
Leeds Multisystem Rehabilitation Service (LEMURS)

Workbook



Leeds Multisystem Rehabilitation Service workbook

This booklet will provide information about how to manage your health condition and symptoms and should be used alongside your attendance of the 7-week virtual symptom management course and in one-to-one therapy sessions.

This is not designed to be read in one session. Please read the section relating to each separate week on the course.

Contents

Appointment log	page 3
Week 1: Fatigue	page 4
Week 2: Pain	page 11
Week 3: Mental wellbeing	page 15
Week 4: Breathlessness	page 22
Week 5: Activity and exercise	page 25
Week 6: Relaxation and sleep	page 29
Week 7: Moving forward	page 34
Appendix	page 39
Additional activity diaries	page 40
Additional goal logs	page 42
Outcome measures log	page 44
Notes page	page 45



This workbook will allow you to:

- Keep note of your App username and password to enable you to log on and complete your questionnaires.
- Keep a record of your input with the team, including upcoming appointments.
- Keep notes, reflect on the weekly virtual programme sessions, and complete the activities to help you to manage your symptoms.
- Keep you actively involved in your care and help you take control of your rehabilitation.

We suggest that you take this workbook with you to all therapy appointments.

Week 1 Fatigue

What is fatigue?

Fatigue is a personal experience which can impact your physical, emotional, cognitive, social and functional health.

It is different from the typical tiredness that we all experience after a long or busy day, as fatigue may not improve with rest.

You may feel:

- Exhausted.
- Physically and/or mentally weak.
- A lack of drive or motivation.
- Feelings of irritability, frustration, or being overwhelmed.

Fatigue can be linked to chronic pain conditions such as Arthritis, Fibromyalgia, ME/CFS, Long Covid, sleep disorders, autonomic issues that lead to low blood pressure, or it may occur without any of these factors.

The words we use to describe our fatigue are often an indication of where it bothers us most. Examples are:

- My bones feel heavy (**physical fatigue**).
- My brain is like mush (**cognitive fatigue**).
- I can't be bothered to do anything (**emotional fatigue**).
- Spending time with people drains my energy (**social fatigue**).
- I can't keep up with daily tasks (**functional fatigue**).

Fatigue can be:

- Distressing, isolating and frustrating.
- Complex, multi-dimensional and multi-factorial.
- Experienced even with good quality sleep.
- Something that can be managed.

How you use your energy budget does have an impact on your symptoms.



If you overexert yourself, you could experience a worsening of symptoms, like fatigue or brain fog. By managing energy carefully (through pacing and resting), you can avoid pushing beyond your limits, allowing your body to recover gradually and prevent setbacks.

What causes fatigue?

Internal causes/primary factors:

- **Pre-existing medical conditions:** Such as pain, ME/CFS, or other chronic illnesses.
- **Poor sleep quality:** Even if you sleep for long periods, the quality of sleep can be affected by your condition.
- **Low mood or depression:** Often linked with chronic illness and can worsen fatigue.
- **Personal values and self-expectations:** For example, the belief that you should push through fatigue or avoid being seen as 'lazy'.
- **Stress:** Both physical and emotional stress can increase fatigue levels.
- **Past trauma:** Which can contribute to heightened sensitivity to pain and fatigue.
- **Immune system dysfunction:** Which can be a factor in conditions like ME/CFS.
- **Increased inflammation:** Common in conditions like fibromyalgia, arthritis, and ME/CFS.

External causes/secondary factors:

- **Lack of understanding or awareness:** How chronic illness affects fatigue.
- **Diet and nutrition:** Poor diet or imbalances can affect energy levels and overall health.
- **Deconditioning:** Muscle weakness or physical decline due to inactivity, often a result of pain or fatigue, discussed later in the booklet.
- **Stopping activities you enjoy or reducing social interaction:** This can lead to emotional fatigue and a sense of isolation, which can make fatigue worse.
- **Medication side effects:** Some medications for pain or other symptoms can increase fatigue.
- **Pressures and expectations:** From work, family, friends, or yourself, can cause stress and worsen fatigue.
- **Societal values or stigma:** Misunderstanding about invisible illnesses like ME/CFS or fibromyalgia, and how it impacts daily life.
- **Financial pressure:** Concerns about money, debts, benefits, housing, etc. can cause ongoing stress that worsens fatigue.

- **Environmental factors:** Such as living in an environment that does not support rest or recovery, like noise, overcrowding, or lack of a comfortable space.

