



The Queen Elizabeth  
Hospital King's Lynn  
NHS Foundation Trust

# Living well with Fibromyalgia Workbook



## Welcome!

We have put this workbook together to help you to live well, despite having fibromyalgia. However long you have been diagnosed and however your life is being affected by this condition, we believe that there is hope!

We have been working with people with fibromyalgia for many years and are passionate about helping people to live their lives well, despite battling a chronic condition. We have listened to what people have told us about what it is like to live with constant pain and disabling fatigue, and the impact on people's lives. We have designed this workbook to address the issues that people tell us are important to them, but we are always learning, so please do let us know if you feel something is missing.

Perhaps you are just trying to get to grips with having this condition, or maybe you have had it for many years, whatever your situation this workbook is designed to help you.

Reading this workbook is not going to change your life – but taking on board what it says and applying those ideas just might make a difference! That is why we have questions for you to answer and sections for you to complete. We hope that you will take the time to read AND apply what you learn.

## Who are we?

### Wendy Hill, Specialist Occupational Therapist



Occupational Therapists focus on helping people to do the things they want to do, despite their health condition. When I started working in the Pain Clinic in 2009, I realised that people with Fibromyalgia had a unique set of difficulties that weren't being fully met by our existing services. I started the "Living Well with Fibromyalgia" group programme to help people manage their lives better. This workbook is based on all that we have learnt since running the groups and we hope that you will find it helpful in enabling you to live your life well.

**Michelle Macartney, Specialist Occupational therapist**

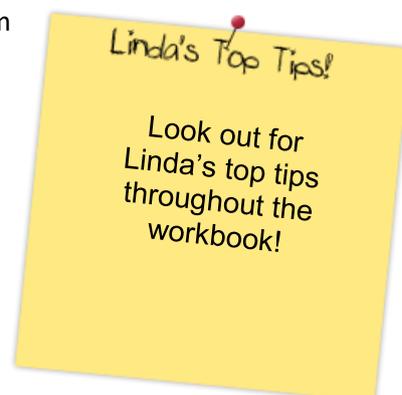
I joined the pain clinic at The Queen Elizabeth Hospital in 2014, having worked in a variety of other settings as an Occupational Therapist prior to this. Having worked with people who have fibromyalgia for the last 6 years, I have learnt that the condition can disrupt a person's life in many different ways. I hope that this workbook will offer you some helpful information about skills and strategies that you can use to enhance your quality of life and enable you to live well with fibromyalgia.

**Dr Louise Robinson, Principal Clinical Psychologist**

I am the Lead Psychologist working within the Pain Clinic and have a specialist interest in working with people living with Fibromyalgia. As a Pain Clinic we think it's important to have Clinical Psychologists like me as part of the team because we recognise that when you live with persistent pain, there is an understandable impact on how you think, feel and behave. It is normal to have an emotional reaction to the changes that have happened in your life as a result of Fibromyalgia. I'll be guiding you through some specific skills and techniques during this workbook to help you take care of your emotional wellbeing as you live alongside the Fibromyalgia condition. I hope you find the workbook useful.

**Linda Brown**

I have lived with Fibromyalgia since 2007 and have been through many stages over the years. Now I have found balance both emotionally and physically and I live a good and happy life. I have been involved in the "Living Well with Fibromyalgia" group since I attended it myself a number of years ago. I found it a great help to me and this workbook contains all the useful information from the group.



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## What is Fibromyalgia?



Perhaps you feel like you understand fibromyalgia really well, or maybe you weren't told much about it at all. Often people are given the diagnosis of fibromyalgia, but are provided with little information about the condition and how to live well with it.

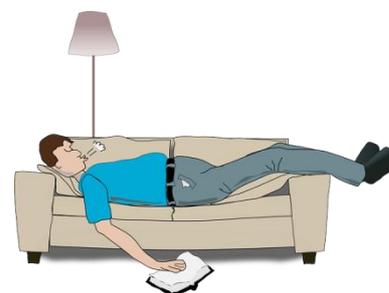
Fibromyalgia is a long term condition that causes widespread body pain and profound fatigue, as well as a range of other possible symptoms. The condition tends to vary from person to person.

Symptoms may also fluctuate from day to day, depending on factors such as stress levels, the weather, or how physically active you have been.

The name fibromyalgia is made up from: fibro = fibrous tissues such as tendons and ligaments; my = muscles; algia = pain

## What are the main symptoms of fibromyalgia?

- **Widespread body pain.** This could be felt as an aching, burning sensation or sharp, stabbing pain throughout the whole body. However, the pain could be worse in particular areas of the body (often those parts most frequently used). The pain is likely to be continuous, but may be better or more severe at different times.
- **Stiffness.** Fibromyalgia can make you feel stiff. Stiffness is likely to be most severe when you have been in the same position for a long period - for example, when you first wake up in the morning.
- **Heightened pain sensitivity.** Fibromyalgia can make you extremely sensitive to pain all over your body. You may find that even the slightest touch is now painful. If you hurt yourself, the pain may continue for much longer than it normally would.
- **Chronic fatigue.** Fibromyalgia can cause extreme tiredness. This can vary from feeling a mild tired feeling to the exhaustion experienced with a flu-like illness. It may come and go. Sometimes severe fatigue may come on suddenly - people can suddenly feel drained of all their energy, as though someone has "pulled out their plug"
- **Sleep disturbance.** Fibromyalgia can affect your sleep. People often wake up feeling tired, even when they have had plenty of sleep. Sometimes sleep can be disturbed by pain or our brains being over active. Some people experience periods of sleeping excessively.



- **Cognitive problems.** Cognitive problems are issues related to mental processes, such as thinking and learning. People with fibromyalgia can experience: difficulty remembering and learning new things, problems with attention and concentration and slow or confused speech. This is sometimes called “brain fog” or “fibro fog”.



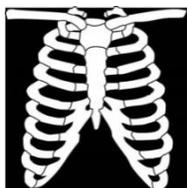
In addition, some people MAY also experience:

- **Headaches** and/or migraines
- **Irritable bowel.** This causes pain and bloating in the stomach and can lead to constipation or diarrhoea. It sometimes separately diagnosed as Irritable Bowel Syndrome (IBS)
- **Dizziness and clumsiness**
- **Strange sensations** like tingling, numbness, prickling or burning sensations in the hands and feet. Sometimes hands and feet can also swell.
- **Feeling too hot or too cold.** This is because you’re not able to regulate your body temperature.
- **Increased sensitivity.** This could include increased sensitivity to hot or cold. temperatures, noise, lights, certain foods, or any other sensory or environmental factors.
- **Restless legs syndrome.** This is an overwhelming urge to move your legs.
- **Low mood.** This can vary from having episodes of feeling sad and fed up to becoming clinically depressed and feeling hopeless and helpless.
- **Feeling more anxious** and stressed.

### Interesting facts about fibromyalgia:

- It is not clear how many people are affected by fibromyalgia as it’s difficult to diagnose. However, it is thought as many as 1 person in 20 may suffer from it.
- It affects around 7 times as many women as men.
- It typically develops between the ages of 30 and 50, but can occur in people of any age, including children and older people.

### How is fibromyalgia diagnosed?



It may have taken you a long time to get a diagnosis of fibromyalgia and you may have had lots of tests to rule out other health conditions. There are no specific blood tests, X-rays or scans that can be carried out to confirm a diagnosis of fibromyalgia.

Doctors will make a diagnosis based on the following symptoms:

- widespread pain lasting three months or more
- fatigue and/or waking up unrefreshed
- problems with thought processes such as memory and concentration



## What causes fibromyalgia?

It's not clear why some people develop fibromyalgia. The exact cause is currently unknown, but it's likely that a number of factors are involved.

Scientists believe the following factors may contribute to its development:

- **Physical or mental trauma** or stress may be a contributing factor as often people report their symptoms started after an illness or accident or following a period of emotional stress. However others can't recall any particular event leading up to the start of their symptoms.
- **Changes in the body's pain pathways** and abnormally low levels of hormones such as serotonin, noradrenaline and dopamine in the brain, are also thought to play a role.
- **Disturbed sleep patterns** may be a cause of fibromyalgia, rather than just a symptom. In an experiment where healthy volunteers were woken during each period of deep sleep, a number of them developed the typical signs and symptoms of fibromyalgia.
- **Genetics** may play a small part in the development of fibromyalgia, with some people perhaps being more likely than others to develop the condition because of their genes.

## Will I get better?

At present, there is no cure for the condition. However, scientists are working hard on understanding the condition better, so they can find a cure.

Evidence from long-term studies suggests that fibromyalgia isn't progressive or degenerative, so doesn't in itself cause any lasting damage to the body's tissues.

Medication can help some people, but doesn't help everyone. People who successfully manage to incorporate self-management strategies into their daily lives, often experience an improvement in what they can do, their quality of life and general well-being. In this workbook we will be looking at various self-management strategies to enable you to live well with fibromyalgia.

## Want to learn more about fibromyalgia?

Look at these websites:

- [www.fmauk.org](http://www.fmauk.org)
- [www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)
- [www.nhs.uk](http://www.nhs.uk)

## What is Pain?

As you will know, pain is one of the main symptoms of fibromyalgia. Scientists' understanding of pain has advanced considerably over the last 25 years. For many years doctors had a simplistic view of pain - that pain either had a physical or psychological cause. This has proven to be wrong, and they now know that pain is much more complex than this. We can use the latest research about pain

to help us learn and understand how to manage our pain more effectively and live well with it. Knowledge is power!

**Understanding your pain is the single most important thing you can do to start on the road to recovery.**

### **What is the purpose of pain? PAIN IS A PROTECTOR**

The purpose of pain is to protect us – to keep us safe. There are number of protective systems in the body, but pain is one of the body's most powerful protective systems. It is like an internal alarm that alerts us to danger. It motivates us to stay safe and take care of any problems in our body. Pain protects us by causing a change in our behaviour.

### **EXAMPLE**

I am walking along and I stand on a drawing pin that goes into my foot; it will be the pain that I experience in my foot, which will stop me from continuing to walk. In other words the pain will change my behaviour - it will make me remove the drawing pin from my foot and take other actions to keep myself safe, such as wash my foot and put a plaster on it.

If I didn't experience the pain, I probably would not realise that I had stood on the drawing pin and continue walking with the pin in my foot. This would likely to cause more damage to the tissues in my foot and possibly result an infection.

Can you see how pain has protected me from these potential dangers?

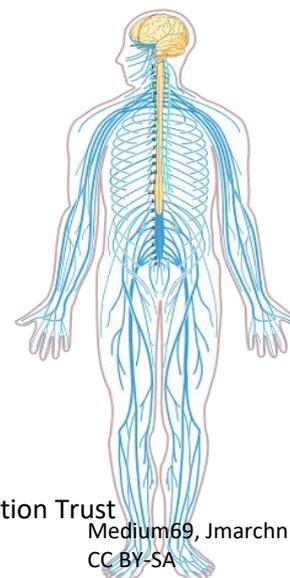
However, scientists have found that pain isn't just related to damage to our body's tissues; it's more complicated than this! Think about people who experience pain in limbs that have been amputated (this is known as phantom limb pain). How can they experience pain in a limb that no longer exists? The purpose of this section of the workbook is to help you understand pain more so that you can learn how to manage it better.

### **How is pain generated in the body?**

Scientists have found that our nervous system is involved in creating pain. Our nervous system consists of our brain, our spinal cord and a network of peripheral nerves which are spread throughout our body.

Sensors, at the end of our peripheral nerves, detect changes in our bodies - for example changes in temperature, pressure, movement. Our sensors send this information via messages (small electrical impulses) to our spinal cord. Our spinal cord then passes the messages onto our brain, to analyse the information and decide if we need to take any action. For example, if the brain receives messages that we're cold, it may decide that we need to put on another jumper or turn up the heating.

