

Sussex MSK Partnership

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Participant Manual

FIBROMYALGIA SELF-MANAGEMENT PROGRAMME

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How do I use the manual?

Used in combination with the programme or as a stand-alone resource, it aims to offer you skills to help you cope better with your symptoms. Designed so that you can easily apply them in most real-life situations, these skills can reduce your symptoms dramatically. As you master these skills, you will find that you can once again engage in activities that you may have previously avoided due to your symptoms.

This manual explains how to use scientifically tested self-management techniques to manage your chronic pain and take back control of your life and your health.

As part of the programme the manual follows the content and the facilitators will refer to it at various times.

The aim is to use the manual not just as an information resource but as a workbook. In addition to providing you with strategies and techniques to reduce your symptoms, it also includes tools to help you become an active participant in your treatment. User-friendly forms to help you set realistic goals, worksheets for practicing skills, blank pages to jot ideas and thoughts and homework exercises make the manual and programme interactive and easy to follow.

Use the manual in the way that works best for you. You may read it from front to back. Or you may want to read different parts as you need them.

There is a list of resources toward the end of the manual.

What is the programme about?

The fibromyalgia self-management programme is a 3 week outpatient programme focusing on improving quality of life.

Various self-management techniques are discussed to help you achieve individualised goals in returning to an active and fulfilling life.

The concepts discussed include self-management, pain management, medication, goal setting, stress management techniques, pacing, sleep hygiene, activity levels, coping with the emotional aspects of living with a long term condition and flare up planning.

Our primary goal is to guide you to restore function and improve quality of life, but other important goals include:

- Returning to regular paced daily activities in a graded way
- Increase physical strength, stamina and flexibility
- Reduce/eliminate use of pain medications
- Learn stress management techniques
- Resume leisure and recreational activities
- Improve interpersonal relationships
- Reduce reliance on health-care professionals,
- Improve ability to self-manage symptoms

The programme offers an opportunity to learn, or re-learn, how to work with your body and mind to meet the challenge of your current health problems and to be more fully awake and present to each moment of life. We hope the programme will start you on a journey towards being able to do a little more, feel good about yourself and enjoy life more.

Patience and persistence

Attending the programme or reading this manual without doing home practice is much like reading the menu in a restaurant without eating the meal: perhaps interesting but not very nourishing! We invite you to make a commitment to your own well-being. If it is right for you now to invest the time and effort to attend the programme or read the manual, do home practice, and wait patiently for results.

If you have difficulties with any aspect of the programme or manual and would like to speak about this privately, please let us know by calling 0300 303 8063.

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Free Thinks

During the programme we undertake 'free thinks'.

This is where we ask the group to feedback on a specific topic in one or two words.

We then write these up on a flip chart for all to think about.

Everyone can contribute to these if they wish, but we ask that during a 'free think' that there is no commenting.

Clarification and questions will progress after a 'free think'.

Timetable for the Fibromyalgia Self-Management Programme

Week 1

Patients register
Questionnaires
Welcome introduction and ground rules
What is self-management?
Understanding Fibromyalgia
Understanding Pain
Managing Pain
Medication
Goal setting and action planning
Breathing and Relaxation
Close

Week 2

Welcome and follow up of goals
Understanding Boom & Bust
Pacing
Improving Sleep
Goal setting and action planning
Mindfulness
Close

Week 3

Welcome and follow up of goals
The Role of Thoughts and Beliefs
Keeping Active
Managing Flares
Keeping Well
Close

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Disclaimer

This manual does not cover all details and variations of living with fibromyalgia or claim to provide for every possible contingency. The information provided is intended to offer a general basis for individuals with fibromyalgia. People who take the information and make decisions regarding their health or medical care, which they believe are based on ideas contained within this manual, do so at their own risk. Should further information be desired or should particular problems arise please consult with a medical professional.

Introduction

This programme is about sharing what we know about fibromyalgia and learning together. We are all here to learn more about fibromyalgia.

Living with a long term condition can feel like we are living the condition rather than being the person we were.

This is a self-management programme about fibromyalgia, we all self-manage every day, but we don't generally call it that.

The idea is to show how you can do things better for you.

We will have a positive emphasis throughout the programme, but it's not about us telling you what to do, but to help you find your own solutions.

Introductions

Pick a partner; spend two minutes each introducing yourself to one another.

You may want to talk about what has brought you to the programme today.

Please identify what you hope to gain or learn from the programme.

My hopes for the programme are:

Pick one of these to feedback to the group.

We may need to adapt the things we are doing in our daily lives to fit with our condition.

Simple skills might be things like knowing when to rest, when to exercise and when to take medications.

It is about understanding the condition and recognising its emotional impact, and being able to adapt the way things are done to get back the feeling that we are in the driving seat.

How we think and feel effects what we believe about our condition and how we behave.

Most people with a long term condition are likely to be already using some skills of self-management to some degree, though they may not realise it.

It takes time and practice, but with some good simple skills we can be good self-managers and make changes in a positive way.

People who actively self-manage say things like:

‘I can do things that are important to me’

‘My life feel so much better, I’m less worried and more in control.’

Understanding Fibromyalgia

A common experience with fibromyalgia is that we get told different things by different people. Some things that are said about fibromyalgia are frustrating and confusing.

What do you understand about fibromyalgia?

What causes fibromyalgia?

How is fibromyalgia managed?

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Understanding Pain

Why do we feel pain?

How We Feel Pain

The brain is the processing centre for messages coming from all over our bodies. These messages are all different, enabling us to feel things like heat, cold, touch and pain and be aware of sights, smells and sounds.

Nerves carry messages from all areas of our bodies to the spinal cord then up to the brain.

If messages about pain do not reach the brain we will not feel pain.

Pain doesn't always equal harm.

Can you give an example of when pain isn't a result of harm?

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Acute pain

Acute pain is short-term.

Nerve endings pick up messages from your body and transmit them up your spine to your brain very quickly. If your brain perceives this as a threat or danger, pain will be felt.

Acute pain is a useful message that means your body has been damaged and needs rest to get better. For example:

If you twist your ankle, or put your hand on something very hot you feel pain.

This warns you to escape from the danger and protect the part that is hurt.

As the muscles, bones and nerves heal, the pain reduces and eventually stops.

If pain persists for more than three months, it is called:

Chronic pain

Chronic pain is long-term.

