

# Chronic Fatigue Resource Pack

## Information for patients, relatives and carers

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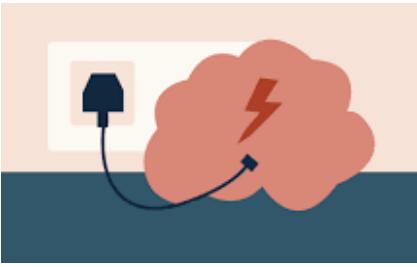
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## What is Chronic Fatigue Syndrome (CFS)?



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*This pack is aimed at children and young people who have Chronic Fatigue Syndrome (CFS), a long-term condition with lots of different symptoms, most commonly extreme tiredness that can't be explained by an underlying medical condition.*

Fatigue is when you feel so tired that you can't do all of the things that you used to, for example, playing sports. With CFS often sleeping or relaxing does not make you feel refreshed, meaning you always feel tired. Some children and young people describe CFS as having 'brain fog' or running on 'low battery power'.

When you are unwell often your body puts all its energy into fighting the virus that initially made you unwell. But then sometimes after you've got better you can still feel really tired. Even though there is no underlying cause of this fatigue, **it is still real**. If this fatigue lasts for a very long time and becomes CFS, you might develop other symptoms, *but remember everyone is different!*

Feeling really tired and not being able to do all the activities you want to can be very stressful and it is perfectly normal to feel upset or angry.

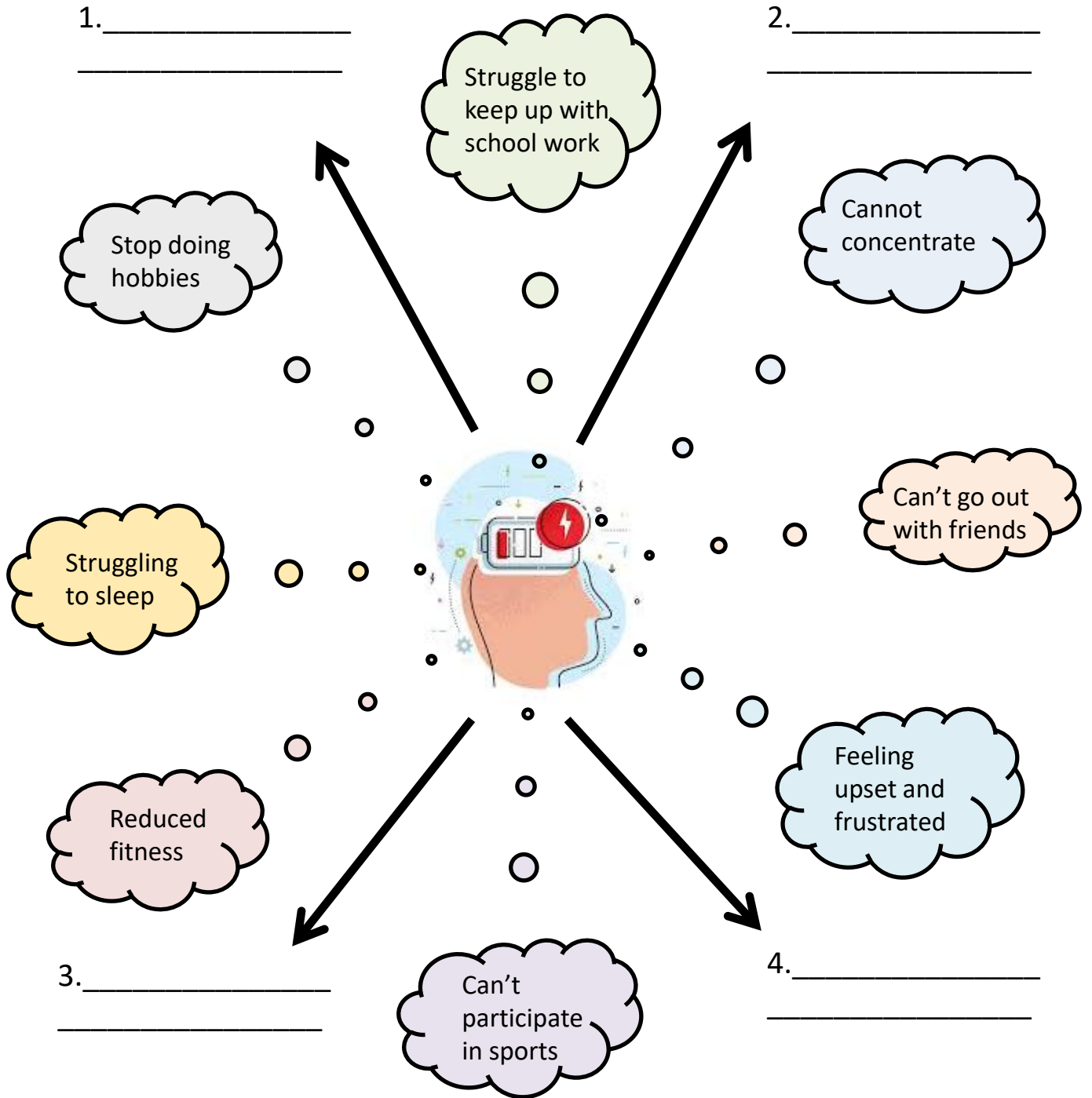
## How Does Your Fatigue Affect You?

Living with Chronic Fatigue Syndrome can often mean you experience lots of other changes in your body and mind. It is important that you can notice your symptoms of chronic fatigue syndrome so we can help try and minimise as many symptoms as possible.

Here is a list of potential symptoms of CFS, alongside the tiredness. Please tick the ones you are experiencing and add more in the blank spaces (if applicable).

- Flu-like Symptoms
- Dizziness
- Tummy ache
- Fainting
- Heart Palpitations
- .....
- Chills
- Sensitivity to loud noises
- Sweats
- Joint Pain
- .....
- Twitching
- Nausea
- Hot Flashes
- Sensitivity to touch
- Headaches
- Food Intolerances
- .....
- .....
- Sensitivity to bright lights
- General Pain
- .....

Living with fatigue can be difficult. It can affect the things you do, it can also impact the way you feel and think, as well as your relationships with friends and family. Have a look at the examples below of how fatigue can affect young people. Use the blank spaces to write other ways in which pain has affected your life.



Children and young people often need a lot of sleep, but they also have erratic sleeping and waking times. When you have CFS these times can become even more erratic! It is not uncommon for children with CFS to sleep for longer than 12 hours, but you can still wake up feeling tired and not refreshed!

When you have CFS it is particularly important to make sure you are getting good quality sleep, rather than just trying to sleep for longer! Some **advantages of good quality sleep** are:

1. You're **awake in the day** so you can see family, friends and go to school more
2. You're **awake for meal times** – you will have even less energy if you don't eat well
3. You will be **less fatigued** – you will be happier, be able to do more exercise, concentrate for longer, be more creative, and lots more!

Think of 3 ways good quality sleep could benefit you:

- 1.
- 2.
- 3.

Chat with your parent/carer to agree **3 goals** to focus on to help you sleep better (for example, "I will leave my phone downstairs")

- 1.
- 2.
- 3.

