

# BODY REPROGRAMMING

*Patient guide for recovery  
using the Hyland model*

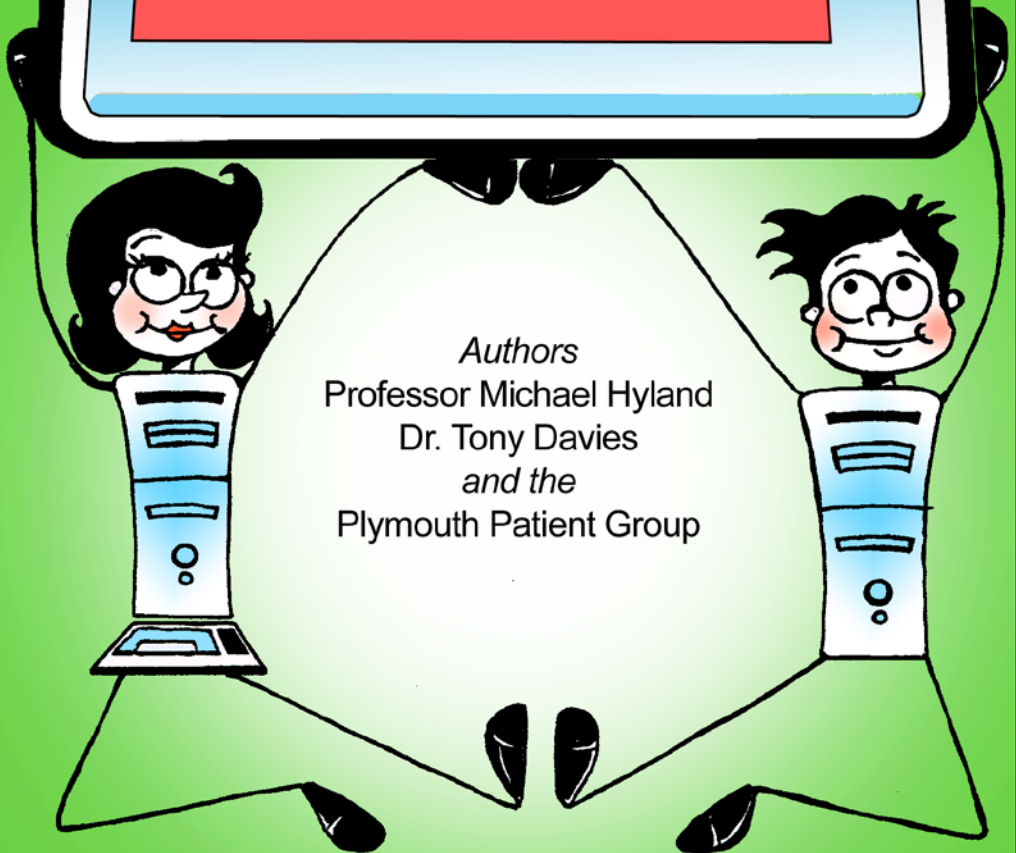
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# **Body Reprogramming for Central Sensitivity Syndromes:** A guide to recovery using the Hyland model

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## ***Acknowledgements***

**We thank the many patients in Plymouth and health professionals who helped develop this guide and Aine Dalton who provided the illustrations. In particular we thank Charlotte Hill for leading body reprogramming sessions and obtaining feedback from patients and Michaela Slocombe for formatting and administrative support.**

# **Body Reprogramming:**

## **A patient guide for recovery using the Hyland model**

### **Who is this guide for?**

The guide is for people who have been diagnosed by their doctor with a Central Sensitivity Syndrome. This includes patients with Fibromyalgia or with medically unexplained symptoms (MUS). It is also for people who have symptoms that their doctor feels might benefit from body reprogramming because they may be developing this condition. It is important to report all symptoms to your doctor, so that any necessary medical treatment can be started. Body reprogramming is not a substitute for other medicines, treatments or therapies prescribed by your doctor. It can be combined with therapies and medical treatments when these are needed by patients.

## **How is this guide to be used?**

This book provides information and gives suggestions. It does not tell you what to do. Treat this book as you would a travel guide. Read it and make up your mind what is the best route of recovery for you. This guide is in four sections:

- The first section describes the theory.
- The second section gives information about what to do to promote recovery, using the theory as a guide.
- The third section provides help with managing symptoms.
- The fourth section gives advice about putting it all into practice.

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# **Section One**

## **What is body reprogramming?**

Body reprogramming is an approach to recovery based on a theory that has been developed by Michael Hyland, a professor that recovered from chronic fatigue syndrome. The Hyland model provides an explanation for the cause of central sensitivity syndromes such as fibromyalgia and how this, and related conditions, can be treated.

Body reprogramming differs from previous approaches as it uses a new way of thinking about the body and how it can become ill. Courses may be available in your area or you may find the contents of this book helpful.

## **The body as a computer**

The body is like a very clever computer that sometimes goes wrong. Like a computer, your body can suffer from hardware and software problems. If the body is understood as a computer, then the hardware is the different parts of the body – what you can see, such as eyes, legs, lungs and heart. The software consists of instructions that are sent throughout the body. The software directs how the computer's hardware functions. The software cannot be seen.



## What is the stop program?

Fibromyalgia and central sensitivity syndromes are caused by a faulty program, a *stop program*. The stop program is equivalent to a computer virus. The stop program generates symptoms that stop you doing things.

People with fibromyalgia have *many* symptoms, not just pain, and many of these symptoms stop activity. People with other central sensitivity syndromes also have *many* symptoms.

Fatigue stops you doing too much. Pain prevents you from damaging yourself. Nausea stops you eating food that is bad for you. These symptoms may be unpleasant, but they are, from your body's point of view, helpful. They stop you doing things that are harmful. These symptoms are the result of the body's *stop signals*.

*Note: Stop signals keep you safe – you need them!*

If, over a period of time, you fail to respond to your body's stop signals, your body gradually *compensates*, and in doing so, it adapts. Your body adapts by changing its software so that the stop signals become stronger. Your body starts to 'shout louder'. If someone isn't listening to you, the natural tendency is to talk louder!

Your shouting body can develop a ‘stop program’. The stop *program* creates stop signals, even when the stop signals are not needed. The stop program is unhelpful and stops you doing things you should be doing. The stop program is the faulty program that your body has developed, as a way of *compensating* for a particular pattern of lifestyle – a pattern of lifestyle where stop signals didn’t produce their intended effect. Getting rid of the stop program is essential to recovery.