Pain can become chronic because:

1. Chemicals that are released at the time of the original injury do not get 'switched off'. They continue to be released and can make the area very sore to touch.
2. The nerves can become very sensitive to the pain messages on their journey towards the brain. The pain messages become 'louder' as they travel along the nerves towards the brain (a bit like turning the volume up on the radio), but the brain may only send out a moderate response to that request to relieve the pain.
3. When the pain message reaches the brain it may not be processed correctly. The brain has a memory of pain, which gets 'stuck', a bit like an annoying tune that you cannot push out of your mind.

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Recap

- Pain is a survival mechanism designed to protect the body when your nervous system thinks you are being damaged. Not being able to feel pain at all is really dangerous.
- Pain is an output of the brain, not an input from the body. You don't feel pain unless the brain interprets the data it gets from the body as a danger. The brain will then encourage you to take action to keep yourself safe.

Bitten by a shark? Wounded in war? – Probably no pain experienced until the threat is over.

But the brain can get it wrong too: sometimes it misinterprets signals wrongly as tissue damage and causes unnecessary pain. For example phantom limb pain in a missing body part.

- Pain breeds pain: the longer it goes on, the better the pain pathway works and the smaller the stimulus that can cause us to feel the pain.

The nervous system usually monitors and adjusts its sensitivity to pain. Unfortunately it seems if severe pain occurs for too long this ability to turn down the sensitivity is damaged or lost.

- Pain can be triggered by things unrelated to physical harm. If you regularly experience pain/get sad/anxious in certain circumstances, being in that place can trigger pain or sad/anxious mood experience.

Bottom Line: When pain continues for long periods of time without a real source of continuing harm it's probably a problem with the pain processing system, not the body.

Medication

Medication is not the answer to treating fibromyalgia but a tool in a tool kit for managing the condition.

Pain killers that can help with short-term pain are often less effective with the long-term pain associated with fibromyalgia.

Pain killers can take the edge off the pain and be useful in a flare-up.

It is better to take the dose that helps you at set times rather than wait until the pain is bad and then take them.

Problems with pain medication:

- Our bodies get used to pain killers and they often become less helpful. When this happens it is natural to take more or to move to a stronger pain killer. This can lead to a lot of side effects. It also limits your options at times of flare up.
- Most pain medication has unpleasant side-effects that continue whether or not the drug is working for your pain.
- Even if your medication is not working well, you may find it hard to stop taking it because it has become a 'habit'.
- Even if you don't like taking medication you may find it difficult to stop if you have no alternative.

Solutions:

- If you are able to stop taking regular medication, or you change the medication you take occasionally (with guidance), you will reduce the effects of tolerance and it is more likely to work when your pain is really bad.
- If you reduce your medication at a slow, controlled rate it is unlikely to increase your pain levels and you may even feel better in yourself.
- Using other pain management skills can help you reduce your pain medication.

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Goal setting and action planning

People stop doing many of the things they value in life when they live with fibromyalgia. A number of factors contribute to this gradual withdrawal from valued activities. These include:

- Fear of making the pain worse
- Basing what you do on how you feel, rather than making choices about engaging in valued activities
- Gradual deconditioning; getting stiffer, weaker and less fit
- Losing confidence

Goal setting is a process of focusing on a particular activity and planning how to achieve it.

Goals may be short or long term, small or large.

It is important to start at an achievable level.

You may be doing this already, it may be completely new to you, or may be something that you used to do before your symptoms of fibromyalgia.

How can goal setting help you?

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Goal setting helps us to identify what we want, make a plan, move into action and keep going.

Goal setting can help you to:

- Pace your everyday activities so that you are not over or under doing it
- Plan ways to increase activity to improve fitness and quality of life.

Setting goals allows us to live in line with our values. It can help us feel a sense of achievement and can make life feel more meaningful.

NOTES:

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Setting a goal

Set a reasonable goal

Something achievable, within a time we set ourselves, ask how much do I want to do this?

Break it down in chunks or action plans

Focus on things that we can do
Break it down into doable chunks

For example if it is getting fitter you may want to start by deciding on an achievable walking distance

Carry out action plans

Do this within a time period you set yourself – for example I will do this distance on one day a week, it's important to do this because it's easy to find a week has gone by.

Check how you are doing

Write down your goal and review it regularly.

Modify the plan if necessary

If the target is more difficult for other reasons such as the weather you could swap to another setting such as a shopping centre.

It may also be that your symptoms mean that you have to modify what you are planning to do

Reward yourself

Sometimes the achievement is a reward in itself

Set a further goal

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Goal Setting

This week I will											
How much?						How often?					
Importance						When?					
Confidence	0	1	2	3	4	5	6	7	8	9	10
Mon	Tue	Wed	Thu	Fri	Sat	Sun					
Comments											

This week I will											
How much?						How often?					
Importance						When?					
Confidence	0	1	2	3	4	5	6	7	8	9	10
Mon	Tue	Wed	Thu	Fri	Sat	Sun					
Comments											

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Breathing and relaxation

Our breathing can be a powerful and effective tool to manage, stress, anxiety, tense muscles, shortness of breath and even pain.

Because we breathe all the time if we learn some simple breathing techniques we can use them to relax anytime and anyplace.

Learning to be aware of our breath is the first stage of effective relaxation. It is also a useful way of monitoring how we are feeling at any time - we call this mindfulness.

Our breathing can be affected for many different reasons. When we are tense or anxious we tend to breathe from high up in our chest.

A simple way to relax is called diaphragmatic breathing. This helps because it can prevent stress building up.

It is quick and easy to do, and you can do it anywhere.

Diaphragmatic Breathing

Place one hand on your upper chest and one on your stomach, just below your ribs.

- As you gently breathe in through your nose, allow your stomach to rise. Your chest will stay fairly still.
- Keep the movement gentle. Relaxed breathing doesn't mean deep breathing.
- Slowly and evenly, breathe out through your nose, feeling your stomach sinking.
- Breathe at a pace that feels natural for you. Again, be aware of the hand on your stomach rising while the hand on your upper chest hardly moves.

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It is ideal to practise this exercise often at first. Eventually you can re-train yourself to breathe differently.

- One or two breaths every hour or so, each day, is ideal.
- Use relaxed breathing to prevent the build up of the stress response on a regular basis, before you are aware of being stressed.
- If you are feeling stressed, the breathing can help you to feel more relaxed.

Remember

You don't need to stop what you are doing to breathe in a relaxed way.