Children need different amounts of sleep depending on their age:

- 0-1 year olds = 14-15 hours
- 1-3 year olds = 12-14 hours
- 3-6 year olds = 10-12 hours
- 7-12 year olds = 10-11 hours
- 12-18 year olds = 8-9 hours

**It is important to remember that a child with CFS may need more than this!**

## Top Tips for better sleep!

- Have some quiet time before bedtime e.g., read a book
- Go to bed at the same time every night
- Only use your bed and bedroom for sleeping (i.e., don't play or work in there)
- Don't have a TV, laptop or phone in your bedroom
- Turn your clock around so you can't see the time
- Have a warm bath before bed
- Don't have the heating on too high, you sleep better when a little cooler
- If your mind is buzzing, write down your thoughts and ideas so you're more likely to stop thinking about them
- Don't drink caffeine, especially before bed
- Once you're awake, get up straight away
- Open the curtains when you wake up
- Get up the same time each day
- When you've got up, get dressed into day clothes



Pain is a common symptom experienced by children and young people with CFS. Therefore, it's important to know how pain works, and what we can do to make it feel better.

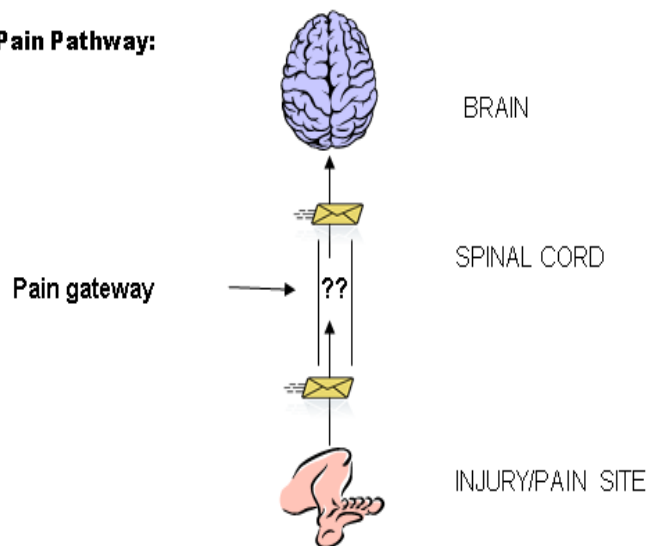
The sensation of pain is affected by both physical and psychological processes. Signals from nerve endings in the nervous system pass through a neural 'gate' in the spinal cord before being passed to the brain. The 'gate' is what determines how much pain we feel.

*The more open the gate is, the more pain we feel.*

Factors that open the gate:

1. **Stress and Tension** – All sorts of emotional states can lead to the gates to pain being more open. These include being anxious, worried, angry, and sad. Having a lot of tension in the body is a common way of opening the pain gates.
2. **Focusing on the pain** – Pain can feel worse when we concentrate on it a lot.
3. **Lack of Activity** – Not moving or and stopping our normal activities can make pain worse. It can also reduce our fitness levels. (This is often particularly challenging when you experiencing pain as a symptom of CFS)

**The Pain Pathway:**



*The more closed the gate is, the less pain we feel.*

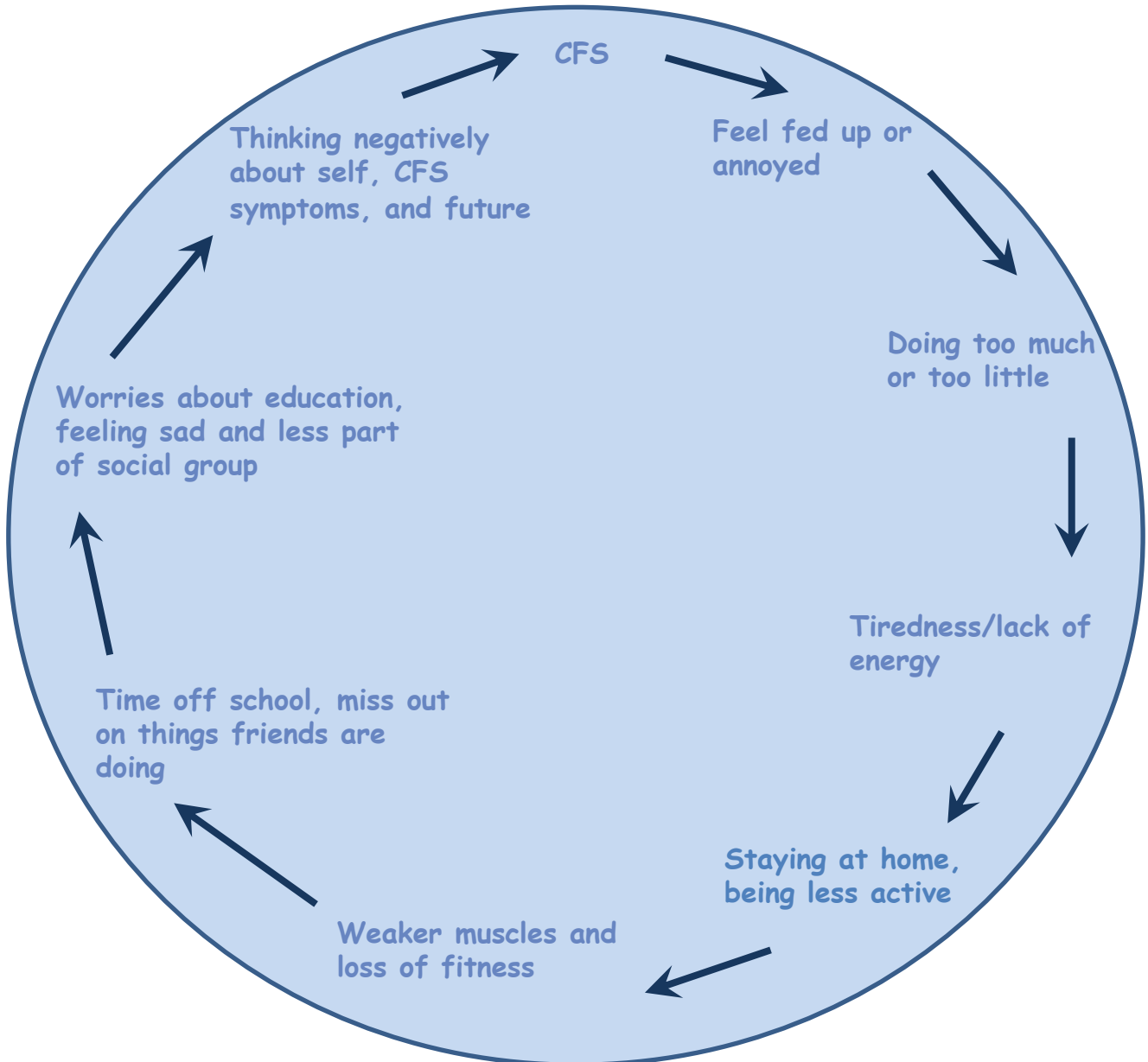
Factors that close the gate:

1. **Relaxation and Contentment** – Feeling generally happy and optimistic has been found to help close the pain gate.
2. **Psychological Factors** - Feeling relaxed and content, possibly by doing relaxation exercises (see worksheets following page 14), keeping your mind busy and distracted with other things, and focusing your attention on doing things that are important to you (rather than focusing on the pain and thoughts associated with it).
3. **Activity** – Being active but not overdoing it so you develop your fitness (see 'Pacing' worksheet, page 10)
4. **Other Physical Factors** – some types of counter-stimulation (heat, massage, and acupuncture) may help.