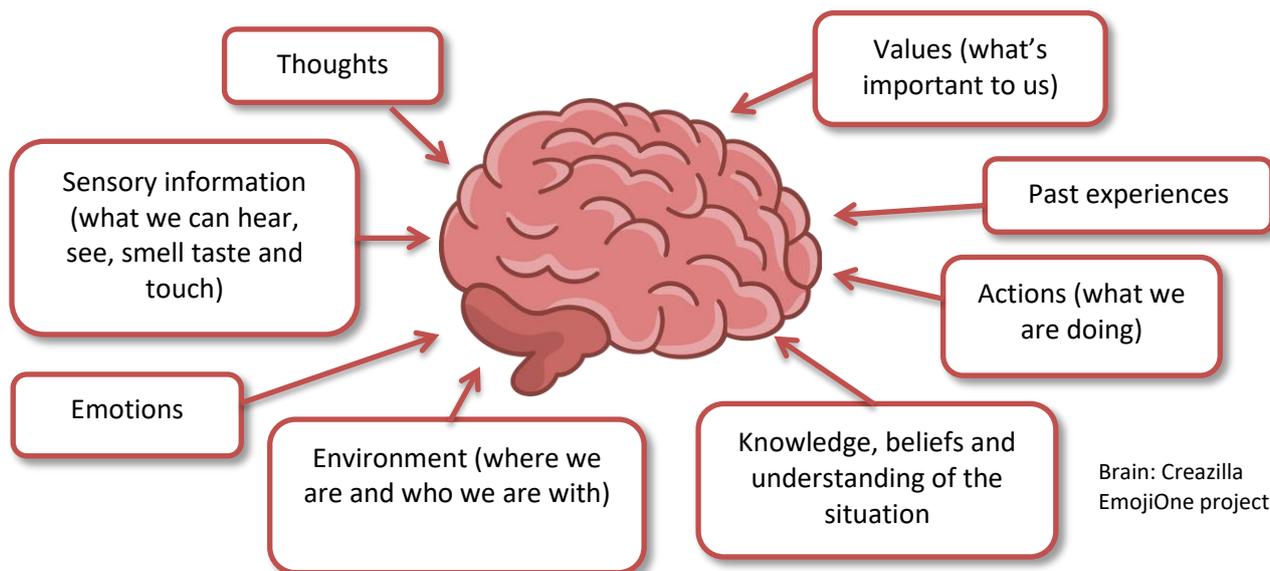
Some of our sensors only send messages when things are getting dangerous or harmful - for example getting too hot, if there's too much



pressure or if a nasty chemical enters the body (such as wasps sting). These danger sensors send warning messages to our brain to analyse.

Scientists have found it is our **brains that decide** whether or not we experience pain, depending upon whether it thinks we are threatened and need protecting.

The brain makes this decision by considering the warning messages it receives from our sensors, as well as other information it receives or has stored. Other factors the brain considers when deciding whether we need protecting include:



The brain analyses and interprets all this information and then decides to whether or not to create pain depending upon whether it thinks we are threatened. Remember, the purpose of pain is to protect us from potential danger! The problem is that sometimes our brain can come to the wrong conclusion and we can experience pain when we are not actually in any danger.

### Are you saying the pain is in my head?

**NO, YOUR PAIN IS REAL.** Just because your brain decides whether you experience pain or not, it does not mean that your pain is imaginary or “in your head”. Scientists have found that brains are always involved in producing pain. There’s no pain without a brain!

## EXAMPLE

One day Professor Lorimer Moseley (a highly acclaimed pain scientist) was walking through the Australian bush chatting with a friend. Whilst walking he felt something touch the outside of his left leg. Thinking nothing of it, he continued walking and chatting, until he suddenly collapsed. He then can't recall anything until he woke up in hospital, only to find out that he'd been bitten by a venomous snake. Luckily, for him he survived.

Several months later, Lorimer went walking in the bush again and was chatting to a friend, when he felt something touch the side of his left leg. Immediately he experienced an excruciating pain, which brought him to the ground. Clutching his leg, he shouted to his friend to call for help as he'd been bitten by a snake again. His friend immediately started looking for the snake, but couldn't find one. His friend then asked to look at his leg. To Lorimer's amazement, there was a small scratch (probably from a stick) on his leg, but no evidence of any snake bite. On realising that he hadn't been bitten by a snake, Lorimer's pain levels immediately started to ease and he was able to complete his walk.

Why did Lorimer not experience pain the first time, when he was in danger, but did the second time, when he wasn't in any danger?

The sensors in Lorimer's leg would have sent the same messages to his brain each time, but the first time his brain remembered that he had walked in the bush many times before and had scratches from bushes without any danger. His brain therefore decided that he was not in danger and so did not need protecting with pain.

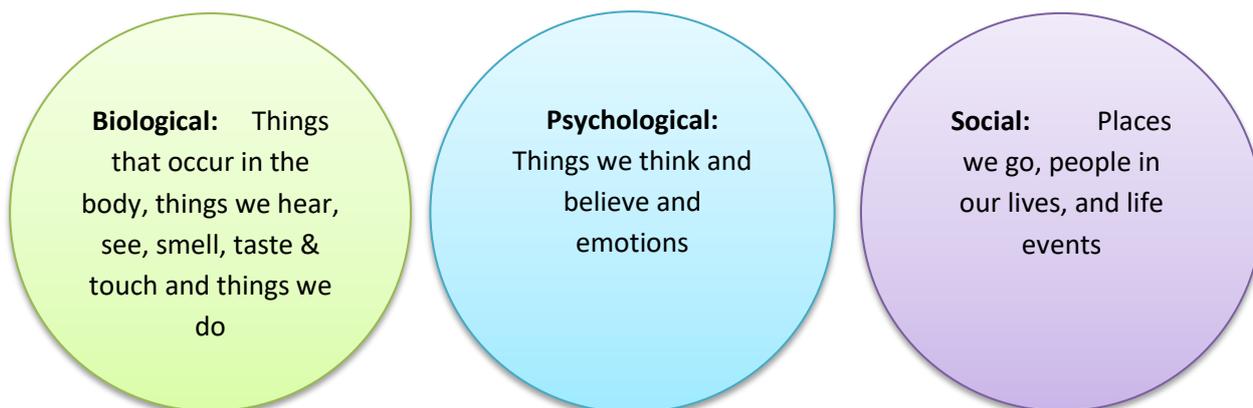
The second time, his brain remembered what had happened the previous time he felt a scratch on his leg, when he had been in danger for his life. So his brain protected him with pain, even though he was not actually in any danger this time.

Can you see from this example how our pain experience is influenced by lots of factors and is not necessarily related to damage to our body's tissues?

Scientists have found that lots of factors influence the pain we experience. In fact they have found that anything that is a threat to our body, our lifestyle, our happiness, or our day to day function, increases the likelihood of our brain producing pain and increases the duration and severity of pain we experience.

However, they have also found that anything that makes us feel safe, stronger, better, healthier, more confident, more secure and certain, reduces the likelihood of our brain producing pain and therefore reduces the duration and severity of pain we experience.

These factors include:



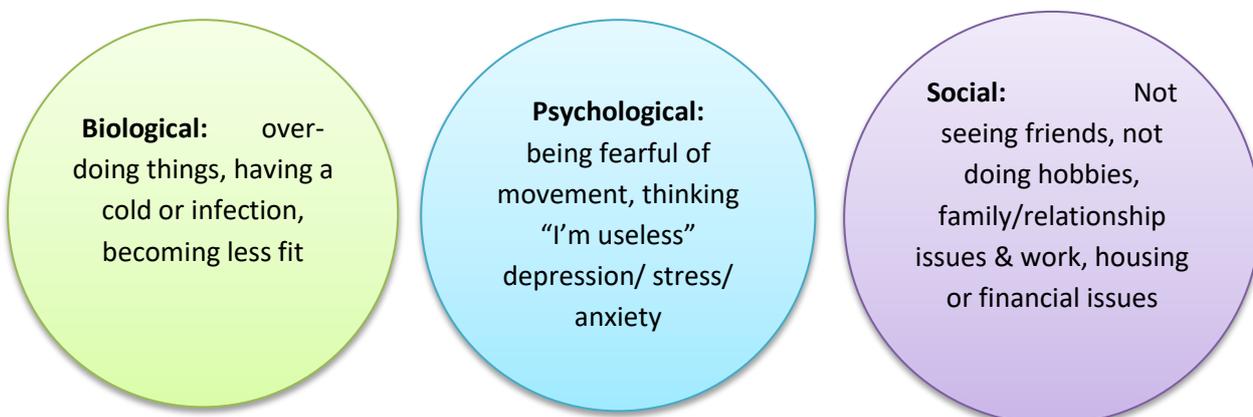
**Biological:** Things that occur in the body, things we hear, see, smell, taste & touch and things we do

**Psychological:** Things we think and believe and emotions

**Social:** Places we go, people in our lives, and life events

This is known as the **biopsychosocial** approach to pain.

Here are some examples of factors that can **increase** our threat level:

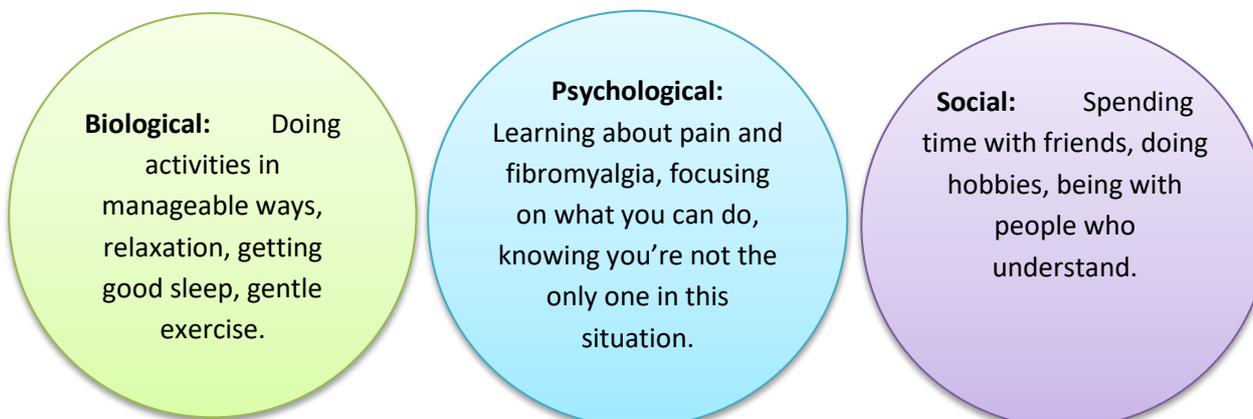


**Biological:** over-doing things, having a cold or infection, becoming less fit

**Psychological:** being fearful of movement, thinking "I'm useless" depression/ stress/ anxiety

**Social:** Not seeing friends, not doing hobbies, family/relationship issues & work, housing or financial issues

Here are some examples of factors that can **reduce** our threat level:



**Biological:** Doing activities in manageable ways, relaxation, getting good sleep, gentle exercise.

**Psychological:** Learning about pain and fibromyalgia, focusing on what you can do, knowing you're not the only one in this situation.

**Social:** Spending time with friends, doing hobbies, being with people who understand.

Later we will explore how we can use this approach to manage our pain levels better.

## Persistent pain

If you have an injury you would expect to have pain, and normally that pain will disappear after a few days or weeks once healing has occurred. However, sometimes it can persist. When pain lasts longer than 3 months it is called chronic or persistent pain. This type of pain continues because even though the body has healed, the nervous system has become over-sensitive. Persistent pain can also start without any injury to the body at all. Persistent pain is the type of pain experienced with fibromyalgia.

The over-sensitive nervous system can cause us to experience pain when you wouldn't expect to, for example:

- things that should hurt a little, start to hurt a lot (for example, hitting your leg on a table)
- things that shouldn't hurt at all start to hurt (such as normal movements or everyday activities)
- pain starts to spontaneously appear randomly in the body.
- old injuries can start to hurt

These are all signs of having an overly sensitive nervous system

### Why does the nervous system become over-sensitive?

At present, scientists do not fully understand why persistent pain starts. However, they have found that when we have pain for a long time, the nerve cells in our body physically change and become more sensitive. The whole pain system becomes switched on and turned up to 'high alert'. The longer our nervous system protects us with pain, the better it gets at doing it.



### Here's another way of thinking about persistent pain:



Let's compare our pain to a fire alarm. A fire-alarm rings to warn you when there's a fire. Just like our pain system can be triggered to warn us of danger. What happens if our fire alarm malfunctions and becomes overly sensitive? It might now be turned on by the heat from a candle, or on a hot day, or you using the toaster! An over-sensitive fire alarm would be activated too often. It would interrupt birthday parties, romantic dinners, or any other events where we might light some candles. The over-sensitive alarm may even go off randomly, without any heat or smoke!!!!

Like a sensitive fire alarm, when the body's nerves become too sensitive, they are activated too often, creating excessive pain that interrupts daily life. What would you do if the fire alarm in your house kept ringing? Initially, you may call out the fire brigade, so they can put out the fire. But if there's no fire and the fire-alarm kept ringing, you would need to fix your overly sensitive fire alarm, rather than call out the fire brigade. Treating persistent pain is similar to fixing a broken fire alarm. The main strategy is to help the nerves of the pain system become less sensitive. The aim is to retrain your nervous system to only provide pain when you need it.