Understanding 'Boom And Bust'

Many people with fibromyalgia change the way they do things: reduce hours at work, do fewer 'fun' things, avoid trying out new things, take more rest during the day.

On days when we have fewer symptoms, it is tempting to do the jobs or activities that we weren't able to do on the days when we were too tired or feeling unwell.

It can be easy to overdo it on these 'good' days. This can lead to having more symptoms on the following days and we cannot do as much.

We overdo it....our symptoms get worse....we rest....our symptoms improve....we do more to catch up....our symptoms get worse....and so on....

This can become a 'boom or bust' cycle.

Write down an activity that causes the 'boom and bust' cycle for you.

How do you feel during the 'boom' phase?

How do you feel during the 'bust' phase?

We sometimes choose to 'boom and bust' because the rewards are so great e.g. attending a party.

This is fine occasionally, however if we keep doing the over activity/under activity cycle we may begin to link being active with feeling unwell and reduce or avoid these things, even enjoyable things like seeing friends.

How can we break out of the over and under activity cycle?

NOTES:

The good news is that there is something we can do, this is called PACING.

Pacing

Pacing plays an important part in managing fibromyalgia. It is about spacing out your activity throughout the day to avoid feeling worse.

Many people force themselves to get things finished. Pacing is the opposite of this.

The key to pacing is that you move or stop before the problem starts, even just for a short while.

So to avoid the over activity/under activity cycle we need to:

- Look at what we are doing and stop before we overdo it, by planning the activity. If we can't do this straight away, then at least consider how you may do things differently another time.
- Think about why we do it. Do we feel pressured to keep going? By whom? Do we find it hard to say 'No'?
- Plan for an activity we feel we have had to avoid, shorten or stop. Change 'all or nothing' thinking and opt for a new approach based on the following principles:

The 3 P's:

- **Prioritising**
Prioritise what has to be done.
Does it all need to be done today?
Does it need to be done at all?
- **Planning**
Plan what has to be done and how
Can I break the job down into different stages?
What activities does each stage involve, that is walking, sitting, standing, etc.
What do I need to carry out this job?
Can I get someone to help me?
- **Pacing**
Do it in chunks – you really don't have to do it all at once

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Balancing life helps us to feel confident, happy and in control. We feel more stressed when things are out of balance.

Having fibromyalgia adds to the demands of everyday life and is a drain using up energy we could use on enjoyable things.

Learning how to pace ourselves will show us that trying different or existing activities won't necessarily mean more pain, anxiety or tiredness. Taking a break before we need it will make us better self-managers.

Using the 3 P's, can you problem solve the activity you named earlier as causing the 'boom and bust' cycle for you?

When thinking about pacing we have to consider that some activities may be more draining than others however, some activities may actually make us feel energised.

NOTES:

Key points

Pace it – don't race it! The aim is to succeed not fail.

Review you progress regularly and adjust your pacing accordingly.

Your goals should be SMART.

Pace activities throughout the day, don't do everything at one time.

Plan to keep a regular amount of activity and rest each day if possible.

Don't fall into the trap of the 'five minutes more' syndrome.

Do slightly less than what you know you are able to manage, and do not be tempted to work through until you start to feel tired.

Improving Sleep

Sleep is important for all of us to feel physically and mentally well however, it is particularly important to people with fibromyalgia as it has been found to be a key driver for chronic pain.

Previous research found that stopping people from sleeping created fibromyalgia symptoms

Another study looked at a large group of patients who all had widespread pain. The single correlating factor between these patients was poor sleep over the preceding 10 years.

Poor sleep is a very common problem for people with fibromyalgia.

It is important for us to look at ways that we can have a healthy sleep pattern, and look at the factors that get in the way of this.

What ways do you help yourself to sleep well?

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Sleeping Tips

ENVIRONMENT

- **Create a restful environment** - Your bedroom should be kept for sleep only. Temperature, lighting and noise should be controlled so that the bedroom environment helps you to fall (and stay) asleep.
- **Make sure your bed is comfortable** – It's difficult to get restful sleep on a mattress that's too soft or hard, or a bed that's too small or old.

ROUTINE AND RITUALS

- **Keep regular hours** - Going to bed and getting up at the same time every day will programme your body to sleep better. Choose a time when you feel sleepy.
- **Try to relax before going to bed** - Have a warm bath, listen to quiet music or do some gentle yoga to relax the mind and body.

DAYTIME ACTIVITIES

- **Exercise regularly** - Moderate exercise on a regular basis, such as swimming or walking, can help to relieve tension. But don't do vigorous exercise too close to bedtime as it may keep you awake.
- **Less caffeine** – Reduce stimulants like caffeine in tea or coffee, especially in the evening. Instead try a warm, milky drink or herbal tea.
- **Don't smoke** - Smokers take longer to fall asleep, they wake up more frequently, and they often have a more disrupted sleep.
- **Don't over-indulge** - Too much food or alcohol, especially late at night, can interrupt your sleep patterns. Alcohol may help you to fall asleep initially, but it will disrupt your sleep later in the night.

QUIET MIND

- **Write away your worries** - If worries keep you awake, try writing them down. If you can't sleep, don't lie there worrying. Get up and do something you find relaxing until you feel sleepy again, then return to bed.

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Introduction to Mindfulness

Often our minds are not really 'with us', they are dreading, remembering, planning, regretting...rather than being with us in the 'here and now'.

Sometimes negative thoughts are uppermost and if they stay at the front of our minds; they can be difficult to shake off. These negative thoughts can begin to dominate our lives and become too much.

Mindfulness can stop us getting into those tangles or fights with the negative thoughts; we can become less preoccupied by them.

It can help us get the most out of living in the present moment.

Mindfulness is about accepting our thoughts and our feelings; it isn't about giving up and avoiding change.

The aim of breathing-based mindfulness is to raise our awareness of our reactions and reality at the same time, to help us to see things for what they really are.

If we decide to practice mindfulness; as we get better at it, we begin to notice how our minds become less busy and less distracted and how we are much more able to focus on living.

We learn to look in a friendly, less critical way at our thoughts and feelings and accept them for what they are, without being overwhelmed or being critical or judgemental of ourselves.

Mindfulness does take practice.

Mindfulness won't suit everyone.

People find mindfulness works best if they don't try too hard. Don't worry about achieving anything, it is more about experiencing it, and accepting yourself with kindness and compassion, than 'doing' something.