Factors	<b>Things That Open The Pain Gate, Causing Pain.</b> 	<b>Things That Close The Pain Gate, Reducing Pain.</b> 
<b>Physical</b>	<ul style="list-style-type: none"> <li>• Tensing muscles.</li> </ul>	<ul style="list-style-type: none"> <li>• Stretching.</li> <li>• Applying a heat pad on the abdomen.</li> <li>• Relaxation exercises.</li> </ul>
<b>Activity/Behaviour</b>	<ul style="list-style-type: none"> <li>• Too much or too little activity.</li> <li>• Focusing attention on the pain.</li> </ul>	<ul style="list-style-type: none"> <li>• Pacing activity level (see pacing worksheet on page 10).</li> <li>• Participating in enjoyable activities.</li> <li>• Doing things that are in line with your values, despite your pain.</li> <li>• Distraction – thinking about and doing something different.</li> </ul>
<b>Emotions/Feelings</b>	<ul style="list-style-type: none"> <li>• Stress and tension.</li> <li>• Feeling sad.</li> <li>• Feeling anxious.</li> <li>• Feeling angry.</li> </ul>	<ul style="list-style-type: none"> <li>• Feeling calm and relaxed.</li> <li>• Being more able to cope with strong emotions.</li> </ul>
<b>Thoughts</b>	<ul style="list-style-type: none"> <li>• Thinking about how you cannot control or stop the pain.</li> <li>• Thinking about how the pain has affected your life.</li> </ul>	<ul style="list-style-type: none"> <li>• Thinking helpful thoughts, such as reminding yourself of different ways you can manage your pain.</li> <li>• Distraction – thinking about, and doing, something different.</li> </ul>
<b>Social</b>	<ul style="list-style-type: none"> <li>• Isolation – being on your own.</li> <li>• Avoiding spending time with family and friends because of your pain.</li> </ul>	<ul style="list-style-type: none"> <li>• Spending time with people who care about you.</li> </ul>



CFS can create a cycle in which we feel trapped. The first step to breaking out of the cycle is to understand what it actually is! By understanding the CFS cycle, we can start to see that there are a number of things that can be done to help manage your CFS.



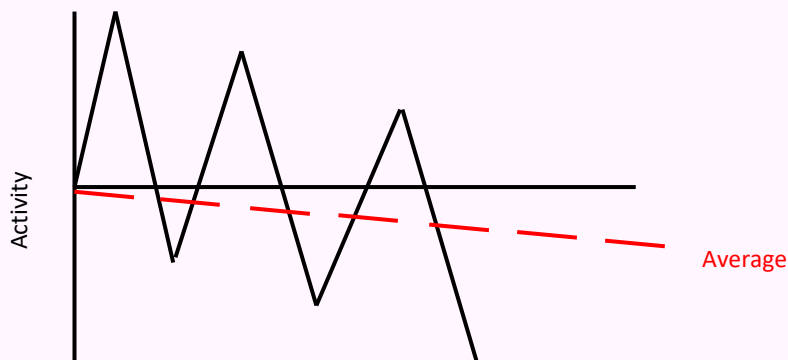
As you can see, CFS can affect you in many different ways. It affects your thoughts, feelings, body and behaviour.

It is also important to remember that everyone experiences different symptoms of CFS. Therefore, your cycle may include some extra steps if you are also managing other symptoms on top of fatigue.

## Changing How I Cope With Fatigue: Doing Too Much or Too Little

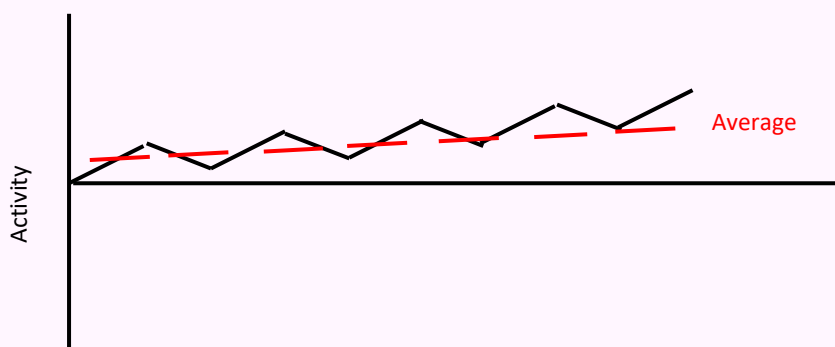
### **Pacing**

Some people who suffer with long-term fatigue choose to do less activity. This makes sense, however, it can result in you missing out on important and fun activities. We know that missing out can negatively impact your mood. Some people try to stay very active on days they feel better. Again, this approach makes sense but can be counterproductive. You may push yourself too hard and end up suffering, resulting in exhaustion, low-mood and pain. This is referred to as a **boom and bust pattern**:



Pacing is a skill which enables you to consistently carry out activities without causing excessive tiredness or inactivity. Pacing is the middle ground between doing nothing and doing too much. Over time you may notice that pacing enables you to do more.

1. Choose an activity, such as seeing your friends or school work.
2. Measure the length of time you feel physically and emotionally comfortable doing this. Do this at least 3 separate times on good and bad days.
3. Take the average of these times. This helps you find your comfortable starting point (amount of time) to spend on these activities. Try to stick to this time, no more and no less.



### **Remember:**

- Pacing can give you more control.
- Pacing is about judging when to stop an activity based on **time** and not mood or tiredness.
- The comfortable starting point should be used on both good, and bad days. It is normal to find it difficult to limit yourself on good days.
- Using a comfortable starting point leads to improved tolerance and achievement.

## Changing How I Cope with Fatigue

*When we experience fatigue, we can often stop doing things that we used to enjoy. However, avoiding things often makes us feel worse in the long-term.*

1. The first step is to think about things you have stopped doing/are doing less/are avoiding as a result of your CFS. Make a note below of things you are avoiding because of how you are feeling.

