



The Newcastle upon Tyne Hospitals
NHS Foundation Trust

CRESTA Fatigue Clinic

Managing your Energy



Healthcare at its best
with people at our heart

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Welcome

Welcome to the CRESTA Clinic Fatigue Booklet.

We hope that this will help you understand more about fatigue and how to manage your symptoms more effectively and improve your life.

This booklet is designed to be read slowly and in several sittings. We have a saying in medicine about starting a course of tablets, but it applies very well to fatigue: "Start low go slow".

Although this period of ill health is distressing, we hope that you will see that it could in fact be a blessing in disguise - an opportunity to do things a little differently, and to learn things that will stand you in good stead for managing difficulties for the rest of your life.

How to use this booklet

Read a little at a time. Take a break. Reflect. Then read a little more.

Throughout this booklet are top tips that you could just flick to and read as you wish.

Stop and Think

If you are interested in finding out more about fatigue, read on!

Take regular breaks and only read what you want to.

Pick and Mix

You won't find all of the strategies discussed in this booklet useful. Choose the ones that appeal to you and try these first. Write a plan for yourself, stick to it, then review how things have gone and make changes accordingly.



You are unlikely to see changes for a few months, so sticking to your plan is crucial.

By planning, stopping and reflecting, you will quickly learn what works best for you.

Remember:

Slow down.

Consider whether a task needs to be done or whether you have to be the one that does it. Is there an easier way for the task to be carried out?

Try breaking up activities into smaller bite size chunks, spread them out over time and intersperse them with rest breaks. This will help to conserve energy and reduce the boom/bust pattern of activity.

Find your baseline and then plan to increase a chosen activity by 10-20% each week.

Understanding fatigue

What is fatigue?

Fatigue is a feeling of extreme exhaustion that is not relieved by sleep and interrupts or stops you from doing activities. Some descriptions people use to describe it include 'brain fog', 'flat batteries' and 'unplugged'.

Fatigue is a bit like having batteries which have gone flat and are struggling to charge back up again. The normal things that once refreshed you such as sleep, a favourite activity or pastime no longer seem to do so. You may also find that you struggle to sleep 'normally'. Human batteries get recharged by activity, the more you do, the more you can do and the less you do, the less you can do.

However, in people with fatigue, once they are flat, or nearly flat, it takes a long time to slowly increase their capacity. You cannot rush the process no matter how much you want to, or how hard you try.

Often people with long term health conditions experience exercise intolerance. This means they fatigue at relatively low levels of activity, which means they must carefully and strategically increase their activity.

It is important to remember that mental and emotional tasks can also be very tiring. This may not have been obvious when you were healthy, but it is completely normal.

Why do some people get fatigue?

Fatigue can be related to diseases (e.g. Sjögren's syndrome, hypothyroidism, Parkinson's disease), sleep disorders, autonomic problems causing low blood pressure, or it may occur without any of these.

Some people may respond to tiring with a surge of adrenaline and over activity of the sympathetic nervous system, which can actually make the symptoms of fatigue worse. You will read more about this later.

Nobody knows exactly what sets off the fatigue in the first place or why some people are more prone to it than others. However, it is likely that in simplistic terms some people overspend their energy, either over a short, or more often, a long period of time.

Imagine your energy is a bank account but that you can't see how much is in it to know how much you can spend; you can however tell if it's 'in the black' or 'in the red' because of the way you feel.

Understanding why you have become fatigued can, quite naturally, feel very important. However, it is probably more important to spend time learning about some of the things which can help you get back on the road to recovery.

If you had your old energy back today but had not learnt how to keep your account 'in the black', then the chances are you would relapse and end up back 'in the red' and feeling fatigued.

People who develop fatigue have often been extremely active before their illness and may not have previously learnt how to properly rest and relax. These are skills that need to be practised and will be discussed in greater detail later.

Everyone is different and all people have different requirements for rest and can tolerate different levels of activity. What may look like someone working very hard might be them doing what they love best, thus they are very relaxed while doing it. You also may not notice other people taking breaks or resting.

Can I get better?

The more realistic question to ask is can I improve - and the answer is - yes, you can! There is no magic pill we can give you that will make the fatigue disappear, but we can help you learn some techniques, which will help you to manage your symptoms so that life feels a bit better

It is likely to take some time to get better, and some people will never have the same levels of energy that they once did. In general fatigue comes on slowly and improvement can also take time; once you start to see measurable improvement in what you can do, life will start to feel a little better.

It usually takes months or even years to recover, but it is possible. As mentioned earlier, human batteries don't recharge quickly and they need some activity to recharge, but not too much. At present, there is no way to quicken recovery.

How can I start to recover?

Learning to manage your fatigue begins with acceptance. Accepting you have fatigue and that the better you become at managing it, the less impact it will have on your life.

Recovery with a fatigue condition is not a return to pre-fatigue lifestyle. It is not helpful to repeatedly fail to achieve previous lifestyle behaviours. It impacts your mood and ability to live your life the way you now need to. This is an ongoing process as you explore what remains important to you and what has become valuable to you within your new circumstances.

Acceptance is not giving up, but it is finding a better way to use your resources. To develop strategies to do things that you value and maybe giving up the things you no longer value.

At the CRESTA clinic we offer the support to begin to explore this new reality. This may mean a re-evaluation of personal goals, values and life priorities.

Fatigue management involves first understanding how the body uses energy, and how it produces extra energy, then incorporating this knowledge into your daily life.

As you begin to accept you have fatigue that you must manage, you must learn to 'live within your 'energy' means', that is, to use energy but not overspend so that you go into energy debt. After that, you can learn how to increase the amount of energy you have, slowly over time.

The fatigue journey looks very different for different people and when they attend the clinic, this will influence what advice they are given. Everyone is an individual and so will improve at different rates. Sharing your journey with others may help you and them understand the situation. However, try not to rate yourself in comparison. Every person's journey through fatigue is unique to them and their personal circumstances.

Where do I start?

As we have already discussed, improving fatigue will take time and practice. You will not get it right first time. You may feel like you are going round in circles, however each time round you will learn a little more about how to manage your symptoms.

Cycle of change

Are you ready for change?

Not everyone is ready for change. For you to get better, it is necessary to make some changes in your life. This can be very difficult, and it is something only you can do. This is all part of this very complicated acceptance process.

Change is a cycle; being aware of how it works can make you feel more forgiving to yourself. It will take time, occur in stages, and you may have a few setbacks along the way. This is normal. (See Figure 1).

You are reading this booklet, so you are obviously aware you have an issue, the contemplative phase. However, before that you may have been unaware there was an issue, the pre-contemplative phase. You may have adopted unhealthy behaviours to get you through the day. More caffeine, an afternoon nap. Once those behaviours had been exhausted, the realisation of the problem and the seeking of help.

At the clinic we will prepare you for change and help you to maintain it. However it is important to note that you will relapse and fall into old, less helpful behaviour patterns. This is the most important part of the cycle, because this is where you review what happened and add a relapse plan in for next time, strengthening your maintenance behaviours.