If you think mindfulness could be helpful to you, please see the mindfulness section at the back of the manual.

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The Role of Thoughts and Beliefs

The way in which we respond to having fibromyalgia will affect how we feel emotionally and how much we feel we are coping with the situation.

The way in which fibromyalgia affects your emotions will partly depend on what you believe and how you are thinking about it.

It will also depend on what you believe and what you are thinking about yourself, and your future.

At the end of the day, while fibromyalgia may be distressing to you, unhelpful thoughts will **add** to your distress.

Unhelpful thinking not only affects how we feel, but it also affects what we do. For instance, if you are saying to yourself “I can’t cope”, then it is likely you will feel less able to find ways of coping with fibromyalgia.

Unhelpful thoughts therefore encourage negative feelings, which in turn stop you from using positive ideas for coping with your symptoms.

Therefore, misunderstandings about symptoms can make self-management more difficult. People with helpful beliefs may find the condition more manageable. An example maybe: I am never going to feel any better. So what kind of unhelpful thoughts might we have?

Please give an example of an unhelpful thought you have had

Unhelpful thoughts about our condition

We may spend a lot of time wondering why we are ill or why symptoms are happening.

As already discussed fibromyalgia is complex and often there is not a simple explanation for why it continues.

If you have had it for a long time, many attempts will have been made to answer this question. Continuing to ask yourself 'why' when there is no apparent answer will get in the way of you taking positive action to deal with your problem. You continue to focus on the past and on your health, rather than looking for solutions or coping strategies. So, rather than asking;

Why did this happen? ASK How do I start feeling better?

Unhelpful thoughts about ourselves

Having fibromyalgia can change the way we see ourselves and eat away at our confidence. Perhaps you have not been able to do something you used to and this has led to you feeling bad about yourself.

If you often think along these lines then you will find yourself avoiding more situations, becoming more inactive, feeling like a failure and focusing more on your fibromyalgia.

Unhelpful thoughts about the future

Some people find it difficult to look to the future. Many people find themselves saying, "I'll never be the same as I used to be". This is likely to be true. None of us, including people without fibromyalgia, can ever re-trace the past.

Wishing or hoping that this is not the case turns this fact into a negative thought which can result in us feeling depressed, demoralised and angry.

Keeping Active

Research shows us that exercise increases ability to function and allows everyday activities to be carried out with greater ease. It is therefore important to think about activity levels in relation to living with fibromyalgia.

In this section we are thinking about doing *regular, planned activity*.

Why should we keep active?

What gets in the way of you remaining active?

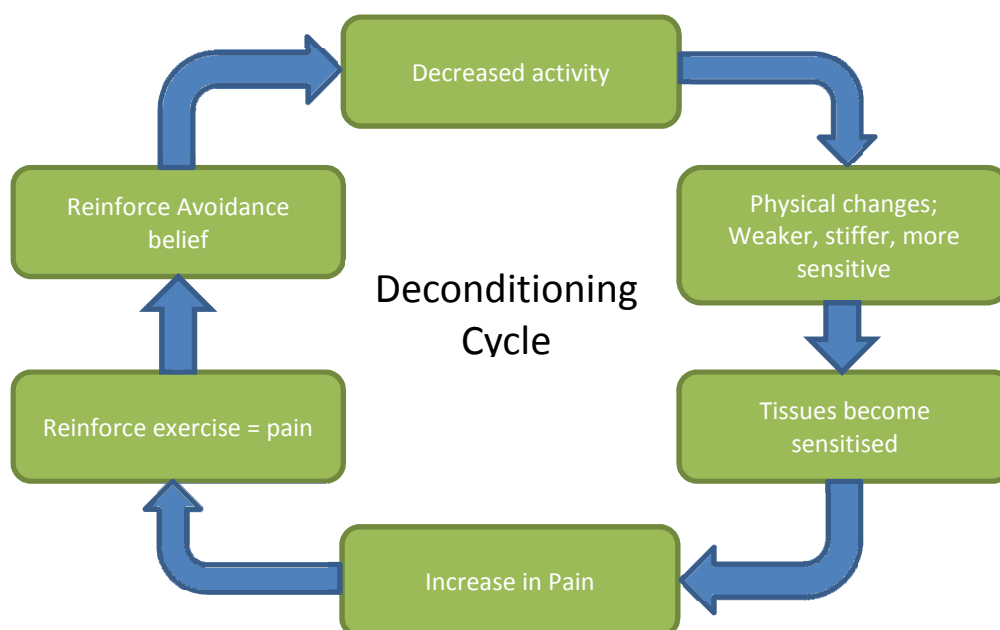
What happens if we don't remain active?

Deconditioning is a term used to describe the process of decreasing fitness when you stop your activities. As we stop being active, a number of deconditioning-related changes occur in our body that may lead to more pain. These include reduced muscle strength, reduced co-ordination and reduced flexibility as well as blood circulation problems.

In addition, people often put on more weight, which can lead to increased pain as there is more load and stress in the muscles and joints.

The body is made to move. If we stay in one position for too long a type of acid is produced in the joints which stimulates pain receptors and produces a pain response. Regular movement prevents the release of this acid and blocks pain receptors.

Deconditioning often starts with an attempt to avoid pain by reducing daily physical activities. While avoiding activity may result in less pain in the short run, the reduction in activity may lead to deconditioning, which then can lead to increased pain. The increase in pain then leads to more avoidance of activity.



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Deconditioning also occurs when people stay in bed for prolonged periods due to the pain. Physicians once recommended prolonged bed rest; however, research showed that this often leads to increased pain levels.

The process of deconditioning happens rapidly, but the increase in pain may take months to develop. How quickly you lose fitness depends on how fit you were before you reduced activity.

The best way to overcome the Deconditioning Cycle is to improve your fitness by staying active.

Unfortunately, this often means that at first you have to engage in some activities that may increase your pain.

Using mind/body pain management strategies that include relaxation and cognitive behavioural or acceptance commitment therapy often help to reduce the pain while you are increasing activity. It is especially helpful when you apply mind/body strategies during exercise.

What kind of activity?

It doesn't matter what you do, any kind of activity will do. It should:

- Be enjoyable or working towards a goal
- Gently challenge your range of movement or cardiovascular
- Be realistic

How do I get started?