## **What causes the stop program?**

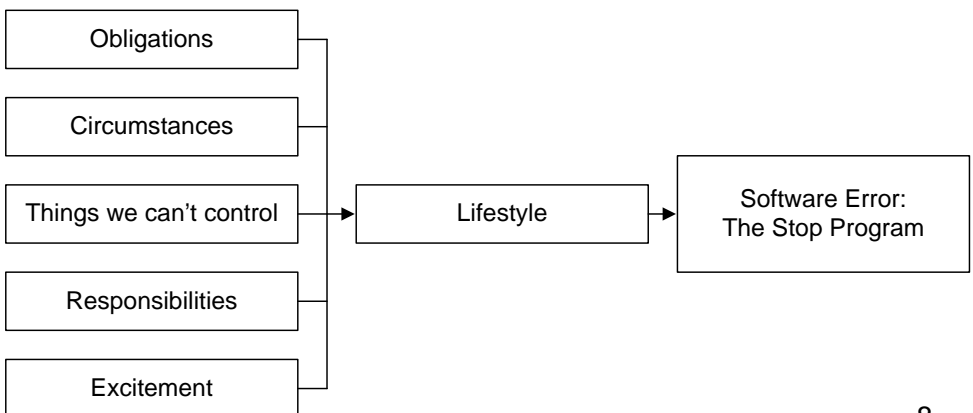
There are lots of different reasons why people, for no fault of their own, keep going and do not respond to stop signals, but the reasons fall into three types;

- **People sometimes keep going even though what they are doing is difficult, tiring and even painful.** There are many reasons why people have to keep going. It may be obligations to look after a child or relative. It may be obligations at work. It may be pride in doing a good job, or not letting others down.
- **People sometimes *have* to keep going because they are in a bad place, and they can’t get away.** People cannot always choose who they live with, where they are, or the life they live.



- **People sometimes *want* to keep going because what they are doing is fun, exciting or successful.** It may be that the person is in a good place, and keeps going because it is exciting. It may be that the person keeps going because of success. People are sometimes unaware that their body is becoming fatigued because of the positive buzz from doing well.

People who try to do their best are particularly prone to getting central sensitivity syndromes. It is the hard working people, people with a sense of responsibility, who tend to get this illness. No one should be blamed for having a stop program! There is no one cause of central sensitivity syndromes, but the Hyland model explains what they all have in common. Everyone one has a different reason for keeping going despite stop signals.



## Section Two

### How the model can be used to promote recovery

The stop program is triggered by lifestyle. The model predicts that the cure is also through lifestyle. By changing your lifestyle you can prevent yourself getting worse and may be able to cure yourself completely. Change in symptoms is slow as improvement takes time.

People with central sensitivity syndromes experience fatigue. It is easy to imagine that your body has run out of energy and you need some more. *Your body hasn't run out of energy — it has put on the brakes!* Doing too much will jam the brakes on harder and too little means the brakes simply remain on. To get better you need to learn to take the brakes off gently.

There are three general rules for eliminating the stop program:

- *Do things that **DO NOT** create stop signals.* You need to be able to teach your body that your behaviour does not create stop signals.
- *Teach your body that the world is a good and safe place.* When there is a stop program, the body interprets the world as a bad and dangerous place.

Pain when moving is the body's way of protecting you from that bad and dangerous world. You need to teach your body that the world is safe.

- *Support your body's software by improving the health of your body.* The body's software is spread throughout the body, and the best way to support it is to make the whole body healthy. There are lots of ways of improving health, but you need to find the way that is right for you at your particular stage of the illness.

Bodies can heal themselves given the right conditions. Some people DO get better. The purpose of this guide is to help you find the right conditions for a journey to recovery.

## **Keep doing things but don't create stop signals**

### **Changing**

*"Variety is the spice of life"*

To reprogram the body, it is necessary to do *things without triggering stop* signals. Doing things for too long, especially when unwell, is a sure way of triggering stop signals.

Animal bodies (and that includes humans!) are designed to produce stop signals when an activity has been carried out for any length of time. These stop signals have evolved for a reason: they make you change what you are doing, encourage curiosity, and curiosity helps survival in challenging environments. Doing *anything* for long periods of time, even if you enjoy it, is going to create stop signals. The simple rule is to do nothing for more than 30 minutes at any one time.



Tips:

1. Don't sit watching television for hours on end. When you watch television you are not active or relaxing. If you want to watch a film, record and watch it in two or more sittings.
2. Change from one activity to another that feels completely different – make the body feel that it is a *real* change.
3. When doing housework, don't do it all in one go. Do housework for a period of time that is less likely to cause a stop signal, for example, 20-30 minutes, then do something else – or at least change the type of housework e.g. vacuuming versus dusting.

4. At work, find ways of getting up from your desk and walking around or doing something different.
5. Discuss with your employer ways in which your shift can be broken up with rest periods or other forms of change.
6. If you have long conversations with a relative, set a timer and explain that you can only talk for short periods.

## **Stress reduction and stress avoidance**

Stress is produced when:



- You work for too long
- You do something that you find frustrating, and you can't achieve the goals you want to achieve
- Other people are unpleasant to you
- You have conflicting demands on your time
- You are cold or hungry
- When you do vigorous activity

People with central sensitivity syndromes commonly have the biological signs and symptoms associated with chronic, long term stress. They are *sensitised* to

anything that is unpleasant, which is why the term sensitivity syndrome is used to describe people with this syndrome. The symptoms of people with a central sensitivity syndrome can become worse with even small amounts of unpleasantness. Stress cannot be avoided completely, because it is part of life, but ill people do best when they experience less challenges to their system.

There is a common misunderstanding that if you are enjoying yourself and don't feel stressed, then your body will not show a stress response. In fact, many stressful activities are enjoyable – people choose to go to amusement parks and go on rides that cause excitement and screaming – these activities cause a stress response.

A lot has been written on stress reduction and avoidance, much of it freely available (see for example: <http://welldoing.org/author/michael-hyland>).

People with central sensitivity syndromes such as fibromyalgia are more likely to show a stress response to events that others do not, so finding out about what causes stress and how to avoid it is important:

- Don't blame yourself for things that have happened in the past. Don't blame yourself for your illness.

- Let go of the past. Don't bear grudges or think about the hurts you have received. Move forward to a better future.
- Spend time with people who make you feel good, not those who make you feel stressed. *Make* your environment a safe and happy one by *choosing* where you go and who you spend time with.
- Learn how to say 'no'. Don't feel guilty when you say no. You can't please everyone all the time, and you shouldn't try to. Your needs are no less important than anyone else. Do what *you* want.
- Try not to feel sorry for yourself. You don't need to keep justifying and explaining yourself.
- Avoid doing things that have a high intensity of action. Exercise can be helpful but exercise is a stressor - it has to be carried out at a very low intensity and for short periods of time.
- Avoid social and other situations that produce high levels of excitement or arousal. Seek happiness by searching for contentment not excitement.
- Work out what is stressful in your life. Try to avoid it. If you can't avoid it, try ways of reducing your body's stress response.

