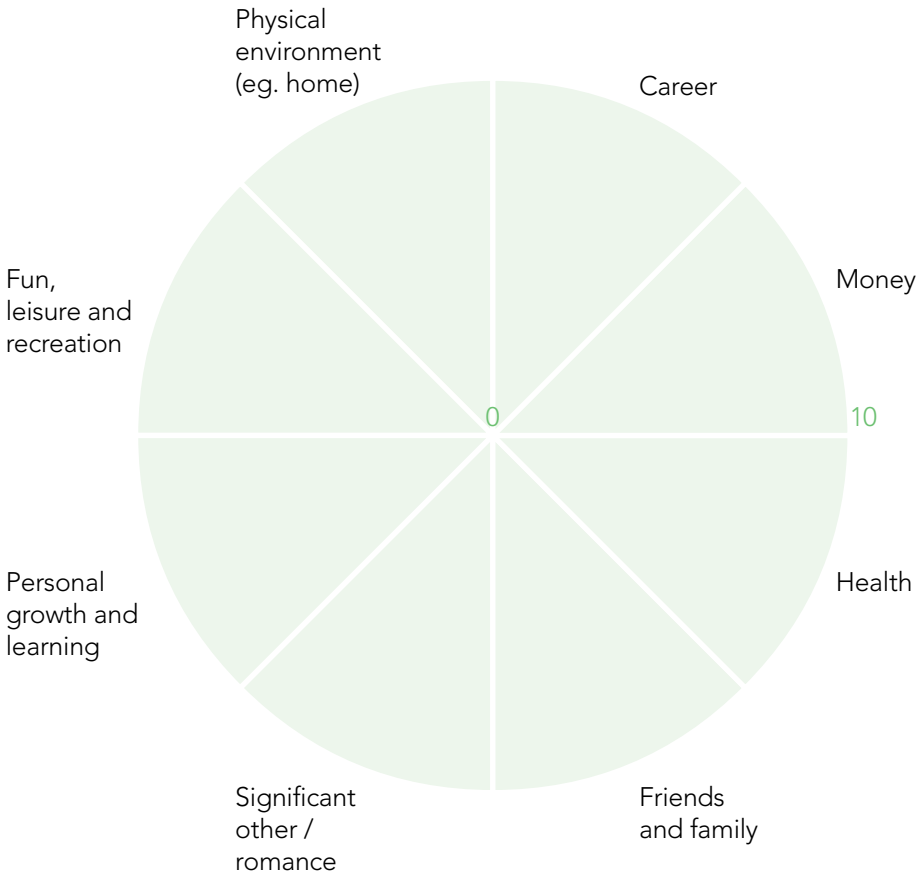
You may like to explore 'timer tools', such as computer apps which pop up at set times to remind you to take a break. You can download apps onto your phone, such as Tibetan bells, which ring gently at set times to remind you to take a break. Stopping for just three minutes, relaxing your body and breathing deeply, a few times each day can be beneficial to your nervous system.

Wheel of life

Some people find this exercise helpful to clarify priorities for goal-setting, allowing you to plan so that your life is closer to your definition of balance, whatever that means for you.

Balance is personal and unique to each individual – what may be balance for some may be stressful or boring for others. Balance must be assessed over time. So, a regular check on how balanced you are can highlight useful patterns and help you learn even more about yourself.

Another option with this exercise is that you can ask someone who knows you well to complete the scores for you. It can be helpful sometimes to see an outside perception of your life balance. Note: This must be someone you trust and whose opinion you value.



Wheel of life instructions

1. Review the eight areas on the wheel. It must, when put together, create a view of a balanced life. If necessary, split categories to add in something that is missing. You can also re-label an area so that it is more meaningful.
2. Think about what success feels like for each area.
3. Rank your level of satisfaction with each area of your life by drawing a line across each segment. Place a value between 1 (very dissatisfied) and 10 (fully satisfied) against each area to show how satisfied you are currently with these elements in your life.
4. The new perimeter of the circle represents your 'Wheel of Life'. Ask yourself, "Is it a bumpy ride?"
5. Now, looking at the wheel here are some questions to ask yourself and take the exercise deeper:
 - Are there any surprises for you?
 - How do you feel about your life as you look at your Wheel?
 - How do you currently spend time in these areas?
 - How would you like to spend time in these areas?
 - Which of these elements would you most like to improve?
 - How could you make space for these changes?
 - Can you effect the necessary changes on your own?
 - What help and cooperation from others might you need?
 - What would make that a score of 10?
 - What would a score of 10 look like?

