

Understanding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

South West London and Surrey Chronic Fatigue Service

What is Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Myalgic Encephalomyelitis (ME) / Chronic fatigue syndrome (CFS) is an illness characterised by:

- Extreme fatigue
- Post exertional malaise
- Sleep disturbance and non-restorative sleep
- Swollen glands and/or sore throat
- Muscle and joint aches and pains
- Impaired concentration and memory
- Mood changes

It is possible to have other illnesses at the same time such as fibromyalgia, irritable bowel syndrome, gynaecological problems, diabetes, anxiety and/or depression.

What causes ME/CFS?

It is not fully understood why people develop ME/CFS but there are some possible causes. These include:

- Persistent viral infection
- Immune disturbance of unknown cause
- Disturbance of the HPA (hypothalamic pituitary axis)
- Primary muscle/nerve disease
- Primary central nervous system disease
- Autonomic nervous system disease
- Prolonged and persistent stress

What are the physical effects of ME/CFS?

The increased fatigue that people with ME/CFS experience usually leads them to take prolonged rest. This prolonged rest has physical consequences. Medical investigations show that there is no disease cause for these physical symptoms. They are related to the dysregulation of several body systems in particular the autonomic nervous system, HPA axis and the immune system. Coping strategies such as prolonged rest and inactivity can inadvertently maintain the symptoms.

The physical effects include:

- Changes in muscle functioning resulting in pain and discomfort
- Changes in body temperature, for example hot flushes and night sweats
- Reduced ability to exercise
- Deconditioning of heart and blood vessels
- Impairment of immune system leading to reduced ability to fight off viral infections
- Changes in body rhythms affecting secretion of hormones leading to problems with sleep, appetite and alertness
- Changes in the nervous system causing hypersensitivity leading to problems such as intolerance to sound and light
- Changes in mental function such as reduced concentration or impaired short term memory

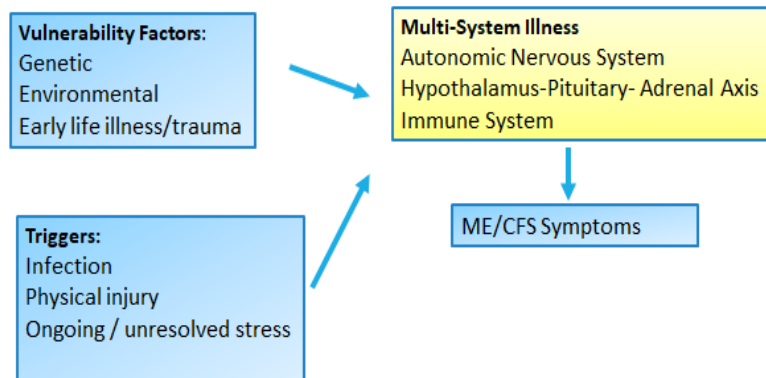
Are stress and anxiety involved in ME/CFS?

Having ME/CFS may be very stressful, not only may a person be feeling unwell but they may also be dealing with other concerns related to their illness, such as financial worries caused by reducing or stopping work, or concerns about the effects their illness is having on their family.

Anxiety is a normal physical response to a stressful situation. When someone is anxious there is increased activity of the central nervous system causing higher levels of adrenaline in the blood stream. Physical symptoms result which include:

- Increased heart rate / alteration in blood flow
- Breathlessness leading to light-headedness, dizziness, faintness, feeling unsteady, blurred vision, pins and needles, muscle spasms, sensitivity to light and noise
- Muscle tension
- Sweating
- Sleep disturbance
- Changes in mental functioning such as irritability, forgetfulness, restlessness and rumination