This is a statement from a fibromyalgia patient:

“When I first read about the helpfulness of exercise, I literally tried to exercise the fibromyalgia right out of me. While bouncing on the stepper, I felt no pain. Endorphins made me feel terrific and invincible. Hours afterward, however, the pain was excruciating. My life became divided between intense workouts and sheer agony. No surprise — I soon stopped exercising altogether.”

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Basically your skill is to take things slowly and progress your exercise/activity level as your body changes as a result of doing your exercises.

This is called *Pacing* and you have discussed that already in another session.

Don't "**Boom & Bust**", **Avoid** or **Push** too far!

General Principles:

- Set a baseline
- Don't start during a flare up
- Set achievable goals, success is important
- If symptoms worsen, decrease the **intensity** before the **frequency** or **duration**

E.g. if you use a static bike twice a week for 10 mins at a resistance level of 3, change the intensity i.e. the resistance level rather than how often or how long you exercise.

NOTES:

Managing Flares

Some people have learnt what causes their pain to 'flare-up'. When they avoid doing these things they have much better pain control and have less pain to cope with.

What is a flare up?

What causes a flare up?

How do you manage a flare up?

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'Flare-ups' happen due to a situation arising where you are unable to plan effectively and may overdo things. It can also happen during a major 'life event', such as moving home, family get togethers or at any time when you start to do more than usual – often without noticing.

It is often difficult to know why a setback happens but it is unlikely that it is caused by any new damage. If you find yourself in this situation it may be difficult for you to keep up your activities and exercises. It is therefore important to recognise that you are having a setback and plan how you are going to deal with it.

TIPS

- **Don't panic!** This is only a temporary setback
- Do not stop everything – try to think about what may have triggered the problem. There may be a pattern that emerges, making it easier to adjust the circumstances for the future
- Keep doing your exercises, but consider reducing the amount
- Increase your relaxation time
- Be aware of negative thoughts
- Make a plan of how you are going to gradually increase your activity
- Set yourself realistic goals
- If you need to use medication, take it 'by the clock' then reduce it gradually.

**Remember how you were before this setback.
A setback can be followed by a 'come-back'**

Keeping Well

Throughout this programme we have discussed the following strategies for the self-management of your fibromyalgia.

- Paced Activity
- Realising it's never too late to start
- Regular, planned activity
- Take joints and tissues through their range
- Strengthen key muscles in arms and legs
- Keep as generally fit as possible
- Medication
- Acceptance / change of mindset
- Cognitive Therapies
- Meditation
- Relaxation
- Education
- A combination of all the above.

Every day demands mean that even with the best intentions it's often hard to keep on track, and it's likely that we will gradually forget our new skills.

Because of this it's helpful to have a wellness plan, here is an example:

What do I need to <u>do</u> every day to stay well?	Eat healthy meals Talk to someone Take medication Get some fresh air
What do I need to <u>check</u> each week?	Have I had some exercise? Have symptoms been getting better or worse? Have I done something for me? Do I feel like things are balanced? How am I doing with my goals? How am I doing with pacing or planning?
What do I need to <u>reflect</u> on each month?	How am I doing with my long term goals? Are there any triggers looming? Looking back is there anything I need to do more or less off? If yes, make an action plan Look over my diary; is there a pattern of symptoms?

Wellness Plan

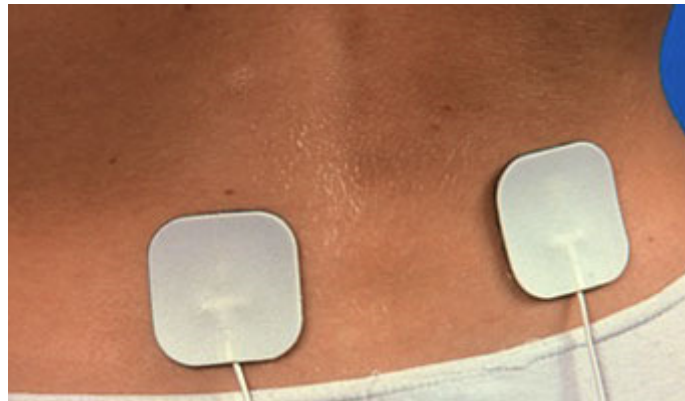
Each day I will	
Each week I will	
Each month I will	

Each day I will	
Each week I will	
Each month I will	

TENS

Transcutaneous electrical nerve stimulation (TENS) is a method of pain relief involving the use of a mild electrical current.

A TENS machine is a small, battery-operated device that has leads connected to sticky pads called electrodes.



You attach the pads directly to your skin. When the machine is switched on, small electrical impulses are delivered to the affected area of your body, which you feel as a tingling sensation.

The electrical impulses can reduce the pain signals going to the spinal cord and brain, which may help relieve pain and relax muscles. They may also stimulate the production of endorphins, which are the body's natural painkillers.

What TENS is used for?

TENS may be able to help reduce pain and muscle spasms caused by a wide range of conditions including:

arthritis
neck pain

period pain
back pain

knee pain
sports injuries

Does TENS work?

There isn't enough good-quality scientific evidence to say for sure whether TENS is a reliable method of pain relief. More research is needed and clinical trials for TENS are ongoing.

Trying TENS

You can choose to buy your own TENS machine without getting medical advice.

If you find TENS effective, you can buy a TENS machine from a pharmacy. They range in price from about £10 to £200. More expensive machines aren't necessarily any better than lower-priced ones, so it's best to do some research before you buy.

How to use TENS

The information below is a general guide on how to use a TENS machine. You should always follow the manufacturer's specific instructions.

TENS machines are small and lightweight, so you can use them while you're working or on the move. You can put it in your pocket, clip it to your belt or hold it in your hand.

You can use TENS throughout the day for as long as you like, although it shouldn't be used while you're driving, operating machinery, or in the bath or shower.

Positioning the pads

Make sure the machine is switched off before you attach the pads to your skin. Position the pads either side of the painful area, at least 2.5cm (1 inch) apart.

Never place the pads over:

- the front or sides of your neck
- your temples
- your mouth or eyes
- your chest and upper back at the same time
- irritated, infected or broken skin
- varicose veins
- numb areas

Turning it on and adjusting the strength

Turn on the TENS machine when the pads are attached in the correct places. You'll feel a slight tingling sensation pass through your skin.

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The machine has a dial that allows you to control the strength of the electrical impulses.

Start on a low setting and gradually increase it until the sensation feels strong but comfortable. If the tingling sensation starts to feel painful or uncomfortable, reduce it slightly.