**Things around the home:**

**Things at work or school:**

**Hobbies and interests:**

**Social activities with friends and family:**

**Anything else?**

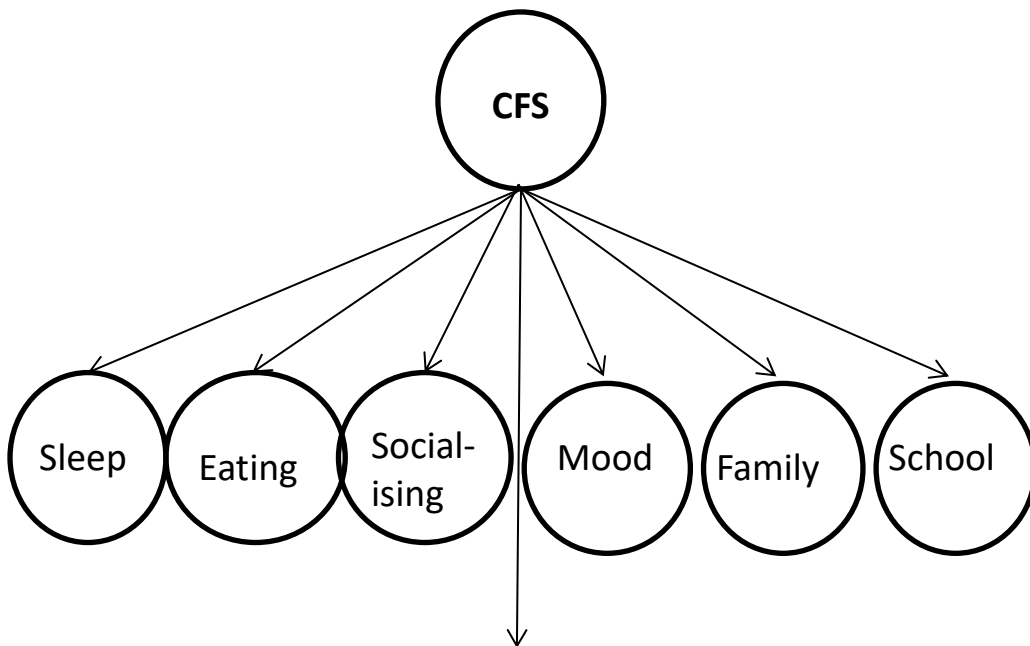
2. Once you have filled in Section 1, the next step is to plan how easy it would be to start doing some of the avoided activities again. It may seem overwhelming in the beginning, however, it is much easier if you break the process down into smaller steps. Create a ladder (hierarchy) of things you avoid with the ones you are most anxious about at the top, and the ones that bother you less at the bottom. Try to include a good mix of the things you wrote down in Section 1. Start to tackle your fears and your CFS by starting at the bottom of the ladder and gradually working your way through each step. Before completing each task, write down what you **think** will happen, and follow this up by writing down what **actually** happened after task completion. Hopefully you will start to see that it is mostly not as bad as you think it is going to be.

	<u>Situation</u>	<u>Difficulty (0-10)</u>
	Example: playing rugby again	10 (most difficult)
	_____	_____
	_____	_____
	_____	_____
	Example: texting a friend	1 (least difficult)
	_____	_____



1. Consider areas that you want to change or improve.
2. Try to set goals you are capable of achieving using determination. Do not underestimate your ability!
3. Have faith in yourself - your thoughts can affect how you physically feel!
4. Write down your goals. It will help you to see what you have achieved.
5. Do not panic if you do not achieve your goal. Think about why. Perhaps you need to add in smaller step to achieve the long term goal?
6. Reward yourself when you achieve a goal!

Areas To Think About When Planning Future Goals, For Reducing The Impact Of CFS



Write down any other areas of your life that have been impacted by your CFS:

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Having Chronic Fatigue Syndrome can cause you to stop taking part in activities you enjoy. Goal setting is about working out what you would like to be able to do, and working towards achieving it. Goal setting is a powerful way of improving your quality of life and sense of control. It is important that goals are meaningful to you and feel good.

**S**pecific: clearly state what you would like to happen

**M**easurable: will you be able to say it was achieved?

**A**chievable: are you able to complete the task independently?

**R**ealistic: are you going to do it?

**T**imely: think whether it is 'the right time' to do this. Set yourself a realistic time limit to achieve this goal.

**Specific**

To create a specific goal it must answer the 6 'W's.

1. **WHO** is this goal for/who is involved in it?
2. **WHAT** is it that needs to be accomplished?
3. **WHERE** should this goal take place?
4. **WHEN** will this goal be completed, or how long will it take?
5. **WHICH** things or requirements, and constraints, need to be identified?
6. **WHY** does this goal need to be accomplished? What is its purpose?

For example:

'I want to use Progressive Muscle Relaxation to help manage my pain' as a SMART goal would be:

'I want to use Progressive Muscle Relaxation 30 minutes, everyday at home for one month, to reduce my symptom severity'.

**Timely**

An important factor in achieving your goals is seeing the progress you have made. Set a time limit to complete your goal.

For example, practice progressive muscle relaxation for 30 minutes each day, for a month before you tackle another goal.

Write down your progress, seeing progress can motivate and encourage you.

**Measurable**

Measurable goals make it easier to stay on track to meeting your goals. Questions like 'how much', or 'how many', or 'how will I tell if I met my goal' is a good way to determine what to measure. For example, practicing Progressive Muscle Relaxation for 30 minutes everyday is quantifiable and measurable. You can track your progress and see results.

**Realistic**

When you are coping with CFS you need to have goals which are realistic and reasonable. It is easy to get ahead of yourself. Sometimes people fall into the trap of getting overwhelmed by goals which seem impossible. Make a realistic goal by breaking into smaller goals.

*A goal is something that you are motivated to work towards and achieve. When you are working on activity levels, it is important to set goals that can help to both motivate you, as well as direct your efforts and energy.*

**Doing more**

Mood can be greatly affected by what we do, when we do it, and with whom.

Keep track of what you do each day and make sure you are spending your time doing enough things that give you a sense of:

*A - achievement*

*C – closeness to others*

*E – enjoyment*

Being mindful of these 3 things when goal setting may help you to set meaningful SMART goals. Doing more also allows less time for negative and unhelpful thoughts and overthinking, which will have a positive effect on mood.

Contents: Guided Self Help Worksheets



Calming The Body - *Feeling relaxed can help reduce symptom severity*

**Progressive Muscle Relaxation (PMR).....(See p.15)**

Muscle tension is commonly associated with stress and anxiety, it is the bodies natural response to potentially dangerous situations. Even when there is no danger, our bodies can still respond in the same way. You may not always realise that your muscles are tense, it may be as subtle as your jaw clenching, or as obvious as your shoulders feeling really tight and hunched. PGR is a deep relaxation technique which is based upon the simple practice of tensing one muscle group at a time . This is followed by a relaxation phase with release of tension. This is very useful before bedtime.

**Deep Breathing.....(See p.16)**

During deep breathing your blood is oxygenated, triggering the release of endorphins, whilst also decreasing the release of stress hormones, and slowing down your heart rate.

Calming The Mind - *Strategies for managing the anxiety and stress that is often associated with abdominal pain*



**Worry Tree.....(See p.17)**

Worry Trees are helpful in reducing levels of anxiety surrounding both hypothetical situations and current problems.

**Visualisation.....(see p.18)**

Help yourself to feel more relaxed by thinking about things that make you feel calm and rested. For example, picturing your favourite place. This can be either independent, or you can take a guided visualisation approach. A guided visual imagery relaxation task has been provided in this pack.

**Safe Place Visualisation.....(see p.19)**

A powerful stress reduction and relaxation tool, that can be applied at any time, in any location.

**Self-Soothing Strategies.....(see p. 20)**

This is a useful technique for remaining grounded in the present, to alleviate symptoms of stress and anxiety.