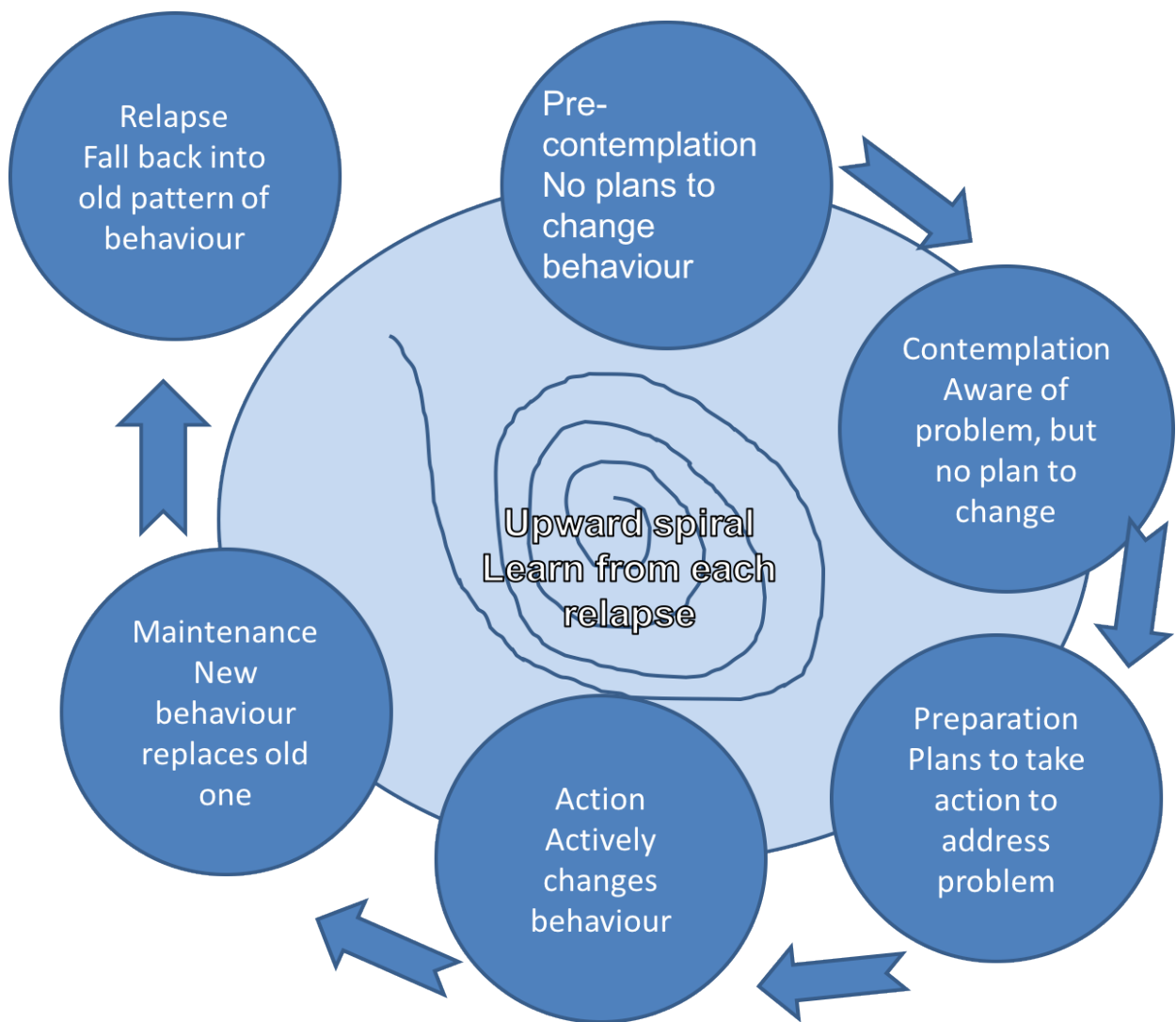
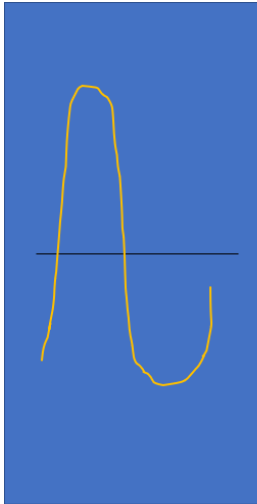


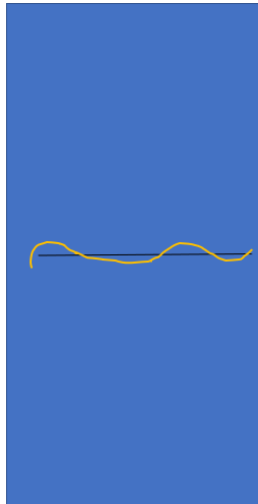
Figure 1: Cycle of Change



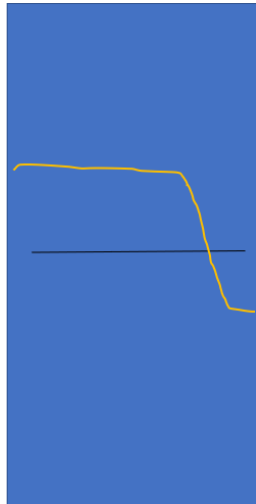
The next step in planning a management strategy is figuring out how you and your fatigue behave. Look at the diagrams below and decide which best reflects your energy levels to know which strategy will best help you



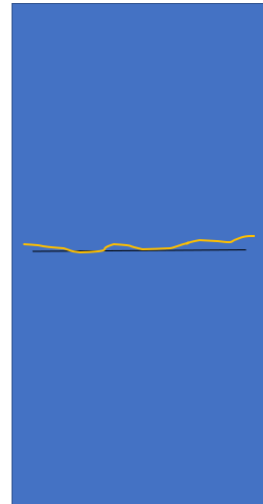
Boom and bust – where you do too much and go into energy debt



Avoidance– where you do too little and lose strength and fitness



Persistence – where you keep going and ignore your body. Leads to exhaustion or injury.



Task modification– appropriate activity pacing with the energy currently available.

Figure 2: Patterns of Fatigue



Pacing

Top tip:

Cruise control - don't use up tomorrow's energy today

It's tempting on a good day to try and do too much but by doing this you risk the phenomenon known as 'boom and bust'. By overdoing it one day, you can then end up spending days or weeks being totally exhausted which can set your progress back. The key is to use only today's energy quota and not to 'borrow' some from tomorrow.

Imagine you set a maximum speed on your body, like cruise control on a car; work out your maximum and don't exceed it. The tricky thing is that no one can tell you how much energy you have to spend on a given day. You must listen to your body and act accordingly.

We will talk about pacing in the clinic and how to modify your activity to get the balance between activity and rest right for you. However, it is important to recognise the various pacing behaviours you may demonstrate during your day or week to progress towards modifying them. See Figure 1.