Switch the TENS machine off after you've finished using it and remove the electrodes from your skin. The electrodes can be placed back on the protective sheet they came on and should last about two weeks approximately.

Are there any risks of side effects?

For most people, TENS is a safe treatment with no side effects.

Some people may be allergic to the pads and their skin may become red and irritated, but special pads for people with allergies are available.

TENS isn't safe for everyone to use. Don't use it without first seeking medical advice if:

- you have a pacemaker or another type of electrical or metal implant in your body
- you're pregnant, or there's a chance you might be pregnant – TENS may not be recommended early in pregnancy
- you have epilepsy or a heart problem

Suppliers

The following list shows a few of the TENS machine suppliers. It is not exhaustive and not intended as a list of recommendation.

You may like to consider the following points when purchasing a TENS unit.

- Having a dual channel TENS allows you to use 4 pads and may give you flexibility in treating larger areas or two pain areas at the same time.
- Some TENS machines take rechargeable batteries
- The cost of the replacement pads, this can vary from company to company.
- Some machines automatically switch off after 15-20 minutes, usually TENS is recommended for a minimum of 45 minutes.
- It may be possible to have a trial period through some companies

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Patterson Medical	www.physiomedhomecare.com
01457 860444	TPN 200 plus
The TENS Company	www.tensmachineuk.com
0161 427 4851	Med-Fit1
Phoenix Healthcare	www.phoenix-healthcare.co.uk
01159656634	TENS complete
Lloyds Pharmacy	www.lloydspharmacy.com
Dual channelled TENS machine	£19.99 - £29.99
Boots Pharmacy	www.boots.com
Boots advanced TENS pain relief unit	£49.99 2 year guarantee
Amazon	www.amazon.co.uk
Tenscare Touch TENS machine + others	Ranging from £22.51 – £55.18

Local Low Cost Acupuncture Clinics 2017

Brighton Acupuncture Clinic, Castle Street, Brighton:

Offers reduction in cost for those in financial difficulty

Tel: 739606

Brighton Community Acupuncture clinic, Hollingdean Community Centre, Brighton:

Prices from £8-£25

Tel: 07964291417

Brighton Low cost Acupuncture Service, 30 The Drive, Hove:

Tues 1-3pm

Price £20 for up to 60 mins

Tel: 771441/07841922384

Dragon Acupuncture, North Laines, Brighton:

Prices range from £20-£30

Tel: 07760492136

Hollistic Health Centre, Beaconsfield Road, Brighton:

Low cost clinic (Wed 10-6pm & Fri 10:30-12:30pm)

Price £20

Tel: 696295

Lewes Community Acupuncture, Station Street, Lewes:

Low cost clinic (Tues & Fri 2-6:30pm)

Prices from £18-£30

Tel: 07929742243 or 07733367803

Rock Clinic, Rock East, Eastern Road, Brighton:

Prices range from £20-£30

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Resources

Local Health and Fitness Services

Brighton

Looking for something to do in Brighton & Hove? **Its Local Actually** can pinpoint an activity that's perfect for you:

<https://www.itslocalactually.org.uk/>

The Right Track Programme run by Possability People in Brighton provide tailored support and guidance to local people who would like to be more physically active. To find out more about the programme and talk to a Community Link Specialist, please contact: Donna@possabilitypeople.org.uk or **01273 208934**.

Brighton and Hove Sports & Physical Activity team provide locally low cost or free activity programmes for adults. Including health walks and discounted leisure card. To find out more, please visit: **Brighton and Hove: Sports & Physical Activity Team**

Call the team on **01273 292724** or email sport.info@brighton-hove.gov.uk

The Brighton and Hove Food Partnership provides tailored advice about community gardens across Brighton and Hove where people grow food together. Outdoor activities run throughout the week as flexible drop ins. Participants report improvements to diet and physical activity, alongside mental wellbeing, skills and reduced isolation.

For more information, please visit: <http://bhfood.org.uk/Community-Garden-Support> Telephone: **01273 431700**

Referral and self-referral Form: **Referral to Healthy Lifestyle Services**

Mid Sussex

The Right Track Programme – Possability People

A local organisation working in partnership with healthcare professionals to help you reduce aches and pains and improve your general wellbeing. Being active, getting out and about, meeting friends, doing activities, joining groups, can help to reduce pain and improve general wellbeing. Living with pain can make it difficult to get started. Right Track can support people with that challenge.

If you would like to know more about Right Track, please contact the Right Track team on: donna@possabilitypeople.org.uk or **01273 208934**.

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Exercise Referral is aimed at individuals who are not used to regular exercise, or who are recovering from, or dealing with, a health issue. After a referral by a health professional, a co-ordinator discusses the reason for referral and develops a programme to match their aims and abilities. The service is available at local leisure centres in Mid Sussex. Telephone: **01444 477191**
Email: wellbeing@midsussex.gov.uk

The Mid Sussex District Council Park Rangers provide a free programme of Healthy Walks across Mid Sussex. The walks are designed to help people get fit and there are a variety of different levels of walks from Level 1 (beginner) to Level 5 (advanced) so there is something for everyone. The programme allows people to progress through the levels as their fitness improves.
Telephone: **01444 477561** Email: rangers@midsussex.gov.uk
For more information, please visit: www.midsussex.gov.uk/healthywalks

Horsham

The Right Track Programme – Possability People

Is a local organisation working in partnership with healthcare professionals to help you reduce aches and pains and improve your general wellbeing. Being active, getting out and about, meeting friends, doing activities, joining groups, can help to reduce pain and improve general wellbeing. Living with pain can make it difficult to get started. Right Track can support people with that challenge. Right track links adults who experience these conditions, and their carers, with the vast range of support in the community and voluntary sector.
If you would like to know more about Right Track, please contact the Right Track team on donna@possabilitypeople.org.uk or **01273 208934**.

Horsham Wellbeing Service has Physical Activity Coordinators

available to help people return to fitness or activity by finding new activities and setting goals. To find out more about getting more physically active with the support of a Physical Activity Coordinator please telephone: **01403 215111** (Monday to Friday 10am-4pm).
Email: info@horshamdistrictwellbeing.org.uk or complete a **referral form** and a member of the team will contact you.