The main thing to remember is that stress reduction is about choices *you* are able to make. You are the only person who can choose what is best for you and can put these choices into practice however finding a lifestyle where stress is reduced is by no means easy. Looking after others (children or elderly relatives) can be particularly demanding. If you cannot avoid stress, then you should try to find some time when you can ‘de-stress’ your body. The following section shows how to do this.

## **Teach your body that the world is a good and safe place**

### **Deep relaxation**

Research shows there are a range of health benefits that result from regular daily periods of relaxation or meditation. Regular practice reduces symptoms of depression and anxiety, improves the functioning of the immune system, of the hormone system and the gut.



People with central sensitivity syndrome have the biological changes that are known to result from long term stress. These biological changes



cause the body to be in a constant state of alert – as though the body is always expecting stress just round the corner. This state of constant alert can be counteracted by deep relaxation. Deep relaxation can be achieved from a variety of relaxation and meditation techniques. Deep relaxation on a regular basis reduces the body's stress response. This reduction will not happen rapidly. It takes time and requires perseverance. At first you may find it difficult, but over time you find deep relaxation gets easier. Stressful events are remembered by the body. Although you cannot undo those stressful events, you remove their influence by teaching your body that the world is a safe place to be. Leave the past in the past. Focus on the present. Stop worrying about the future. That way you will counteract your body memory of stress in the past and create new good memories, and counteract the faulty program with new, positive information.

Twice a day, try to find a time when you can go into a state of deep relaxation for 10-15 minutes. Deep relaxation means that your body *and* mind are completely relaxed. Your body can enter a state of deep relaxation only when it feels safe. Relaxation and feeling safe go together. By having regular experiences of deep relaxation, your body will gradually learn that the world is a safe place. There are many different techniques that can produce deep relaxation. They include

- word repetition
- mindfulness meditation
- body scanning
- positive self-guided imagery (such as, self-compassion therapy, gratitude therapy).
- visualisation

Different people prefer different techniques. The techniques that are most effective are the ones you find easiest to do.

Each of the five techniques can be practised in different ways:

### **Word repetition:**

This is the simplest technique to use. It involves saying the same word or group of words over and over again. Repeating a word or a group of words occupies the mind and so it is not capable of, for example, worrying or thinking about the past at the same time. This helps the mind to become calmer.

There are several ways of doing this, such as:

- Count 12345123451234512345 over and over again in your head.

- Find a word that means something nice to you and say it over and over again in your head.
- Repeat a word that has relaxing properties over and over again, such as the word 'calm' or the word 'peace'.
- Make up a word that you keep just to yourself and you repeat only when you are relaxing and only when you feel the need to relax.

## Mindfulness

This technique involves being mindful of your body, your feelings, or your surroundings. Just observe what is happening: don't judge it. There are several ways of being mindful:



- Focus your mind on breathing - observe yourself breathing in and out.
  - Focus your mind on where you are and the sounds around you.
  - Become conscious of being present where you are.
- Focus your mind on the thoughts that are in your head. Observe your thoughts, observe your feelings.

Don't try to do anything about them. Just observe yourself, without judgement.

- Try to empty your mind of all thoughts and become conscious of being conscious.

Some people find it difficult to 'observe yourself' without feeling uncomfortable. If you experience this, then try another form of relaxation. But if you find it is helpful, then mindfulness can also be treated as something you do all the time. The aim is to live in the present, rather than think about past memories. Live in the present rather than have imaginary conversations for the future. The aim is to 'be' rather than to 'do'. When you walk down the street, look at the buildings and people around you. Don't have that imaginary conversation with someone!

A good exercise is to draw or paint on a piece of paper without trying to make a picture. Just focus on making straight or wavy lines on a piece of paper or putting on blobs of paint. Don't worry what it looks like – just enjoy the doing, making whatever kind of mark feels right without trying to achieve anything.

When you draw a line on the paper, focus on how you draw the line. Be mindful of yourself doing the drawing. When you put blobs of paint on the paper, focus on the feeling of putting blobs of paint – and try to enjoy it. Of course, not everyone is going to enjoy painting and

drawing, but the purpose of the exercise is to show you that you can enjoy the simplest of things, so long as you focus on what you are doing. If you used to enjoy drawing or painting as a child, give it a go! Adult colouring books can be purchased to help people develop mindfulness - some patients have reported that they find these helpful.

## **Body scanning**

This technique involves focusing on different parts of the body and relaxing each part in turn.

Lie on the ground with your hands beside you (palms down can be more comfortable), or sit in a comfortable chair where you can be completely relaxed. Focus on the fingers of the right hand, and feel them becoming relaxed. Focus on the whole hand, and let that feel relaxed. Then move your attention to the whole arm and feel it becoming relaxed. Now, focus on the left hand and then the arm. Continue to focus on different parts of the body and letting each part relax in turn.

Don't tense and then relax – it is better just to relax. Relaxing means letting go. A good way to visualise this is to imagine you are sinking downwards into the floor or into the chair.

## **Positive self-guided imagery**

This technique combines relaxation with a positive emotional experience.

- Every evening when you are lying in bed about to go to sleep, think about all the things that have gone well on that day, however small. Try to feel grateful, even for the small things. Each evening try to find three things that you can be grateful for. Concentrate on the feeling of gratitude.
- Generate feelings of forgiveness and compassion towards yourself and those around you.
- Generate feelings of love towards yourself. Extend that feeling of love to other people you know and love or like, and even to those who you find difficult to get on with.
- There are many different techniques for achieving relaxation through positive imagery. Information about these techniques can be found in books and on the internet.

## **Visualisation**

This technique combines relaxation with the body's own self-healing mechanisms – also called the placebo effect. Expectations and intentions about the body can have real effects.

- Find a comfortable place where you can relax and concentrate. Imagine rays of light coming into you and healing your body. Try to feel your body recovering its health by visualising the healing. Visualise the different parts relaxing and getting better. Imagine your symptoms disappearing one by one.



People often report that it is difficult to find a time and place to engage in deep relaxation. The only person who can solve this problem is you!

There are several resources online that provide advice and help with relaxation. Some are free, for example:

<https://www.dartmouth.edu/~healthed/relax/downloads.html#deep>

## **Creating positive emotions: doing things you enjoy**

The immune system is sensitive to the thoughts that are going on in the brain. Positive thoughts not only improve the functioning of the immune system, they have wide ranging effects on other parts of the body too. The best way to improve the functioning of the immune system is to enjoy life. Happiness is good for you!