Boom and bust

Most people are aware of boom and bust. It can happen on the days you feel well, and you jump at the chance to get on top of the job's you've needed to do. You boom! You do more than your body was possibly able to do and you spend the next few days recovering – you bust!

Avoidance

Avoidance occurs with the activities you know will just make you feel worse, so you don't do them. You avoid them. For some people it's standing for too long, for others it may be shopping. It has been shown that avoiding activity can lead to reduced function and lowers your mood. If you recognise this pattern with a certain activity, think about ways you could modify it to make it bite size or graded. If you need help ask us at clinic to guide you.



Persistence

Persistence is a behaviour whereby the job just needs starting and finishing. It may be the weather is fine and the garden needs a tidy. This is your only opportunity, so you are going to keep going until it's done. It maybe another activity, the hoovering, the ironing, a task at work. This behaviour can lead to reduced mobility and lowered mood, it leads to increased symptoms that may make you feel miserable.

Task modification

Matching the available energy with the task to work within your energy limits to maintain a stable baseline.

At the clinic, we would like all patients to recognise these behaviours and be able to modify them appropriately to gain a stable foundation to progress further. It is complicated, and it takes time and as you improve it changes again, but learning this skill will stand you well in the future to manage your work load and time within the limits of your condition. The hope being those limits get pushed further out with your careful management of your pacing skills.

It can take a long time to get a long-term health condition or fatigue diagnosis. In that time, people can adopt less helpful behaviours as they try to get better and manage their health.

It is important to remember you are now managing a long-term condition and be kind to yourself. We can often adopt unhealthy, sickness behaviours where we either ignore, or take too much notice of our symptoms. There is a balance to be struck and a period of convalescence may be appropriate while you learn how to manage your health.

Life-style medicine is an evolving area of healthcare and looks at how we live. It addresses diet, sleep, exercise, and stress. Consider looking at these four aspects of your life and try and optimise them to ensure you are providing the right conditions for your body to heal and recover. It may help to call this time a period of convalescence.

Finding your baseline

Your baseline is the level of a specific activity you can achieve without creating a significant increase of symptoms. It is a starting point. It very much links to your pacing behaviours. If you currently experience the 'overspending' pattern of fatigue, a boom and bust, it is important to find your baseline to begin living within your means.

It may help to understand how your body responds to demand when beginning to plan in pacing strategies.

See the figure 3 below.

Planning Pacing

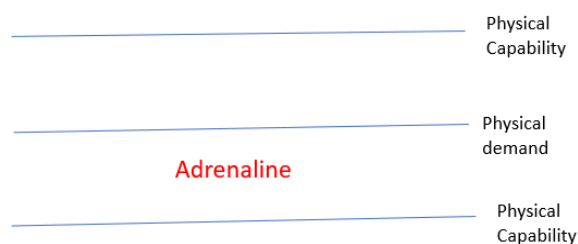


Figure 3. Planning pacing

We all have a capability, our ability to respond to the demand we are faced with. However, if we have been unwell and have been managing through various less helpful pacing behaviours our ability may be changed if we have reduced our fitness level.

If we think of any given activity, we either have the capability or we don't.

Lying in bed is an easy activity, more often, our capability is beyond the demand with this activity, so we will not find it taxing.

If we have been ill for a time and our fitness levels have reduced, our ability to complete a task may be depleted.

For example a super market shop, which was once easy, we may find more difficult. It is beyond our capability. In order to achieve this task we must use a different energy resource. We may use adrenalin to get round the store. This is okay in the short term, however, if we begin to rely on adrenalin for every day activities, we will soon begin to feel the symptoms of that adrenalin use. This explain further, later on.



You will have to experiment to work out what your baseline is for any given activity, which may take time. Keep a record of your baseline for each activity. Later, as you begin to increase your activity levels, you will be able to keep track of how your energy is increasing.

Noticing Fatigue

The best way to find your baseline and stop yourself from doing too much is by learning to notice when you are starting to do too much. If you can rest or slow down before you get too tired, then your energy will come back more quickly, and you can avoid a bust.

This is difficult as everyone is different! It's worth keeping a diary or log of how you are feeling during this period to help you decide what your warning signs are.

S's story

"I knew I felt exhausted - I'd be doing something and suddenly I would just feel drained, my heart would start beating, and I'd start sweating. I was determined not to give in so I just carried on because I thought that's what strong people did. Then I'd feel awful for days afterwards."

Top tip:

Listen to your body

Try to remember how you feel when you do too much.

Does your heart race? Do you start to sweat? Do you sense that you are doing too much? Write this down and keep it somewhere close at hand so that you can remind yourself to slow down when you start to feel this way.

Often people who are prone to fatigue simply don't recognise or take action when they start to overdo things. By thinking about the symptoms you experience when you're pushing things too much, you can learn to spot them quickly and slow down.

Some people find sweating, and an increase in heart rate helps to warn them that they have their foot on the gas and that it needs to come off. Others may find that they want to sit down or their muscles begin to ache. Try to recognise your own warning signs and 'take your foot off the gas'. Allow yourself the luxury of properly



relaxing when you think you've started to overdo it. You could read a book or magazine, spend some time noticing what is going on outside the window or look at the clouds.

Creative people find that this state of relaxation is what inspires their best work.

Take your foot off the gas

How you spend your time may be one of the first things the CRESTA Fatigue team asks you to look at and make some changes to. It can seem very difficult to take time out from one activity in order to redirect it to a different task, or to rest when your time is already so pressured.

In order to improve your health, you will need to practise this and learn to prioritise activities.

Time is a resource. It is finite, and we have lots to fit in to it.

If nothing changes, nothing changes.

Finding time to change

A useful task is ranking your activities in order of importance. Take a moment to think about what activities you do on a day-to-day basis. Write the activities in the first column in Table 1 below and the approximate time you spend doing each activity in the second.

Now rank those activities depending on the value you give them. Some activities are just necessary, washing and dressing, cooking. Some activities you may find are nurturing, a warm bath, brushing your hair. Others you may love, walking your dog, reading to your children, going to work. Finally, some you may just find depleting, driving the car, supermarket shopping.

Categorise the value you place on each task. Is it just necessary, is it nurturing, do you love it, or do you find it depletes you?

When you have completed the task, think was it always this way? have some tasks that you once loved become depleting and is there anything you can do to create more time for those tasks so you can love them again.

Table 1: Ranking Activity Against Time and Value

Activity	Time Spent	Value

In the list above, have you included time to improve your fatigue symptoms? It is important to allocate time to improving. It requires time to begin to understand your condition, how it should be managed and to make any necessary changes. If no time has been allocated to do this in your day, then the patterns of change cannot be laid down.

Do you spend the most time doing what you value?

The Three P's: Prioritising, Pacing and Planning

Prioritising

At different times in our lives, everyday tasks take on different values. It is important to reflect on present circumstances and understand if the tasks we spend time doing are actually as important as they once were to us.