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Exercise Referral is aimed at individuals who are not used to regular exercise, or who are recovering from, or dealing with, a health issue. After a referral by a health professional, a co-ordinator discusses the reason for referral and develops a programme to match their aims and abilities. The service is available at local leisure centres in Horsham District. Telephone: **01403 215111**

Information leaflet: <http://horsham.westsussexwellbeing.org.uk/>

Crawley

The Right Track Programme – Possability People is a local organisation working in partnership with healthcare professionals to help you reduce aches and pains and improve your general wellbeing. Being active, getting out and about, meeting friends, doing activities, joining groups, can help to reduce pain and improve general wellbeing. Living with pain can make it difficult to get started. Right Track can support people with that challenge. Right track links adults who experience these conditions, and their carers, with the vast range of support in the community and voluntary sector.

If you would like to know more about Right Track, please contact the Right Track team on: donna@possabilitypeople.org.uk or telephone: **01273 208934**

Crawley Wellbeing Service has **Physical Activity Coordinators** available to help people return to fitness or activity by finding new activities and setting goals. To find out more about getting more physically active with the support of a Physical Activity Coordinator please contact:

Telephone: **01293 585317** Email: wellbeing@crawley.gov.uk

Or use the online enquiry form: <https://crawleybc.enquiryform>

Active Life Criteria (from Dave Brice, Active Life Coordinator):

The Active Life Programme is a scheme for Medical Professionals to refer their patients to when they consider their patients quality of life will be enhanced by additional activity, which is provided by independent exercise in the K2 Gym.

It is for patients with Medical Conditions e.g. Cancer, Cardio Issues, OrthoMusculo/Skeletal, MS, Diabetes etc. It is NOT a weight management programme as this is catered for by the WOW or by taking a Gym Membership.

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Where Patients have been referred for Active Life and WOW it is recommended that they attend the WOW first before participating in Active Life. This gives them the opportunity to establish an attendance discipline plus reduce bodyweight thus reducing loading on the patients joints while exercising (particularly important for Obese Patients).

Further Active Life information can be obtained by contacting the Coordinator via **01293-585333** or preferably sign post to the Hub or complete a GP referral e-form.

Health Walks (self-referral)

Walking for Health Accredited Scheme

30 to 60 minutes walks are led by a qualified health walk leader

Self-referral – simply turn up to a walk to take part. New walkers will be asked to complete a walker registration form

Weekly, fortnightly and monthly walks available in several locations in Crawley

For full information, visit: www.crawley.gov.uk/healthwalks

Community Low Level Physical Activity sessions and courses

Crawley Wellbeing offer a range of low level physical activity sessions and courses in various locations in the community

Activities include: seated exercise classes, gentle exercise to music, outdoor Gym, Walk to Run, inclusive cycling etc

For the latest activities and courses please sign post to the Hub

Falls Prevention – Well Balanced

Community Falls Prevention programme for pre-fallers

A free 15 week course for over 65s to help prevent falls and keep moving

A beginners class focused on building confidence through balance and stability and an advanced class to incorporate strength, flexibility and coordination

Delivered by qualified PSI Instructors

Self-referral call **01293 585352**

Screening questions (FRAT) and an assessment day will be required prior to starting a course

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Chronic Pain

Helpful references to assist with your understanding of chronic pain alongside helpful and unhelpful strategies when trying to deal effectively with chronic/long-term pain.

Living with Chronic Pain

If you would like information about effective pain management strategies, we recommend that you make use of the CD 'Living with Chronic Pain'.

It includes an introduction to formal relaxation and why this is such a beneficial pain management strategy.

Go to **www.paincd.org.uk**

You can purchase the CD for £2 (£1 for delivery)

You can download the CD for free

You can listen to the CD for free

You can also contact the author Neil Berry, an NHS Consultant Clinical Psychologist who works full time with people who live with chronic pain.

By sending an email to **neil@paincd.org.uk**

By post to: PO Box 84
Blackburn
BB2 7GH
United Kingdom

The Spoon Theory

A good document to help you think about how you can explain the impact of chronic pain on your energy levels and general functioning is called "But you don't look sick" or "The Spoon Theory" at **www.butyoudontlooksick.com**. You can also go onto You Tube and see the author explain the Spoon Theory.

The Pain Tool Kit Website

Go to **www.pain toolkit.org** for many useful resources regarding managing long-term pain. You can also go to **www.pain toolkit.org/store**

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to access the actual pain tool kit which gives 12 strategies for managing long-term pain more effectively. Also look for 'Explain Pain Leaflet'.

British Pain Society Website www.britishpainsociety.org

Arthritis Research UK www.arthritisresearchuk.org

Fibromyalgia Action UK www.fmauk.org

<http://knowpain.co.uk/wp-content/uploads/2014/05/TazzyPersistentPainBooklet.pdf>

<http://www.belfasttrust.hscni.net/pdf/CHRONICPAININFORMAION.pdf>

Books

'Mindfulness for Health' by Vidyamala Burch & Dr Danny Penman (includes CD with Mindfulness and Movement exercises)

'Living with the Enemy' by Ray Owen (includes good stuff on preparing for and managing challenges & setbacks with pain and disability and is good for increasing family members understanding of each others struggles too)

'Happiness Trap Pocket Book' by Russ Harris (simple ideas and diagrams to help you look at life the life you really want for yourself and how to keep on track to have it)

Local Mental Health Services

Brighton and Hove Wellbeing Service

Telephone: **0300 002 0060**

For more information visit:

<http://www.hereweare.org.uk/what-we-do/brighton-hove-wellbeing-service/>

Email: BICS.brighton-and-hove-wellbeing@nhs.net

Mid Sussex: Time to Talk

Time to Talk is a friendly and approachable service offering talking therapies to people who are struggling with the following issues: stress, worry and general anxiety, depression, panic attacks and agoraphobia, phobias, social anxiety, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), health anxiety, post natal depression, low self-esteem or low confidence, relationship difficulties or bereavement and reactions to loss.

Telephone: **01444 251084**

For more information:

www.sussexcommunity.nhs.uk/services/servicedetails.htm.DirectoryID-16358

Horsham District Wellbeing

The hub offers a mental health service for adults in the Horsham District. To find out more, please

visit: **<http://horsham.westsussexwellbeing.org.uk/topics/healthy-mind/local-services>**

Patients can self-refer by contacting Horsham District Wellbeing on **01403 215111**.

Crawley Time to Talk

Offer a mental health service for adults in Crawley.