**Does this mean my nervous system will be over-sensitive for ever?**

No, scientists have found that just as nerve cells can change to become over-sensitive, they can also adapt to become less sensitive. The nervous system can be retrained to become less sensitive. This is good news for people with persistent pain, such as those with fibromyalgia.

In this workbook, we will be looking at various ways to help you adapt your nervous system to become less sensitive. There are many ways of achieving this. It will involve you doing things differently and thinking differently, and it won't happen overnight. However, with practise, patience and persistence changes can occur.



**What influences your pain experience?**

As we have discussed, we know that multiple factors influence the onset, duration and severity of our pain experience. Remember the biopsychosocial approach? It can be useful to identify factors that influence your pain experience, in order to better understand your pain and to find ways to manage it better.

**Over to You**

Write down any things in your life that make you feel threatened, worried or increase your pain experience:



**Over to You**

Write down any things in your life that make you feel safer, happier, or reduce your pain experience:



By trying to reduce the factors that contribute to **increasing** our “threat level”, and increasing the factors that **reduce** our “threat level”, we can start to calm down the sensitivity of our nervous system. It may not be possible to change or eliminate all the factors that contribute to our pain levels, but by looking at those things that we can control, we can learn to manage our pain more effectively. In the next sections of this workbook, we will explore ways of doing this.

## Further Information

### Websites:

- [www.tamethebeast.org](http://www.tamethebeast.org)
- [www.retrainpain.org](http://www.retrainpain.org)

### YouTube videos:

- Understanding Pain and What to do about it in less than five minutes
- Why Things Hurt
- Pain and Me: Tamar Pincus talks about chronic pain, acceptance and commitment
- The mysterious science of pain - Joshua W. Pate
- TEDxAdelaide - Lorimer Moseley - Why Things Hurt (telling the snake story!)

### Book:

- The Explain Pain Handbook: Protectometer by GL Mosely and DS Butler

## Managing Activities

I expect that you have seen quite a change in the types and amount of activity that you can do since having fibromyalgia. There may be things that you struggle with, and other things that you can't do at all.

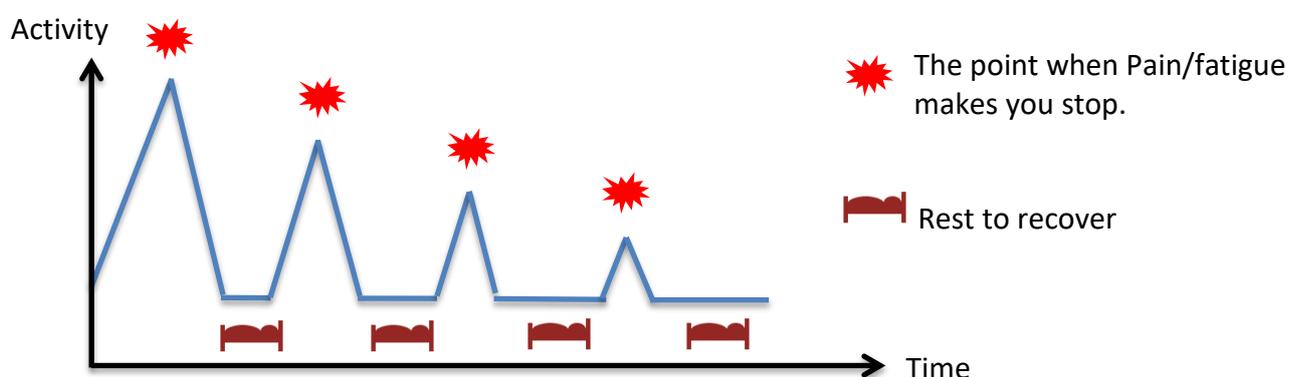
In the previous section, we have been learning about the oversensitive nervous system including our over-protective brain. One of the problems with an oversensitive system is that when we try and do more activity, our brain doesn't like it because it thinks we are danger, so it tries to protect us with more pain.



You may have tried pushing through the pain, but I am guessing this has just made things worse!

How do you decide when it's time to stop doing something? Is it when the pain or fatigue gets so bad that you can't go on? That is a very common way to do things, but unfortunately if you have an overprotective brain, that approach just makes everything worse! Your brain tries to stop you doing anything it thinks will hurt you and gives you more pain – even sooner.

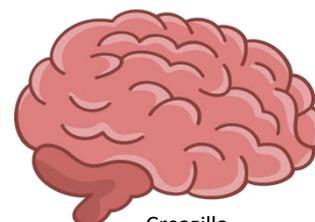
Unfortunately, over time, our brain becomes so good at protecting us that we can do less and less before the pain comes on and we take longer and longer to recover.



So what is the answer? The good news is that we can calm down our sensitive nervous system and retrain our brain to be less protective. The bad news is that this takes time and perseverance!

**There are some specific ways that can help you to retrain your brain to cope better with activity.**

- Pacing
- Planning
- Prioritising



Creazilla  
EmojiOne project

## Pacing

You may have been told, “you must pace yourself”. But what does that actually mean, and why is it important?



Pacing is a way of calming down the brain by stopping activities BEFORE your body (pain/fatigue) tells you to. This is VERY difficult to do because it doesn't feel natural to stop when you feel like you can go on. But by pushing until pain tells you to stop, you are causing your brain to become MORE protective which will mean you will get pain even sooner.

To pace your activities, you should try and do small amounts of activity with frequent rest breaks. This takes a bit of trial and error as it means trying to work out how long you can do an activity before your pain or fatigue get worse. We call this your baseline. It's the starting point which you can build on.

### EXAMPLE

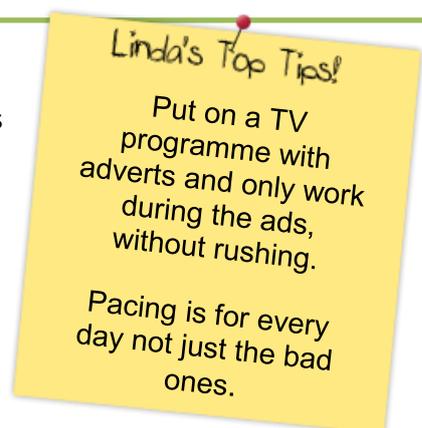
**Jenny finds that if she stands for 5 minutes her pain increases, so she has decided she will only stand for 4 minutes before having a break. She wants to do the washing up and has worked out that she can wash 10 items in 4 minutes. So, after washing 10 items, she sits down at the kitchen table for a couple of minutes and then gets up and does another 10 items.**



### EXAMPLE

**Mark works in an office but struggles to sit for more than 15 minutes. After sitting at his desk for 14 minutes, he gets up and stands behind his chair for 30 seconds before sitting down again for another 14 minutes.**

Pacing is also about varying the types of activity you do. Activities all have different types of demands – physical, cognitive, social and emotional. Activities that you can do sitting down, for example sorting out your banking, might be less physically demanding than say, cleaning, but will be cognitively demanding because of the amount of concentration you need. Using your brain can be just as exhausting as using your body!



### EXAMPLE

**John has found that he can dust for 10 minutes comfortably and then sits down to do paperwork for 20 minutes. He then carries on with the dusting for another 10 minutes before having a rest or doing another task sitting down.**



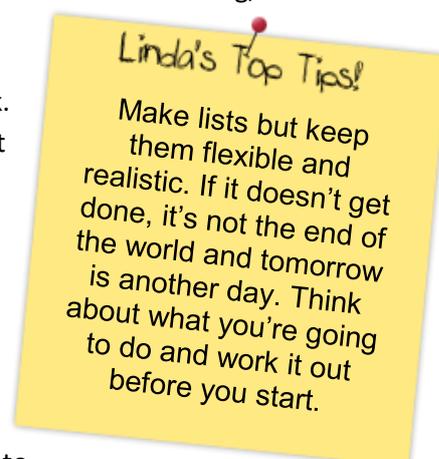
## Planning and Prioritising

We often have routines of activities that we do when we are well, that don't always work for us when we have pain and fatigue. It is good to stop and think about what we are doing, when and how we are doing it.

If possible, it is good to spread out activities over the day and week. You probably can't do everything that you want to do, so think about the activities that are most important and make them a priority. Perhaps some jobs don't need to be done so often.

Have you ever started a job and then struggled to finish it? Perhaps you have pushed yourself to get it done? It is really hard to leave a job not finished, which means we can be tempted to push through until it's done and then suffer later. If you think about breaking down jobs into smaller tasks it may be easier to stop when you need to.

There are lots of jobs that we do that could be broken down into smaller chunks and spread across the day or week.



## EXAMPLE

**In the past Barbara cleaned her bathroom everyday but now she struggles to cope with it. She has decided that she only really needs to do it all once a week, and just clean the toilet and sink twice a week. She broke it down into four tasks: toilet + bath/shower + sink + tiles. She now cleans each item on different days rather than all on the same day. Her weekly plan looks like this:**

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Toilet	shower	sink	toilet	tiles	sink	rest

**This way her bathroom is completely cleaned each week – but it doesn't all have to be done on the same day.**

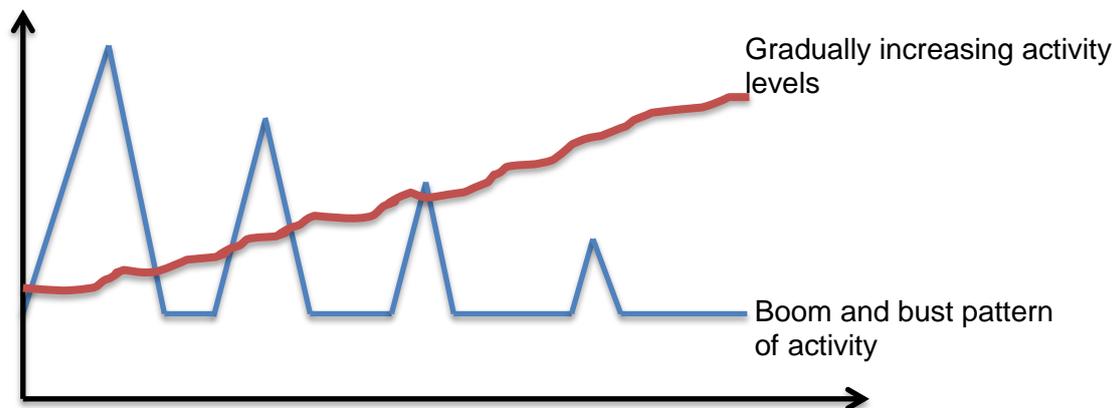
## How can I do more?

If the purpose of this workbook is to help you to do more – then why does it seem we are telling you to do less?!

In order to calm down the oversensitive nervous system, we have to start by working within our pain limits – not pushing through them. But this isn't the end of the story! The whole point is that as your brain becomes less protective you can start to do more without it over-reacting.

**EXAMPLE**

Mary struggles to get the dinner ready for her family. By the time it gets to the time to prepare it, she is already exhausted. Her children also come home from school and want her attention. She now breaks down the preparation into smaller chunks and spreads it throughout the day. For example, she can prepare the vegetables at different times in the day. This means that she has much less to do when it comes to dinner time. She also makes larger amounts so that she can freeze some for those days when she really doesn't feel up to doing anything.



When you feel you have got your activity levels more even, then you can start to gradually increase by **very small amounts** at a time.

Examples: Jenny and Mark (see earlier example)

**EXAMPLE**

Mark wants to increase the amount of time he can sit at his desk. He can manage 15 minutes comfortably but then starts to increase to 16 minutes before getting up. He does that for a week and as his pain hasn't got worse, he increases again to 17 minutes.

**EXAMPLE**

Jenny wants to increase the amount of time she can wash up for. So once she can do 10 items comfortably, she increases to 11 items. After a few days, she increases again to 12 items.



Mark and Jenny can continue to build up the amount of time they stand or sit gradually. If their pain increases, they can just go back to the previous stage and they can try and slowly increase again.

**Over to You**

Think of some activities that you could try to pace. Write down how long you normally do this for. Then time how long it is before your pain starts to get worse. What would be a good baseline?

Activity	How long I do it for now	How long before my pain/fatigue gets worse	Baseline
<b>Eg. Washing up</b>	<b>Until it's finished! (About 15 minutes)</b>	<b>5 minutes</b>	<b>4 minutes</b>

## Where am I heading?



Lots of things will have changed since you have had fibromyalgia. You may well have stopped doing things that you previously enjoyed. Sometimes people tell us that they don't feel like the same person anymore. This is because the things we do express something about who we are and what is important to us. So when we can't do those things, it can feel like we can't be ourselves.

For some people, being in pain makes them focus on what is really important, but for others it feels like the really important stuff gets lost in the middle of just trying to cope with life. If we are spending all our energy fighting against fibromyalgia, we can't move towards what is important to us.