Not every task can be valued, if they were, they would lose their value. For example, when you were well it may have seemed important to dust and vacuum almost daily. You may have to think about reducing the amount of time spent cleaning to make space for resting and repairing your body. (See Figure 4).

If you rank what you feel is important to you, you can prioritise your time more appropriately. You can come back and reflect on this as you begin to feel better, or if you are having an 'off day'. With practice you will become better skilled at organising your time depending on that particular day's requirements. This is appropriate activity pacing.



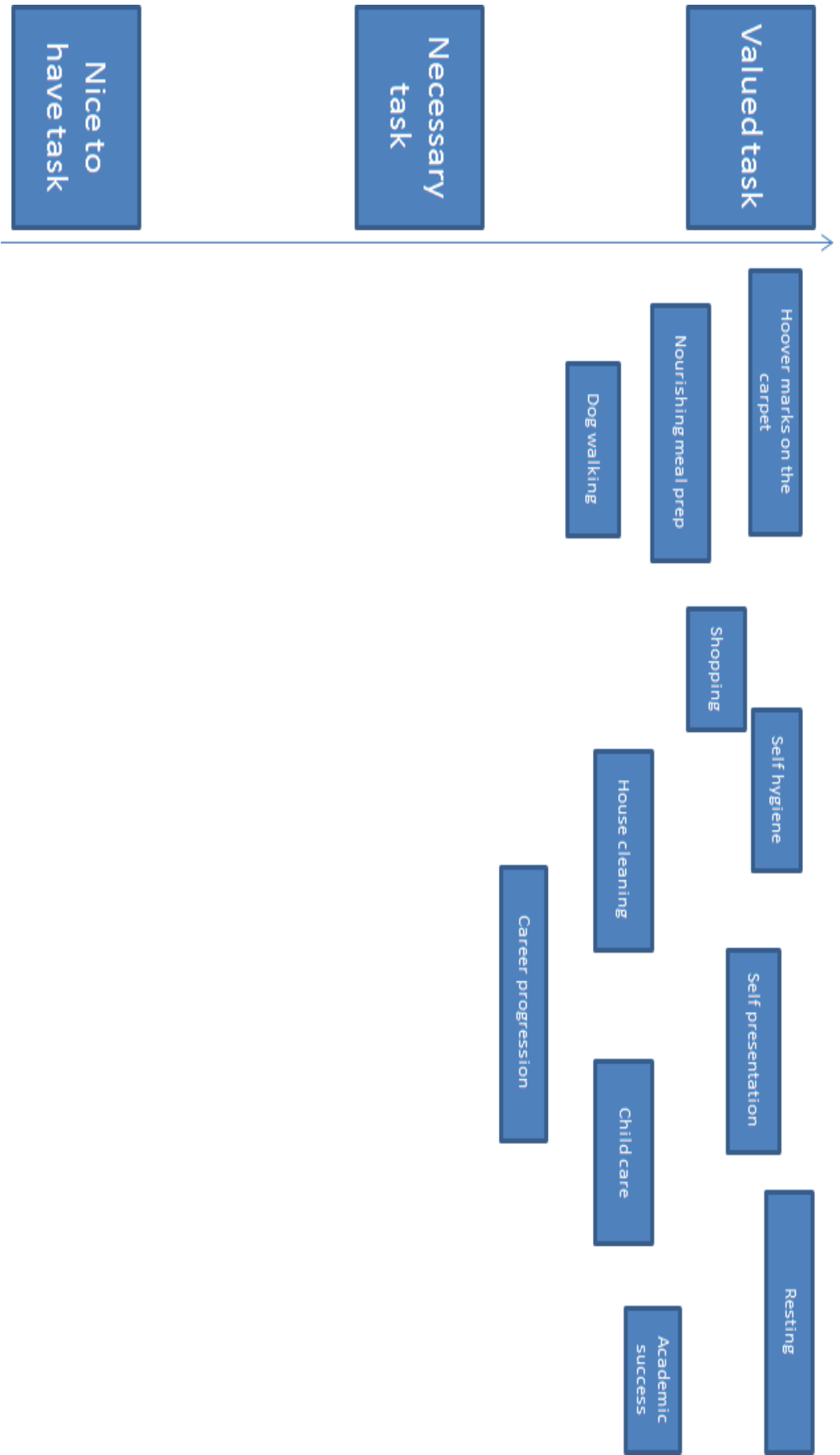


Figure 4: Relative Importance of Daily Tasks

Table 2: Tasks and Energy Levels

High energy	Medium energy	Low energy

Where is my energy going?

People use different amounts of energy for different tasks. For example, you might use a lot of energy planning meals for the week but find writing letters to people very easy. You might find getting washed and ready for the day very tiring, while another person might find cooking more exhausting.

Use Table 2 to organise your activities according to the amount of energy they use.

Once you understand which tasks use the most energy you can plan adjustments to make them less tiring. For example, having a sit down and a drink while out shopping might mean you can finish shopping without feeling exhausted. If you combine this with practical adjustments such as not carrying heavy bags, you may find shopping a very different experience.



Consider whether you need to be the person that does all of the tasks on your list. Can someone else help? Is there an easier way of doing something such as shopping online and getting groceries delivered?

Look at the activities you have placed in each column in Table 2. Think about any adjustments you could make so that they use less energy.

Pacing

We have discussed different pacing behaviours. Pacing involves working at less than your maximal capacity in order to prolong the time you can spend doing an activity. It's a technique used by athletes who are experts at knowing how to optimise their energy use.

In daily life this involves changing your way of thinking about tasks in order to do them more slowly and break them up with rests.

For example, instead of vacuuming the whole house in one go (persisting or boom and busting), you might want to break it up into rooms. You could vacuum one or two rooms and then sit down.

You could have a rest break or do a less physically demanding task, such as spending a few minutes on a crossword or making a telephone call. You may not vacuum the whole house in one day, but instead decide to spread it out over two, or more days (appropriate task modification).

This might involve lowering your standards slightly and not completing everything you would have ideally wanted to do.

Learning to accept that this is okay is part of the challenge. Learning to pace yourself might involve asking others for help.

You may need to say no to certain things or delay them until you have more time or energy.

Plan ahead for events you know are likely to need a lot of organisation (e.g. Christmas, birthdays) but be willing to alter your plan if things aren't going so well. For example, this year you might just buy some vouchers from the supermarket rather than individually chosen presents.

This is a big part of you learning how to manage your energy better so try not to feel guilty about it.

If you have a list, use the 80:20 rule. It is better to do 20% with 80% efficiency than complete 80% of tasks with only 20% efficiency. Carry over other tasks to the



next day or week. If you do use lists, make sure you break down bigger or unpleasant jobs into smaller tasks, more manageable tasks.

Planning

Now that you have had a chance to think about the activities you do, and looked at how important they are, and how much energy they take, you can start to plan and prioritise your time accordingly, remembering to pace yourself. You could use Table 4, found at the back of this booklet to plan your time for the next week. Remember to include rest breaks.

Don't worry if you do not stick to this. Write down how you actually spend your time and use that to adjust your plans for the following week.