The 4 Ps of fatigue management:

Plan: Planning what you are going to do ahead of time can help to maximise your energy levels and help in managing your levels of fatigue.

Pace: Pacing involves changing your thinking around completing tasks. To pace yourself, you may do a task more slowly or break it up with rests to prevent making your fatigue worse. You may also ask others for help in completing certain tasks. It includes spreading out the activities that you do more evenly throughout the day or across the week.

Prioritise: This involves identifying the most important tasks and activities and focusing your energy on those, while delegating or postponing less crucial tasks. Doing things we enjoy puts energy in the budget. The right amount of exercise, sleep, fun, nutrition, time in nature and relaxation are all important things to put energy back and to recharge.

Position: Think about your body position while completing tasks throughout the day. Bending and reaching can cause fatigue and shortness of breath. Consider sitting down for some activities to conserve energy. Try keeping objects in easy to reach places.

The more you can learn about what fatigues you the better you will be able to implement strategies to help manage your fatigue.

Activity

How might you apply the 4 Ps approach to an activity that currently uses a lot of energy?

Thinking about your diet and nutrition, as we know staying hydrated and eating a balanced diet is so important for recovery, you can use the 4 Ps principles to ensure you eat well. For example:

- **Batch cook on the days when you feel better.** Prepare larger quantities and freeze portions for low-energy days.
- **Use ready-made or partially prepared items.** These save energy while still helping you eat well.
- **Choose recipes with fewer steps, one-pan, slow cooker or air fryer meals.** These minimise effort, dishes and cleanup.
- **Spread tasks out throughout 1-2 days** e.g. split preparation, cooking and washing up into different tasks, rather than trying to do them all at once.

Dietary changes you can make to help improve fatigue

- Aim for a healthy diet which includes protein, carbohydrates, vegetables, fruit and healthy fats. This can be important in improving your energy levels and reducing muscle loss.
- Low glycaemic index (GI) carbohydrates, also known as slow-release carbohydrates can help to manage energy levels. It can be beneficial to have a low GI food with each meal. Low GI meal ideas include:
 - Porridge with semi-skimmed milk, fruit, nuts and seeds.
 - Wholegrain or seeded bread/toast with beans, egg, falafels, cheese, tuna or lean meat.
 - New potatoes in skins with vegetables and fish or chicken or legumes such as kidney beans or chickpeas.
 - Chickpea, lentil or chicken and vegetable curry with a chapatti.



For more information: <https://www.bda.uk.com/resource/glycaemic-index.html>

- Cravings for caffeine and sugar are common. Intake of these leads to a short increase and then drop in energy levels which can leave you feeling worse. Try to limit caffeine and sugary foods and drinks e.g. energy drinks, full-sugar soft drinks, sweets, biscuits etc.

- Drink at least 6-8 cups of fluid a day.



Resources:

British Dietetic Association (BDA) food fact sheets are written by dietitians based on evidence and research. They cover a range of topics and conditions.

<https://www.bda.uk.com/food-health/food-facts.html>

NHS Eat Well: Information and guidance about eating a healthy, balanced diet.

<https://www.nhs.uk/live-well/eat-well/>



Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

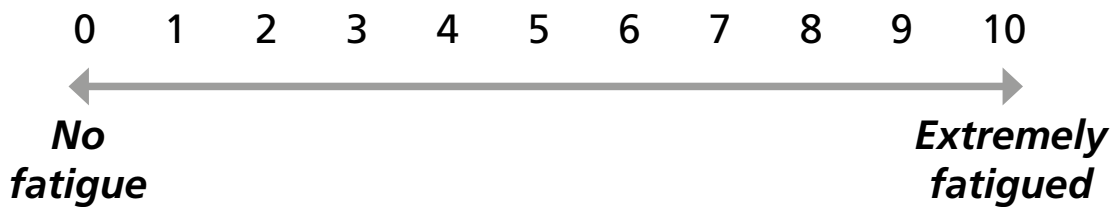
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Activity diaries

Activity diaries can help you understand your energy expenditure and the impact on your body. They can also help you plan activities within your current energy budget.

We understand that activity diaries take energy to complete. However, if you feel you are being controlled by fatigue rather than feeling that you understand your energy patterns, these diaries can help you to get a better understanding of your fatigue.

When completing the activity diaries, we ask you to write what you have been doing throughout the day then score your fatigue on a scale of 0-10.