A dull and monotonous life teaches your body that the world is a dull and monotonous place. You want to teach your body that the world is a good place. Teach your body that the world is good and full of opportunities for you to explore and enjoy.

It is difficult to enjoy life when you are ill. Illness can make life dull and uninteresting – it can make you grumpy. Although it may seem difficult, you should try to find things to do that you enjoy. The more things that give you pleasure, the better. Don't forget: variety is the spice of life.

Each person is different and will have different ways of enjoying themselves. The secret is to find what works for you. The only way to find out is to try!

Try something new. Do something that you have never done before. Recovery means that you need to be your own expert. You also need to be your own expert about the sorts of things you enjoy and how to enjoy them.



If you find an activity you enjoy, it is important that you don't do it for too long - if you enjoy something, you will not notice the stop signals, so keep a strict eye on the length of time you do things.



Just because you enjoy something, it doesn't necessarily follow that it is good for you. Watching television can be enjoyable but you aren't *doing* anything when watching television. Your body changes its program only when you *do* something. Watching television for long periods of time is not to be recommended. It is better to watch a film at several different times.

Try to avoid watching horror or violent films. Your body may not be able to distinguish between what happens on the television and what happens to you. If you watch violence, your body will learn that the world is a violent place. It is best to watch feel-good films or comedy. There is evidence that humour can improve health.



Take the time to pamper yourself, perhaps with a long soak in a warm bath. Spa treatments and some types of complementary therapy can pamper the body. Do not pay over the odds for any complementary therapy, and do it only if it makes you feel safe and pampered.

Humour is a good way of teaching the body that the world is good. Try to have fun, laugh, and enjoy yourself – search for 'laughter therapy' online or see

<http://www.skillsyouneed.com/ps/therapeutic-laughter.html>

Try to arrange your schedule so you don't have to rush. Try to avoid situations where you are late and have to rush. Rushing teaches the body that the world is not as good as it could be. Walk slowly and eat slowly. Take your time, so that your body realises that there is no external threat. Set off early so you can drive more slowly. Set the alarm 5 minutes earlier in the morning so breakfast is more leisurely.

Think about doing something new, such as a new hobby. Or do something that you enjoyed doing and stopped doing at some time before you got ill.

Several psychological therapies help people develop positive emotions. These include:

- Self-compassion therapy  
<http://www.self-compassion.org/>
- Acceptance and commitment therapy  
[http://www.actmindfully.com.au/acceptance\\_&\\_commitment\\_therapy](http://www.actmindfully.com.au/acceptance_&_commitment_therapy)

# **Support your body's hardware and software**

## **Optimal Movement**

Pain is a powerful stop signal. People with a central sensitivity syndrome often experience pain when moving. This shows that the body 'thinks' that movement is dangerous. The body needs to be reprogrammed so that body interprets movement as safe.

Physical activity is an important part of recovery. It is important to try to include physical activity as one of your short activities every day, and preferably you should do it two or more times a day. Physical activity means anything you do where there is body movement – walking, gardening and going to the gym are all examples of physical activity

However, be careful! Everyone is different. You must try to optimise the activity to what is best for you. You are the only person who can do this! You need to optimise two things; the type of activity and the length of time you do the activity.

The type of physical activity needs to vary with the severity of the illness. To use an analogy, in central sensitivity syndromes such as fibromyalgia, the brake is

on. You should not accelerate until the brake starts coming off.

In severe cases activity should be slow so as not to produce a rapid heart rate – slow walking can be helpful. For very ill people, static exercises can be best. Static exercises are those where you stand or sit in particular positions (put 'Qigong' in a search engine to see some examples). For those people who are slightly less ill, slow movement may be best (e.g. Tai Chi, yoga). The speed of movement can be increased as recovery proceeds. Running or vigorous exercise is to be attempted when recovery is well advanced.

People with central sensitivity syndrome often experience pain whatever movement they make. It is important to select a simple repetitive form of movement that can be achieved with a minimum of distress.

The length of time doing the physical activity also varies with severity. Very ill people should do it for no more than 5 minutes, and most should limit it to 20 minutes. It is far better for activity or exercise to be 'little and often' rather than bunched up into one time. Two periods of 10 minutes may be better than 20 minutes. A little every day is better than doing lots once or twice a week. The length of time can be extended, only when recovery is well under way.

Optimum physical activity has one other important feature. The movement should be combined with a mental state of feeling happy. Imagine how the slow movement is helping you recover. Do the slow exercise in a nice environment. In summer, you might like to do it outside. Do it somewhere where it feels peaceful and safe.

Your aim is to trick your body so that it doesn't try to stop you moving. Your aim is to tell your body that your movement will not place you in danger. Your aim is to teach your body that movement is OK because the 'world is a good and safe place.'

The type of exercise recommended here exists in the form of:



- Qigong
- Tai Chi
- Yoga
- Slow walking
- Pilates

Search the web and there are many different types of exercises. A couple of links you may find useful are shown below:

<http://www.youtube.com/watch?v=PNtWqDxwwMg>

<http://www.youtube.com/watch?v=EaEZVfhn07o>

Patients may find it helpful to invent their own form of Tai chi or yoga by finding a movement that causes the least distress. A good idea is to practice movement with mindfulness, or practice movement with visualisation or self-guided imagery.

Optimum exercise is an important part of your recovery program and an important way in which you can reprogram the body so that the stop program can be eliminated.

### **Linking relaxation and physical activity**

Walking is a very useful form of exercise. For very ill people, a combination of a slow walk with mindfulness is recommended. For example, focus on how you place one foot in front of another. If you are walking, it is important to walk somewhere where you feel safe. You are trying to teach the body that the world is a good and safe place, and that you can exercise in this good, safe world. Don't rush. Try to avoid rushing because your body associates rushing with problems.

Going for a couple of short walks, one in the morning and one in the afternoon can be a sensible plan. Look about you as you walk and try to enjoy it. Don't keep trying to extend how long or how far you can walk. Your

aim is to change your body's software. Any increase should be very, very gradual. If you find that you are worse the next day, you have probably overdone things. Little and often is the best strategy, but make sure you do it, however little you can manage.

The body learns about the world in many different ways. If you stand or sit in a stressed posture, the body 'thinks' that you are stressed. If you stand or sit in a relaxed posture, the body thinks that you are relaxed. When you are stressed, the muscles of your spine contract and you lean forward - you can show your body that you are relaxed through your posture.

Imagine a string at the top of your head pulling you upwards, so that your shoulders fall downwards and your spine lengthens. Let your hands fall down by your side. Imagine this happening when you are sitting, standing and walking. Techniques designed to help you sit, stand and move in a relaxed way are taught in a form of therapy, called *the Alexander technique*. The Alexander technique encourages people to focus on their body posture so that, in their everyday lives, they move and stand in a relaxed way. That relaxation then influences the biology of the body, leading to improved health. Like, Tai chi, yoga, and Pilates, Alexander technique classes and teachers may be found in your local area.