**Developing Coping-Self Talk.....(see p.21)**

These are phrases that you can say to yourself that are supportive. For example “Just because it has happened before it does not mean it will happen again”

**Supporting Children and Teenagers with CFS.....(see p.22)**

This includes tips and advice for parents of caregivers of children with CFS

**Online Support.....(see p.23)**

**Local Support.....(see p.24)**

## Progressive Muscle Relaxation

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<b>1</b>	Get comfortable in a distraction free environment. You can either lay down or sit upright in a chair. Closing your eyes will help you focus on the different muscle groups, but you do not have to if you don't want to! <b>For all steps, hold the tense position for a couple of deep breaths, or however long is comfortable for you, then relax. Repeat each step three times.</b>
<b>2</b>	Draw a deep breath in through your nose and feel your abdomen rise as you fill your body with air. Then slowly exhale from your mouth, pulling your belly-button towards your spine.
<b>3</b>	Start with your feet. Clench your toes with your heel pressing towards the ground. Squeeze tightly for a couple of breaths and then release. It may help to say 'relax' whilst you release the tension. Next, flex your feet with your toes pointing towards your head.
<b>4</b>	Next move to your legs. Stretch your leg out, with your toes pointing towards the sky, feel the back of your leg tightening. Hold this for a couple of deep breaths and then release. Then, point your toes down into the ground with your leg straight for a couple of deep breaths.
<b>5</b>	Now move onto your glutes. Squeeze your buttocks muscles for a couple of deep breaths. Remember, you should only feel tension and not pain.
<b>6</b>	To tense your stomach and chest, pull your belly button in towards your naval as tight as you can. Breath in deeply, filling up your chest and lungs with air.
<b>7</b>	Next, tense your shoulder blades and back. Push your shoulder blades backwards, as if you are trying to get them to touch. This will push your chest forwards.
<b>8</b>	Now tense the muscles in your shoulders as you bring your shoulders up towards your ears.
<b>9</b>	Be careful when tensing your neck muscles! Face forward, and <u>SLOWLY</u> pull your head back to look up at the ceiling.
<b>10</b>	Squeeze your teeth together to tense your jaw. Open your mouth as wide as you can, as if you are yawning, to relax your mouth and jaw.
<b>11</b>	To tense your eyes and cheeks, squeeze your eyes tight shut.
<b>12</b>	Raise your eyebrows as high as they will go, as if you were surprised, to tense your forehead.
<b>13</b>	To tense your upper arms, bring your forearms up to your shoulder to 'make a muscle'.
<b>14</b>	Finally, to tense your hand and forearm, make fists with both of your hands.

*Practice means progress. Only through practice can you become more aware of how your muscles respond to tensions and relaxation. Training your body to respond differently to stress is like any training – practice is the key!*

## Calming The Body: Deep Breathing

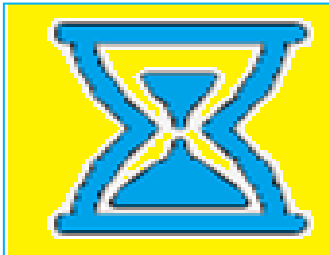
16

During periods of anxiety, the body triggers the **Fight or Flight Response**. Breathing is shallow, uncontrolled, and muscles become tense. Deep breathing triggers the **Relaxation Response**, whereby breathing becomes deeper, controlled, slower, and the symptoms of anxiety reduce.

Sit or lie down comfortably. Close your eyes if it makes you feel more comfortable. Place your hand on your stomach, if you breath deeply enough, you should notice your hand rising and falling with each inhalation and exhalation. Imagine a balloon blowing up in your stomach as you breath in, and deflating as you breath out.



1. **Inhale.** Breath in slowly through your nose for 4-8 seconds.



2. **Pause.** Hold the air in your lungs for 4-8 seconds (however long is most comfortable for you).



3. **Exhale.** Breath out slowly through your mouth for 4-8 seconds.

**Repeat.** Practice for at least 2 minutes. As your technique improves, practice for 5-10 minutes.

### Tips

1. **Slow down.** The most common mistake is breathing too quickly. Count each step slowly as you do so.
2. **Counting your breaths** takes your mind off of the source of anxiety. Counting acts as a distraction, whenever you catch your mind wandering, return to counting.



1. What is making you worry?

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2. Can I do anything about this issue?

NO

YES

Try to distract myself to ease my worry

Make a mind-map or list showing what different things I can do to stop or improve my worry.

3. Can I do anything about it **right now**?

Yes, I can...

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No, I cannot do anything about it in this moment.

Do this now!

Make a mind-map or action plan of what I can do in the future to help ease my worry.

Stop worrying and distract yourself.

Do my best to stop worrying by distracting myself, until I can action my plan.

Tip: make your mind-maps and lists colourful, you will be more likely to remember what you have written, and engage with the material more!

## Guided Visual Imagery Relaxation: The Beach

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*Lay down, or sit comfortably in a quiet room. Use the deep breathing techniques you learnt earlier in this pack, close your eyes and listen to somebody read you the following script. You can also read this script to yourself. You may find it more relaxing to play an audio track of crashing waves on the beach; this can be sourced on YouTube, Spotify, and most other online music platforms.*

You're walking down a long wooden stairway to a big, beautiful beach. It is very quiet and stretches off into the distance as far as you can see. As you look down you notice that the sunlight is reflecting off of the golden sand. You step into the sand, it feels warm so you wriggle your toes. You notice the warmth from the sand between your toes and around your feet. You notice the sounds of the waves crashing and chasing you up the shore, the water sparkles like a diamond as it retreats back. The roaring sound of the waves is so soothing that you can just let go of any worries.

The ocean is a beautiful light blue, with patches of darker sapphire in the deep. As you look at these deep blue areas you notice a small sailboat on the horizon. All of these sights help you to let go of any worries and relax even more.

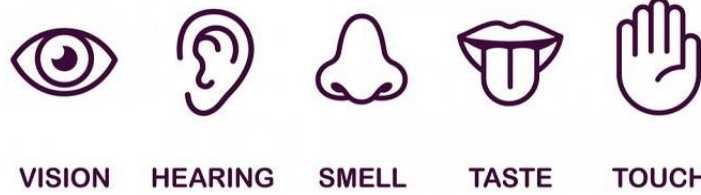
As you continue walking along the beach, you become aware of the fresh salty sea air. You look up take a slow deep breath in, and breath out. This breath makes you feel refreshed and relaxed. As you look up you notice two seagulls, the wind gusts and they appear to dance in graceful circles above you. It makes you wonder how it would feel if you could fly under the warm sun.

You find yourself settling into a deep state of relaxation as you walk further down the beach. You feel the sun wrap its warm arms around you, the warmth relaxes all of your muscles. You notice a beach chair as you walk down the beach, once you reach it you take a seat. Laying back in this comfortable chair makes you reflect on everything you have felt, seen and thought at this beach. You drift into a deeper state of relaxation.

Now, feeling relaxed and at peace, you slowly rise from the beach chair and step into the warm sand to walk home. As you walk, you remember how relaxing this beach has been, and you know that you can come back to this place anytime you like. You start to climb the wooden stairs and gradually bring yourself back into the room.

When you are ready, you can open your eyes.

All visualisations can be strengthened by engaging all of your senses in creating your 'Safe Place'. If you any negative thoughts enter your positive imagery, discard that image and create another one.



Get comfortable in a quiet place where you won't be disturbed. Sit, or lie, comfortably. Take a few minutes to practice some deep breathing, become aware of any tension in your body, and release it with each breath.