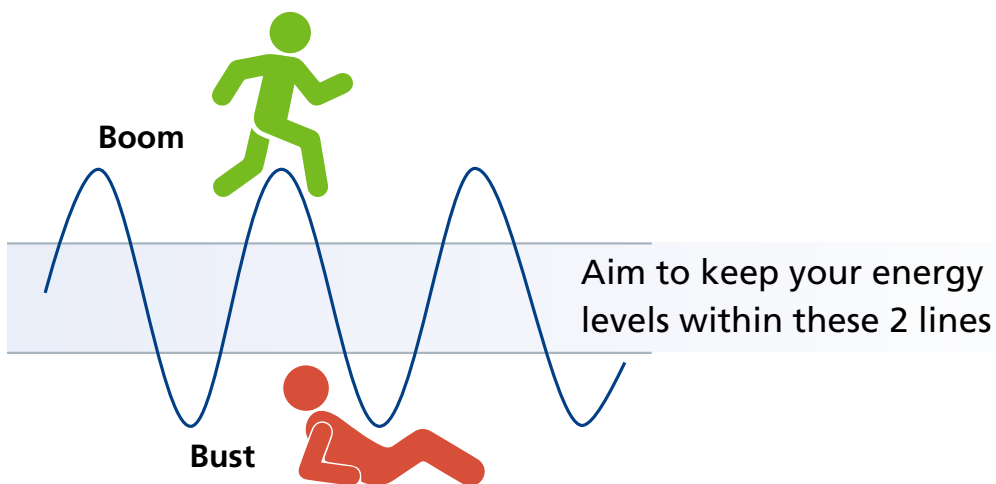
A version of a diary has been included in this workbook for you. Please aim to complete this if fatigue is a big symptom for you and bring it to your one-to-one session with your therapist for discussion.

Remember to consider the cognitive, emotional and social demands of activities, as well as the physical demands.

Activity and Fatigue Diary

Day	6-9am		9-12pm		12-3pm		3-6pm		6pm - bedtime		Sleep quality/hrs
	Activity	Score	Activity	Score	Activity	Score	Activity	Score	Activity	Score	
Mon											(Sun night)
Tues											(Mon night)
Wed											(Tues night)
Thurs											(Wed night)
Fri											(Thurs night)
Sat											(Fri night)
Sun											(Sat night)

Post Exertional Symptom Exacerbation (PESE)



This is an illustration of what happens when you go beyond your energy budget. You might have heard this also being called Post Exertional Malaise (PEM), which can both lead to a 'Boom-bust cycle'.

Lots of people who experience fatigue find themselves in the Boom-Bust cycle. This is when we do too much on a good day(s) and then have a 'crash' period afterwards. People often describe trying to fit everything in while they feel like they have some charge in their battery. It is tempting to do as much as possible while the energy is there and push past our limits - this 'flattens the battery' even more. When the battery has been flattened, there is no choice but to stop and actively rest to 'recharge'.