And remember: if you like doing it, then it will work. If you don't like doing it, then the chances are it won't!

## Eating

The human body is designed to eat food in a relaxed state. Humans evolved to hunt and eat mammoths, but not to do both at the same time!



People who are stressed are more prone to put on weight. The reason is that chronic stress alters the body's chemistry in ways that are not helpful. Stress encourages the body to lay down fat.

Eat food when your body feels relaxed. Avoid eating when your body is stressed. If you have been busy doing something, have a few minutes relaxing before you eat. A little bit of deep relaxation before you eat can help if you have been feeling stressed. Don't do exercise for at least half an hour after eating. Don't eat immediately after exercise.

Eat slowly, chew your food. If you are eating with other people, make sure you are not the first to finish! Avoid watching the television, reading, or listening to the radio when eating. Do one thing at a time. Eat and make sure



you focus on the eating and relaxation when eating. Be mindful of your eating.

Don't go hungry. Hunger creates stress. Eat regular meals. Some people find it better to eat several small meals rather than fewer large ones.

The gut is sometimes described as the 'second brain.' The gut is full of nerves, and these nerves connect to the emotion centre of the brain. The gut can 'feel' just as much stress as the brain. Your gut is designed to digest food when you are relaxed. Stress can produce problems everywhere in the body, but particularly in the gut.

According to the Hyland model, you should eat a nutritious, balanced diet because doing so supports the body's software. Research shows that eating a healthy diet can reduce fatigue. There is a lot of information available on the Internet and in books on healthy eating, so this information is not reproduced here. Unfortunately, there is some disagreement amongst experts about what exactly constitutes a healthy diet. This book does not take sides in what is sometimes a heated debate, beyond noting that what may suit one person may not suit another, and that strange and extreme diets are unlikely to be helpful.

Here are a few more points about eating:



- Try to make your life enjoyable.

Eating food is an activity, so like everything you do, try to make it enjoyable! Make eating one of life's pleasures, and don't restrict yourself by following stern and strict rules

about what is healthy and unhealthy. Focus on enjoying food. If you like chocolate, get the chocolate you like most, and eat it slowly, enjoying every mouthful. Make eating fun. Ask yourself: Do the plates you eat off make a difference – or candle light? If so, create the setting that you enjoy. Make each meal special even if it is just for yourself. Making your food enjoyable is not a luxury. It is part of your therapy!

- Variety is the spice of life.

Make sure that you have a varied diet. Evidence shows that variety is a key part of a healthy diet. A monotonous diet restricted to a few 'healthy' foods is not a good idea. Good nutrition requires variety.

- Listen to your body.

An important part of body reprogramming is to learn what is good for you and what is not good for you. If you find a food disagrees with you (increases your symptoms either immediately or after a little while) then avoid that food. Some people find that it is helpful to cut out certain foods but what is helpful will vary between people, so there are no hard and fast rules. There is no sure test of food intolerance other than through experience. One recommendation by an expert in the field is through the elimination diet. You avoid a particular food for a week or so, and then reintroduce it into your diet. If you find you get worse when you reintroduce it, you know the food upsets you. It is easier to notice things getting worse than getting better.

- Don't believe everything you read!

Energy drinks don't give you energy. They give excess sugar and caffeine, neither of which will do you any good!

We have included a link below to an article that may be of interested. It will also provide details of a book by Brostoff and Gamlin which is widely viewed as one of the best on the subject of food intolerance.

<http://www.positivehealth.com/article/allergy-testing-1/the-elimination-diet-a-foolproof-way-of-diagnosing-food-intolerance>

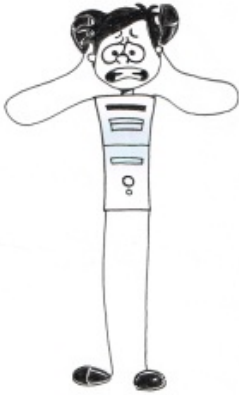
## **Supplements**

Sometimes people have low levels of vitamins and minerals despite a healthy diet, because of problems with absorption or excretion. If you are deficient in any vitamin or mineral, then your health may be improved by correct supplementation. However, without testing it is difficult to tell whether you are deficient or not. Low vitamin D is common, particularly in the winter months in the Northern hemisphere and there is a link between low vitamin D and chronic pain. 'Good oils' found in oily fish and olive oil may be helpful in reducing inflammation. There is no evidence that supplements cure central sensitivity syndromes.

## **Medicines**

Medicines are designed to help people who are ill and are prescribed by doctors for many different reasons. Sometimes medicines can cure - antibiotics kill bacteria and cure bacterial infections. In others illnesses, medicines can supplement the body's needs. For example, insulin is used in diabetes and thyroxine for an underactive thyroid. Where there is severe inflammation, such as inflammatory arthritis, steroids are sometimes used to dampen down the inflammation. Medicines can save lives. It is important to take medicines when they are needed.

People with central sensitivity syndromes are often prescribed medicines to ease some of their symptoms such as pain, dizziness and nausea. When used in this way, medicines are helpful as they can dampen down symptoms, but they do not cure the illness. In essence they do not fix the problem. Medicines are generally more helpful where there is a specific hardware problem rather than a software problem.



When used to control symptoms of fibromyalgia, medicines often show some benefit when started. However, many patients will comment that they “no longer work” after a period of time. In fact there have been no well-designed studies that show that pain medicines are effective after the initial 4 to 6 months of use.

According to the Hyland model, central sensitivity syndromes can develop because symptoms were suppressed over time. As result, the body has created a stop program - using medicines to dampen symptoms further may make matters worse if you haven't made any positive changes to your lifestyle. It may however be useful to use symptom controlling medicines for a short period while learning new strategies to manage your condition.

Some medicines to control pain can be obtained over the counter without a doctor's prescription. These include paracetamol, aspirin and ibuprofen and other pain medicines that have an anti-inflammatory effect. They can be helpful for some types of pain, such as pain after surgery. However, anti-inflammatories can cause stomach problems when taken regularly.

There are other types of pain medicine that can be used to control symptoms in central sensitivity syndromes. When used, these are prescribed by a doctor. The three main types of these medicines are:

- Morphine type medicines
- Older-style anti-depressants
- Medicines developed to help in epilepsy

## **Morphine type medicines**

Common examples are codeine, tramadol, morphine tablets or fentanyl and buprenorphine skin patches. These can be effective where there is newly damaged tissue but as the body heals the medicine becomes unnecessary. This medicine is useful for hardware problems, not software problems. In fibromyalgia, tramadol has been shown to provide short term benefit but there is no clear evidence of longer term benefit.