Multi-System Illness Model of ME/CFS



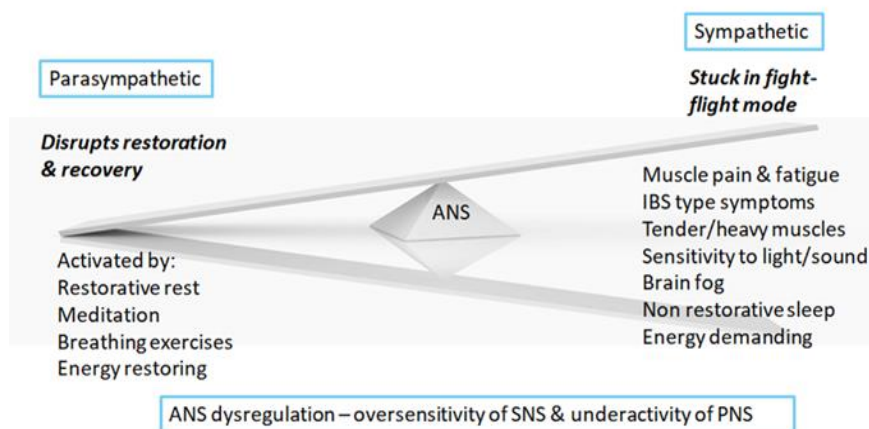
This diagram shows how a number of vulnerability factors and triggers lead to dysregulation in multiple body systems. One of the key systems that is dysregulated is the autonomic nervous system.

The Autonomic Nervous System (ANS) controls the automatic functions of the body that we do not consciously think about such as breathing rate, heart rate, blood pressure, digestion and dilation of pupils. The autonomic nervous system is divided into 2 opposing sections

1. Sympathetic nervous system (SNS) – energy demanding, this stimulates the fight or flight response.
2. Parasympathetic nervous system (PNS) – is energy conserving, the rest and digest response.

The Autonomic Nervous System balances the sympathetic (fight or flight) response with the parasympathetic (rest and digest) response. The Autonomic Nervous System is thought to be dysregulated or out of balance in ME/CFS patients. This leads to oversensitivity of the sympathetic nervous system (SNS) and underactivity of the parasympathetic nervous system (PNS). Therefore, the body becomes stuck in fight or flight mode even when resting or sleeping. The consequences of this can help to explain some of the ME/CFS symptoms. See the diagram below.

Autonomic Nervous System



Dysregulation of these systems leaves a person feeling both physical unwell and mentally fatigued. The diagram above shows that the parasympathetic nervous system can be activated by restorative rest, meditation and breathing exercises. This will help to reset the autonomic nervous system balance.

How can ME/CFS be managed?

As there is no medical cure for ME/CFS, management of symptoms is aimed at breaking the virus, stress, fatigue and autonomic nervous system cycle, to aid recovery and improve one's quality of life. However, making changes is initially challenging but should help you to improve your overall quality of life in the longer term. Making changes is a bit like getting a new pair of slippers, they may not be comfortable at first, but over time the more you wear them the more comfortable they become. Making changes and forming new habits can be uncomfortable but eventually they can become second nature just like the old ones.

Using a biopsychosocial model of care provides a framework which addresses all aspects of one's life to promote lasting change.

This is achieved through implementing a range of techniques and strategies which include:

1. Cognitive behavioural therapy
2. Deep relaxation/Mindfulness
3. Pacing and grading activity
4. Medications

What is the Biopsychosocial model?

'**Biopsychosocial**' is a term we use to understand the various factors that affect people with ME/CFS. As you will have experienced, your ME/CFS causes many different symptoms and influences many different parts of your life.

For example, when you have ME/CFS you are:

- physically unwell and have several **biological** symptoms – fatigue and pain
- you may feel less like your normal self and more unhappy – **psychological**
- you may not feel able to see friends as much – **social**

Whatever is happening to your body **physically** (e.g. fatigue, pain, dizziness) is also having a knock-on effect **psychologically** (changes in the way you feel and behave) and **socially** (changes in activity, working life, seeing friends). In addition, the psychological and social consequences can further aggravate your symptoms of ME/CFS. It is important to understand how ME/CFS affects these aspects of your life (not just the physical symptoms) in order to help you improve the quality of your life.

1. What is Cognitive Behavioural Therapy (CBT)?

Despite ME/CFS being defined as a physical illness, seeing a psychologist can be helpful as the mind and the body are interlinked. Living with a range of ME/CFS related symptoms produce a whole range of thoughts and feelings as you learn to adjust living with this long term illness.

CBT is a model used to help explain the interactions between our physical states (ME/CFS symptoms) with our cognitions (or thoughts), our feelings, and our behaviours. Understanding how your thoughts and feelings influence your behaviour, can help you to identify which behaviours are helpful and which unhelpful in your management of ME/CFS. Therefore, looking at thoughts and feelings does not mean that ME/CFS is a psychological problem or that it is 'all in your head' – ME/CFS is a physical illness requiring a broader intervention.