It is really common to think back to what you used to do and feel that it is all out of reach now. That can leave us feeling sad, frustrated and generally fed up! It can even make us lose motivation to try anything at all because it's not the same as what we did in the past.

Moving towards what we value, what is important to us, is still hugely important when you have a chronic health condition – perhaps more so. Moving towards our values helps us to feel less restricted by our health condition and to enjoy our lives more.

## What are my values?



Values are not the same as goals. Goals are things we want to achieve, and we know when we've achieved them eg. losing weight, getting a new job, going on holiday. A goal is a sign that we are on the right path – but a value is the direction in which we are travelling. Values are like a compass that guides our direction; goals are more like landmarks that we reach along the way.

We all have values – things that are important to us, things that we really care about. These are what guide our choices in life and motivate us as we move through life. Every one of us is different and our values will also be different. Values often change over time. For example, what is important to us at 18 years old may not be the same as at 45.

When we can't act according to our values we can feel frustrated. Sometimes we don't realise how much we value something until we are unable to act on that value. For example, if you value being the financial provider for your family but you are unable to work because of poor health, or you value being independent but then need to rely on others because you can't do things for yourself.



## Are goals important?

Someone once said, “If you aim at nothing, you are sure to get there”! The good thing about goals is that they can help us move forward towards the things we value. They can also help us see the progress we are making. Living with pain and fatigue makes everything really hard. It can be difficult to get motivated to do things – even the things that we normally enjoy doing. Setting goals can help us move forward and feel like we are making progress.



We should choose goals that help us move towards our values.

### Examples of values and goals:



Value: being a mother and caring for my children.



Goal: To walk my children to school twice a week.



Value: being respected for my skills



Goal: To work in a job where I can use my skills



Value: having friendships/ being a friend



Goal: To go out with my friends once a week.

## How do I set a goal?

Once we know what direction we want to move in (our values) we can then choose goals to help us along the way. Any goal we set should be Specific, Measurable, Achievable, Rewarding and Time limited (SMART).

Example of some goals:

-  To be able to walk to the local shop and back (150m), in 2 months' time.
-  To be able to sit for 2 hours so that I can go on holiday in an aeroplane in July.
-  To do voluntary work for 3 hours per week by Christmas.

Goals may need to be further broken down into smaller goals which will be the steps you take towards the bigger goal.

**In the first example above:**

-  To be able to walk to the local shop and back (150m), in 2 months' time.

**Smaller goals:**

-  To be able to walk to the end of my road and back (50m), in 3 weeks' time
-  To walk to the post box and back (100m) in 6 weeks' time

### EXAMPLE

One of Robert's values is being a dad. It is really important to him that he is involved with his children and able to have fun with them. Previously he would play games in the park and run around with them. He can't do that now. He has thought about what other things he could do that would enable him to still fulfil that value. He wants to be able to walk with his children to the park and push his daughter on the swing. He sets a goal:



To be able to push my daughter on the swing in the park for 5 minutes, in 6 weeks' time.

### EXAMPLE

Mary really values learning new things. It is important to her that she can study and increase her knowledge. She also loves helping people and values being able to support people who are going through difficult times. She wants to learn about counselling as she would love to work as a counsellor in the future. She sets a goal:



To complete an "Introduction to Counselling" online course, by Christmas.

Once you have a goal, you can use the principles you have learnt in the previous section on managing activity, to plan how you will work towards it.

### EXAMPLE

Robert makes a plan to go to the park with his daughter 3 times a week and to gradually increase the amount of time he can push her. To start with he can only push her for 2 minutes before the pain gets worse.

Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
2 mins	2.5 mins	3 mins	3.5 mins	4 mins	5 mins

### EXAMPLE

Mary thinks about what she needs to be able to do, to cope with the course. She identifies that she struggles to sit for more than 20 minutes and she struggles to concentrate for more than 15 minutes. In order to do her studies, she would like to work for an hour at a time, with mini breaks to change her posture. She makes a plan to gradually increase her sitting tolerance and to gradually increase her concentration. She also thinks about her study area and makes sure she has an adjustable chair and her desk is the right height.

**Over to You**

Think about your values. You could consider your values in the following areas:

1. Family relations.
2. Friendships/social life.
3. Career/employment.
4. Education/personal growth and development.
5. Recreation/fun/leisure.
6. Spirituality.
7. Citizenship/ environment/ community life.
8. Health/physical well-being.

Have a go at writing down some of your values. You could start with, "I value...", or "It's important to me that...". We have given some examples to help you see what we mean.

**Examples:**

*I value my friendships and it's important to me that I am a good friend.*

*It's important to me that I can learn new things.*

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**Over to You**

Now think about setting some goals based on your values and the things you are struggling with. It is also useful to think about the things that might get in the way so you can begin to plan how to overcome those things. Think about what you can do to start moving towards your goal. An example has been given to help you.

What I value	What I want to do	When I will achieve it	What might stop me	What I can do
<i>I value my friendships and being a good friend</i>	<i>Meet up with my friends for coffee once a week</i>	<i>2 months' time</i>	<i>Being too tired and in too much pain. I might not cope.</i>	<i>Start by going out once, just for half an hour. Go somewhere close by. Let my friends know what I'm trying to do so they can support me.</i>

## Beating “Fibro fog”

Do you forget what someone just told you, or struggle to find the right word? These are just two of the cognitive difficulties that people with fibromyalgia often struggle with. The common term for this is “fibro fog” or “brain fog” and it is very common in fibromyalgia.

Lots of people tell us that they are worried that they have dementia because their memory is so poor. If you are worried, you can ask your GP for an assessment, but it is very likely that “fibro fog” is the cause of your difficulties.

These are some of the common difficulties that brain fog can cause:



- Not being able to find the right words, or the words coming out in a different order than when they were in your brain
- Losing your train of thought, often mid-sentence
- Poor spelling or difficulty reading
- Jumbled thoughts
- Poor memory
- Disorientation
- Poor concentration and attention

These symptoms can be really distressing. Many people find that they start avoiding situations because they find them so difficult. Often the people around you don't understand and it can be particularly difficult to manage these challenges if you are working.

## What can I do?

### 1. Write things down

Write everything in one place so you know where to look if you are trying to remember something. This could be a notepad or your mobile phone or other devices. The act of writing will itself help you to remember.



### 2. Speaking things out loud

Speaking things out loud also helps. When you talk to yourself as you do something, it helps you to remember it. Even saying, “I must remember to...” out loud can help.

### 3. Keep your mind and body active

Do activities that use your brain, such as puzzles, as this helps to keep your brain active. Also don't forget that there is a lot of evidence to show that even gentle exercise helps the brain.

### 4. Break up tasks into manageable chunks

Pace activities that use your brain in the same way that you would pace physical activities. Break up the activity into smaller chunks and have breaks.

### 5. Avoid distractions

People with fibromyalgia are often sensitive to noise. It can be difficult to focus when there is background noise. Limit distractions - turn the TV off, or find a quiet spot away from noise. Meet friends in a quiet café rather than a noisy pub to make conversation easier for you.

### 6. Take time to think

Don't be afraid to tell people you may need some time to think, or that you may forget – it happens to everyone at times. Some people find it helpful to formulate a sentence in their mind before they say it.



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### 7. Ask for a recap

If you are in a large group, such as a party, ask a friend to give you a recap of the conversations if required.

### 8. Manage your other symptoms as well as you can

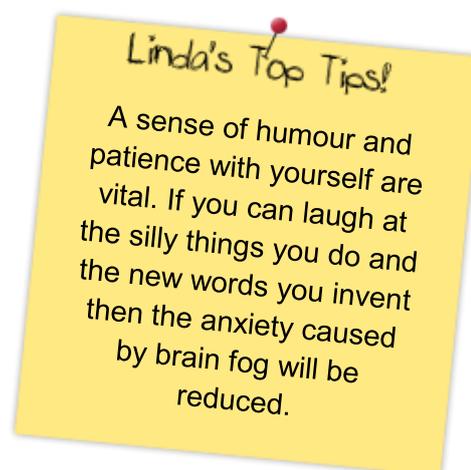
Poor sleep, pain and fatigue will all increase brain fog.

### 9. Manage your stress

Stress makes everything worse – including brain fog! Managing your stress is as important in managing your fibro fog as it is in managing your pain and fatigue.

### 10. Talking to others

Many people tell us that they feel embarrassed about their brain fog and feel that the people around them just don't understand. It is good to be able to help the people around you to understand the difficulties you are having. Many people find it helpful to be explain to the people closest to them what it is like having brain fog, so they can be a bit more patient and understanding.



**Over to You**

Think about what you could do to help you manage your fibro fog.

<b>My fibro fog difficulties</b>	<b>What I can do to try and help</b>
<p><i>Example:</i></p> <p><i>Forgetting whether I locked the front door when I leave the house.</i></p>	<p><i>Say out loud, "I am locking the door" when I lock the door to help me remember.</i></p>

## Tips to Improve Sleep with Fibromyalgia

Do you have difficulty sleeping? Do you wake up feeling exhausted? You are not alone! Most people with fibromyalgia have difficulty sleeping. It may be that pain wakes you up, or perhaps you feel exhausted but you just can't get to sleep. Life with fibromyalgia is hard, but not getting enough sleep makes everything a lot harder.



Scientists are discovering just how important sleep is. We now know that lots of things happen during our sleep. For example, our muscles repair themselves, our memories are logged and stored, hunger hormones that regulate our appetite are produced and the parts of our brain that help us manage stress are more active.

Interestingly, in an experiment where healthy volunteers were woken during each period of deep sleep, a number of them developed the typical signs and symptoms of fibromyalgia.

It can be hard to sleep well because of pain, but there is also evidence that fibromyalgia may be connected with abnormal brain waveforms in deep sleep. This means that you may not feel you get a good night's sleep even when you have been sleeping. This is called, "non-restorative sleep".

Doing everything we can to get a good night's sleep is important for everyone, but especially when you have fibromyalgia.

**Here are some tips to consider:**

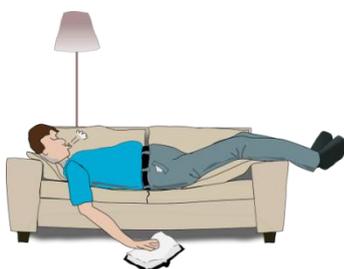
### **Tip 1: Keep in sync with your body's natural sleep-wake cycle**



We have a body clock in our brains that helps us to know when it's time to be awake and when we should be sleeping. This is called our circadian rhythm. Everyone is different, some people are naturally night owls and can cope with being up late at night, and others are larks and like to get up early in the morning. You may have found that since having fibromyalgia, your body clock has changed. Perhaps you just feel sleepy all the time!

Fatigue is a big part of fibromyalgia, but even if you always feel sleepy, sleeping more isn't always the answer to feeling more refreshed. It is important to get a good routine of sleep.

**Try to go to sleep and get up at the same time every day.** This helps set your body's internal clock which helps your body to sleep at the right time. Choose a bed time when you normally feel tired, so that you don't toss and turn. Set an alarm to get up in the morning at the same time every day if possible. It may feel nice to sleep in some days, but ideally it's best to get up at the same time. If you have had a really bad night, you could have a daytime nap instead of sleeping in later.



**Be smart about napping.** While napping is a good way to make up for lost sleep, if you have trouble falling asleep or staying asleep at night,

napping can make things worse. Limit naps to 15 to 20 minutes in the early afternoon.

**Fight after-dinner drowsiness.** If you get sleepy way before your bedtime, get off the couch and do something mildly stimulating, such as washing the dishes, calling a friend, or getting clothes ready for the next day. If you give in to the drowsiness, you may wake up later in the night and have trouble getting back to sleep.

## **Tip 2: Control your exposure to light**

Our sleep-wake cycle is also affected by a hormone called Melatonin that our brain produces. The brain produces more melatonin when it's dark—making us sleepy—and less when it's light—making us more alert. The problem is that sometimes what we do can prevent our brains producing the Melatonin that we need at the right time. We need the right amount of light in the daytime, and less light in the evening and night. There are some simple things we can do to help with this.



Get as much daylight as possible during the day:

**Expose yourself to bright sunlight in the morning.** The closer to the time you get up, the better. Have your coffee outside, for example, or eat breakfast by a sunny window. The light on your face will help you wake up

**Spend more time outside during daylight.** Take your work breaks outside in sunlight, sit in the garden with a cup of tea, exercise outside, or walk your dog during the day instead of at night.



**Let as much natural light into your home or workspace as possible.** Keep curtains and blinds open during the day, and try to move your desk closer to the window.