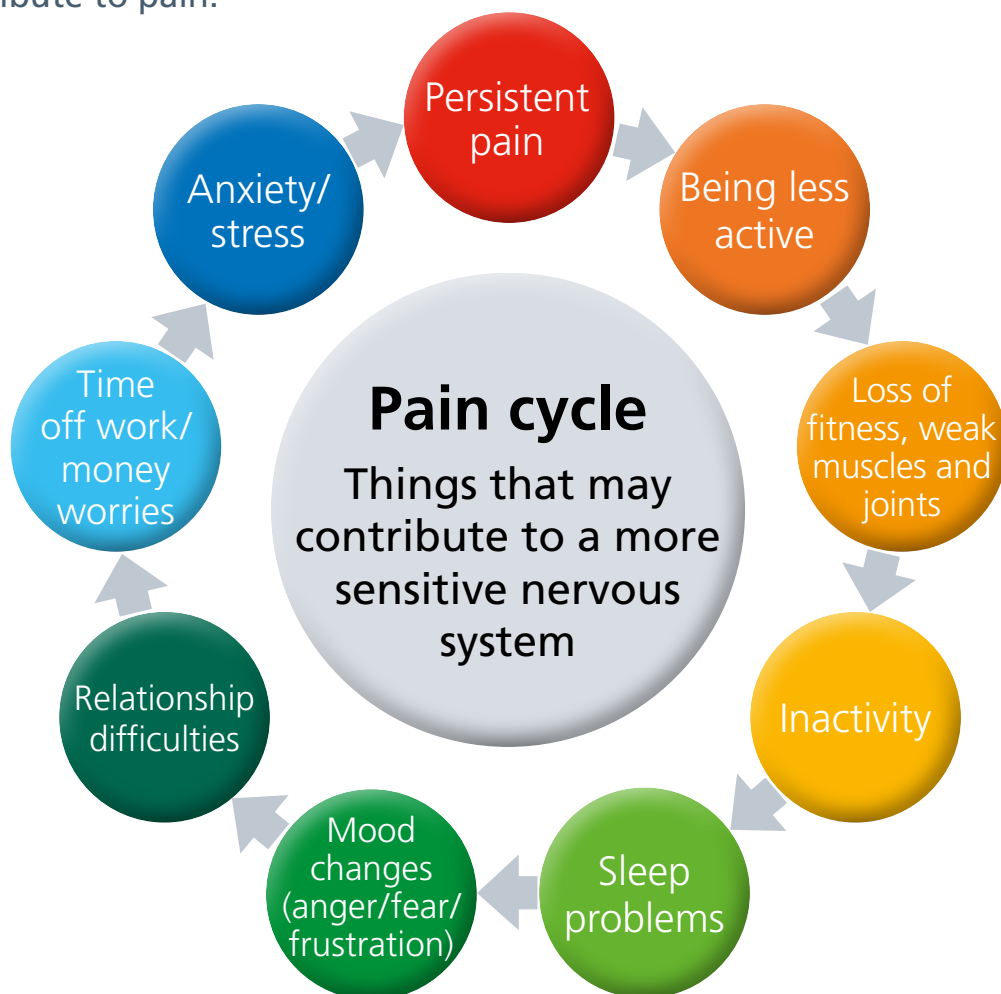
Going over your energy budget causes many of your symptoms to increase, not just your fatigue symptoms. To avoid PESE, we must work to the optimum of our energy pack and not stretch too far beyond or beneath it. We must remember that our use of energy impacts on our recovery. PESE can manifest up to 72 hours after doing too much. Research has shown that by slowly increasing activity, our battery is able to charge more fully. It is therefore more effective on our physical and psychological wellbeing to pace, prioritise and plan activities.

Week 2 Pain

Pain is the body's natural defence mechanism telling us that something hurts, most injuries, both soft tissue and bone normally heal within 3-6 months.

Persistent pain is pain that has continued for longer than 3 months and is often due to a combination of factors, including:

- A chronic condition, such as Rheumatoid Arthritis.
- Increased sensitivity of the nervous system. The nervous system becomes so sensitive it reacts quicker, needing fewer stimuli to generate a painful response. Pain often extends beyond the initial injury / site of pain because joining nerves also become stimulated and don't turn off. Normal movement can become painful.
- Not doing as much activity or stopping yourself from doing activities impacts on how we move; this often leads to stiffer and more painful joints and muscles, which can contribute to pain.



Pain can cause low mood, anxiety, anger, stress, weight changes, lack of sleep - all these factors can further increase pain and the sensitivity of the nervous system, affecting our ability to cope with the pain.

The 6 key principles of pain science:

- Persistent pain is common and can affect anyone.
- Hurt does not always mean harm.
- Everything matters when it comes to pain.
- Medicines and surgeries are often not the answer.
- Understanding your pain can be key.
- Recovery is possible.

For more information on pain science see:

Lorimer Moseley ted talk: <https://www.youtube.com/watch?v=nifGFluVkUk>

Pain Science: <https://www.flippinpain.co.uk/event/fms/>

Living well with pain: <https://livewellwithpain.co.uk/>

The pain CD: <http://www.paincd.org.uk/home>

Rethinking persistent pain: <https://www.tamethebeast.org/>

Retrain pain: <https://www.retrainpain.org/languages/english>

Here is a recap of a few things that can help with pain management:



Understanding the triggers of your pain



Relaxation techniques



Quality sleep



Appropriate physical activity



Diet and weight management



Regular support



Knowing when to seek advice



Distraction techniques



Hot and cold therapies



Laughter



Doing more of what you love



Being outside in the daylight



Pet therapy



Music therapy

Activity

Have a think about what practical things you currently do or could implement that may help your pain management.

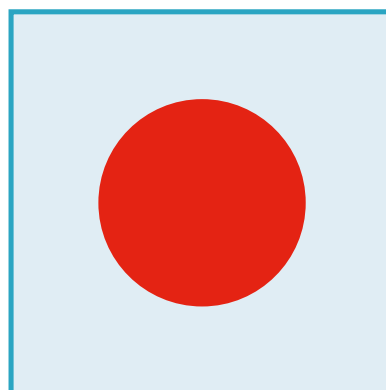
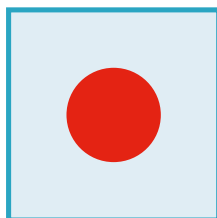
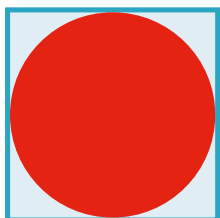
Key message: do more of what makes you, you:

<https://www.youtube.com/watch?v=ZUXPqphwp2U>

Square = person

Circle = impact of pain

The aim is not to reduce the pain.