M's story

"I'd worked out by this point that I needed rest days before and after stressful things and that I could only manage a certain amount of time working. I'd start to feel this weight on my chest about 2pm and I'd think, right, time to go. Work were great, thank goodness, about letting me work flexibly, so nobody thought anything of it. I used to have a rest in the car before I drove home and then another rest just before I picked my son up. I didn't understand why I had to do this at the time, just that it seemed to work. I didn't know how to make it any better. It just felt like I was stuck"

Energy Levels

How we regulate energy – the science

Sometimes it is good to understand the biological process of energy to gain a deeper understanding of your fatigue and how complicated it is.

We have evolved from hunter-gatherers. At that time man was surrounded by lots of threats and needed to decide whether to fight or flee. This fight or flight mechanism kept man safe in life threatening situations. Despite the differences in lifestyle and causes of stress, this mechanism is still in place in our bodies today. The part of the body that decides if we fight or flee is the autonomic system, which sits



in the central nervous system.

The autonomic system has two parts that work in opposition and therefore cannot work at the same time. The sympathetic system is the switched on, high alert system, the parasympathetic system is the restorative calm system (see Figure 4)

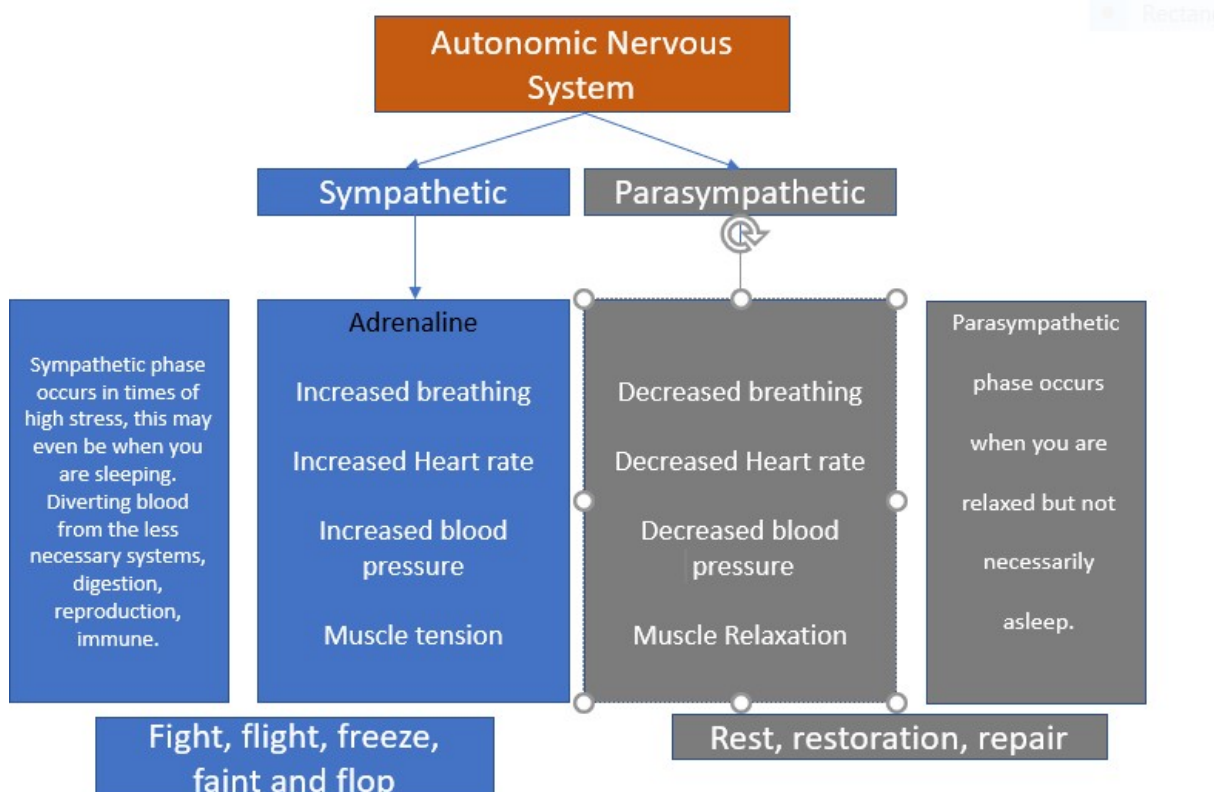


Figure 4: Autonomic Nervous System

When the body is working in the sympathetic phase it is preparing for danger. The heart rate increases along with breathing and blood pressure. Muscles become tense as they are in effect preparing for battle. During this phase, the parasympathetic phase cannot be accessed, meaning that restoration and repair cannot take place.

Nowadays the stress trigger could be something like food shopping or a social gathering, as discussed previously, rather than a sabre tooth tiger, but our bodies react in the same way. In life threatening situations the body prepares to fight or flee, and once the danger has passed, we are able to rest. However, many of the stress triggers we experience today are more continuous and we do not give ourselves time to rest and relax. This puts a lot of pressure on the autonomic nervous system, as it is constantly on high alert. For many people this leads to health problems such as fatigue.

We need to learn to stop, rest and relax



When you overspend your energy, your body goes into 'fight or flight' mode; the sympathetic nervous system takes over and you actually use up any remaining fuel much more quickly.

This would have been an ancient protective response to get you out of danger and to a safe place when there was a threat. This would have been a one-off response, rather than something you experienced frequently and endured for prolonged periods of time.

I sit down but it doesn't make me feel better

Sitting down can stop physical activity but we often forget that mental or emotional tasks can be just as tiring as physical ones. If you sit down but you are still thinking about everything you need to do, or worrying about something, then you will not get the rest your body needs.

What is needed to recharge your batteries or 'top up your bank account' is true relaxation. Learning to relax and rest properly is a skill. It will take and practice, so don't give up if you find it difficult!

People who are not used to taking rest breaks can feel guilty about doing so. This fictional scenario may help:

Dr. Helen tells her patient to take a prescribed tablet for their fatigue 5 times a day. (There is not an effective medicine available yet to treat fatigue). After taking the tablet Dr. Helen's patient is told they must sit down and rest quietly for 20 minutes in order for the tablets to work.

Does this advice seem reasonable?

As we just said, unfortunately yet there is no effective medicine that can be prescribed for fatigue.

What if Dr. Helen advised her patient to sit down and rest for 20 minutes 5 times a day, but this time without the tablet? She tells her patient that this would help to break up their activities and get some rest in between.



Some people find that listening to a short relaxation or mindfulness track can help them relax, especially if they are not in the habit of taking a rest. Others may find doing a restful activity that they enjoy relaxing, as it distracts them from over thinking.

Learning to relax is a skill. It re-programmes our bodies away from fight or flight to restoration and repair. This allows us to move between the pathways as we need. Rather than, move through exhaustion, towards fight or flight and adrenaline.

Like any skill, it takes practise and time. Initially it may feel very foreign and wrong, however, persevere with whatever technique you use. This is where your body is repairing itself and particularly if you have a long-term condition, you need more of this in your life.