**If necessary, use a light therapy box.** This simulates sunshine and can be especially useful during short winter days.

Reduce light exposure at night:

**Avoid bright screens within 1-2 hours of your bedtime.** The blue light emitted by your phone, tablet, computer, or TV is especially disruptive. You can minimize the impact by using devices with smaller screens, turning the brightness down, or changing the settings that many gadgets now have to reduce the blue light.



**When it's time to sleep, make sure the room is dark.** Use heavy curtains or shades to block light from windows, or try a sleep mask. Also consider covering up electronics that emit light.

**Keep the lights down if you get up during the night.** If you need some light to move around safely, try installing a dim nightlight in the hall or bathroom or using a small flashlight. This will make it easier for you to fall back to sleep.

### **Tip 3: Exercise during the day**



Exercise has been proven to help people sleep, but you may struggle to do any form of exercise. Even though you can't do anything too strenuous, just going for a walk is a good way of getting daylight and getting in some exercise. Try and do something regularly if you can. *(See the Exercise section on page 56 for more ideas)*

Relaxing, low-impact exercises such as yoga or gentle stretching in the evening can help promote sleep.

### **Tip 4: Be smart about what you eat and drink**

Your daytime eating habits play a role in how well you sleep, especially in the hours before bedtime.

**Limit caffeine and nicotine.** You might be surprised to know that caffeine can cause sleep problems up to ten to twelve hours after drinking it! Similarly, smoking is another stimulant that can disrupt your sleep, especially if you smoke close to bedtime.



**Avoid big meals at night.** Try to make dinner time earlier in the evening, and avoid heavy, rich foods within two hours of bed. Spicy or acidic foods can cause stomach trouble and heartburn.



**Avoid alcohol before bed.** While a nightcap may help you relax, it interferes with your sleep cycle once you're asleep.

**Avoid drinking too many liquids in the evening.** Drinking lots of fluids may result in frequent bathroom trips throughout the night.

### **Tip 5: Wind down and clear your head**

Have you ever gone to bed really tired and then your brain just won't switch off? It's very frustrating! Unfortunately there isn't a switch to turn off our brains at night! Sometimes it's just thoughts about the day that may be going through our mind, or it could be things we are worried about.



**Think about something else.** One way to help get rid of the thoughts that are keeping us awake is to replace them with something less stressful. We can't actually think of more than one thing at a time so if we choose to think about something different, we can't also think about those worrying thoughts. Here are some examples:

- go through the alphabet – boys/girls names beginning with A, B,... etc, (or plants / towns – whatever you like!)
- count backwards from 100 in threes
- think about a wonderful holiday you've had or plan a holiday where money is not limited.

**Put worries to one side.** Writing down worries and concerns can also be helpful as it makes us think about what it is that is on our mind and what action we can take, if any. Once they are written down, put to one side and decide to think about it in the morning.

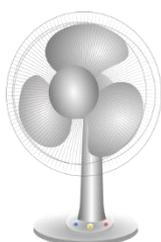


**Have a wind-down period.** After a busy day of being focussed on lots of things, it's difficult to slow down enough to sleep. Have a wind-down period before bed that calms you down ready for sleep. You may want a bath, or to read a book. A peaceful bedtime routine sends a powerful signal to your brain that it's time to wind down and let go of the day's stresses.

### **Tip 6: Improve your sleep environment**

Sometimes even small changes to your environment can make a big difference to your quality of sleep.

**Keep noise down.** If you can't avoid or eliminate noise from neighbors, traffic, or other people in your household, try masking it with a fan or sound machine. Earplugs may also help.



**Keep your room cool.** Most people sleep best in a slightly cool room (around 65° F or 18° C) with adequate ventilation. A bedroom that is too hot or too cold can interfere with quality sleep.

**Make sure your bed is comfortable.** Your bed covers should leave you enough room to stretch and turn comfortably without becoming tangled. If you often wake up with a sore back or an aching neck, you may need to experiment with different levels of mattress firmness, foam toppers, and pillows that provide more or less support.

**Reserve your bed for sleeping and sex.** By not working, watching TV, or using your phone, tablet, or computer in bed, your brain will associate the bedroom with just sleep and sex, which makes it easier to wind down at night.

### **Tip 7: Learn ways to get back to sleep**

It's normal to wake briefly during the night but if you're



having trouble falling back asleep, these tips may help:

**Don't stay in bed if you are awake for more than 20 minutes.** Tossing and turning in bed just makes us get more frustrated and keeps us awake. Also, if we spend a lot of time in bed awake, our brains begin to associate the bed with being awake, not being asleep, which just makes it even harder to sleep! Get out of bed and do a quiet, non-stimulating activity, such as reading a book. Keep the lights dim and avoid screens so as not to make your body think that it's time to wake up.

**Make relaxation your goal, not sleep.** Unfortunately, telling yourself to go to sleep doesn't work! So rather than focusing on trying to sleep, try a relaxation technique such as visualization, progressive muscle relaxation, or meditation, which can be done without even getting out of bed. Even though it's not a replacement for sleep, relaxation can still help rejuvenate your body. *(There is more information on relaxation in the Managing Stress section on page 43.)*

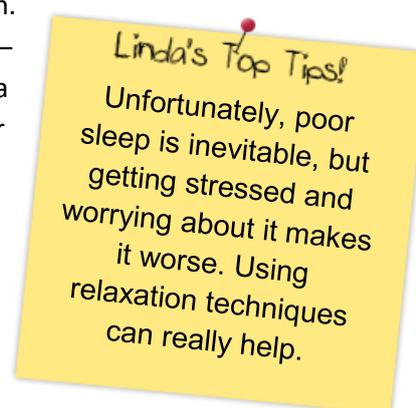
**Postpone worrying and brainstorming.** If you wake during the night feeling anxious about something, make a brief note of it on paper and tell yourself you can worry about it in the morning, then try the distraction techniques mentioned earlier. Similarly, if a great idea is keeping you awake, make a note of it on paper and fall back to sleep knowing you'll be much more productive after a good night's rest.



**Don't panic!** The worst thing about being awake in the night is worrying about not being able to get to sleep! Use the techniques above and try and tell yourself that you will cope without a full night's sleep – you've done it before!

### **Tip 7: Get professional advice**

Some people have other sleep disorders like sleep apnoea that can be treated, so it is always a good idea to talk to your doctor if nothing seems to help. Some medication can help in the short term, but these aren't generally recommended as a long-term solution. Sometimes other medication that we take can make you awake – even medications that should make people drowsy! It's always a good idea to check with your doctor whether any of your medications could be stopping you sleeping.



### **Resources for more help**

#### **Apps (recommended by the NHS)**

<https://www.nhs.uk/apps-library/pzizz/>

The Pzizz app helps you quickly calm your mind, fall asleep fast, stay asleep, and wake up refreshed. It uses "dreamscapes" – a mix of music, voiceovers and sound effects designed using the latest clinical research – to help you sleep better at night or take power naps during the day.

**<https://www.nhs.uk/apps-library/sleepstation/> (Free with GP referral)**

Sleepstation is a 6-week online course for people who struggle to fall asleep or stay asleep through the night. The course is tailored to your needs, using the information you provide, and gives you access to a team of sleep experts who will offer helpful advice and support throughout.

**More information:** [www.sleepstation.org.uk/articles/](http://www.sleepstation.org.uk/articles/)

[www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/](http://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/)

### My Sleep Plan

## Over to You

Think about what makes sleep difficult for you. Identify something that you could try. You will need to try it out for at least a week to see if it will make any difference.

**Bed time:**

**Time to get up:**

What stops me sleeping?	What could I try?	Does it work?
<i>Example:</i>  <i>Worrying about tomorrow</i>	<i>Write down what is worrying me.</i>  <i>Try distraction techniques.</i>	

## Managing Low Mood

### What do we mean by 'low mood'?

Everyone feels low or down from time to time. It does not always mean something is wrong. Feeling low is common after distressing events or major life changes, but sometimes periods of low mood happen for no obvious reason.

You may feel tired, lacking confidence, frustrated, angry and worried. But a low mood will often pass after a couple of days or weeks – and there are some easy things you can try and small changes you can make that will usually help improve your mood.



Creazilla  
EmojiOne project

If you're still feeling down or no longer get pleasure from things for most of each day and this lasts for several weeks, you may be experiencing depression. The tips in this booklet should help, but you may also want to find out about what further support is available.

Take a moment to write down some things that make you feel low here:

**Over to You**

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### What are the common signs of low mood?

You may notice some of the following signs or symptoms. Tick those that apply to you.

#### Emotions or feelings

- Feeling sad, guilty, upset, or numb
- Little enjoyment in things
- Feeling alone even when you're with people
- Crying a lot or unable to cry when a truly sad event occurs
- Feeling angry, irritable or frustrated
- Feeling worried, anxious or panicked

#### Physical signs

- Tiredness
- Lack of energy
- Restlessness
- Sleep problems or changes to your normal sleep pattern such as waking early
- Changes in weight, appetite and eating

**Thoughts**

- Losing confidence in yourself
- Expecting the worst and having negative or gloomy thoughts
- Thinking that everything seems hopeless
- Thinking that you dislike yourself
- Poor memory or concentration

**Behaviour**

- Difficulty in making decisions
- Lack of motivation
- Putting things off
- Not doing things you used to enjoy
- Avoiding seeing people, even those you care about

If you're still feeling down or no longer get pleasure from things for most of each day and this lasts for several weeks, you may be experiencing depression. When we are depressed, we tend to think more negatively about our past, are critical of ourselves and feel hopeless about our future.

You will notice that some of the symptoms listed above can also be associated with fibromyalgia or side effects from particular medication. Sometimes it can be hard to separate out which is which.



Mohamed Hassan  
On Pixabay

If you're having thoughts that life's not worth living, or you're self-harming or thinking about doing so, it's important to tell someone. You do not have to struggle alone – urgent help and support is available right now if you need it. There is some information at the end of this section about where you can get help.

**What causes low mood?**

Life affects us all differently. We all go through difficult times, and negative emotions can be a healthy reaction to the challenges we face. But for many of us, things can become more serious, and each year as many as 1 in 4 of us experiences a mental health problem.

Being aware of what can affect our mental health can make it easier to understand when we, or someone we care about, are struggling, and helps us think about what we can do to improve things or where to get support.

Our mental health can be affected by our childhood experiences which shape our brain development when young. The experiences we have throughout our life will also have an impact, including the relationships we have. Our genes and personality may also make some of us more likely to develop certain kinds of mental health problems.



The way we think about life and the challenges we face, will be affected by all of these things. There are many situations or life events that can affect us and make us feel distressed or less able to cope. We all respond to life's challenges differently – there's no single "right way" to react.

It may be everyday events, one-off experiences or several things building up. Even experiences that are positive can be difficult to cope with sometimes. How we feel is often a completely natural reaction to challenges. But for some of us, these feelings can become more difficult to manage, especially if they do not go away after a while.

Things that affect our mental wellbeing include:



Some of us are more deeply affected by events than others. How we deal with things can also depend on how well other parts of our life are going or how well supported we feel.

### Is there a link between low mood and fibromyalgia?

Research has found people with fibromyalgia have abnormally low levels of the hormones serotonin, noradrenaline and dopamine in their brains.

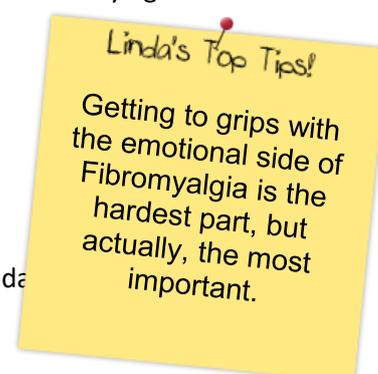
Low levels of these hormones may be a key factor in the cause of fibromyalgia, as they're important in regulating things like:

- mood
- appetite
- sleep
- behaviour
- response to stressful situations

These hormones also play a role in processing pain messages sent by the nerves. Increasing the hormone levels with medication can disrupt these signals.

Some researchers have also suggested that changes in the levels of some other hormones, such as cortisol, which is released when the body is under stress, may contribute to fibromyalgia.

### What can I do to improve my mood?

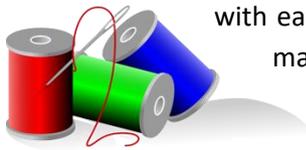


The good news is that many of the skills and techniques we talked about in the 'Managing Stress' section apply to managing low mood too.