The reason is that the body adapts to this kind of medicine very quickly and, once adapted there can be unpleasant withdrawal symptoms when the medicine is discontinued. As these medicines also have side effects, including hallucinations and constipation, many doctors prefer not to prescribe them for people with fibromyalgia. An increasing number of experts believe that these morphine type medication can make central sensitivity syndromes worse over time.

### **Older-style anti-depressants**

Common examples are amitriptyline, imipramine, nortriptyline and duloxetine. When used in high doses they can be effective in depression but low doses are often used to help persistent pain and sleep problems. They are particularly useful with nerve type pain. It is important that these are taken earlier in the evening rather than just before you go to bed, in order to avoid a feeling of a dry mouth and hangover in the morning. Unlike the morphine type medicines, they are not addictive but can still have unpleasant side effects when stopped quickly. If a person with a central sensitivity syndrome does have depression, then a different sort of anti-depressant is normally used.

## **Medicines developed to help in epilepsy**

Common examples are gabapentin and pregabalin. They are helpful in some types of chronic pain but again do not cure the underlying problem in fibromyalgia. Are they effective? Studies show that pregabalin has a real effect in only one in eight patients. It is not a particularly effective medicine. Like most medicines they can have side-effects and these will include sleepiness, and balance problems. A common complaint with this type of medicine is that patients put on weight and can affect concentration and memory. As the body adapts to these medicines, it can be difficult to come off them.

### **What can I do?**

It is important to avoid taking many different types of pain medicines as the body adapts to any medicine that tries to mimic the way the brain and spinal cord normally deals with pain. Patients can often find themselves on large doses of medication with little benefit. Flare ups are best managed by over the counter medicines, and other techniques that help reduce pain such as heat, TENS machine, and other lifestyle changes. Always discuss your choice of medicine with your doctor.

If you are concerned about the large number of pain medicines you are taking and want to reduce them you should consult your doctor. When you reduce, reduce

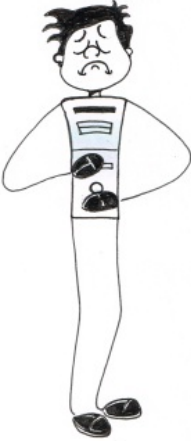


very slowly, and only one medicine at a time. There is no rush. Don't do it in a way that encourages stop signals. If you are trying to reduce, make sure you engage in creating positive emotions. Try to make your life as pleasant as possible while reducing, and choose a time when you are not going to be stressed.

When you stop, it will take up to 8 weeks for the body to reset itself. Do not worry if your symptoms increase slightly during this time, as this is likely while the body is adapting back to where it was. It can be a great sense of achievement to reduce the dose of your pain medicines, even if you don't come off them completely.

# Section Three

## Symptoms



In Central sensitivity syndromes it is not 'just' pain symptoms. All patients experience fatigue to a greater or lesser extent. Our own data suggests that on average people with fibromyalgia experience 35 symptoms a week. The more severe the illness, the more symptoms there are and the more frequently the symptoms occur. Some people are diagnosed with both

ME/CFS and fibromyalgia or Irritable Bowel Syndrome (IBS) and fibromyalgia. People with both diagnoses typically have a more severe form of the illness rather than separate conditions and have more symptoms than others.

A general symptom questionnaire is available on the [body reprogramming website](http://www.bodyreprogramming.org), [www.bodyreprogramming.org](http://www.bodyreprogramming.org). People who are ill do not always have the same symptoms, but they all have symptoms. The more symptoms the more severe their illness.

One of the important symptom features in people with central sensitivity syndromes such as fibromyalgia is

that they vary over a period of time. Symptoms usually tend to get worse and better together. Variation in symptoms and management of that variation is therefore important.

**Please note:** If you experience a new symptom, then you should get it checked out by your doctor. Most new symptoms are found to be part of your illness but it is reassuring for your doctor to confirm that this is the case and not a separate problem.

It can be helpful to try to understand why symptoms sometimes get worse. By monitoring your changing symptoms you will be better able to adjust your lifestyle to one that promotes better health.

First, it is important to recognise that symptoms can vary for no reason other than the fact that your body is in an unstable state. If you can find a reason for the deterioration, then this may be useful to guide for your future behaviour.

Sometimes when you overdo an activity – for example, too much walking – you feel exhausted the next day and the following days you don't feel much better. If you notice a consistent deterioration in what you are able to do over a period of time then you are almost certainly over-doing things. If you are sure that you are not over-doing an activity, the deterioration may occur as a result of doing too little.

You may do an activity you enjoy and believe it to be therapeutic. You feel tired the next day and in the following days you feel a lot better. The initial experience of symptom deterioration may be part of the recovery process. If you notice that something you do helps a little while later, then it is helping.

Finally, if you develop an infection, injure yourself, or life gets difficult, then it is very likely that your symptoms will get worse. If this happens then it is important to 'listen to your body' and increase the amount of deep relaxation you experience every day. If you have a hardware problem – such as an infection – then you need to teach your body that you are capable of responding to that hardware problem in an appropriate way – this includes resting and getting support from your doctor.

It isn't easy to know why your symptoms vary as some times the body fluctuates by itself without a straightforward explanation. What you do should depend on why you think your symptoms have changed. You need to be able to show your body that you are capable of responding to the messages your body gives you. At the same time, you must never let your symptoms stop you from doing things. It is only by doing things and not eliciting the stop signals that you will get better - if your body is telling you the truth, then listen to your body and change your behaviour. If your body is not telling the truth then don't pay too much

attention. There is no easy guide to knowing whether your body is telling the truth or not. You are the only person who can find this out.

Recovery is a journey. You need to become your own expert and find the things that work for you. As you start on this journey you will find ways in which you learn about yourself. Learning is the key to recovery, but it takes time. Be patient!

Recovery is often a zigzag process because your body is in an fluctuating state. Do not get discouraged when you are feeling bad. Never lose hope. Some people are able to recover completely, though they still have to avoid the circumstances that led to the illness in the first place.

## **Pain**

Pain is reported by all patients with fibromyalgia and most with other central sensitivity syndromes. Pain trumps all other symptoms. It is the symptom that patients often find most distressing and the one they report to the doctor – even when they have many other symptoms.

Try not to let pain rule your life, and stop you doing the things you want to do.

There are two main reasons why people have pain

- Actual damage
- Threat of damage

## **Actual Damage**

If the body is damaged, for example a broken leg, then the body needs time to recover and heal. The body produces, a stop signal, i.e., pain, but not a stop program. When the body heals, the pain will disappear. Even with the most severe cases of damage, the healing will have taken place by three months.