Pain management aims to 'expand' your quality of life rather than living a life trying to avoid or fight pain and suffering, to enable you to live a life doing whatever matters to you.

How does what I eat link with pain?

When the body is in pain it creates an inflammatory response. What you eat can help with pain because certain foods can reduce inflammation in the body whilst other foods can increase inflammation in the body.

The Mediterranean style of eating has proven anti-inflammatory properties which means it reduces inflammation in the body and therefore can help to reduce pain.

Some research has shown that people with persistent pain who followed a Mediterranean style of eating for 6 weeks reported a reduction in their pain and those that followed this way of eating for 12 weeks reported an improvement in their mood as well.

This style of eating will involve increasing your intake of some foods and reducing your intake of others. The table below gives you some examples of foods to eat more and foods to eat less.



Try to eat more ↑

Nuts and seeds

Oily fish (aim for once a week)

Variety of fruits and vegetables

Fermented foods

Wholegrains

Try to eat less ↓

Fatty and processed meats

White flour foods

Processed foods

Manufactured biscuits and cakes

Fast food

Nutrition resources:

Rethinking pain: <https://rethinkingpain.org/diet-therapy/>

Living well with pain: <https://livewellwithpain.co.uk/resources-for-people-with-pain/nutrition-and-pain/nutrition-top-tips/>

Week 3 Mental Wellbeing

Managing your physical health in combination with your mental wellbeing and thinking about things in a holistic way has been shown to improve people's mood and help them manage the challenges of living with their health condition. It is common to feel distressed when you are experiencing a health condition. Distress affects people in different ways.

Here are some common psychological challenges that people can experience when they are living with a health condition:

- Low mood/depression
- Feeling overwhelmed
- Shock/disbelief
- Avoidance of people/places/things
- Feeling lonely/isolated/misunderstood
- Distressing thoughts/worries
- Panic/anxiety attacks
- Frustration/feeling irritable
- Anxiety/fear
- Change in self- perception.

As a result of the above, this can often lead to additional stressors, which can further impact mental wellbeing:

- Changes to hobbies/activities
- Changes to parenting/relationships
- Loss of daily routines/structure
- Housing/environmental changes
- Financial stress/benefit worries
- Employment changes.



Activity

Have you noticed an impact to your mental wellbeing due to your physical health symptoms, or vice versa? If so, reflect on this below to explore further with your clinician.