CBT has been used as an aid to help in management of other conditions such as chronic pain, cardiac rehabilitation, diabetes, and cancer as well as anxiety, depression and phobias. There is also increasing evidence of the effectiveness of third wave CBT approaches for long term health conditions such as Acceptance and Commitment Therapy (ACT) and Compassion Focussed Therapy (CFT).

Psychological interventions can help you:

- Accept your diagnosis
- Feel more in control of your symptoms
- Challenge or work on accepting those thoughts and feelings that could interfere with your ability to manage your ME/CFS.
- Gain a better understanding of how your behaviour can affect the condition

You will have an opportunity to look at how you are managing the difficulties associated with ME/CFS and how to improve your coping strategies. You will be supported to make and maintain changes to help you live a life according to your values and what is important for you.

2. Why is deep relaxation important?

People with ME/CFS often have a state of mental hyperactivity that makes sleeping difficult and also impairs their concentration and short term memory. This means that they are unable to truly relax and in consequence they suffer a heavy and draining demand on their mental and physical energy.

Interestingly, this persistent neural hyperactivity may explain the phenomenon of 'crowding' and 'brain fog' that many patients with ME/CFS suffer in crowded or busy situations.

For these reasons it is important for those with ME/CFS to practice some form of deep relaxation therapy daily. This can be done using guided relaxation, mindfulness, meditation, yoga or self-hypnosis,.

An easy and economical way to get started with deep relaxation is to use a free app on your smartphone that use techniques such as breathing exercises, visualisation and muscular relaxation exercises to help learn to relax or find techniques from "YouTube"

Why are breathing exercises recommended in ME/CFS?

When the Autonomic Nervous System is out of balance and the body is in flight and fight mode, your body needs to maximise the amount of oxygen that gets to the muscles so you can either fight or run away. Two things happen to help this:

- Your breathing rate increases and you take smaller shallower breaths so your breathing is more rapid to increase oxygen intake
- Your heart rate rises so you can pump oxygenated blood quicker

This means that your breathing becomes less efficient.

If you do not use this extra oxygen by running or fighting there is temporarily an imbalance in the amount of oxygen and carbon dioxide in our blood

This can cause you to feel faint, dizzy, tingling and to feel palpitations or to have a tight chest. Sometimes people feel like they are looking in on themselves.

Learning relaxed efficient breathing can help to slow down your breathing, redress the imbalance of oxygen and carbon dioxide and can help to switch on the 'rest & digest' parasympathetic response to balance the flight and fight

Controlling the rate of breathing and correcting the low carbon dioxide level could therefore be an important tool to use in the management of Chronic Fatigue Syndrome.

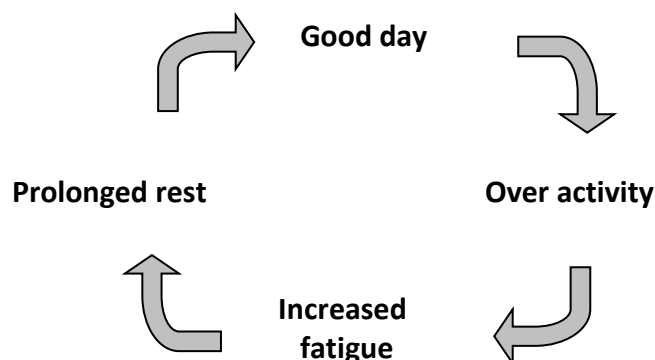
The control of breathing has been found helpful by several of our patients with severe Chronic Fatigue Syndrome where, in addition to relieving the tiredness, it has helped to reduce muscle aching and spasms and contributed to an improvement in concentration and stamina

3. Why is pacing and grading activity important?

Pacing and grading activity can help those with ME/CFS break the **Activity Cycle**.

People with ME/CFS have fluctuating levels of energy and often intuitively manage their activity to match these energy levels, attempting to do too much on a 'good' day and much less on a 'bad' day. This can result in pushing through on a good day when energy levels are high and crashing on a bad day. After a period of rest, feelings of frustration and despair often follow this. This is referred to as the **boom and bust cycle** or **activity cycling**. This can interfere with improving energy levels and contribute to maintaining fatigue.