Learning to relax and rest is absolutely key to recovering from fatigue



Relaxation

How do you relax?

Think about how you best relax. What leaves you feeling most refreshed afterwards? Do you enjoy having a bath, reading or talking to friends? Try and write down some activities that help you to relax in the box below.



If you find it hard to relax

Sometimes even when you start to do the things you used to find relaxing, you just can't switch off. When you go to bed at night you still feel wired, unable to stop your mind from racing. This can be simply because you're overtired, and it takes a long time to wind

down. It can also be because you have been using your fight or flight pathways to gain energy to get you through the day. We move into fight or flight when we feel threatened, This threat may come from a lack of capability to complete a task, as discussed and adrenaline is released to complete the task. Our minds tend to search out threats when we are in fight or flight. We search for the potential problems and this can lead us to feel anxious. Taking time through the day to dampen down the adrenaline can help to reduce this feeling of being wired or anxious at bedtime.

However, it may be that there is something else going on such as grief, anxiety or depression.

Top tip: **Gentle activity can help you sleep**

Although doing too much activity can cause exhaustion and reduce energy levels, gentle activity can help you get a better nights' sleep and make you feel more refreshed the next day. Activity is also good at reducing anxiety because of the natural endorphins released.

If anxiety is keeping you awake, try some simple exercises earlier on in the evening. Even gentle stretches can help to relax your body and help you begin to wind down in the evening before going to bed.

Dealing with Strong Emotions

Suppressing emotions can be useful for continuing with our daily lives, or pushing us to achieve our goals, but it will take a vast amount of energy and make relaxing very difficult. Processing emotions also takes a lot of energy, but it also can lead to resolution of these feelings.



If you are dealing with strong emotions, if you know that you are anxious or depressed, or are struggling with grief, then you may need some extra skills or help to deal with these.

You may find that relaxation strategies are helpful. (see Further Reading at the back of this booklet).

Strong emotions like this should be discussed at your first appointment at the CRESTA Fatigue Clinic, please be sure to mention anything relating to this.

Is it possible to rest too much? - a bit more science

Although proper rest is extremely important when you are struggling with fatigue, too much rest can also have a negative effect. This can happen if your behaviours bias more towards avoidance of what makes your symptoms worse.

Top tip:

Avoid naps in the daytime

We know that naps disrupt the usual sleep cycle and may stop you getting to sleep normally at night, which then reinforces the cycle of poor sleep. Try to avoid going to bed in the day and take a rest in a chair if need be. If you do doze off, try not to sleep for too long. Longer naps and those taken in the afternoon or evening are more likely to disrupt night-time sleep.

It is best to avoid napping in the day as much as possible as it can interrupt your night-time sleep. There is a reversible process called deconditioning, whereby multiple processes deteriorate because they have not been challenged. If you lie down for more than 8 hours out of the 24 in a day your body will begin to decondition in



only a few days. This will ultimately make it harder to get going again.

Muscles and other soft tissues such as ligaments and tendons will shorten to the position where they spend the most time. More rounded postures tend to be more restful and create feelings of lethargy. Extended upright postures tend to be more energising. A flexed posture that has been held for a time will require more energy to move away from.

If you need a lot of rest, soft tissues such as muscle and tendons will begin to adapt to rested, flexed positions

Gravity

Our bodies have evolved to function in the presence of gravity. Our bones and muscles have to work to support and move us and our hearts pump our blood against this constant downward force.

Our bodies like to be upright for 2/3's of the day and resting in a lying position for 1/3 of the day. If we alter this ratio for any reason, we begin to lose the physical and biological skills we use to keep our bodies up against gravity; we begin to decondition, get less fit.

We develop our skills against gravity by moving our bodies in a certain way. Our bodies will reflect what we do. For example, a footballer has a very different body to a ballet dancer (see Figure 5). This is because they practise moving their bodies in very different ways.



Figure 5: Footballer and Ballet Dancer



If you have a chronic condition that prevents you moving as much, your body will begin to reflect this decrease in movement.

It is more difficult to maintain fitness if you have a chronic condition, because it will always present a limiting factor. Your health may prevent you moving as well or as far or as fast as you may wish to. It is important to reintroduce exercise slowly and to increase it in a controlled way, gradually over time, with a period rest and relaxation between. This will allow the repair and restorative phase of the autonomic nervous system to be accessed each time you appropriately challenge your body to improve (see Figure 1 and Figure 4).

What happens when our lying to standing ratio alters?

Lying down for long periods of time changes how gravity effects our bodies. Each organ that works against gravity when we stand weakens if we lie down regularly.

You could think of it like swimming without the presence of water. You can practice the movement, but this won't enable you to actually swim effectively through water.

The effects of long-term bed rest can have similar outcomes as those experienced by astronauts. After being in space for prolonged periods, astronauts are unable to even stand up when they come back to earth. This is because there is very little gravitational force in space and an astronaut's ability to be in gravity on earth weakens. Astronauts decondition without gravity just as people who need to spend time in bed decondition.

The Canadian astronaut Chris Hadfield spent 5 months in space without gravity. On his return to earth he reported his next big venture was intensive rehabilitation to be able to function against gravity again (see Figure 6)



Figure 6: U.S. astronaut Thomas Marshburn, Russian cosmonaut Roman Romanenko and Canadian astronaut Chris Hadfield



In the photograph (Figure 6) note how the astronauts are in wheelchairs. From their posture you can see that staying upright against gravity is a task in itself. Their muscle, bones, hearts and lungs have all deteriorated without the presence of gravity during their time in space.

What should I do during a relapse?

The most important thing is **DO NOT PANIC**. As we have already discussed, this is the most important part of the cycle of change and is what will ultimately embed and reinforce healthy behaviours.

The aim is to **maintain a low level of function** during bust or relapse periods.

Top tip: **Bad days happen**

If you have a bad few days, or a 'bust', you may need to rest more but try not to stop doing all activities. Just take things down a notch or two while you start to get back on track. This way you won't lose all the progress you've made.

Treat your bust period as an opportunity to learn, quietly and gently, how to help your body recover.

There are strategies that can be taught to limit the negative effects of prolonged resting. These are similar techniques to those used with patients in Intensive Care who are unavoidably lying down for long periods.

These strategies are:

Taking time to rest and relax in a comfortable sitting position, possibly whilst practising some meditation techniques to help to relax your mind, rather than lying down all day.

Gentle stretches from your bed to take your joints through their full range to maintain your muscle length and joint movement.

Stand up from a chair five times in a row to maintain muscle strength in your legs.

Or pick out a few of the exercises from the clinic to do every day.



Top tip: Charge back up - slowly

Extend what you do, little by little. We often talk about humans as having batteries; human batteries improve their capacity to charge up again by increasing what they do, so the best way to recover from fatigue is to try and do a little bit more each week. We do mean a little! We advise that you make increases to your activity gradually. We advise that you make small, stepped increases of no more than 10-20%.