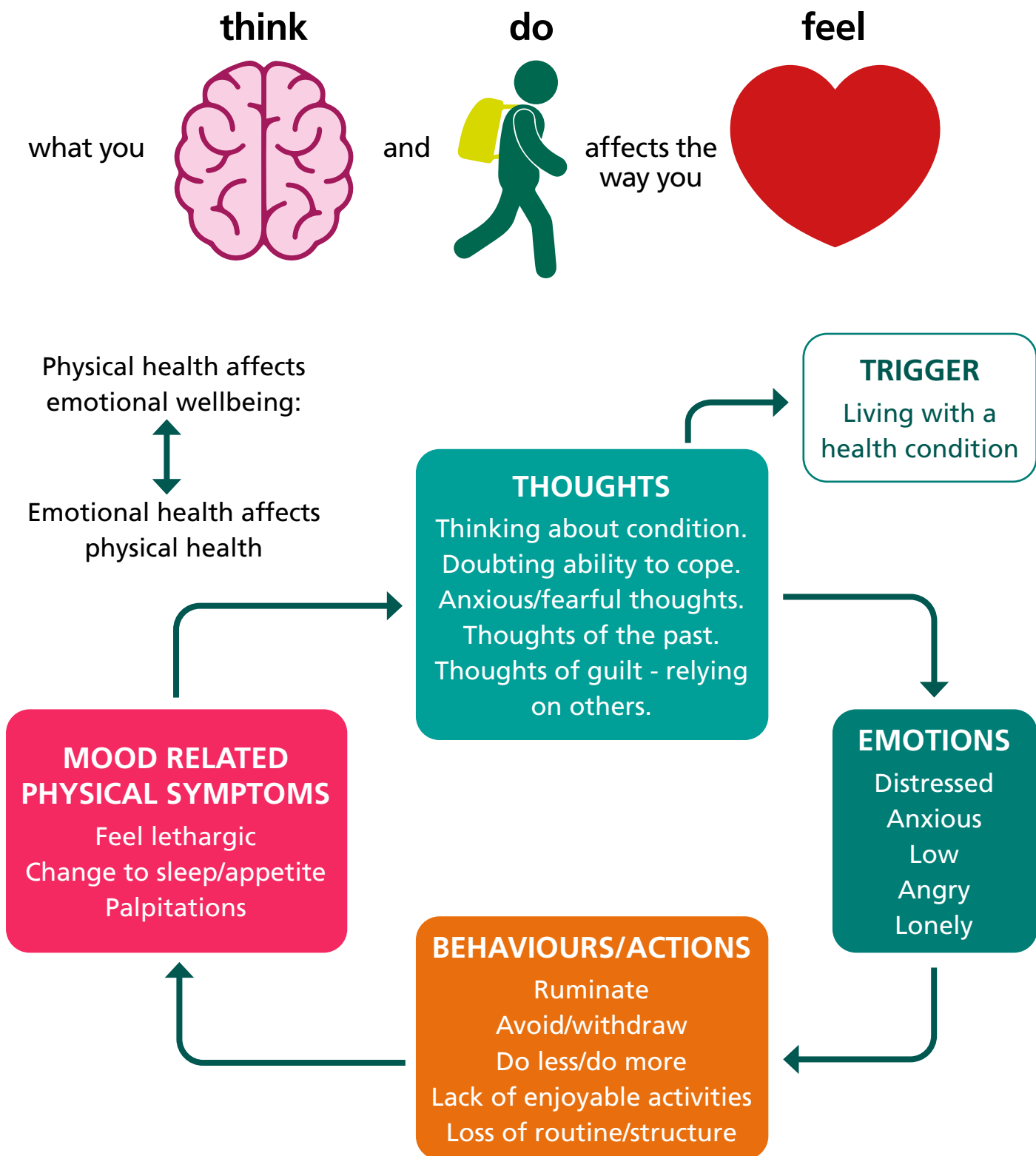
Adapting to change

Health conditions bring challenging physical symptoms and changes to your life that you did not expect. These changes can involve feelings of loss, changes to roles, lack of structure, family, employment and financial challenges amongst others. Accepting and adjusting to these changes is a process and this process is different for everyone; there is no right or wrong length of time. Accessing support and using recommended techniques for both your physical and emotional wellbeing can help you with this process. Aim to use a compassionate self-help approach whilst allowing yourself time to adapt.

The vicious cycle

The vicious cycle below illustrates that health conditions can bring changes to the way people think, feel and what they do. Everyone can have distressing thoughts and feelings from time to time. Unfortunately, when these distressing thoughts, feelings and behaviours become a habit, a vicious cycle can form. Our thoughts, emotions and behaviours are all linked. They also contribute to physiological symptoms with changes to our sleep, appetite, lethargy, palpitations, digestive symptoms etc. The vicious cycle demonstrates how physical health can influence mental wellbeing and vice versa and the importance of trying to manage both areas.

The vicious cycle



The role of resilience in managing your mental wellbeing

Resilience can be described as the ability to cope with adversity and difficult situations. It plays an important role in managing health and wellbeing. Managing a

health condition takes resilience, but unfortunately, over time, day-to-day challenges can also affect resilience. Using support and techniques can help to strengthen resilience.

Activity

Have a think about your own resilience and write some examples below, e.g. using practical strategies, improving any social isolation, applying self-compassion on more challenging days.

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-
-
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-
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-
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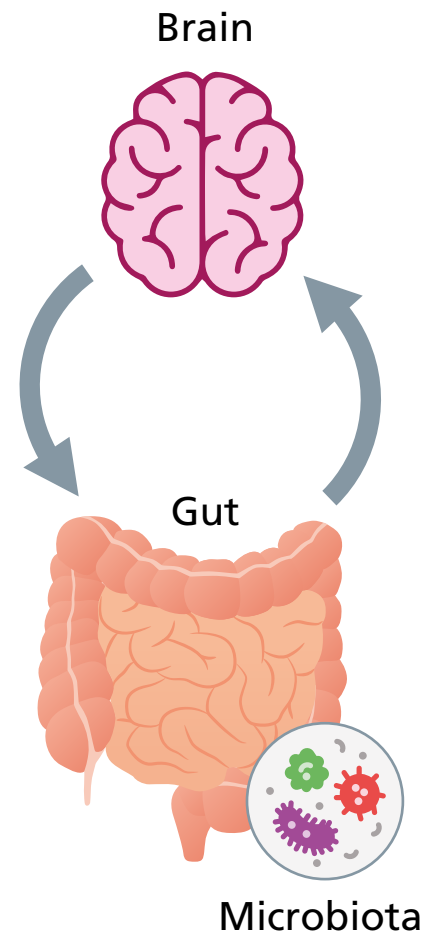
How diet and nutrition can impact your mental wellbeing