Imagine a place where you can feel safe and relaxed. Your safe place can be somewhere you have been on holiday, somewhere you have seen a picture of, or a completely new place you create. Avoid using your home as your safe place.



Look around your safe place, pay attention all the colours and shapes around you. Describe what you see aloud.

Now focus on what you can hear. Listen to the sounds far away from you, and those close to you. Perhaps you hear is silence. You may hear the sound of running water, or the crunch of leaves under your feet.



Now focus on any skin sensations. Notice the feel of the ground beneath your feet, or whatever is supporting you in this place. Pay attention to the temperature and direction of the wind, and anything else you can feel.

Take a deep breath in. Place your hand on your stomach, and imagine a balloon inflating in your stomach. Can you notice any smells there? Maybe you can taste the salty sea air as you inhale?



Pay attention to all of these sensations whilst you spend time relaxing in your safe place.

Whilst you're in your safe place, give it a name that you can use to bring that image back at any time.

You can choose to stay for a while, enjoying the calmness and tranquillity. You can leave when you are ready by slowly opening your eyes and bringing yourself back to alertness in the present.



## Self-Soothing

### **5, 4, 3, 2, 1 Grounding Technique**

This approach explores your five senses to help keep you grounded in the present. This is a calming technique that can help you get through periods of anxiety, or headaches. It can be done independently, making it useful for when you are alone.

Take a deep belly breath to begin. Imagine a balloon in your stomach filling up with air as you breath in.

**LOOK:** Look around for **5** things that you can see, and say them out loud. For example, you could say, I see the TV, I see the pencil case, I see a vase of flowers.



**FEEL:** Pay attention to your body and think of **4** things that you can feel, and say them out loud. For example, you could say, I feel my feet warm in my slippers, I feel the grass beneath my feet, or I feel the beanbag I am sitting on.



**LISTEN:** Listen for **3** sounds. It could be the sound of traffic outside, the sound of typing or the sound of your tummy rumbling. Say the three things out loud.



**SMELL:** Say **2** things you can smell. If you're allowed to, it's okay to move to another spot and sniff something. If you can't smell anything at the moment or you can't move, then name your 2 favourite smells. You may say, I can smell dinner cooking, or I can smell perfume.



**TASTE:** Say **1** thing you can taste. It may be the toothpaste from brushing your teeth, or sweetness from fruit. If you can't taste anything, then say your favourite thing to taste.

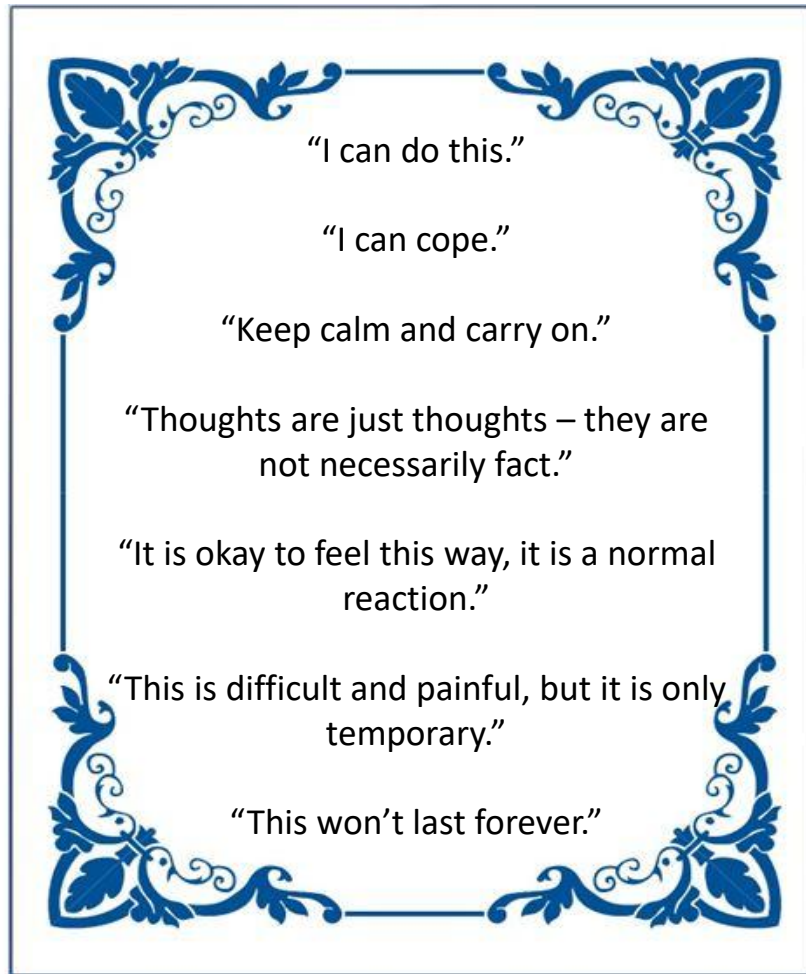


Take another deep belly breath to end.

## Develop Coping Thoughts/Positive Self-Talk

Positive statements encourage us and help us cope in distressing times. We can act as our own coach by saying encouraging things to ourselves, especially when our symptoms are worse (e.g. pain). Creating a sentence that you can say to yourself when you are feeling low or struggling to cope with your CFS can be very useful. Some children keep a copy of these in their pencil case or wallet so that they are always available.

Some examples include:



### Activity:

Fill in the empty spaces with a coping thought you could use in this situation:

Situation	Coping Thought/Positive Statement
Example: I have got really bad stomach pain, I am supposed to have a test at school today.	‘The pain will pass, like it has done before. I can still go and do my best, and talk to a teacher to tell them about how I am feeling’.
I was supposed to go out with my friends today, I’m too tired today.	
I keep missing out on taking part in sports.	

It can be difficult to see a child/teenager fatigued and struggling. However, as an adult there are ways in which you can help improve their ability to cope with CFS:

- 1. Set Routine and Record** – It is important that the young person establishes a routine to ensure they get enough sleep, but also so they can live a balanced life where their energy is dedicated to family time and hobbies, as well as schoolwork. Keeping a diary can really help with this as it allows you and your child to track their energy levels and understand what activities use up more energy resources. You can find an activity, rest and sleep diary using this link - [https://www.ruh.nhs.uk/patients/services/clinical\\_depts/paediatric\\_cfs\\_me/documents/CFSActivityRestSleepdiary.pdf](https://www.ruh.nhs.uk/patients/services/clinical_depts/paediatric_cfs_me/documents/CFSActivityRestSleepdiary.pdf)
- 2. Distract and reduce focus on fatigue and other CFS symptoms** - It can be difficult to know how to respond to a child/ young adult who is experiencing symptoms of CFS. Often, the natural urge is to pay attention to signs that the young person may be struggling. It is important to avoid making the child/ young person worry or become anxious, as they may focus on their symptoms more. Although it is challenging as a parent, it is important to minimise attention on the symptoms, for example, by not asking how fatigued they are.
- 3. Encourage normal activities** – It is important that the young person continues to participate in activities they enjoy, rather than dedicating all their energy to schoolwork. These activities may need to become less frequent/shorter, but you can still support them to participate despite having CFS.
- 4. Provide encouragement** – Children and young people will feel more confident in their ability to cope with their CFS with your support and confidence. Your role is to provide positive encouragement that they can cope with and manage their CFS.
- 5. Support and communicate**– CFS may affect your child/teenager’s ability to attend school, complete homework, coursework and revision. Offering support with studies may relieve some of the stress, and in turn decrease fatigue. You may like to provide this information booklet to their school/college so they can provide extra support where necessary.