For example, if you go for a 5 minute walk every day, a 20% increase would mean walking for an extra minute for the next week or so. It may not seem like much, but over the weeks, you will start to see a measurable improvement in what you can do. You may find that the symptoms of fatigue are worse for a few days, but stick with it and the symptoms will settle. Walking for 6 minutes will now be your new baseline until you decide to make another small increase.

Thinking tasks use energy too. It is beneficial to practise mindfulness to relax the mind and allow access to the restoration and repair phase of the autonomic nervous system.

Grading

By this stage, hopefully you understand more about your own, personal behaviour patterns from Figure 2. You understand how to live within your body's energy supply, and potentially you are getting better. To make further improvements, you need to learn to gradually increase what you can do to improve your baseline.

Remember that human batteries recharge by activity. Now that your battery is no longer going flat, you can start doing a little bit more to increase its capacity. It is very important to take things slowly and not to increase your activity by more than 10-20% each week; you don't want to risk having a bust!

Don't wait to feel better to start increasing your activity; it works the other way round. We will use the example from the Top Tips.



If your baseline is walking for five minutes without getting fatigued, then we need to work out what 20% of this is, and add it on.

20% of five minutes is one minute. So that would mean that you would increase your daily walking from five minutes, to six minutes. Do this every day for one week.

However, we have discussed how each fatigue experience is unique. It may be, initially, you walk 6 minutes one day, 5 minutes for 2, to allow for recovery. When this feels manageable, alternate 5 minutes one day and 6 minutes the next. When this feels manageable, 6 minutes, every day for a week.

Pushing the boundaries may well make you feel a little worse in the first few days, take time to rest and recover but keep going, and soon this will be your new normal. If you get fatigued, then rest, recover and next time try increasing your walking by 10%, or 30 seconds.

When you can manage 6 minutes and you don't get more fatigued after a week, then your new baseline is six minutes.

You can then increase your walking up to seven minutes, or just over, in the coming weeks. In the same way as you increased to 6 minutes. However, you may find you can increase faster.

Although this may not seem like much, it will soon add up and you will begin to notice a difference. Be patient.

Some people prefer to grade their walking by using distance instead of time. They may aim to walk to the next lamppost or street corner. This is also fine, as long as you don't increase your activity by more than 20% each week.

Start small!

Choose one activity as your goal for the week. Make your goal specific, small and measurable so you know exactly what you have to do.

Track Progress and Reflect

Tracking your progress is important because it allows you to see how you are improving even when it feels like your recovery is slow.

If you get disheartened, look back and see how far you've come

Plan some time at the end of each week to reflect and plan for the following one. Think about what went well, what didn't work and how you can make changes to improve this. Now incorporate these changes into your plan for the coming week.



As you improve and you are able to manage longer periods of activity, then you will be able to start working on increasing speed or effort, if that is important to you.

Moving forward

As we have acknowledged, acceptance is an important pre-condition for therapy to work. It allows people with fatigue to fairly assess and adjust their lifestyle within their energy limits.

Acceptance is complicated. It's acknowledging the reality of living with a fatigue condition and the understanding that there is not a magic solution or medicine to take the symptoms away. Fatigue needs careful management. Strategies such as activity pacing and goal prioritisation within a more achievable framework can be practised. This will allow you to lead your life without your symptoms impacting it to make you miserable. This takes a lot of hard work and courage to change behaviour strategies to allow you to live a meaningful life within your restrictions of fatigue.

Recovery with a fatigue condition is not a return to pre-fatigue lifestyle. It is not helpful to repeatedly fail to achieve previous lifestyle behaviours. It impacts mood and ability to live your life the way you now need to. This is an ongoing process as you explore what remains important to you and what has become valuable to you within your new circumstances.

Acceptance is not giving up, but finding a better way to use your resources. To develop strategies to do things that you value and maybe giving up the things you don't.

At the CRESTA clinic we offer the support to begin to explore this new reality. This may mean a search for a new identity, involving a re-evaluation of personal goals, values and life priorities.

You may need letters of support from the clinic to explain and educate your employer about your new situation. Fatigue is recognised within the Equality Act 2010 and reasonable workplace adjustments may need to be made to allow you to continue to work without it impacting your health. Or your family and friends may need some help to understand the issues you face. In which case bring them into clinic with you.

Sleep

It is not unusual for people with chronic fatigue symptoms to wake up in the morning feeling as if they have not been restored by the previous night's sleep. Some people may actually be sleeping much more than usual, while others may have quite disturbed nights.

If we sleep too much, the quality of our sleep is likely to be reduced. If you are sleeping for more than 9 or 10 hours in a 24-hour period, it may be worth gradually trying to reduce the amount of time you spend asleep.

Avoid naps in the daytime

We know that naps disrupt the usual sleep cycle and may stop you getting to sleep normally at night, which then reinforces the cycle of poor sleep. Try to avoid going to bed in the day and take a rest in a chair if need be. If you do doze off, try not to sleep for too long. Longer naps and those taken in the afternoon or evening are more likely to disrupt night-time sleep.

If you have difficulty getting off to sleep or staying asleep in the night, there are several things you can try.

- Go to bed and get up at a similar time each day
- Have a wind-down routine in the evening where you feel relaxed before you go to bed. Try not to watch anything disturbing on TV prior to bed.
- Ensure the bedroom is an inviting place to be. Only use the bed for sleep or sex. Avoid using screens, reading books or doing crafts in bed. Do these elsewhere in the house.
- Avoid caffeine in the evening and avoid alcohol.
- If you struggle to fall asleep after going to bed, get up if it feels like you are starting to 'try' and sleep (e.g. after what feels like about 15-20 minutes). Go and sit elsewhere in the house. You may wish to read or watch TV, but return to bed as



soon as you feel sleepy. You can also use this technique if you wake during the night.

If you struggle with worrying thoughts after you have switched the lights out, it may help to take 10 minutes early on each evening which you dedicate to these concerns. Use a notepad to write a list of things that are concerning you left side of the page. On the right side of the page write down some solutions or things you can do about each of the concerns on your list. It may also help to have a blank notepad next to the bed to jot down any concerns/ things you need to remember the next day, if a thought comes into your mind preventing you from getting off to sleep.

Relapse

Relapses often occur when recovering from fatigue. They can be very frustrating, especially when you feel as though you have been making progress.

Overspending your energy is usually the cause of a relapse and can be triggered by forgetting to pace yourself, too much activity, stress and worry, or a life event. Illness will also often cause a relapse because your body is using your limited supply of energy to fight off disease. Alternatively, too much rest and inactivity could also cause a relapse due to deconditioning of the body, as explained earlier.

If you notice that you are particularly stressed, if you have a life event or begin to feel yourself becoming ill, reduce the amount of activity you're doing. This will give your body the best chance of recovering quickly and avoiding a relapse.

During a relapse try to keep a low level of activity going to avoid deconditioning your body and undoing what you have already achieved. Remember what you've learnt. Employ all your relaxation strategies, and above all be kind to yourself.