Here are some helpful tips on how your diet and nutrition can support your mental wellbeing:

- The low Glycaemic Index (GI) approach can prevent dips in blood sugar levels that can lead to irritability.
- Ensuring a good daily fluid intake will aid cognition and concentration.
- To function adequately the central nervous system needs amino acids found in high protein foods.
- Essential fatty acids such as omega 3 and 6 as mentioned in the Mediterranean diet aid proper blood flow in the brain which is associated with better performance of cognitive tasks.
- Because of the link between the gut and the brain, looking after our gut health improves gut symptoms which helps with changes in mood and anxiety.

The Gut-Brain Axis

There is a 2-way communication between the gut and the brain known as the gut-brain axis (see diagram opposite). The brain influences the gut and the gut influences the brain. Emotional or physiological stress can impact the gut. During times of stress, stress hormones are released. An increase in stress hormones can mean that digestion and absorption are compromised. You can notice your emotions in the gut by having a 'gut wrenching feeling' or 'butterflies in the stomach'. Feeling stressed or anxious can make your gut slow down or speed up, leading to problems with digestion, maybe feeling bloated or constipated.



Improve your mood with goal setting

- For people living with health conditions, goal setting is important.
- Goals give you a sense of structure, purpose. They help to keep you focused.
- Goals can be described in many ways: Having an aim, a plan, a target, a focus.
- Start by setting the smallest micro goals, these help you build up momentum and create motivation.
- Accomplishing even the smallest of goals provides a sense of achievement, confidence and can help you feel more in charge of your daily life.

Consider the benefits of goal setting

- Write your goal or your aim clearly and precisely in the box below.
- E.g. Get washed and dressed by 11:30am. Make a cuppa ready to listen to my favourite radio show at noon.
- Consider the benefits of doing this goal. List the advantages that completing this goal will bring you.
- Make a list of exactly what you will do and when you will do it. This helps to make your goal more likely to become a reality.
- Consider asking others to support you to help you complete your goal.
- Keep each step of your goal as small as possible. Just focus on one small step at a time.

Your goal/aim/focus	Benefit of goal	What/how/when
Get washed and dressed by 11:30am. Make a cuppa ready to listen to my favourite radio show at noon.	Helps my mood and routine, provides structure. I enjoy listening to the speakers on the radio show.	Set a final alarm for 11 am. Get next day's clothes ready the evening before.

Benefits of self-compassion

- It can be common to experience self-critical thoughts when coping with challenging symptoms.
- These self-critical thoughts make living with your health condition even harder. Remember the vicious cycle? What you say to yourself influences the way you feel.
- Try to keep your 'self-talk' supportive and compassionate especially when you have difficult days.
- Many people benefit from either using self-help strategies or accessing further support.
- We have options available in our service to help you manage and improve your mental wellbeing.
- Please speak to your clinician for advice.

Useful resources:

Self help resources: www.mindwell-leeds.org.uk

Samaritans is always open to talk about whatever you're going through. Open 24/7. Call **116 123** (free phone).

West Yorkshire 24-hour mental health helpline offers support, advice and information for anyone in Leeds. Open 24/7. Call **0800 183 0558** (free phone).

Connect helpline is a survivor-led service offering emotional support to people in Leeds. Open every night 6pm to 2am. Call **0808 800 1212** (free phone).