A diagram illustrating the activity cycle



Sometimes people fall into an activity pattern called 'walking off the cliff'; this is common with people that are working or have regular week day commitments. In this pattern people tend to push through early warning signs and increasing symptoms to meet their commitments during the week and then crash at the weekend.

4. What is Activity Management?

We know that for some individuals with ME/CFS in the early stages of their illness they experienced prolonged periods of inactivity where the amount of physical activity they are able to do decreases, and the body naturally adapts to a lower level of activity. This is a normal adaptation and causes changes in our cardiovascular system and to our muscles – you may sometimes hear this referred to as deconditioning.

It is important to take some time to understand your normal pattern of activity – are you activity cycling or walking off the cliff? Are you doing all your activity together? Which activities drain my energy the most? Activity management involves pacing activity – spreading key activities across the week and balancing high/moderate level activities with lower level activities, soothing activities and rest, breaking activities down into manageable chunks and keeping a good sleep routine. This helps to establish and maintain a baseline upon which build activity levels.

Building activity levels is then done with an individualized programme to establish small incremental changes in activity levels that are repeatable and can be maintained to slowly work towards an agreed physical or lifestyle goal.

5. Are medicines useful in ME/CFS?

There is no cure for ME/CFS but sometimes medicines may be used to help relieve symptoms or aid recovery.

Due to the nature of ME/CFS and the multiple sensitivities some individuals' experience, many people with ME/CFS are intolerant to any drug therapy leaving no alternative but lifestyle management.

Of those patients who are able to tolerate medication and have shown improvement, the effect is not always long lasting.

Benefit with medication is usually seen within the first four to eight weeks. If there is no benefit within this period it is unlikely that the therapy is going to work.

What medicines are used in ME/CFS?

Different medicines are used depending on the symptom being treated. We would encourage your GP to access the British Association for ME/CFS: Therapy and Symptom Management in ME/CFS at www.bacme.info

Getting Started - Managing your ME/CFS.

South West London and Surrey Chronic Fatigue Service

Following a diagnosis of Chronic Fatigue Syndrome (ME/CFS), people often describe experiencing a number of mixed feelings. These may include feeling relieved that their symptoms are finally validated and at the same time feeling anxious, or angry, or sad in relation to learning to live with a chronic condition.

There is often a lot of information to take in at this stage. Most of the information we share on the management of ME/CFS is covered in our comprehensive website www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome.

This handout has specifically been designed to help you know what you can do to get started in managing your ME/CFS symptoms and includes information on:

- Activity Management
- Sleep Management
- Implementing Rest and Relaxation
- Breathing exercises

Activity Management

ME/CFS symptoms often fluctuate which can have a direct impact on what you feel you can do in your day. It is common for people to report that they find themselves doing more on their 'good days' which increases their risk of post exertional malaise often resulting in being able to do little or rest for long periods to recover. This activity pattern is called 'boom and bust'.

Some people with chronic fatigue no longer have good days and end up being able to manage low levels of activity only with long rest periods. Avoiding or reducing what you do as a way of controlling your symptoms often may help in the short term; however, it can prevent you from longer term gains of energy improvement. Prolonged rest can produce weakness and loss of strength (deconditioning) and fatigue. It can also result in a reduction of activity, feelings of demoralization, loss of control and a very restricted life.

- The first important goal is to establish a consistent level of activity across the week.
- Doing too much or too little are both problematic with the management of ME/CFS.
- An activity diary is a useful way to help you to record the time you spend in activity, rest and sleep each day over the course of two weeks.

(See Completing Activity, Rest & Sleep Diary information pack).

You can use this information to calculate your baseline (or an average) of how much activity you can do on a good and a bad day (that causes less suffering related to your fatigue).

This may result in you:

1. Reducing your activity in the first instance
2. Learning how to pace your activity with small chunks of activity followed by rest breaks
3. Using a graded/incremental approach to increase your activity.

The diaries can also help you aim to establish consistency with your rest and sleep at night. (See the rest and sleep sections in this handout). Another way to establish a consistent activity level is by using a step counter.

Once you have successfully stabilised your activity (which may take some time), you can then start to gradually increase your activity. An incremental approach is recommended where every 2-3 weeks, you can increase your activity by no more than 10-20%. If you experience a bad day with your ME/CFS, it is recommended to remain at your activity level (with an increase in rest breaks) and delay any planned incremental increase.