For more information, please

visit: **<http://crawley.westsussexwellbeing.org.uk/topics/healthy-mind/time-to-talk>**

Telephone: **01403 227048**

Information leaflet: **<http://www.sussexcommunity.nhs.uk/downloads/>**

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The following services are also available:

Name of Service	Description / Further Information	Phone Number	Email / Website
Mental Health Rapid Response Service	Call this service if you feel you are not able to keep yourself safe, and do not need immediate medical assistance. This service can offer immediate support. They can be reached on	01273 242220 8am - 10pm Mon–Fri 10am - 10pm Weekends and bank holidays	
Samaritans	A confidential non-judgemental emotional support 24 hours a day on the phone. The Brighton Branch is open to visitors from 10am to 10pm every day (Please phone ahead)	116 123 (free from landline and mobile) Or 01273 772277	www.samaritans.org Email: jo@samaritans.org
NHS Direct	Available 24 hours a day, 365 days a year – online and on the telephone.	111	www.nhsdirect.nhs.uk
Sane Line	A national out-of-hours telephone helpline offering emotional support and information for people affected by mental health problems. Phone lines open 6-11pm.	0845 767 8000	www.sane.org.uk

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GP	If out of hours your GP Surgery will be able to provide you with the emergency on-call GP service.		
Social Care Emergency Line	For social care emergencies phone the Brighton & Hove Social Care & Health Emergency Duty Service available from 5pm – 8:30am	01273 295555	
Sussex Mental Health Line	Support and information for anyone experiencing mental health problems and carers. Lines open Monday to Friday 5pm-9am. Weekends and Bank Holidays – 24 Hours	0300 5000 101	
Mind	Support and information for anyone experiencing mental health problems.	0300 123 3393 01273 666950	www.mind.org.uk Email: info@mind.org.uk
Elefriends	A supportive online community where you can be yourself.		www.elefriends.org.uk

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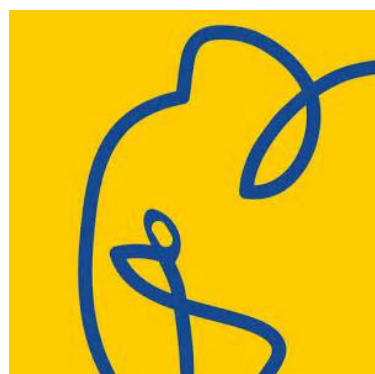
Apps for wellbeing and mental health

These days so many of us use apps in our everyday life, but have you considered using them to look after your wellbeing and mental health?

Listed below are some FREE* apps to get you started. Whilst these apps can be useful, they are not a replacement for seeking medical advice.



Wellmind is your free NHS mental health and wellbeing app designed to help you with stress, anxiety and depression. The app includes advice, tips and tools to improve your mental health and boost your wellbeing.



Elefriends is a supportive online community from the mental health charity MIND. We all know what it is like to struggle sometimes, but now there's a safe place to listen, share and be heard. Whether you're feeling good right now, or really low, it's a place to share experiences and listen to others.



Stay Alive is a pocket suicide prevention resource, packed full of useful information to help you stay safe. You can use it if you are having thoughts of suicide or if you are concerned about someone else who may be considering suicide.

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Royal College of Psychiatrists
Mental Health App

RCPsych Mental Health App

1. Provide general public information about key mental health disorders
2. Provide links to relevant videos and podcasts
3. Provide links to the Royal College Website to which members of the public could find further information about mental health disorders.



Five Ways to Wellbeing offers a practical way to help you feel good and function well in the world. Reflect on your wellbeing, set activities to help you improve your wellbeing and track your progress. Based on substantial research, use the Five Ways to Connect, Take Notice, Be Active, Keep Learning and Give your way to improved wellbeing.



Emoodji app – tracks your mood so you can see how you're doing, and is packed with tips on dealing with different aspects of student life.



What's Up? Utilises some of the best Cognitive Behavioural Therapy and Acceptance and Commitment Therapy methods to help you cope with Depression, Anxiety, Anger, Stress and more. A modern design, simple heading and easy-to-follow methods.



Stress and Anxiety Companion gives you the tools you need to manage anxious feelings and identify their triggers so they won't trip you up in the future. It can build your mental muscles to make you stronger and happier.

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SAM: Self-help for Anxiety Management helps you understand and manage anxiety. It will help you to understand what causes your anxiety through self-help exercises and private reflection.



Calm Harm provides tasks that help you resist or manage the urge to self-harm. You can add your own tasks too and it's completely private and password protected.



Relax Melodies is a relaxation and sleep app that allows you to select sounds and melodies that you like and combine them to create a mix. Lay back, listen, and enjoy falling asleep. This app can also be used in many other situations.



MindShift designed to help teens and young adults cope with anxiety. It can help you change how you think about anxiety. Rather than trying to avoid anxiety, you can make an important shift to face it. It will help you learn how to relax and develop more helpful ways of thinking.



Moody Me provides you with the ability to review charts, graphs and a calendar that all provide a detailed history of your moods and their causes. Investigate if your current emotional state is part of a trend or something new in need of reporting.



Happier helps you stay more present and positive throughout the day. Use it to lift your mood, take a quick meditation pause, or capture and savour the small happy moments that you find in your day.

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Podcast

Podcasts available from the Mental Health Foundation Website. To help you live mentally happier – from New Years' Resolutions to Relaxation for Better Sleep to Mindfulness and How to Overcome Fear and Anxiety.



7 Cups of Tea for Android – free, anonymous and confidential conversations with trained active listeners. Emotional support on demand.



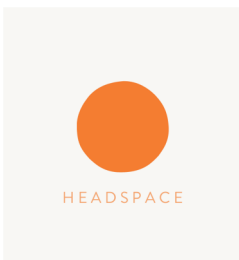
Daylio enables you to keep a private diary without having to type a single line. Pick your mood and add your activities. You can add notes and keep an old school diary. This format will help you understand your habits better.



Mental Health Recovery Guide will help you to get well and stay well. For people who suffer with depression, schizophrenia, bipolar disorder or a mental health outpatient.



MoodTools – Depression Aid for when you are feeling sad, anxious or depressed; this app can help you lift your mood. It aims to help you combat depression and alleviate your negative moods.



Headspace – a free downloadable app offering 10 minute mindfulness exercises.

*Whilst the apps listed are free to download, if you are using any apps, please check any costs involved and also compatibility to your device.

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**Congratulations for taking part in the
Fibromyalgia Self-Management Programme.
We wish you every success with your plans.**