As a reminder, here are our top tips:

### 1. Increase helpful activity

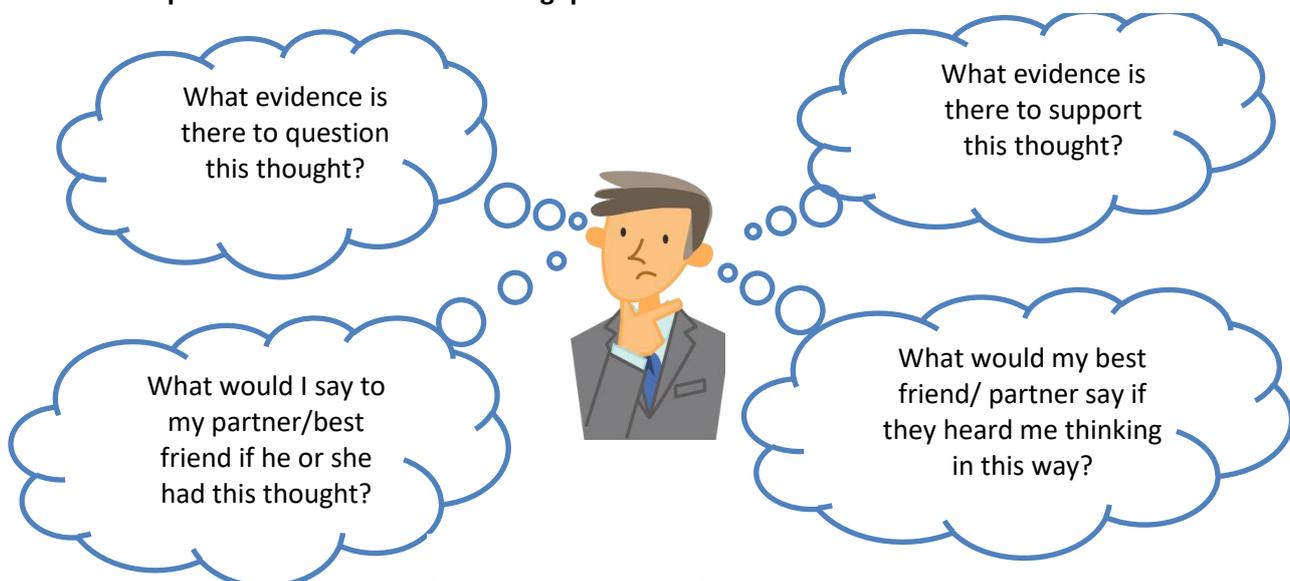
Low mood can stop us doing important or enjoyable activities. Try listing these things and doing some each day. Research tells us that increased activity is very helpful in managing low mood. Start with easier ones and, as you progress, your mood should improve. It can help to make a daily plan and stick to it as if it were an important appointment that you need to keep.



### 2. Challenge unhelpful thoughts

The way we think affects the way we feel. Sometimes negative thoughts can stop us from doing the things that we would normally do and are important to us. We might say to ourselves 'what's the point?' or 'I can't face it' and this can have a negative effect on our activity levels. As a result, we can experience self-critical thoughts about being lazy, irresponsible or guilty, which make us feel even worse and able to do less and less. It can help us to challenge these thoughts when we first notice them before they take hold.

It can help to ask ourselves the following questions:



Now try to think up an alternative balanced thought.

Here is an example to show you what we mean...

## EXAMPLE

Imagine you are in a local shop and someone you know well walks by and doesn't speak to you.

What do you immediately think? You could explain this to yourself in a number of ways. Let us say that you jumped to the very negative conclusion that 'She doesn't like me'. You might notice some altered physical symptoms such as feeling low in energy and restless; that evening you may have difficulty sleeping. This might lead to altered emotions (feeling even lower in mood). Your altered physical and emotional feelings may cause you to go home and avoid company. In the longer term you might possibly avoid the person or act differently towards her, and ultimately may lose the friendship.

Can you see how unhelpful thoughts and altered behaviour in this instance may act to keeping the low mood going? Avoidance of this friend in future can prevent us from recognising that our interpretation of her behaviour was both unhelpful and untrue. These actions can end up reducing your confidence still further and maintaining the low mood.

**But...** what if you have misinterpreted your friend's behaviour? Revisit the questions above to challenge the thoughts that 'She doesn't like me'. Ask yourself the following:

**What evidence is there to support this thought?** *She walked past me without looking at me.*

**What evidence is there to question this thought?** *Maybe she was trying to remember what she needed to buy from the shop and wasn't concentrating. Perhaps she genuinely didn't see me.*

**What would my best friend/partner say if they heard me thinking in this way?** *They'd say I was a good friend, friendly and approachable. Maybe she was preoccupied and really didn't see me in the shop.*

**What would I say to my partner/best friend if he or she had this thought?** *I would say that I know that friend has a busy family life and she was probably rushing to get everything done and wasn't paying attention to who else was in the shop. It's nothing to worry about and doesn't mean she has changed her mind about being my friend.*

**Perhaps a more balanced thought could be something like:** *'There's no evidence that she doesn't like me anymore. She was probably busy or preoccupied and just didn't see me. I would like to catch up with her though...maybe I will give her a call tomorrow and see how she is.'*

### Get good quality sleep

Low moods can make us feel tired. Tiredness can also have a bad impact on our mood, which in turn can have an impact on our pain levels. If sleep is a difficulty for you, make sure to work through the section on sleep (*page 28*) which goes into greater detail about managing sleep difficulties.



### 3. Be kind to yourself

Try to break big tasks down into manageable chunks, and do not try to do everything at once. Give yourself credit when you complete each bit. Try to focus on the things you have achieved rather than the things you haven't. Some people find it helpful to keep a gratitude diary to record things that went well and/or they feel grateful for each day. Choose a time in the evening and spend a few minutes jotting down two or three things you are grateful for you from the day. You might like to have a nice notebook especially for this.



### 4. Use relaxation/meditation regularly

When we feel particularly stressed or low, our muscles can become tense and our minds can race with thoughts. Sometimes we can feel overwhelmed with the thoughts our minds produce, and it can help to use relaxation exercises to calm the mind and body. There are many different types of relaxation, with different types appealing to different people, which is why it is important to try out some different kinds to see what suits you best.

*See the next section on Managing Stress for more information and ideas about relaxation.*

**Over to You**

Using the ideas above, think about what steps you could take to help improve how you feel.

**My ideas of what I can do to help:**

Increasing helpful activity	
Challenging unhelpful thoughts	
Getting good quality sleep	
Being Kind to myself	
Using relaxation	
Other ideas	

## Further sources of support

**If you feel so low that thoughts of harming yourself, or ending your own life have been in your mind, then please visit your GP as soon as possible and ask for help. If you cannot visit your GP and feel that you cannot keep yourself safe, please attend A&E and ask for help from the Mental Health Service.**

### Useful organisations:

*Samaritans*

Tel: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org) [www.samaritans.org](http://www.samaritans.org)

Confidential support for anyone in a crisis.

### Useful Apps/Websites;

*Bipolar UK*

A charity helping people living with manic depression or bipolar disorder.

Website: [www.bipolaruk.org.uk](http://www.bipolaruk.org.uk)

*Men's Health Forum*

24/7 stress support for men by text, chat and email.

Website: [www.menshealthforum.org.uk](http://www.menshealthforum.org.uk)

*Mental Health Foundation*

Provides information and support for anyone with mental health problems or learning disabilities.

Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

*Mind*

Promotes the views and needs of people with mental health problems.

Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)

Website: [www.mind.org.uk](http://www.mind.org.uk)

*SANE*

Emotional support, information and guidance for people affected by mental illness, their families and carers.

Textcare: comfort and care via text message, sent when the person needs it most:  
[www.sane.org.uk/textcare](http://www.sane.org.uk/textcare) Peer support forum: [www.sane.org.uk/supportforum](http://www.sane.org.uk/supportforum)

Website: [www.sane.org.uk/support](http://www.sane.org.uk/support)

- Calm App
- Headspace
- Stop, Breathe & Think app
- Insight Timer app

[www.mindfulness.org](http://www.mindfulness.org)

[www.freemindfulness.org](http://www.freemindfulness.org)

## Managing Stress

Stress affects the body in a number of ways both physically and psychologically. It is particularly important to understand stress when living with fibromyalgia since the central nervous system can become highly sensitive in this condition. Stress can increase our experience of pain because of the already sensitive nervous system.



Publicdomainq.net

It's therefore important to build up our understanding and coping strategies to manage stress and low mood effectively.

### How do we define stress?

Let's make a start by thinking about what we mean when we say 'stress'. We can define stress as "the difference between the demands made upon a person and that person's perceived ability to cope with them". It can be a little bit like a set of weigh scales;



In other words, if you feel that you can cope with the demands being asked of you then you will be fine, but if you feel you cannot cope, the balance of the scales will tip and you may end up feeling stressed.

Stress is not a mental illness, nor will it cause mental illness. It is a normal human experience. Most of us will feel stressed at some point in our lives. Stress is what we feel when we are under pressure. It is a completely normal response which we all experience from time to time and is our body's reaction to feeling under threat. It is not dangerous and in certain situations it can be helpful and motivating.

### Over to You

Take a moment to write down some things that are making you feel stressed at the moment:

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### Why do we experience stress?

Stress causes what is known as the fight or flight response, which is found in the majority of animal species. The origins of this can be traced back millions of years. Take cavemen for example: they often had to deal with life-threatening situations, and stress caused their bodies to react quickly - increasing their chances of survival.



### Why do we need the fight or flight response today?



Whilst we are not faced with as many life-threatening situations as a caveman would have been, it is still useful. For example, if you are walking through a wood and see a snake, the changes that occur in the body due to stress enable us to deal with the situation more effectively.

### What are the signs of stress?

The early warning signs of stress vary person to person. The physical signs we notice are mostly linked to our ancient survival strategy; the fight or flight response as described above. This releases hormones such as cortisol and adrenaline into our body, literally preparing us to do battle or to run away. The pressures we face today are very different from our ancestors and are not usually helped by the fight or flight response. We cannot run away or fight financial difficulties, family problems, and stressful life events or from the other things you wrote in section 2 above. Many people are worried when they feel the signs of stress and think that they may be symptoms of a heart attack or of mental health difficulties. The symptoms of stress are not dangerous and are in fact very common.



### What happens in your body when you feel stressed?

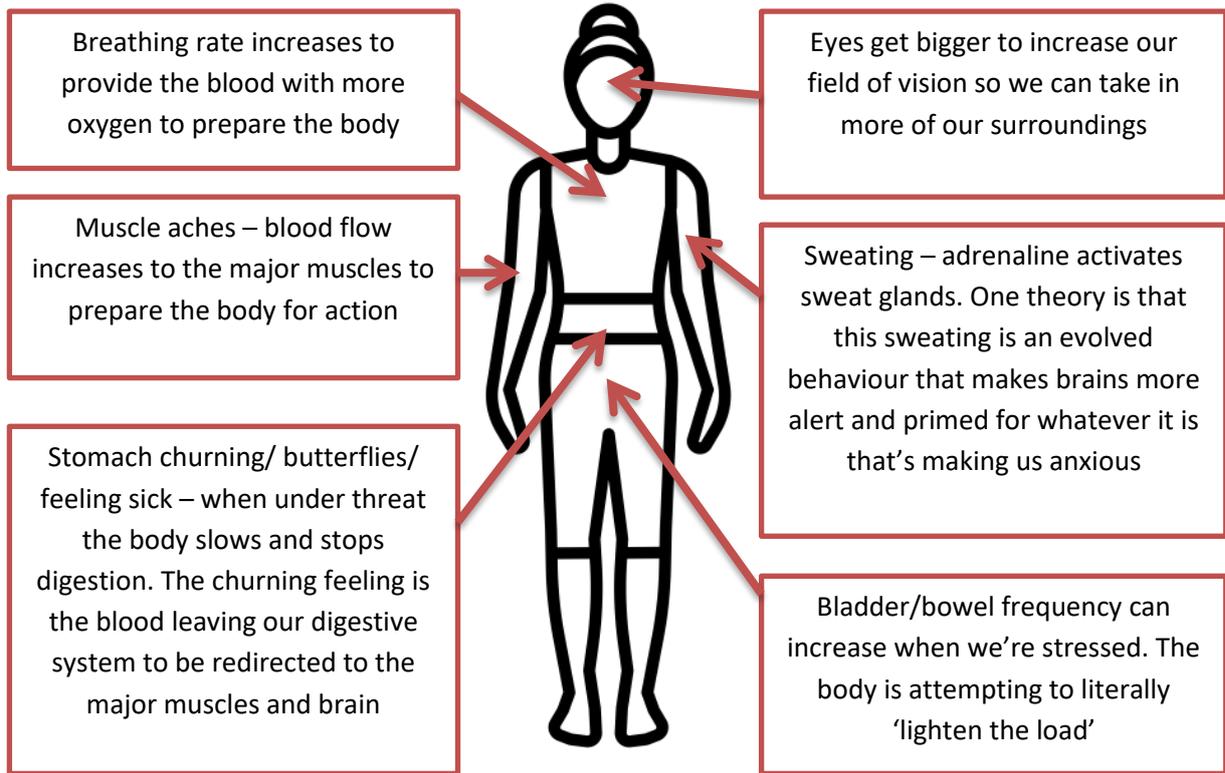
These are some of the symptoms of stress:

#### Over to You

Tick the ones above that you experience when you are stressed.

