CRESTA
Fatigue Clinic

Managing your Energy
# Table of Contents

Welcome .................................................................................................................. 3
How to Use This Booklet ......................................................................................... 3
Ten Top Tips For Dealing With Fatigue ................................................................. 4
Stop and Think ......................................................................................................... 7
Pick and Mix ........................................................................................................... 7
Remember ............................................................................................................... 7
Understanding Fatigue ........................................................................................... 8
  What Is Fatigue?..................................................................................................... 8
  Why Do Some People Get Fatigue?....................................................................... 8
  Can I Get Better?.................................................................................................. 9
  How Can I Start to Recover?................................................................................ 10
Where Do I Start?.................................................................................................... 11
  Boom and Bust .................................................................................................. 12
  Finding Your Baseline ......................................................................................... 12
  Noticing Fatigue ................................................................................................. 13
Cycle of Change ..................................................................................................... 14
  Ready for Change?............................................................................................. 14
  Finding Time to Change .................................................................................... 16
Prioritising .............................................................................................................. 17
  Where is My Energy Going?............................................................................. 19
  Pacing ............................................................................................................... 20
  Planning ............................................................................................................ 21
Energy Levels ......................................................................................................... 22
  How We Regulate Energy – The Science .......................................................... 22
  I Sit Down but it Doesn’t Make Me Feel Better .............................................. 24
Relaxation ................................................................................................................. 26
  How do you relax?............................................................................................. 26
  If you find it hard to relax ................................................................................. 27
  Dealing with Strong Emotions ......................................................................... 27
Is It Possible To Rest Too Much? - A Bit More Science ...................................... 27
  Gravity ............................................................................................................ 28
  What Happens When Our Lying to Standing Ratio Alters?............................ 29
What Should I Do During A ‘Bust’?....................................................................... 31
Grading .................................................................................................................... 31
Track Progress and Reflect ................................................................................... 33
Relapses ................................................................................................................... 34
Understanding How We React to Illness ............................................................. 35
A System Management Approach to Illness ....................................................... 36
Physical Symptoms: medication and rest ............................................................. 37
Finally...................................................................................................................... 40
  Energy Chart .................................................................................................... 41
  Weekly Planner ................................................................................................. 42
Contact details ....................................................................................................... 44
Welcome

Welcome to the CRESTA Clinic Fatigue Booklet.

We hope that this will help you understand more about fatigue and how to get started on the road to recovery by helping you to manage your symptoms more effectively.

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

At the beginning of this booklet are ten top tips for managing fatigue. You may wish to just read these for the time being, until you feel up to moving on to the next section.

Read a little at a time. Take a break. Reflect.

Then read a little more.
Ten Top Tips for Dealing with Fatigue

Slow down and take your foot off the gas - think fuel economy

Sometimes when you’re tired you actually force yourself to move and think at a faster pace, perhaps to try and get the task done more quickly or because it feels like you’re slowing down. This will only worsen your fatigue. Learn to recognise when you are doing this and deliberately slow your pace down. You may discover that you are able to complete more tasks at a slower pace, and may even find that you still have some energy left at the end.

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.

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.
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.

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 don’t have more than a 20% increase in what you can do.

If you walk for 5 minutes, a 20% increase would mean walking for an extra minute. It may not seem like much, but over time 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.

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 before bed. Even gentle stretches can help to relax your body ready for sleep.

**Do something that you enjoy**

Is there something you used to do that you’ve given up because of your fatigue? Think of activities that used to give you pleasure and then see if there’s a way to make them less strenuous. For example, if you like gardening but digging is too tiring, you could plant some seeds instead.

**Be kind to yourself**

It is enormously frustrating to feel drained of energy all the time, especially if you’ve always been very active. Sometimes medical professionals, spouses, family or friends may not understand what you’re going through. As you start to improve it can be helpful to note down your progress so you can look back and see how far you’ve come when you have bad days. Give yourself positive rewards to look forward to. A trip to the cinema or organise a trip out or meet up with friends.

**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.

**Take the easy route**

Be creative about making life easier for yourself. For example, you can buy ready chopped onions from the freezer section in the supermarket. Having a ‘beans night’ and a ‘jacket potato night’ each week might take the pressure off cooking. Could a friend drop your child off at swimming one night a week? If you got your clothes ready the night before would that help in the morning?
Stop and Think

Now that you have read our Top 10 Tips for Fatigue, stop and take a break. Think about what you have read, what might be relevant to you and how you can apply this to your life.

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?
Take short rest breaks in the middle of activities in order to conserve energy and continue stabilisation.
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 that have gone flat but that won’t 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 once they’ve gone 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 associate fatigue with physical 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 same position.

People who develop fatigue have often been extremely active before their illness, and may not have 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 short 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?**

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

First you must learn to ‘live within your 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.

Different people may be at different points along the fatigue journey when they attend the clinic and this will influence what advice they are given. Everyone is an individual and so will improve at different rates. Do not compare your journey with others.
Where Do I Start?

As we have already discussed, improving fatigue will take time and practice. You will not get it right first time.

The first step in planning a management strategy is figuring out how you currently experience the symptom of fatigue. Look at the diagrams below and decide which best reflects your energy levels to know which strategy will best help you (See Error! Reference source not found.).