### Apps:

Mindfulness and Sleep: <https://www.smilingmind.com.au/>

Meditation and Sleep: <https://www.calm.com/>

Meditation: <https://www.headspace.com/kids>

Progressive Muscle Relaxation: <https://www.thinkpacific.com>

Emerge Pacing – track your energy levels, log your activity

### Other CFS resources:

Parent and caregiver resource guide for children/young adults with ME/CFS or Long COVID: <https://solvecfs.org/wp-content/uploads/2022/05/Children-and-Teens-with-MECFS-or-Long-Covid.pdf>

ME/CFS NHS webpage: [Myalgic encephalomyelitis or chronic fatigue syndrome \(ME/CFS\) - NHS \(www.nhs.uk\)](https://www.nhs.uk/conditions/myalgic-encephalomyelitis-or-chronic-fatigue-syndrome)

ME/CFS NHS frequently asked questions: <https://www.nbt.nhs.uk/our-services/a-z-services/bristol-me-service/mecfs-frequently-asked-questions>

NHS Long COVID Information: <https://www.nbt.nhs.uk/our-services/a-z-services/bristol-me-service/long-covid-information>

### Other useful websites:

Resources for Teachers, Parents, Carers, and Children: <http://www.youngminds.org.uk/>

Free Online Counselling: <https://www.kooth.com/>

Stress and Anxiety: <https://www.moodcafe.co.uk/for-children-and-young-people/feeling-worried,-frightened,-stressed-or-anxious.aspx>

Anxiety and Depression: <https://www.nhs.uk/conditions/stress-anxiety-depression/anxiety-in-children/>

Mindful Breathing: [www.getselfhelp.co.uk/mindfulness.htm](http://www.getselfhelp.co.uk/mindfulness.htm)

Mindful Activity: [www.getselfhelp.co.uk/mindfulness.htm](http://www.getselfhelp.co.uk/mindfulness.htm)

Relaxation Techniques: [www.getselfhelp.co.uk/relax.htm](http://www.getselfhelp.co.uk/relax.htm)

Relaxing Imagery: [www.getselfhelp.co.uk/imagery.htm](http://www.getselfhelp.co.uk/imagery.htm)

Thought Distancing: [www.getselfhelp.co.uk/cbtsetp6.htm](http://www.getselfhelp.co.uk/cbtsetp6.htm)

Supporting Sleep: [www.getselfhelp.co.uk/sleep.htm](http://www.getselfhelp.co.uk/sleep.htm)

# Local Free Youth Counselling and Mental Health Services: Berkshire



Frimley Health  
NHS Foundation Trust

## **Number 22**

*\*must be aged between 12-25 and live in Windsor, Maidenhead or Slough\**

27 Church Street, Slough, SL1 1PL  
Tel: 01628 636661  
Email: [info@number22.org](mailto:info@number22.org)

Self Referral Link:

<https://number22.org/enquiry-form/>

Telephone support line, aged 11+, bookable 25- minute telephone appointment.

Link to book telephone appointment:

<https://number22.org/support22/>

## **Time to Talk**

*\*Must be aged 11-25 and live in West Berkshire.\**

Up to 12 free counselling sessions. Face-to-face, online or telephone sessions.

Broadway House, 4-8 The Broadway, Newbury, RG14 2BA

Tel: 01635 760 331

Email: [office@t2twb.org](mailto:office@t2twb.org)

Self Referral Link:

<https://t2twb.counsel360.co.uk/referral/create>

## **Youthline**

*\*Must be aged 12-25 and live in Bracknell Forest.\**

Counselling sessions in person, online and by telephone.

Tel: 01344 311200

Email: [ask@youthlineuk.com](mailto:ask@youthlineuk.com)

Self Referral Link:

<https://www.youthlineuk.com/counselling-enquiry>

## **ARC Youth Counselling**

*\*must be aged 11+ and live in Wokingham\**

Counselling sessions face-to-face or online.

Tel: 0118 977 6710

Email: [Office@arcweb.org.uk](mailto:Office@arcweb.org.uk)

Self Referral Link:

<https://arcweb.org.uk/get-in-touch/>

## **Child and Adolescent Mental Health Service (CAHMS)**

*\*Must be age 0-17 and live in Berkshire\*.*

For more serious concerns about your child's mental health.

Tel: 0300 365 1234 (for non-urgent enquiries)

For urgent mental health concerns about a young person: Call the mental health access team on 0300 247 0000.

Link to Refer:

<https://forms.berkshirehealthcare.nhs.uk/cyfp/>

For lower level mental health concerns, search for the **Getting Help Team** in Buckinghamshire, which can be accessed via Early Help.

## **Berkshire Talking Therapies**

*\*must be aged 17+ and live in Berkshire\**

Talking therapy for anxiety, low mood & stress.

Tel: 0300 365 2000

Email: [talkingtherapies@berkshire.nhs.uk](mailto:talkingtherapies@berkshire.nhs.uk)

Self Referral Link:

<https://gateway.mayden.co.uk/referral-v2/7c824928-ff62-4838-855e-80d1281dfb94>



# Local Free Youth Counselling and Mental Health Services: Buckinghamshire



**Frimley Health**  
NHS Foundation Trust

## **Bucks Mind**

*\*Must be aged 13-21 and live in Buckinghamshire\**

Face-to-face and online appointments.

Tel: 01494 463364.

Email: [ypcounselling@bucksmind.org.uk](mailto:ypcounselling@bucksmind.org.uk)

Referral Link:

<https://www.bucksmind.org.uk/young-peoples-counselling-referral-form/>

## **Youth Enquiry Service (YES Wycombe)**

*\*Must be aged between 13-35 and live in High Wycombe\**

52 Frogmoor, High Wycombe, HP13 5DG

Tel: 01494 437373

Email: [info@yeswycombe.org](mailto:info@yeswycombe.org)

Referral Link:

<https://www.yeswycombe.org/get-in-touch>

## **Buckinghamshire Talking Therapies**

*\*must be aged 17+ and live in Buckinghamshire\**

Talking therapy for anxiety and depression.

Tel: 01865 901 600

Text: Text TALK and your name to - 07798 667 169

Self Referral Link:

<https://www.iaptportal.co.uk/ServiceUser/SelfReferralForm.aspx?sd=eb19256a-1304-4192-bbc3-56aab5e1c7c6>

## **Youth Concern**

*\*must be aged between 13-25 and live in Aylesbury Vale, Buckinghamshire\**

Offer 20 free counselling sessions face-to-face, by phone or virtual.

The Uptown Coffee Bar, Whitehill Lane, Aylesbury, HP19 8FL.

