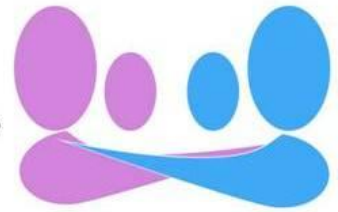


Hampshire Friends With M.E.



www.friendswithme.org.uk

Registered Charity No. 1101610

Information Sheet 1: Living Well with ME/CFS

© Hampshire Friends with M.E. 2017 all rights reserved. May not be used without acknowledgement or copied without permission

When there aren't agreed treatments, or sometimes even understanding from medical professionals, the best strategy when you have ME/CFS is to become expert in what helps you. Taking a holistic approach to self-management can greatly improve your quality of life. This can seem like a huge task but, done one step at a time, it's a good way to take some control.

These are all things that many people with ME/CFS have found helpful. Remember we are all different so what works for one doesn't always work for another, and you may need to try a few things out to find what suits you best: (see separate sheet for 'Pacing for ME/CFS')

Acceptance and Self-Compassion.

Before you can consider making changes you will need to accept that you have ME/CFS. This may seem difficult but the common response of 'fighting' it and trying to carry on as before can result in becoming more seriously ill. When you slow down and start to listen to your body you can begin to notice when you have overdone it, when you need to rest, what makes things worse and what helps. ME/CFS is a real physical illness that affects every part of life and wishing you don't have it won't change that. Acceptance does not mean giving up; it means that you are being realistic about your situation and it is from the point of acceptance that things can start to improve as you learn ways to live *with* ME/CFS.

It can be hard to have compassion for yourself but being hard on yourself during ill health doesn't help. A useful question is 'What would I say to someone else in my situation?' We often find it easier to say to others 'You are doing your best', 'It's ok, you are ill', 'it must be so difficult'....Try turning this around for you. Living with the uncertainty and unpredictability of ME/CFS is extremely challenging, being kind to yourself and acknowledging how you cope day to day will help you stay positive. If you struggle with guilt, poor self-esteem and anger see the 'emotional support' section below.

Relaxation & Rest.

Things you found relaxing before your illness (watching TV, socialising, gaming) may now overstimulate and increase symptoms, so a new approach to relaxation is useful. We are all different, so you need to work out what feels restful to you. Here are some tips:

- When you do the activity, do you feel calm?

- Do you quickly notice an increase in brain fog or feel your energy draining away? If so, the activity may not be giving you what you need.
- Can you focus on it completely, losing yourself in it? 'Flow' activities are things we can get completely absorbed in, which can be very restful and even rejuvenating.

Try something new, or maybe things you used to love, such as drawing, guided visualisation, crafts, writing, listening to music, podcasts or audiobooks. Doing absolutely nothing, just being, is the ultimate relaxation but may not feel restful if your mind is racing or you are in pain, which leads us on to mindfulness.

Mindfulness.

Mindfulness is a way of life rather than a technique, and develops your ability to focus the mind in the 'here and now' rather than getting lost in thoughts and worries, living more in the present moment. It is not about avoiding difficult emotions or sensations, but the practice of being with them and accepting whatever is happening at any given moment by observing, without becoming overwhelmed. There is a huge body of evidence showing that mindfulness meditation is beneficial to everyone's mental and physical health, improving sleep, boosting the immune system, reducing anxiety, and assisting in pain management.

With regular practice, it is scientifically proven to calm the nervous system, which is very beneficial for people with ME/CFS, and can transform your experience of living with chronic illness, helping you reconnect with life's simple pleasures. Mindfulness can be practised by bringing attention to your breath or senses; during activities, and in formal sitting meditation and there are various ways to learn from free downloads online, through apps to CD's or attending groups and courses. See below for resources.

Self-care and Assertiveness.