Figure 1: Patterns of Fatigue
Boom and Bust

As discussed in the ‘Top 10 Tips’, the ‘boom and bust’ phenomenon describes the energy levels of many people who struggle with fatigue. When you have a good day, or a ‘boom’ it can be tempting to do too much and try to get things done, as you want to make the most of having energy. This usually results in days or weeks spent feeling exhausted, known as a ‘bust’. Instead you must try to learn to use only today’s energy for the tasks you do today instead of ‘borrowing’ energy from tomorrow.

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. If you currently experience the ‘overspending’ pattern of fatigue it is important to find your baseline in order to begin living within your means.

Imagine you’re a car and you can use cruise control on your body. Set a maximum speed for yourself and don’t exceed that speed. Make a note of what speed you chose. In the next few days see whether you feel more fatigued. If you do, you probably need to set your cruise control at a lower speed, say 5-10 mph lower and then have another go.

For example, your baseline for walking might be 5 minutes. This would mean that you can walk for 5 minutes and do not feel more fatigued afterwards. If you walk for 6 minutes however, you do feel more fatigued afterwards.

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."

"I knew I felt exhausted- I'd be doing something and suddenly I would just feel drained and my heart would start beating, and I'd start sweating. But 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."

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’.

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, or just to stare into space or at the clouds.

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

Ready for Change?

Not everyone is ready for change. In order for you to get better, you have to make some changes in your life. This can be very difficult and it is something only you can do.

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.
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 2).

**Figure 2: Cycle of Change**
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, where 0 is relatively unimportant and 3 is very important.

Table 1: Ranking Activity Against Time and Value

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time Spent</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the list above, have you included time to improve your fatigue? It is important to allocate time to getting better. 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?
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.

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 3 on the following page).

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.
Figure 3: Relative Importance of Daily Tasks
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 it 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**

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, 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.

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 , 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).
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 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.

**Does this advice seem reasonable?**

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.

If you don't learn to relax and make time for rest in your day, you will continually spend energy and therefore be continually fatigued.

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

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.

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 rest a lot, tissues 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.

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.
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. 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 the same outcomes as those experienced by astronauts, who, when space for prolonged
periods, are unable to even stand up when they come back to earth. This is because there is very little gravitational force in space and 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 above (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 ‘Bust’?

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

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.

- 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 you have hopefully moved from the first diagram in figure 1 to the second; you know how to live within your body’s energy supply but are not getting better. You now 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 10 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.

Pushing the boundaries may well make you feel a little worse in the first few days, but keep going, and soon this will be your new normal. If you are not feeling better after a week, then you may want to continue at 6 minutes. Alternatively, if you get fatigued, then rest, recover and next time try increasing your walking by 10%, or 30 seconds.

If 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, the week after.

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.
Relapses

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.

<table>
<thead>
<tr>
<th>Physical Symptoms:</th>
<th>they might feel awful, breathless, weak, tired and have chest pains if they exert themselves even a little bit.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feelings and Emotions:</td>
<td>they have, understandably, become very anxious about having another heart attack and are terrified every time they feel a twinge in their chest.</td>
</tr>
<tr>
<td>Behaviour:</td>
<td>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.</td>
</tr>
<tr>
<td>Beliefs:</td>
<td>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.</td>
</tr>
</tbody>
</table>
Medication could help with some of the physical symptoms, but the majority of what needs to be done is actually to do with 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.

| Physical Symptoms | Feelings and Emotions |
| Extreme fatigue | Constant anxiety and worry about failure and ‘being found out’. |
| Pain in throat and loss of voice | Anxiety about getting ill again |
| Some stomach symptoms of bloating and diarrhoea. | Low mood because life is now just a drudge |
Information about the document is not available.
Table 3: A System Management Approach to Illness

<table>
<thead>
<tr>
<th>Physical Symptoms</th>
<th>Feelings and Emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Thoughts and Beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.
Energy Chart - Mark your energy levels on the graph below to keep track and see how it changes

Figure 7: Energy Chart

Initially this could be in hours over the course of a day. Then as you become better at managing your energy, it could be days over a week.
Weekly Planner - Try using this to schedule in next week’s activities and rests

<table>
<thead>
<tr>
<th>Time</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4: Weekly Planner

Don’t forget to plan the rests!
Further Reading and Useful Information

Body Control Pilates website:

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

Health Champions

Blog: CRESTAchamps.blogspot.com
Twitter: @Crestachamps
Email: Crestachamps@gmail.com
Face/Google+: Cresta Fatigue Clinic Health Champions

Useful Reading

Don’t sweat the small stuff by Richard Carlson
Audiobooks 7 Habits of an Effective Person Steven Covey
Fighting Fatigue: Managing the Symptoms of CFS/ME by Sue Pemberton and Catherine Berry

Meditation

NHS choices:
http://franticworld.com/free-meditations-from-mindfulness/
YouTube- search meditation
Headspace App (Free)
http://www.getselfhelp.co.uk
Contact details

Victoria Strassheim, telephone (0191 2087299 or 0191 2088335) on Monday mornings

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

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.

Information produced by:
Kat Ratcliffe (Medical Student), Victoria Ewan (Spr), Victoria Strassheim (Band 6 Physiotherapist)
Date: 14 03 2017
Review Date: 14.03.2020