Keep your chin up and learn what you can from this episode to inform what you do in the future. Remember that you know more about managing your condition and are therefore in a much better position than you once were.

It's worth developing a relapse plan early on, while you are feeling better. This way you can remind yourself of what to do, and how to think, so that you can improve more quickly if a relapse occurs.

During a relapse all activities can be exhausting but by having a plan ready, it is one less thing to worry about doing.



Understanding how we react to illness

No one is ever only physically ill. Illness always has effects beyond the immediate symptoms. For example, someone with very bad back pain is not able to do many of the activities that they used to take for granted. These restrictions will have some 'secondary effects'. It is common for people who have stopped going out as much because of their pain to lose confidence in their social skills.

If you have had any time off work or school due to illness, you may have noticed that it can be a little awkward when you go back. This may cause you to feel a little nervous or shy. People who do less due to pain, fatigue or illness often lose confidence in things that they used to do.

Pain, fatigue and illness can also have quite a profound effect upon mood. Depression and anxiety, for instance, are common in people with chronic pain.

Illness affects more than the body

This area has been the subject of much research over the last 50 or so years and it has led to a great deal of insight into how illness affects peoples' lives.

In many long-term health conditions, it has been found that improving the secondary effects of the illness can make a considerable difference to the person's well-being and, in some cases, have a large impact on the illness itself.

By looking at the management of all aspects of your life that are affected by illness, you have the best chance of a quick recovery.

A system management approach to illness

In any illness there are at least four areas that can impact with each other and can influence a person's experience of their illness.

Physical Symptoms

Emotions: thoughts and feeling related to what has happened

Behaviour: what they do in response to being ill

Beliefs: about their illness, management and recovery

Below is an example of someone who has had a major heart attack, and how that has affected them.

Physical Symptoms: They might feel awful, breathless, weak, tired and have chest pains if they exert themselves even a little bit.



Feelings and Emotions: They have, understandably, become very anxious about having another heart attack and are terrified every time they feel a twinge in their chest.

Behaviour: They might be avoiding activity, sitting or lying down all day and be scared to move. They may well feel low and anxious, meaning that they drink and smoke to try and relax them, even though they know that is not helping. This then makes them feel guilty.

Beliefs: They may feel quite hopeless, believing that there is nothing they can do that will make a difference. Their mood is low and they can be very irritable with those around them.

Medication could help with some of the physical symptoms, but the majority of what needs to be done is actually through addressing their thoughts, their feelings and their behaviour.

Physical Symptoms: Medication and rest

Feelings and Emotions: Gaining knowledge of their situation, through information leaflets may help them to understand that the symptoms they are experiencing are normal and will get better with time.

Behaviour: A very gentle exercise programme and making some changes to their lifestyle, can not only have a positive effect on their mood and general well being, but also reduce their risk of having another heart attack.

Beliefs: Knowing that the symptoms they are experiencing are normal, that they are now having treatment to reduce the chance of having another heart attack and being able to take some action themselves through gentle activity will help them to feel more in control and positive about the future.



The following example is related to a patient who had fatigue and came from someone who described herself as a 'perfectionist'.

She worked hard at her job and was constantly worried about not doing well enough. She first experienced fatigue when she was under pressure at work and was working for 14 hours a day.

<p>Physical Symptoms</p> <p>Extreme fatigue Pain in throat and loss of voice Some stomach symptoms of bloating and diarrhoea.</p>	<p>Feelings and Emotions</p> <p>Constant anxiety and worry about failure and 'being found out'. Anxiety about getting ill again Low mood because life is now just a drudge</p>
<p>Behaviour</p> <p>Overworking, over-preparing, taking no breaks at all at work No time off work and no time for enjoyment Dropped her social life and stopped doing the sports she used to enjoy</p>	<p>Thoughts and Beliefs</p> <p>"I'm not good enough at my job. I must push myself harder, otherwise I am going to lose it." "I never get anything right." "My colleagues will think I am slacking at my job if I slow down."</p>

In the example fatigue was only part of the problem. Treatment started with looking at the patterns of activity and rest.

This plan included:

- Working less and spending more time doing enjoyable or relaxing activities.
- Using strategies to help her to improve her quality of sleep
- Working on reducing her self-critical thoughts and worrying.
- Challenging her beliefs that she "was never good enough" and "always got things wrong", and realising that there was little evidence to support them.

Gradually, she began to accept and trust that she was good at her job and was able to



reduce the number of unpaid hours she had been working. As a result, she began to feel better and her fatigue improved.

These examples may not be relevant to your specific situation but hopefully they can help you understand the system management approach.

Use the table below to write down some of your symptoms, feelings, behaviour and beliefs.

Table 3: A System Management Approach to Illness

Physical Symptoms	Feelings and Emotions
Behaviour	Thoughts and Beliefs

Now reflect on how these have an impact on your experience of illness. Think about ways in which you could challenge your thinking, or change your behaviour in order to help you recover more quickly. Incorporate these changes into your plan.



Finally....

We hope you have found this booklet helpful.

We are delighted to receive feedback to improve it for others. You may wish to use the next pages for notes or fill in the graph to track your progress over time.

On the last page we have listed some places, which offer sessions, or courses that you may find helpful along with some useful websites.

Also included is a simple fatigue questionnaire so that you can monitor your own fatigue levels and map them on a calendar so you can see the impact of their activities on a formal level.

Further Reading and Useful Information

Body Control Pilates website:

<http://www.bodycontrolpilates.com/shop/>

Link to the CRESTA Fatigue exercise booklet

Useful Links

PoTS UK website: <https://www.potsuk.org/>

NHS CFS info

<https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/>

NICE guidance:

<https://www.nice.org.uk/guidance/cg53/ifp/chapter/Managing-CFSME>

ME Research UK

<https://www.mereseach.org.uk/what-is-me/>

ME Association:

<https://www.meassociation.org.uk/information-and-support-line/information/>



Useful Reading

- Don't sweat the small stuff by Richard Carlson
- Fighting Fatigue: Managing the Symptoms of CFS/ME by Sue Pemberton and Catherine Berry
- The Power of Now by Eckhart Tolle Silence Your Mind by Ramesh Manocha
- Notes on a Nervous Planet by Matt Haigh
- How to be Human The Manual by Ruby Wax The Four Pillar Plan by Rangan Chatterjee

Meditation

NHS choices:

<http://www.nhs.uk/conditions/stress-anxiety-depression/pages/mindfulness.aspx> <http://franticworld.com/free-meditations-from-mindfulness/>

YouTube

Search meditation Headspace App (Free)
<http://www.getselfhelp.co.uk> Calm App

Podcasts

Feel better, Live More by Rangan Chatterjee
All about ME – supported by the ME Association

Useful websites:

If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk.

On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful



Table 4 Weekly Planner - Try using this to schedule in next week's activities and

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
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Contact details

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The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS.

You can contact them on freephone **0800 032 02 02** or e-mail: northoftynepals@nhct.nhs.uk

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Review Date: 1 7 2023



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