## **Threat of damage**

Sometimes the body isn't damaged or the body believes it hasn't recovered from damage; the body remains on high alert and tries to protect itself by maintaining the symptom of pain, even after the healing is complete. In these circumstances, there is no hardware problem, but there is an ongoing software problem. The pain of fibromyalgia gives you the impression that there is something wrong with a particular part of you and your body. It gives you the impression that there is a hardware problem. This impression is wrong. The reality is that the pain is due to a software problem. You need to change the software. You needn't worry about the hardware, apart from trying to make it as healthy as possible!

## Is my pain due to a hardware or software problem?

Your doctor will help diagnose whether or not you have a hardware problem. As people get older, they can develop 'wear and tear' problems, that are usually easily managed but in the case of people with central sensitivity syndromes, the software problem can make these symptoms much worse. Think of the hardware problem in this case as a small fire, if you have this condition it is like pouring petrol over the flames.



Have a conversation with your body – tell it that pain isn't needed any more. Find whatever strategy you can to teach your body that it is safe and pain isn't needed.

Pain is seldom constant. It varies from day to day and over the course of a day, and you will notice that the pain can often appear to move. In central sensitivity syndromes the whole body can feel sensitive, where even touch can feel like pain. Have you noticed how even a hug from a loved one can be uncomfortable? The body will focus on the most intense sensation of pain at any time. If this eases slightly, you will notice the next most intense area of pain. It makes little sense to

chase the pain round your body trying to control each separate area in turn.

When pain changes from day to day it can be for two reasons: something you have done or it is just way your body is working at that moment in time. If increased pain is due to you over-doing things, then it is important to pay attention and stop over-doing things – remember the rule is little and often.

However, sometimes pain increases for no apparent reason. Why is this? In central sensitivity syndromes, the body's software isn't stable. It changes by itself. If pain increases without any obvious explanation, then this is part of the process. It doesn't mean you are getting worse. Try to focus your attention on something else, something pleasant. Try to distract yourself from the pain. You may notice that football players who get injured often feel no pain because they are so engrossed in the game. If pain is occurring for no reason, then engross yourself in something else. Of course, it is important that you do not ignore pain if it is caused by you overdoing things – but your response should be to stop what you are doing rather to feel miserable about the pain.

The message for managing pain is the same message for managing any symptom: if your body is telling you the truth, then listen to your body and change your



behaviour. If your body is not telling the truth then don't pay too much attention. It is not easy to work it out, but only you can do it.

## **Fatigue**

Most people with central sensitivity syndromes such as fibromyalgia experience fatigue. Feeling tired when waking in the morning is an almost universal experience for those with central sensitivity syndromes. In addition, many people with central sensitivity syndromes experience more fatigue a day after they have been too active or due to a cold.

Fatigue is an almost universal signal the body gives when it is unwell. Fatigue tells you that something is wrong. It doesn't tell what is wrong. It is a software message to stop you doing things, but there are many different reasons why the body provides this particular type of stop signal.

There are no biological treatments for fatigue. Energy foods and energy drinks do not provide energy. If they contain sugar, the sugar is converted into fat. If they contain stimulants, there can be – though not necessarily – a short term benefit. However, that short term benefit can then cause the boom and bust behaviours that are so counter-productive for people with central sensitivity syndromes. Stimulants are best avoided, as they do not cure the underlying problem.

The underlying problem is the body is unwell, and fatigue will disappear only when the body is well again.

## Sleep

Many people with this condition have difficulty sleeping. People usually wake from sleep still feeling tired. These sleep problems are the result of your condition, and can improve when health improves. There are several types of advice that help reduce sleep problems, and it can be sensible to follow this advice if you are having problems.

- Try to go to bed at the same time each day.
- Don't eat just before you go to bed. Some people find a warm milky drink can help.
- Sometimes a bath or shower before sleeping can help.
- Avoid using sleeping tablets if possible – all medicines have side effects and the body adapts quickly.
- Make sure your bed is comfortable.
- 10 minutes of deep relaxation before you go to sleep can help

If you find that you can't sleep, *don't worry*. Instead try a simple relaxation technique. Your body *will* sleep if it needs it. *Worry* just makes things worse.



Your body has an internal clock. That internal clock alters how the body is functioning. Having a regular time of going to sleep means that your body is in its best 'going to sleep' state. Sleep needs vary between people, so don't worry if you are not sleeping. If you don't sleep, make sure you rest. Lying in bed resting is much better for you than lying in bed and worrying.

Some people find they are awake in the middle of the night. Knowing a little about the history of sleep may help. Before 1850 when artificial lighting became common, people seldom slept right through night. Instead they had a first sleep, were awake for a few hours, and then had a second sleep. Some believe that having two periods of sleep, a first and second sleep is better for us. So don't worry if you are awake or wake up in the middle of the night. There is nothing wrong with cat-napping in the day. In some countries, the afternoon siesta is considered normal. Let your body do what it wants without worrying.

## **Irritable bowel syndrome**

Some patients with fibromyalgia or ME/CFS are also diagnosed with irritable bowel syndrome (IBS), and many who do not have this diagnosis have the symptoms of IBS. IBS like fibromyalgia cannot be

explained only in terms of biology and is best thought of as a software problem.

The main symptoms of IBS are

- Stomach pain
- Constipation
- Diarrhoea
- Bloating of the stomach.

These symptoms vary. They vary depending on

- what you eat
- what you do

Some people have periods of constipation alternating with periods of diarrhoea.

The symptoms of IBS are often linked to eating but they are also linked to stress. It is helpful to distinguish food allergy from food intolerance. If a person is allergic to a food, there will be a rapid and predictable response to eating that food. There are also clear biological indicators of food allergy, including specific types of rash and facial swelling.

## Section 4



### Putting it into practice

Body reprogramming is a form of lifestyle medicine, where people change their lifestyle in order to get better. Changing lifestyle is not easy.

### Looking after yourself

Many people develop these conditions because they always put others first. To get better you need to find some time each day when you put yourself first. Putting yourself first is not being selfish. If you don't get better, others suffer. It is important that you find some 'me time' each day when you can work on your recovery. If necessary, explain this to others – or show them this guide!

“If I am only for myself, what am I?

If I am not for myself, who is?

And if not now, when?”

(Saying attributed to Hillel, written about 2000 years ago)

Every human being is unique. Each person develops the condition in a slightly different way. Each person is

at a different stage of their condition. Each person needs to find their best way to recover.

It isn't easy to do the things that are needed to promote recovery, and there are many barriers that make 'doing the right thing' difficult. Understanding those barriers is a first step in overcoming them.