If you struggle to take care of yourself it can be hard to consider your own needs and try self-management strategies. You may need to identify what's getting in your way: is it a role such as 'carer' or 'breadwinner'; a belief you must be 'strong' for others; lack of self-worth: 'I don't deserve to spend time on me'? Vocalising your needs, learning to say 'no' and put yourself into decision making can be hard, but the payoff also benefits others if it means you can better manage your illness.

It's helpful to develop the ability to get in touch with your gut instinct when someone asks you something: did you feel dread but quickly override it with 'I should say yes because they want/need me to'? One strategy when asked a favour or to a social event is to buy yourself some time by saying: 'Can I think about it and get back to you?' You can then weigh up whether you think it is worth it in terms of payback, what help you might be able to get and what changes you might make to minimize impact.

It can take practice and repetition to assert your needs, if you find it really hard it may be worth seeing a counsellor experienced in working with people who have chronic physical illness to explore any blocks you have to looking after yourself.

Gentle Movement.

This can be anything from stretching and movement exercises at home to going to a gentle yoga class if you can manage it. If you have mild to moderate ME/CFS, short gentle walks outside can be beneficial as long as with all other activities, you stay well within your current level of stamina. (see 'Pacing for ME/CFS' sheet). If you spend most of your time lying down but can sit in a chair with your feet on the floor this is a good thing to do. Keeping the body mobile is important even when you are ill as changes to muscles and posture in sedentary people are rapid, and can actually increase pain, tension and fatigue and may bring other health problems.

Diaphragmatic Breathing.

Although we all breathe continually, when ill, anxious or in pain we tend to breathe less deeply, which can make us feel even worse. This is a simple deep breathing technique that has multiple benefits: you can do it in any situation to help ground yourself, focus and relax by increasing oxygen flow to the brain and body.

Place one hand on the chest and one on the belly, noticing which moves the most with the breath. Then breathe as deeply as you can, imagining there is a balloon in your stomach that you are trying to inflate. The hand on your belly moves the most when you are breathing as deeply as possible. Practice this for 5 minutes a few times a day until it becomes automatic. Other techniques and even courses are available, and yoga and mindfulness also involve focussing on the breathing.

Sleep Hygiene.

People with ME/CFS usually have disordered sleep, whether disturbed, under or over-sleeping. It's also easy to develop poor sleep habits when you are ill. Here are some ideas to help support you to wind down in the evening and maintain a good sleep routine, suitable depending on the severity of your illness:

- Set an alarm and go to sleep and wake up at the same time every day.
- If you can get up and rest in a living room chair rather than lying down during the day do so, this helps you associate sleep with your bed and night time.

- If you can possibly manage, don't sleep for longer than 20 minutes during the day as this can affect the quality of your night-time sleep, further disrupting your sleep/wake cycle.
- Get some sunlight during the day if you can and lower the lights in the evening, this supports the body's natural circadian rhythm.

- Avoid alcohol, caffeine and cigarettes in the evening, they all reduce sleep quality.
- Avoid stimulation (internet; emotive conversation; TV drama) in the two hours before sleep.
- Keep your bedroom quiet, cool & dark and only for sleep.

- Don't go to bed hungry or eat a heavy meal close to bedtime.
- Turn mobile phone, tablet or laptop off at least one hour before sleep and don't use them if you wake in the night. The combination of stimulating content and light they emit is the enemy of sleep.

- Follow a similar routine for winding down (bath, reading, relaxation CD...) at the same time each evening, this helps the brain prepare for sleep.

Eating for Energy Management.

Unbalanced blood sugar is often a problem for people who have ME/CFS. This contributes to energy crashes, and low energy means craving sugary foods which further disrupt blood sugar, maintaining a cycle of imbalance. While changing your eating won't cure ME/CFS unfortunately how we eat can exacerbate symptoms, so some knowledge about how foods release energy in the body can be beneficial.