Frequent headaches	Changes to vision
Muscle tension, aches and pains	Feeling sick
Tingling hands	Sweating
Racing heart	Churning stomach
Bowel and bladder problems	Dry mouth
Feelings of tiredness and exhaustion	Changes in breathing; fast, shallow, sometimes breathlessness

These **physical symptoms** are an indication of your body preparing for fight or flight:



**What happens psychologically when you feel stressed?**

Being stressed doesn’t just affect our bodies, it affects how we think and feel.

**Effects on how we feel:**

- Worrying all the time
- Having racing thoughts that won’t switch off
- Expect the worst
- Thinking negatively
- Criticising yourself and others
- Poor concentration and memory
- Setting too high expectations of yourself and others

**Effects on our thinking:**

- Angry, irritable and wound up
- Impatient
- Anxious
- Unhappy, upset and tearful
- Lacking in interest
- Overwhelmed and frustrated
- Guilty and worthless

**Over to You**

Do you notice these things when you feel stressed? Are there any other early warning signs of stress for you? Make some notes below if you wish;

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## When does stress become a problem?

Stress is not usually a problem in the short-term. As mentioned in section 2 earlier, sometimes stress can be motivating and useful. For instance, stress can help you meet daily challenges and motivates you to reach your goals. In fact, stress can help you accomplish tasks more efficiently. It can even boost memory, as in exam situations or job interviews.



Stress becomes a problem if it goes on for a long period of time and can have a negative impact on pain, therefore it is important to recognise when you are stressed. We have already discussed what some of the early warning signs of stress are. It is important to recognise what these signs are for you, as they will be different for each of us, so that we can take steps to manage stress.

### Over to You

Pause here to write down all the things that you currently do when you feel stressed (be honest!);

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### Over to You

There is a tool you may find useful to understand how stress affects you. This is called the **Perceived Stress Scale** and can be found at the end of this section.

## How can we reduce stress?

Hopefully you were able to write some ways you are currently using to manage stress above. Some of those things might be healthy, helpful things and some of those may be less healthy.

### Here are some more ideas from us:

- Don't take on more than you can handle! Say "no" to people if you need to.
- Slow down and stop rushing around.
- Exercise regularly, as gentle exercise (as approved by your doctor) is an excellent way of reducing stress.
- Reduce your caffeine intake, as caffeine induces stress hormone release.
- Build up a support network of friends and family that you can look to for support.
- Learn to be satisfied with what you do achieve rather than what you don't achieve.
- Make sure you have enough relaxing things to do.
- Make sure you have enough time to do relaxing things



**Over to You**

Make some notes here if you wish to about whether there are some things you could do differently or if you have thoughts about the above ideas.

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**Stress Reducing Ideas: How can we manage stress in our body?**

As the stress response is largely physical, our body is one of the first things to be affected. Practicing engaging activities, regular relaxation, and mindful breathing can all help in reducing tension and reduce the physical effects of stress.

**1. Engaging activities**



**Exercise:** Taking exercise regularly has great benefits for both our physical and psychological health. It can also be a great way to relieve stress and physical tension. Exercise can reduce levels of the body’s stress hormones and stimulate the production of serotonin and endorphins, our natural feel-good hormones. The main thing is to find a form of exercise that is right for your body and that you enjoy, as this will make it much

JoyPixels: EmojiOne Project easier to keep doing it regularly.

*(See section on Exercise on page 56)*

**Hobbies:** Anything we do that absorbs, calms and interests us can help to reduce the physical effects of stress on our bodies. As clever as our brains are, we can only truly give one thing our full attention at a time. If are engaged in meaningful activities it can help to give our brains some light relief from getting caught up with stressful thoughts. *(Use the strategies from the Managing Activities section to help you do the things that you want to do.)*



**Self-Care:** There are other ways to calm and soothe ourselves such as taking a warm bath; drinking a cup of your favourite tea; or stroking a pet.

**Over to You**

What sort of activities do you do currently that help with stressful situations? Make a list here;

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## 2. Relaxation



As well as engaging activity, practicing regular relaxation can help us to manage stress levels. Many people find it hard to relax and our bodies hold physical tension, which can in turn increase pain levels. With practice you can learn skills in relaxation which will help to ease feelings of tension, which can be used anytime you need.

There are lots of different types of relaxation and different things suit different people. You may need to experiment with a variety of strategies to find out what works for you. Before you get started here are some general guidelines on relaxation;

- Make sure that the room is as quiet as possible (you may want to turn off your phone, or ask others that you live with not to disturb you, unless they want to join in)
- Find a comfortable position
- Loosen any tight clothing
- You should practice the relaxation routine at least once a day, or do it more often if you wish
- Try to get into the habit of practicing around the same time every day
- Most people find that their mind wanders when they first start practicing – don't worry about this. If your thoughts wander, gently bring your concentration back to the exercise
- When you have finished allow yourself time to enjoy the relaxed feeling for a few minutes
- Remember, learning to relax is a skill and takes time and regular practice

### Relaxation practice: Stop, Drop and Flop

This is a very simple exercise that you can do almost anywhere. This exercise doesn't take up much time meaning you can fit it in around your daily activities. It is particularly good if you carry lots of tension in your neck and shoulders. If you notice that your shoulders are particularly tense, do the following;

- STOP whatever you are doing.
- DROP your shoulders and your chest.
- FLOP your head forwards (taking care of your neck) and breathe slowly through your nose until the tension passes. Try to imagine that you are breathing right down to your belly button and all the way out again.



### Over to You

How did that feel? Were you able to release some tension from your neck and shoulders? If you found it useful, you might like to try out practicing it a few times a day (perhaps while you are waiting for the kettle to boil!)

### Relaxation practice: Guided visualisation

This exercise is best practised at home, in a quiet environment.

- Sit comfortably, close your eyes and rest your hands on your thighs.
- Picture a safe and pleasurable setting such as your favourite walk, a place in your garden, a park, or a holiday etc. It could be somewhere you've been once; it could be somewhere you've been to many times. It could also be somewhere completely imaginary so long as it somewhere you can feel safe and calm.
- Try to involve all of your senses – what can you see, hear, smell, taste and feel in this place? Try out saying the word 'calm' or 'relax' to yourself as you breathe out.
- Stay in your calm, safe place for as long as you feel you need to before gently bringing yourself back into awareness of the present day.



#### Over to You

How was that experience? Could you think of a safe, calm place to imagine yourself in? Use this space to make any notes you feel you need to;

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### Relaxation practice: Progressive muscle relaxation



Start off by finding a comfortable position. This type of relaxation takes you through different muscle groups on the body teaching you firstly to tense, and then relax. Don't tense your muscles too tightly. It should not be painful. When you let go of the tension, your muscles will relax. Think about the difference in the way they feel when they are tense compared to when they are relaxed.

- **Hands** – start with your hands. Clench one fist first and notice the tension in your hand and forearm. Hold it and study the tension for a few seconds...and then relax. You might feel a slight tingling; this is the relaxation beginning to develop.
- **Arms** – bend your elbows and tense your arms. Feel the tension especially in your upper arms. Remember, do this for a few seconds and then relax.
- **Neck** – press your head back and roll it gently from side to side. Feel how the tension moves. Then bring your head forward into a comfortable position.
- **Face** – there are several muscles here, but it is enough to think about your forehead and jaw. First raise your eyebrows and then relax the forehead. Now clench the jaw, notice the tension and relax.
- **Shoulders** – Shrug your shoulders up towards your ears and then relax. Notice as the tension eases away as you drop your shoulders down. Circle your shoulders slowly to let go of any remaining tension.
- **Chest** – take a deep breath, hold it in for a few seconds, notice the tension then relax. Let your breathing return to normal.
- **Stomach** – tense your stomach muscles as tightly as you can and relax.

- **Buttocks** – squeeze your buttocks together and then relax.
- **Legs** – Straighten your legs and bend your feet towards your face then relax
- **Feet** – point your toes to the floor, hold it for a few seconds, then wiggle your toes. Imagine you are letting go of the last bit of tension through your feet.

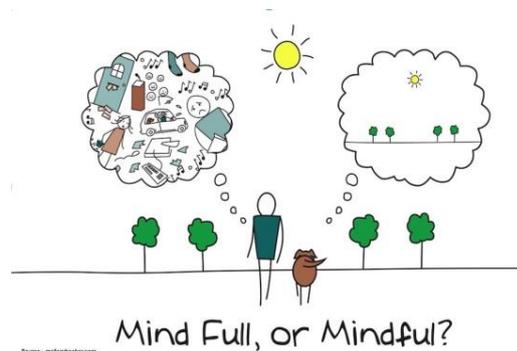
### Over to You

How did you find that exercise? Were you able to let go of tension in your muscles? If you wish to make any notes, please do so here;

### Relaxation practice: Mindful breathing

This is a different approach to managing stress. The aim is to concentrate in the present moment, on purpose and without judgement. Let's explore this idea further...

Have you ever had the experience of driving somewhere, perhaps a journey that's very familiar to you, and when you arrive at your destination you suddenly think "I can't really remember the journey. I must have driven here because I've arrived, but I don't remember getting here."?



If you have had this experience, this is an example of us being *mindless* in our activity. This means that although your body is present and performing the skill of driving, your mind is elsewhere. You might be thinking about things that have happened in the past or you might be focusing on what you need to do next. Although this is normal it does mean that while we are hooked into thoughts about the past or worries about the future, we are missing out on the present. Being in the present is what being *mindful* is all about.

Being mindful helps us to train our attention. Our minds wander about 50% of the time, but every time we practise being mindful, we are exercising our attention "muscle" and becoming mentally fitter. We can take more control over our focus of attention, and choose what we focus on rather than allowing our attention to be dominated by things that make us feel stressed and takes us away from the present moment.

The practice of mindfulness accepts that thoughts, feelings and memories will come into our minds. Mindfulness is not about denying those things or attempting to ignore or suppress them. It is about noticing that the thoughts are there, choosing not to engage with them and letting the thoughts pass you by.





Imagine that you are on a train platform. The trains coming into the station in front of you are your thoughts, feelings and memories. There is not use denying the trains that are your thoughts are present because you can see them as clear as day. What you can do is decide whether to get on the train and go with it, even if you don't like the journey your thoughts take you on or how you feel when you arrive. The practice of mindfulness is the act of staying on the platform and allowing the trains to pass you by. No matter how many times the same trains come along, keep allowing them to pass you by and focus on the present.

You may like to try the following exercise;

- Find a comfortable position, with your eyes closed and your spine reasonably straight, and with both feet flat on the ground.
- Notice the weight of your body on the chair and the pressure of your feet on the floor.
- Bring your attention to your breathing. There's no need to change how you are breathing in any way, but just notice each breath as you inhale and exhale.
- Notice how the air feels as it enters your nostrils, fills your lungs and leaves again. Be aware of the sensations in your body as you breathe – your nostrils, your chest, your abdomen.
- Thoughts will come into your mind, and that's okay, because that's just what the mind does. Simply notice these thoughts, then bring your attention back to your breathing.
- You might also notice sounds, tension or discomfort in your body, and emotions, and again, just bring your attention back to your breath.
- You don't have to get involved with these thoughts or feelings. Don't judge yourself for having them, or analyse them in any way. It's okay for the thoughts to be there. Just notice these thoughts, and let them go by, bringing your attention back to your breathing.
- It's ok and natural for thoughts to arise, and for your attention to follow them. No matter how many times this happens, just keep bringing your attention back to your breathing.
- When you're ready, start to bring your attention back to the room around you. Move, stretch and open your eyes.



### Over to You

How did you find that mindful breathing exercise? Were you able to let thoughts that came up pass you by?

Sometimes it is helpful while practicing mindfulness to imagine that there is a stream in front of you. You can place any thoughts that come up onto a leaf and allow the stream to carry it gently away from you. Remember; it is not about denying or ignoring the thoughts. It is simply about choosing not to engage with them at that given time.