Tel: 01296 431183

Text or Whatsapp: 07470 833500

Email: [admin@youthconcern.org.uk](mailto:admin@youthconcern.org.uk)

Self Referral:

You can ask for counselling by contacting

Margaret: [counselling@youthconcern.org.uk](mailto:counselling@youthconcern.org.uk)

## **Child and Adolescent Mental Health Service (CAHMS)**

*\*Must be age 0-17 and live in Buckinghamshire\*.*

For more serious concerns about your child's mental health.

Tel: 01865 901 951

Email: [BucksCAMHSSPA@oxfordhealth.nhs.uk](mailto:BucksCAMHSSPA@oxfordhealth.nhs.uk)

Link to Refer:

<https://secureforms.oxfordhealth.nhs.uk/camhs/Buckinghamshire.aspx>

For lower level mental health concerns, search for the **Getting Help Team** in Buckinghamshire, which can be accessed via Early Help

<https://www.buckssafeguarding.org.uk/childrenpartnership/professionals/early-help/>

# Local Free Youth Counselling and Mental Health Services: Surrey and Northeast Hampshire



Frimley Health  
NHS Foundation Trust

## **Mindworks Surrey**

*\*Must be age 0-17 and live in **Surrey or Northeast Hampshire**\**

Emotional wellbeing and mental health service

## **Early Support**

Self-referral and lots of helpful resources at  
[www.mindworks-surrey.org](http://www.mindworks-surrey.org)

Tel: 0300 222 5850

## **Community Mental Health Teams (CAMHS)**

These services are for more serious concerns about your child's mental health. Referrals must be made by a professional.

Crisis line (6+ years): 0800 915 4644

## **Hampshire Child and Adolescent Mental Health Service (CAMHS)**

*\*Must be aged between 8-18 and live in **Hampshire**, n.b. for Northeast Hampshire see Mindworks Surrey\**

Support for a range of emotional and mental health difficulties

Tel: 02382 317 912

Email:

[hantscamhsspa@southernhealth.nhs.uk](mailto:hantscamhsspa@southernhealth.nhs.uk)

Referral Link:

[www.portal.hampshirecamhs.nhs.uk](http://www.portal.hampshirecamhs.nhs.uk)

## **Hampshire Youth Access**

*\*must be aged between 5-17 (or 24 for care leavers and SEND) and live in **Hampshire**\**

Counselling, mental health and emotional wellbeing advice and support.

Tel: 02382 147 755

Text: text 'HANTS' to 85258

Email: [enquiries@hampshireyouthaccess.org.uk](mailto:enquiries@hampshireyouthaccess.org.uk)

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

## **Talking Therapies Hampshire**

*\*must be aged 16+ and registered with a GP in **Hampshire**\**

Talking therapy for anxiety and depression.

Tel: 023 8038 3920

Email: [info@italk.org.uk](mailto:info@italk.org.uk)

Self Referral Link: [www.italk.org.uk/self-referral/](http://www.italk.org.uk/self-referral/)

## **Healthy Surrey Talking Therapies**

*\*must be aged 17+ and registered with a GP in **Surrey**\**

Talking therapy for anxiety and depression.

Organisations within Healthy Surrey:

Centre for Psychology:

[www.centreforpsychology.co.uk](http://www.centreforpsychology.co.uk)

DHC Talking Therapies:

[www.dhctalkingtherapies.co.uk](http://www.dhctalkingtherapies.co.uk)

IESO digital health:

[www.iesohealth.com/areas/surrey](http://www.iesohealth.com/areas/surrey)

Mind Matters:

[www.mindmattersnhs.co.uk](http://www.mindmattersnhs.co.uk)

With you: [www.wearewithyou.org.uk](http://www.wearewithyou.org.uk)

A wealth of general health and wellbeing resources: [www.healthysurrey.org.uk](http://www.healthysurrey.org.uk)

## Free National Services

### **Emergency Services**

If you feel like you may attempt suicide, have injured yourself, taken an overdose, or are worried about immediate safety call **999**

Call the NHS on **111** and select option 2.  
Contact your GP.

Call **HOPELINEUK** on 0800 068 4141  
Call **Samaritans** on 116 123.  
Text **SHOUT** to Shout's textline on 85258.

### **Childline**

Free confidential online service where you can talk about anything. Online resources for young people for a variety of struggles  
Website link: [www.childline.org.uk](http://www.childline.org.uk)

Tel and online chats open 24/7

Tel: 0800 1111

Link to 1-to1 webchats with online counsellors

-  
<https://www.childline.org.uk/get-support/1-2-1-counsellor-chat/>

Support aimed for children under 12:

[www.childline.org.uk/get-support/u12-landing/](http://www.childline.org.uk/get-support/u12-landing/)

### **Kooth**

*\*For young people aged 11-25\**

Free, anonymous online counselling, via a live chat service or messages.

Website link: <https://www.kooth.com/>

Link to sign up for support:

<https://www.kooth.com/signup/available-in-many-areas>

### **The Mix**

*\*Ages 11-25\**

Telephone or webchat counselling.

Contact Link:

<https://www.themix.org.uk/about-us/contact-us>

Self Referral Link:

<https://themix.my.salesforce-sites.com/CounsellingBooking>

### **Mind**

Website link:

<https://www.mind.org.uk/for-young-people/>

Variety of resources and information regarding mental health and wellbeing for young people

## Local Youth Support Services

### **Fleet Phoenix**

*\*young people and families living in **Hart district**\**

Music projects, youth clubs and mentoring projects, anxiety workshops, and community outreach programmes

Website link-

[www.fleetphoenix.co.uk](http://www.fleetphoenix.co.uk)

### **Berkshire Youth Support Service**

*\*Youth clubs for those living in **Berkshire**\**

Website link -

<https://www.berkshireyouth.co.uk/>

### **Action4Youth**





*\*For young people living in **Buckinghamshire**\**

Youth groups

Website link -

<https://www.action4youth.org/youth-groups/>

For a translation of this leaflet or to access this information in another format including:

Large Print				
	Easy read	Translated	Audio	Braille

Please contact the Patient Advice and Liaison Service (PALS) on:

### Frimley Park Hospital

**Telephone:** 0300 613 6530

**Email:** [fhft.palsfrimleypark@nhs.net](mailto:fhft.palsfrimleypark@nhs.net)

### Wexham Park and Heatherwood Hospitals

**Telephone:** 0300 615 3365

**Email:** [fhft.palswexhampark@nhs.net](mailto:fhft.palswexhampark@nhs.net)

<b>Frimley Park Hospital</b> Portsmouth Road Frimley Surrey GU16 7UJ	<b>Heatherwood Hospital</b> Brook Avenue Ascot Berkshire SL5 7GB	<b>Wexham Park Hospital</b> Wexham Street Slough Berkshire SL2 4HL
<b>Switchboard:</b> 0300 614 5000		<b>Website:</b> <a href="http://www.fhft.nhs.uk">www.fhft.nhs.uk</a>

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<b>Author</b>	Jessica Stacey, Undergraduate Assistant Psychologist Dr. Hayley Thompson, Principal Clinical Psychologist	<b>Department</b>	Paediatric Psychology Service		
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#### Legal notice

Please remember that this leaflet is intended as general information only. We aim to make the information as up to date and accurate as possible. Please therefore always check specific advice or any concerns you may have with your doctor.