The Glycaemic Index (G.I.) was designed to help people with diabetes manage their blood sugar levels and its principles have been shown to reduce anxiety, heart disease and many other health problems in the general population. Basing your diet on slower releasing wholefoods (oats, brown basmati rice, beans) and being mindful of eating sugary and fast releasing carbs can help you balance the energy dips food can bring. Eating regularly and having small amounts of protein with every meal and snack can help.

It is also important to be aware of what you drink. When you have fatigue it is tempting to drink stimulating caffeinated tea, coffee, soda and energy drinks but these can all contribute to energy crashes because they disrupt blood sugar levels. If you can still tolerate alcohol be aware of the difference in sugar levels between drinks. Also bear in mind that alcohol is a depressant that disrupts deep sleep. Keeping well hydrated with water and sugar/caffeine-free drinks is very important as this can also affect levels of fatigue and brain fog. (for more on nutrition and ME/CFS see 'Alternative Approaches to ME/CFS' sheet.)

Emotional Support.

The emotional impact of ME/CFS - fear, anger, frustration, loneliness, guilt, sadness, grief - can be the hardest thing about it, and paying attention to this is central to how you cope. Anxiety and depression are common as a result of living with the challenges of any chronic physical illness and suicide risk is increased in people with ME/CFS making mental wellbeing a vital area of self-care.

Support can be found in a variety of ways: keeping a diary of your feelings; social media can be a great community for people with ME/CFS; local support groups to meet others who are going through similar challenges; friends who also live with chronic conditions; improving the understanding of someone close to you; talking to trusted person; being open with supportive Health Care Professionals, if you have them, and speaking to a GP or calling or emailing the Samaritans if you feel suicidal.

Counselling with a therapist experienced in working with people with ME/CFS can really help if you are struggling with your natural emotional reactions to your illness; the impact on your relationships; losses you have experienced; feelings of anxiety or low mood, or adjusting to disability. Such a therapist won't be aiming to 'treat' your ME/CFS so a good question to ask is 'what do you think ME/CFS is and how can you help me with it?' However, just as for people living with cancer, epilepsy, chronic pain, and many other disabling physical conditions, psychological therapy can be very effective in developing coping skills and protecting your mental health.

Conclusion.

These are all strategies you can try that can improve your quality of life as you live with ME/CFS. They are not expensive, won't do you harm and there is plenty of free information about them available online. It is usual to find that a combination of things tried gently and with patience, to give yourself a chance to see their effect, is the best approach to finding out what works for you.

Resources.

Mindfulness:

Free guided mindfulness meditations **UCLA Mindful Awareness Research Center** website
<http://marc.ucla.edu/body.cfm?id=22>

Book '**Living Well with Pain & Illness - The mindful way to free yourself from pain & suffering**' by Vidyamala Burch, 2008, Piatkus, London is a great resource.

A free introductory mindfulness course is available by **Headspace** via a free app:
<https://www.headspace.com/>.

Gentle Movement:

Yoga for Energy and ME/CFS online resource, books and DVD's <http://fionaagombar.co.uk/>

Eating for energy management:

Book on the Glycaemic Index: Dr Anthony Leeds, Prof. Jennie Brand Miller, Kaye Foster-Powell and Dr Stephen Colagiuri (2003) **The New Glucose Revolution** (Third edition) London: Hodder & Stoughton.

Emotional Support:

To find a counsellor who has completed Vicky Mould's ME/CFS awareness training

'Working with ME in Counselling':

<http://www.azaleacounselling.net/phdi/p1.nsf/supppages/6756?opendocument&part=5>

British Association for Counselling & Psychotherapy (BACP) online directory for local counsellors
'It's Good to Talk' <http://www.itsgoodtotalk.org.uk/>

Samaritans free telephone support 365 days a year 24 hours a day. Call **116 123** or email jo@samaritans.org

Written by Patron of Hampshire Friends with ME Elizabeth Turp www.elizabethturp.co.uk Twitter @lizahpool