Remember to try to include a pleasurable or meaningful activity daily.

Sleep Management

Difficulty with sleep, e.g. unrefreshing sleep, is common for people with ME/CFS. Often people think that if they are tired they need sleep, but fatigue in ME/CFS is not improved by sleep.

The quality of sleep is likely to have a significant impact on fatigue levels during the day. Here are a few key tips for improving your quality of sleep:

- Establishing a regular sleep pattern is very important so try to wake up and go to bed at the same time (within an hour) to synchronise your body clock.
- Have a wind down period prior to going to bed to help cue your body it is time to sleep, e.g. stop work at least 30 minutes before going to bed and do something non-stressful, e.g. read, have a bath, listen to music, listen to a relaxation CD.
- Try to use your bedroom only for sleep. Activities such as reading, eating, watching T.V., and talking about problems are likely to make you associate bed with wakefulness and alertness which may interfere with you getting to sleep.
- Avoid cat napping during the day as this can lead to over sleeping or not being able to sleep at night.
- Make your sleeping environment conducive to sleep. Minimise noise and light, bedroom temperature should be cool, take a light bedtime snack such as a warm glass of milk or a banana, avoid stimulants like caffeine after 4pm, or write down any worry thoughts before you go to sleep.

Resolving sleep problems takes time and requires effort. Try one thing at a time and whilst your sleep routine may never be perfect, any improvement in your sleep routine can be beneficial and can lead to an improvement in ME/CFS symptoms.

Implementing Rest and Relaxation.

Rest is an important aspect of pacing activity. We can say that we are resting when there is minimal brain and body activity and when we are “re-charging”. Relaxation is a form of rest. All activities require some level of energy. Activities such as watching television and reading are still quite demanding in terms of energy use although are less demanding than going out shopping or doing housework.

- Taking short regular frequent rest breaks throughout your entire day can help sustain your energy across your day.
- Rest is about reducing stimulation both mentally and physically. – Quiet time.
- You can rest sitting up or lying down. Try not to rest on the bed you sleep on as you are more likely to fall asleep.

- Have a go at implementing short frequent regular rest breaks throughout your day. (i.e. 5 – 10 mins) dispersed between activity.
- Try to be proactive with your rest breaks; don't wait until you have run out of energy.

Relaxation is an ideal form of rest as it enables the body to re-charge and to gain back some energy. As well as providing effective rest, relaxation helps in the management of anxiety by decreasing muscle tension and stressful thoughts. It can also help reduce adrenaline levels which results in symptoms such as brain fog, mental crowding, impaired attention and therefore memory, fatigue and general symptoms of adrenaline such as pounding heart, pins and needles, temperature fluctuations.

Relaxation helps with fatigue and improving sleep patterns as well as preventing 'sensory overload'. Relaxation is an important tool in helping people with pain control. Incorporating regular rest and relaxation breaks into your daily routine assists with pacing activities, helps restore energy and enables you to feel more in control of managing your symptoms.

- Daily – set a manageable goal. E.g. 10 minutes a day.
- Try to schedule a relaxation break earlier in the day; this may reduce likelihood of falling asleep.
- Avoid undertaking directly after meal times or using your bed (sleep space) as you are more likely to fall asleep.
- If you are likely to fall asleep – set an alarm.
- Trial various techniques to find the style that will suit you and will be easier maintain, e.g. breathing exercises, visualisation, progressive muscular relaxation. Guided relaxation in the form of "You Tube", smart phone apps or CDs may be helpful.
- Be comfortable – warm environment, consider a supported sitting or a lying position.
- Remember, relaxation is not watching TV, reading, listening to music.

People differ in the techniques that they find useful so it can be worth trying several (You can access a variety of different techniques via YouTube or smartphone Apps). Relaxation is a skill and takes time and practice, so it is important to persist with it. The more opportunity you have to practice, the more benefit you will notice. Lying positions give a great deal more rest than sitting positions. Remember that rest is giving the brain minimal information from the body or from the mind. When you sit your balance reactions are constantly sending information to the brain. When you lie down the amount of information is greatly reduced. Remember also that closing your eyes reduces the amount of information being sent to the brain.

Breathing Exercises

There are 2 main types of breathing: **Chest** breathing and **Diaphragmatic** breathing.