## **Yourself**

People who develop central sensitivity syndromes often put others first. People with fibromyalgia and ME/CFS are 'nice people'. Over the years, there is often a pattern of putting your own needs second in order to satisfy the needs of others, often family members. Putting yourself first, even occasionally, can be difficult. Patients often say to us "I can't do this; I feel guilty and selfish if I put my needs first". It takes time to realise that you can help others best if you yourself are well.

On airplanes, passengers who have children with them, are told, "in an emergency, put your own oxygen mask on before putting your child's oxygen mask on". It may seem difficult to do this, but it is the rational thing to do, just as it is the rational thing to find time in the day to do the things that make you better.

One way of helping you overcome the barrier of helping yourself is to use 'self-talk'. Speak to yourself using your name. Suppose your name is Susan. Say to yourself, "Susan you must find time in the day to do the things that make you better". "Susan, you haven't had any relaxation today. Stop what you are doing, and practice some meditation".

It can take time to overcome a lifetime of neglecting yourself for the sake of others, and finding the best way to help yourself can be difficult. However, in the long run, you can help others best if you help yourself first.

## **Other people**

People are happiest and healthiest when they have good relations with other people, and when they feel loved by others and they can depend on others. You cannot choose your relatives, but you can choose your friends. Choose friends who make you happy. Try to have good relationships with others as this will be helpful to you. It may be necessary to forgive others for hurting you. Feelings of resentment and anger will not help your body recover.

Other people can often be a barrier because they prevent you doing the things you know can make you better.

- A partner or other family member who doesn't understand what you need to do in order to get better,
- People at work where work patterns are unhelpful.

Education is often the best solution. Give the partner or family member this guide to read. In our body reprogramming courses, we always invite partners and family members to attend to the first session, so they can understand the Hyland model and so understand what you need to do. Explain the need to have some 'me time' when you are not troubled by children – or anyone else.

If you are working, then educating your employer about central sensitivity syndromes such as fibromyalgia can help - though employers are not always sympathetic despite the legal requirement to make reasonable adjustments to your illness. It may be that you can ask to take more breaks than other people. It may be that you should consider going part time or finding another job.

Everyone's life is different, so everyone will need to find their own solution. However, that solution is unlikely to come from yourself alone, but with the assistance of others, from friends, relatives, work colleagues and line managers. The help you can get from other people will be an important factor in your recovery.



## **Employment**

For some people, it is particularly difficult to put the principles of body reprogramming into practice at work. Adjustments to working practice depend to a large extent on the work involved, and the willingness of the employer to make adjustments.

To help patients with fibromyalgia we have prepared a guide for employers and relatives which can be found at the end of the booklet. A .pdf copy of the guide is also available on the body reprogramming website.

## **Finding a routine**

If you do not have a routine, then it is difficult to make sure you find time in a busy day to do things that you find helpful for recovery. A useful tip provided by some patients is to make a timetable for each day, so that your day is planned with the various activities (e.g. rest, positive mood, movement etc.) that promote recovery. Some patients find that keeping a diary helps because it shows what they have done or not done, as well as giving an indication about what is working or not working.

Each day you should plan for at least one period of

- deep relaxation

- positive activity
- optimal movement

Don't forget to plan when you are going to eat, and to have a treat. Treats are important. The aim of body reprogramming is teach your body the world is a good place.

Planning is important because it so easy to become busy and forget to look after yourself. Planning to a schedule means that you are conscious of the time, and time is an important part of **changing**. To get better, it is necessary to keep working at it, to keep to a schedule that ensures you do all the right things, a schedule that gives you a lifestyle that improves your health.

Only you can find the lifestyle that leads to recovery – trust your own judgement.

## **Final thought**

Hope and time are both good healers. Keep hoping and keep working at getting better. Don't be disappointed by set-backs. Recovery is a zigzag process. Once you start recovering, you know that you are doing things right. If you attend a body reprogramming course, the end of the course is not the end of your therapy. It is not the beginning of the end. It is just the end of the

beginning. From now on, it is up to you to put the things you have learned into practice. Keep working at it.

Keep at it month after month. The body reprograms itself slowly. You can't hurry your body. Take your time.



Good luck with your journey! Good luck with your recovery to better health!

# **Information for Employers and Relatives of People with a Central Sensitivity Syndrome including Fibromyalgia**

## **What is fibromyalgia?**

Fibromyalgia is a common but poorly understood medical condition which results in widespread pain and fatigue. The main current theory is that people with fibromyalgia have developed an oversensitivity to pain signals. This is called central sensitisation and evidence suggests that it can result from a person overdoing things and not listening to their body. There is no simple cure. People with fibromyalgia are often perfectionists and this conscientious approach is often a factor in the development of the condition. They often have “good” and “bad” days with the latter usually due to a temporary flare in pain. They are not malingering. They have a genuine illness.

## **Treatment**

Your employee or relative is attending or has attended a body reprogramming course. This course provides advice about lifestyle modification that can help recovery.

The aim of this document is to provide a brief description of advice that is relevant when the patient

works or interacts with others. Patients have been given a longer patient guide.

### **At work:**

The patient has been advised to change from one activity to another on a regular basis, and to manage their condition. Much of working life involves a continual pattern of behaviour over several hours. Fibromyalgia patients will find things easier if they are given regular breaks, or if the type of work they do is changed throughout the day. Fibromyalgia patients will also benefit from brief (e.g., 10 minute) periods of complete relaxation, though this may be difficult to achieve in a busy work environment. If they are working in an office, then the opportunity to move around may be helpful. Frequent stress-inducing deadlines are likely to be unhelpful, as will conflict at work. Patients are their own best guide. They are the best people to advise on work related modifications that will help their recovery.

### **At home:**

Fibromyalgia patients benefit from variety of activities over the course of the day. They are encouraged to engage in optimal physical activity, relaxation and doing things that create enjoyment, but regularly change from one activity to another. They will benefit from a

nutritious diet. Patients are advised against watching the television or being static for long periods of time.

Patients are encouraged to listen to their bodies when their bodies provide signals. Frequent change of positive activity is key to potential improvement rather than just prolonged rest. Patients are their own best guide. Prolonged stress should be avoided, and patients should be encouraged to enjoy life as much as possible.

This information sheet has been given to a patient who is attending/has attended a body reprogramming course which is provided by Plymouth Hospitals NHS Trust for patients with fibromyalgia.

### **Become your own expert!**

Knowing exactly what to do to help yourself can be a barrier. Find out for yourself what helps and do more of it. Find out what does not help and do less of it. Take the long term view. Ask yourself how you are doing over a period of a month or six months. If you are getting better, keep doing what you are doing. If not, you need to do something else. Take charge, look after yourself and find your own road to recovery.

## About the authors

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