Make any notes about mindfulness here:

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### Further relaxation resources

The Department of Clinical Health Psychology has produced six free audio relaxation tracks for patients to use. Please read through the general guidelines before you try the exercises. Please consult your GP for advice before using these tracks.

Do not listen to relaxation recordings whilst driving or operating machinery. If the exercises cause you any distress or worrying thoughts do not continue without consulting a health professional.



You can access the free audio relaxation tracks online here;

<http://www.qehkl.nhs.uk/relaxationaudio.asp>

#### Track Guide

Track 1: Morning beach imagery (9:21mins)

Track 2: Forest visualisation (12mins)

Track 3: Stretch and relax (20:10mins)

Track 4: One Word (2:10)

Track 5: Garden relaxation (18:03)

Track 6: Mindfulness (5:24mins)

## Further sources of support

If you feel so stressed that thoughts of harming yourself or ending your own life have been in your mind then please visit your GP as soon as possible and ask for help.

### Useful organisations

#### *Mental Health Matters*

Tel: 0191 516 3500

Email: [info@mh.org.uk](mailto:info@mh.org.uk) [www.mhm.org.uk](http://www.mhm.org.uk)

A national organisation which provides support and information on employment, housing, community support and psychological services.

#### *Rethink*

Tel: 0300 500 0927

Email: [advice@rethink.org](mailto:advice@rethink.org) [www.rethink.org](http://www.rethink.org)

Provides information and a helpline for anyone affected by mental health problems.

#### *Samaritans*

Tel: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org) [www.samaritans.org](http://www.samaritans.org)

Confidential support for anyone in a crisis.

### Useful books;

*The Relaxation and Stress Reduction Workbook (7<sup>th</sup> edition)* by Martha Davis, Matthew McKay and Elizabeth Robbins Eshelman (2019). Easy-to-use, step-by-step instructions for using progressive relaxation, self-hypnosis, visualisation, mindfulness and more.

*Stress Control: A Mind, Body, Life Approach to Boosting your Well-being* by Jim White (2017). This accessible, jargon-free book combines clinically proven methods from cognitive behavioural therapy (CBT), positive psychology and mindfulness to give you tools to improve your mind, body and life.

*The Happiness Trap* by Dr Russ Harris (2008). Offers techniques using mindfulness skills to enable you to experience a full and happy life and to overcome depression and anxiety.

## Perceived Stress Scale (PSS)

The Perceived Stress Scale (PSS) is a classic stress assessment instrument. This tool, while originally developed in 1983, remains a popular choice for helping us understand how different situations affect our feelings and our perceived stress.

The questions in this scale ask about your feelings and thoughts during the last month. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way; rather indicate the alternative that seems like a reasonable estimate.

The idea here is to help you recognise the early warning signs of stress so that you can take action to manage it. Simply circle your response on each item.

Once you have completed the scale, simply add up your score for each question and write your total here:

**Total:** \_\_\_\_\_

Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress.

Scores ranging from 0-13 would be considered low stress.

Scores ranging from 14-26 would be considered moderate stress.

Scores ranging from 27-40 would be considered high perceived stress.

The Perceived Stress Scale is interesting and important because your perception of what is happening in your life is most important. Not everyone will respond the same way to the same experiences. Two individuals could have the exact same events and experiences in their lives for the past month but they could think very differently about those experiences. One person could find them very stressful, while another might not find them stressful at all.

**Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)**

	Never	Almost never	Sometimes	Fairly often	Very often
1. In the last month how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the last month how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3. In the last month how often have you felt nervous and stressed?	0	1	2	3	4
4. In the last month how often have you felt confident about your ability to handle your personal problems?	4	3	2	1	0
5. In the last month how often have you felt that things were going your way?	4	3	2	1	0
6. In the last month how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month how often have you been able to control irritations in your life?	4	3	2	1	0
8. In the last month how often have you felt that you were on top of things?	4	3	2	1	0
9. In the last month how often have you been angered because of things that happened that were outside of your control?	0	1	2	3	4
10. In the last month how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

## Fibromyalgia and Exercise

For many people with fibromyalgia, the idea of exercise seems a million miles away. You may find just walking about the house exhausting! We have found that many people with fibromyalgia used to be very active, and it is really difficult to accept that they can't do what they used to.

If you are struggling with fatigue, the idea of exercise might feel like an impossible dream! But "Exercise" can include any movement and studies have shown that exercise is actually **good** for people with fibromyalgia – **if** it is done in the right way.

Exercise may include daily walks, stretching routines, swimming, yoga, tai chi, Pilates and other low-impact exercise programmes.

### The benefits of exercise

We are forever being told that exercise is good for our health, so I am sure that you don't need us to tell you that! But you may not know that exercise has some particular benefits that can really help people with fibromyalgia.

- **Helps fight pain** – exercise boosts levels of natural endorphins, which are the pain-fighting molecules that may be responsible for the well-known "runner's high". These endorphins also help to reduce anxiety, stress and depression.
- **Helps keep us calm** – scientists have found that some people with fibromyalgia have low levels of serotonin (a chemical in the brain). Serotonin is an important substance that helps to keep our mood stable and helps us feel positive and calm.
- **Boosts alertness** - Studies have also shown that exercise triggers the release of adrenaline and noradrenaline, hormones that are known to boost alertness. It also helps to reduce stress.
- **Improving sleep** - Physical activity improves sleep quality and increases sleep duration. Exercise may also bolster sleep in other ways, because it reduces stress and tires you out. Early morning and afternoon exercise may also help reset the sleep wake cycle, although exercising too late will keep you awake!
- **Preventing muscle pain** – weak muscles will hurt when we use them, so if you haven't done much exercise for a while, even everyday activities can hurt. Doing some form of exercise strengthens our muscles and actually prevents them from hurting so much.
- **Reduces fatigue** – it might sound strange that exercise can make you LESS tired, but research has shown that keeping active actually reduces fatigue.



Wikimedia commons by Videoplasty

## What sort of exercise is good?

I hope that you will have understood by now that we are not suggesting you push through your pain and we definitely don't want you to start exercising in a way that will flare up your pain and fatigue!



Whatever you decide to do, start VERY slowly and gently. There is no exercise that is particularly harmful for people with fibromyalgia, but anything that you do that is different to your normal movement is likely to cause your over-sensitive brain to react! So choose something that is really easy to begin with. What you do will depend on what is manageable for you.

Remember that using muscles haven't used for a while will hurt! That is the same for everyone. So it may be that you have a bit of extra muscle soreness, but this should pass.

The key aim with exercise is consistency. Doing 5 minutes a day is better than doing an hour a week. You can build up from 5 minutes in very small amounts. It is also important to find something you enjoy. You could make going for a walk more enjoyable by going with a friend, or combining it with developing your photography skills, for example.

Some people find that Yoga, Tai Chi and Pilates can be really helpful but, like everything, start off very slowly. If you attend a class, make sure the teacher knows you have fibromyalgia. They may be able to adapt some of the workout for you. Exercising in a warm pool is also often found to help. If you find the public pool too cold, noisy or busy, there are some local private pools that owners allow people to book for private sessions.

**Linda's Top Tips!**  
Don't judge yourself by other people's activity levels as fibromyalgia can be different for everyone. Like pacing, start small and work up gradually until you find your level and never push yourself too hard. It can be a case of trial and error whilst you learn your capabilities.

**Linda's Top Tips!**  
Too little activity can be just as harmful as overdoing it so even on your worst days, try to move about. Tensing, releasing and stretching muscles is a good way to start and generally moving about the house.

## EXAMPLE

**Jenny would like to go swimming. She used to be a good swimmer but she hasn't been for 3 years due to pain and fatigue. She is worried about not coping with it and getting frustrated because she can't do what she used to. She decides to ask a friend to go with her to drive her there, to help her get dressed afterwards and also to help her feel more confident. She makes a plan to go and spends just 15 minutes in the pool. She sits on the side to rest before getting showered and changed.**

**Over to You**

What types of exercise are you doing at the moment?

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What would you like to do? (realistically!)

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What is stopping you?

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What could you do to overcome the barriers?

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Look again at the section on Values and Goals and write a goal related to exercise.

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## Managing Flare-ups

You will no doubt have experienced times when your pain and fatigue have got worse and you are unable to do the normal things you would do. This is called a “flare-up” which means a temporary increase in your unpleasant symptoms.

We hope that by learning to manage your pain and fatigue, you will experience less flare-ups, but unfortunately these do happen. Flare-ups can be brought on by overdoing it, or by stressful circumstances. It is not always possible to avoid flare-ups so it is good to have a plan of how you will handle it if it happens.

So what is the best way to handle these flare-ups?

Firstly – **DON'T PANIC!!** Remember that every flare-up has a flare-down.



Here are some things you may want to consider:

- **Reduce your sitting, standing and walking levels.**  
Whatever your normal limit is for how long you can sit, stand or walk, reduce it. You can gradually increase these limits as your flare-up subsides. *Follow the principles in the **Managing Activities** section.*
- **Review your pacing**  
Have another look at what you are doing and increase your rest breaks. Review the **Managing Activities** section to remind you what to consider and gain some fresh ideas.
- **Prioritise what needs to be done.**  
You can't do as much, so prioritise what is really important for now.
- **Continue to stretch/exercise if possible, but reduce the amount**  
It is important to keep moving, but reduce the exercise you normally do to comfortable levels. You can gradually build this back up again once the flare-up improves.
- **Increase your relaxation**  
If you normally use relaxation then increase it. If you don't then it might be worth having another look at it. See the **section on Stress**.
- **Use what helps**  
You probably have a range of things that help you, like heat packs, TENS, having a bath, or something else. During this time, use those things more often.
- **Take any flare-up medication you have been prescribed**



If you have been prescribed medication to help you when your pain is worse, then you may want to use this while you are suffering with more pain. Try and reduce it again once the pain starts to ease though, otherwise it won't be useful for those times when you have a flare-up.

- **Accept more help**

It can be hard to accept help that is offered, and even harder to ask for help, but when you are having a flare-up, this can be part of your plan. Once you start to pick up again you can reduce the amount of help that you need from others.



- **Set small realistic goals**

As you are going to be more limited, your goals need to reflect what you can do at the moment. Set small, realistic goals so that you feel you are making progress. If you have larger goals you are working towards, you can get back on track once the flare-up is reducing.

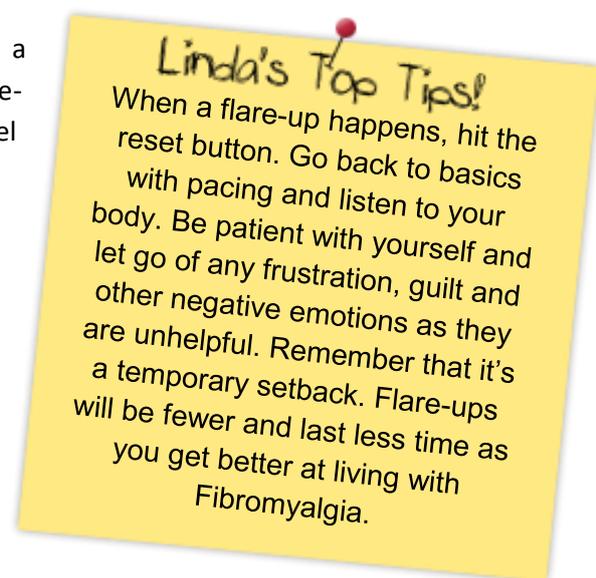


- **Keep a record of what helped, so you can learn from it**

Often it is possible to identify what caused the flare-up and it is useful to learn from this. Sometimes it is useful to talk to the people around you as they often notice what you have been doing that may have caused the flare-up. If there are things that really help you when you have your flare-up, keep a note of this for future use.

- **Plan a reward for your flare-down**

It can be hard to stay positive when you are going through a flare-up, so planning something nice to do for when your flare-up improves can help. This can be very simple but it will feel very rewarding when you manage to do it.



## Over to You

It is really useful to have a flare-up plan. This is like a toolbox of things you can use when you are having a flare-up. Think about what sort of things you may put in your plan. We have given some examples.

What I could do	How this would help
<i>Use ready meals, or easy to prepare meals.</i>	<i>I won't have to cook for the family which is really hard when I'm tired and can't stand for long.</i>
<i>Ask friends to do the school runs for me.</i>	<i>I can't walk to school when I'm bad. This means I can rest more.</i>
<i>Use my TENS machine at work.</i>	<i>TENS helps me and when I'm bad I want to keep working if I can.</i>

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### Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment, please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

**Telephone:** 01553 613351 or 01553 613343

**Email:** [pals@qehkl.nhs.uk](mailto:pals@qehkl.nhs.uk)

**Letter:** PALS, The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust, Gayton Road, King's Lynn PE30 4ET

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