We tend to use **chest** breathing during exercise and in situations when we are tense or stressed. **Diaphragmatic** breathing is much slower and more calming. This is the best type of breathing for relaxation and also has the advantage of giving our internal organs a gentle massage which helps keep them healthy.

Spend a few minutes practicing some Diaphragmatic breathing as outlined below.

Sitting comfortably, with your shoulders relaxed, place one hand on your upper chest and the other on your stomach, just below your rib cage. As you breathe in through your nose and out through your mouth, notice which hand rises first – the one on your chest or the one on your stomach. This will indicate whether you are breathing from the chest or from the diaphragm.

Focus now on breathing only from the diaphragm. As you inhale, allow the stomach to rise. As you exhale gently, feel your stomach flatten. There should be little or no movement in the chest. Allow yourself a little time to get into a regular rhythm. When you are confident that you are continuing to breathe from the diaphragm, you might want to close your eyes.

Continue the breathing exercise for a few minutes.

Using the guidance it is recommended that the breathing exercises are done daily for 3 months and if helpful can be continued long term.

Additional Resources

South West London and Surrey Chronic Fatigue Service

Books

- Charles Shepherd and Abhijit Chaudhuri (2018) ME/CFS/PVFS An Exploration of Key Clinical Issues. The ME Association.
- David Burns (1999) The Feeling Good Handbook. Penguin.
- Mary Burgess with Trudie Chalder (2009) Overcoming Chronic Fatigue: A Self-help Guide Using Cognitive Behavioural Techniques. Robinson.
- W. Collinge (1994) Recovering from M.E.: A guide to self-empowerment. Souvenir Press.
- Ray Owen (2013) Living with the Enemy: Coping with stress of chronic illness using CBT, mindfulness and acceptance. Routledge.
- Gillian Butler & Tony Hope (2018). Manage Your Mind. The Mental Fitness Guide (3rd Edition). Oxford University Press.
- Dennis Greenberger & Christine A. Padesky. (2015). Mind Over Mood. Change How You Feel By Changing The Way That You Think 2nd Edition. The Guildford Press.
- Jon Kabat-Zinn (2013) Full Catastrophe Living: How to Cope with Stress, Pain and Illness Using Mindfulness Meditation. Piatkus.
- S. Milstrey Wells (2000) A Delicate Balance: Living successfully with Chronic Illness. Da Capo Press.

Video

- Understanding central sensitisation by Dr Sletten
<https://www.youtube.com/watch?v=8defN4ilbho>

Websites

- **EPSOM & ST. HELIER UNIVERSITY HOSPITALS NHS TRUST**
www.epsom-sthelier.nhs.uk/chronic-fatigue-syndrome
- **NICE (The National Institute for Health and Care Excellence) guidelines** – Chronic Fatigue Syndrome (currently under review)
www.nice.org.uk/guidance/conditions-and-diseases/chronic-fatigue-syndrome
- **BACME – British Association for ME/CFS**
www.bacme.info

- **The ME Association**
Tel: 0844 576 5326
www.meassociation.org.uk
admin@meassociation.org.uk
- **ACTION FOR ME- Patient support organisation**
<http://www.afme.org.uk/>
work related information
<http://www.actionforme.org.uk/professionals/employers-and-managers>
To access your local groups go to the main website and search local services using your postcode.
- **Direct Gov Website:**
Provides information under the disabled persons link: on employment, benefits, education, transport, housing, rights and obligations, leisure and travel.
<http://www.direct.gov.uk/en/DisabledPeople/index.htm>

Local Support Groups

There are a number of support groups that can be found via social media.

Popin Club – support group for people with Fibromyalgia, Fatigue and Chronic pain conditions

No 2, 11th Avenue,

Holly Lodge,

Lower Kingswood,

KT20 6SL

Tel: 0844 887 2579 (local rates)

www.fmcppopinclub.wordpress.com

Richmond and Kingston ME group

www.richmondandkingstonmegroup.org

randkmegroup@yahoo.co.uk

Surrey ME/CFS and Fibromyalgia Support Group

www.facebook.com/surreymegroup

Psychological Therapy

For help with depression and anxiety you can self-refer to your local IAPT (Improving Access to Psychological Therapies) or ask your GP for details.

Mindfulness

There are a number of applications available for smart phones/tablets or guidance videos via “YouTube”

Headspace

Calm

Insight timer

Mindfulness

Breathe

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