Appendix III: Useful resources and contacts

Information and support about M.E.

Action for M.E. offers information, support and signposting online, by phone, by email and by post, plus a searchable services directory, the M.E. Friends Online peer-support forum and expert welfare benefit advice (see p X).

Tel: 0117 927 9551

Email: admin@actionforme.org.uk

www.actionforme.org.uk

Association of Young People with M.E. offers information and support to children and young people with M.E. and their families

Tel: 0330 221 1223

www.ayme.org.uk

Carers Scotland (part of Carers UK) offers information and support to carers, including a directory of local carers centres and support groups

Tel: 0808 808 7777

<https://www.carersuk.org/Scotland>

Publications that people with M.E. have found useful

Better recovery from viral illnesses by Dr Darrel Ho-Yen

Fighting fatigue: managing the symptoms of CFS/M.E. by Sue Pemberton and Catherine Berry

Arthritis Care produces a guide to gentle exercises for people with chronic pain

www.arthritiscare.org.uk/what-is-arthritis/resources/218-exercise-and-arthritis

Campaign resources

Action for M.E. raises awareness and understanding of M.E., and our campaign toolkits can be downloaded free from our website.

www.actionforme.org.uk/make-a-difference

#MEAction

An international network of patients empowering each other to fight for health equality for M.E.

www.meaction.net

Health Rising

A website dedicated to providing timely, accurate information to people with M.E., with articles focusing on research and advocacy.

www.cortjohnson.org

Healthcare resources

Managing M.E.: a guide for GPs in Scotland is a booklet published by Action for M.E.

www.actionforme.org.uk/health-and-care-professionals

The Scottish Good Practice Statement on M.E./CFS provides GPs with guidance to assist with the diagnosis and clinical management of patients with M.E.

www.show.scot.nhs.uk/scottish-good-practice-statement-on-me-cfs

NHS 24 is Scotland's national telehealth and telecare organisation

Tel: 111

www.nhs24.com

NHS Inform is the national NHS quality-controlled health and care information for Scotland

www.nhsinform.co.uk

Patient Opinion is an independent service endorsed by NHS Scotland which allows patients to leave feedback and receive responses through a dedicated website

www.patientopinion.org.uk/services/nhs-scotland

Patient Advice and Support Service

Delivered by Citizens Advice Scotland, this provides free, confidential information, advice and support to anyone who uses the NHS in Scotland.

www.patientadvicescotland.org.uk

Welfare benefits advice

Action for M.E.'s Welfare Advice and Support Service offers expert, confidential welfare benefit advice to people affected by M.E. in the UK.

Tel: 0800 138 6544

Email: welfare@actionforme.org.uk

Citizens Advice Scotland offers confidential, face-to-face advice on everything from consumer rights to welfare benefit payments. Appointments should be booked in advance as early as possible as waiting times can be long.

Tel: 0808 800 9060

www.adviceguide.org.uk/scotland

Employment support

Advisory, Conciliation and Arbitration Service (ACAS) provides free and impartial information, advice, training, conciliation and other services for employers and employees in the UK to help prevent or resolve workplace problems.

Tel: 0300 123 1100

www.acas.org.uk

Access to Work is a UK Government service that offers free assessment for practical support to enable people with disabilities and long term conditions to start working, stay in work or move into self-employment.

Tel: 0345 268 8489

www.gov.uk/access-to-work/overview

Jobcentre Plus is a UK Government service offering employment support

Tel: 0800 055 6688

www.gov.uk/contact-jobcentre-plus

Space for personal notes

Space for personal notes

Acknowledgements and afterword

Action for M.E. is grateful to all those who attended *Living and learning with M.E.* project discussion sessions in Edinburgh during September to November 2015. Without these contributions this guide would not exist. Thank you also to our medical advisers and volunteers for the time and energy they committed to reviewing this resource.

Thank you to the Health and Social Alliance Scotland for funding the project through the Self-Management Impact Fund and to the Scottish Government for hosting the sessions.

As a result of *Living and learning with M.E.*, Action for M.E. is undertaking a five-year project to set up a peer mentoring network for people with M.E. in Scotland.

"I regard learning to manage M.E. as my 'Mount Everest.'"



42 Temple Street
Keynsham
BS31 1EH

T 0117 927 9551

E admin@actionforme.org.uk
www.actionforme.org.uk

 www.facebook.com/actionforme

 www.twitter.com/actionforme

Registered charity

Registered charity in England and Wales no. 1036419

Registered in Scotland no. SC040452

Company limited by guarantee, registered in England no. 2906840

©Action for M.E. April 2016