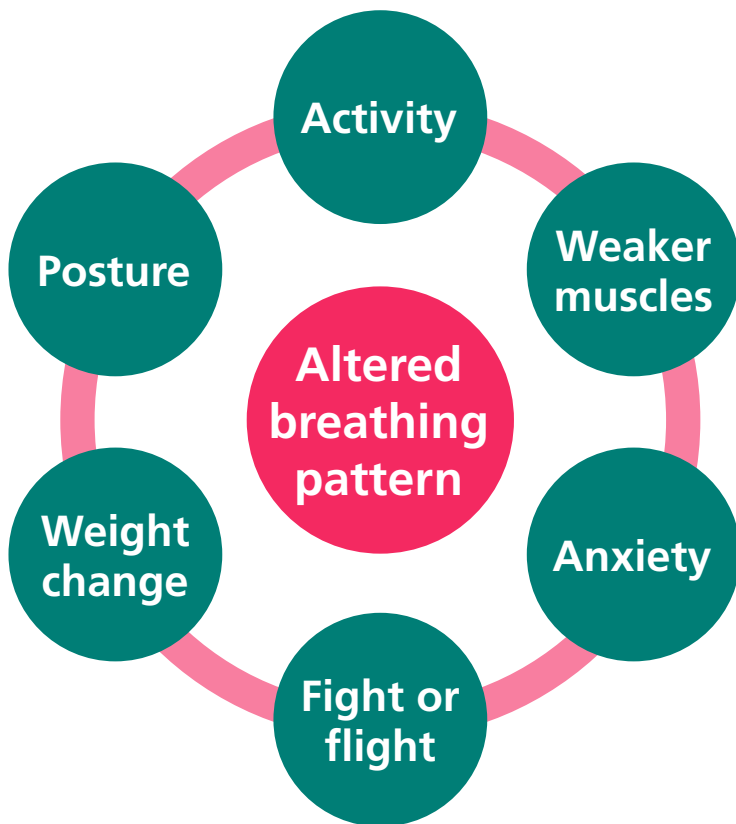
Connect BSL helpline is on Mondays at 7pm to 11pm, facetime/skype/glide with BSL trained staff. Call **07500 870 987**

Shout text service struggling to cope? Text SHOUT to **85258** (free) any time 24/7 for support. Messages are anonymous and won't appear on your phone bill.

Contact 111: option 2 to speak with the mental health team for urgent help in a crisis.

Week 4 Breathlessness

What can cause breathlessness?



There are many factors that can impact on our breathing pattern aside from lung damage associated with conditions such as COPD. These can include what activity we are undertaking, how strong the muscles that help us breathe are, the posture we are in, changes in our weight, if we are feeling anxious or if our body is interpreting a stress that has placed us in fight or flight mode.

It is by addressing these factors that we can aim to make a change in breathlessness symptoms, but to do so we must understand what a GOOD breathing pattern looks like.

Good breathing pattern:

- Movement should come from the bottom of your lungs to engage the diaphragm.
- Breathing out should not require effort.
- It should be quiet.
- Take 8-12 breaths per minute at rest.
- Your breath out should be longer than your breath in.
- It should be regular, rhythmical and relaxed.



Why is it important?

Normal breathing pattern uses 3% of our daily energy budget, whereas a dysfunctional breathing pattern can use up to 30% of our daily energy.

Activity

Considering what good breathing should look like think about how you are breathing right now. Is there anything you can improve?

What to do when feeling breathless

Breathing control

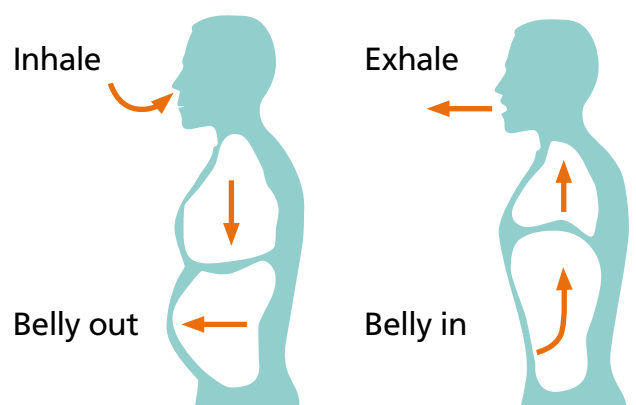
Breathing control is a gentle breathing technique that helps with breathlessness, anxiety and panic.

You should practice regularly for 10-15 minutes when you feel relaxed. Practising little and often should help make it second nature when you lack control over your breathing.

It focuses on making your breathing more efficient by breathing from your tummy (abdominal breathing), using the lower chest rather than the top of the lungs and shoulders.

It is completed in the following way:

- Start in a comfortable and well supported position, with shoulders relaxed, chest open and elbows by your side.
- Place hands on your tummy, just above your belly button.
- Breathe in gently through your nose, focus on drawing air right to the bottom of your lungs and allow your tummy to rise (imagine a balloon inside your tummy is inflating).



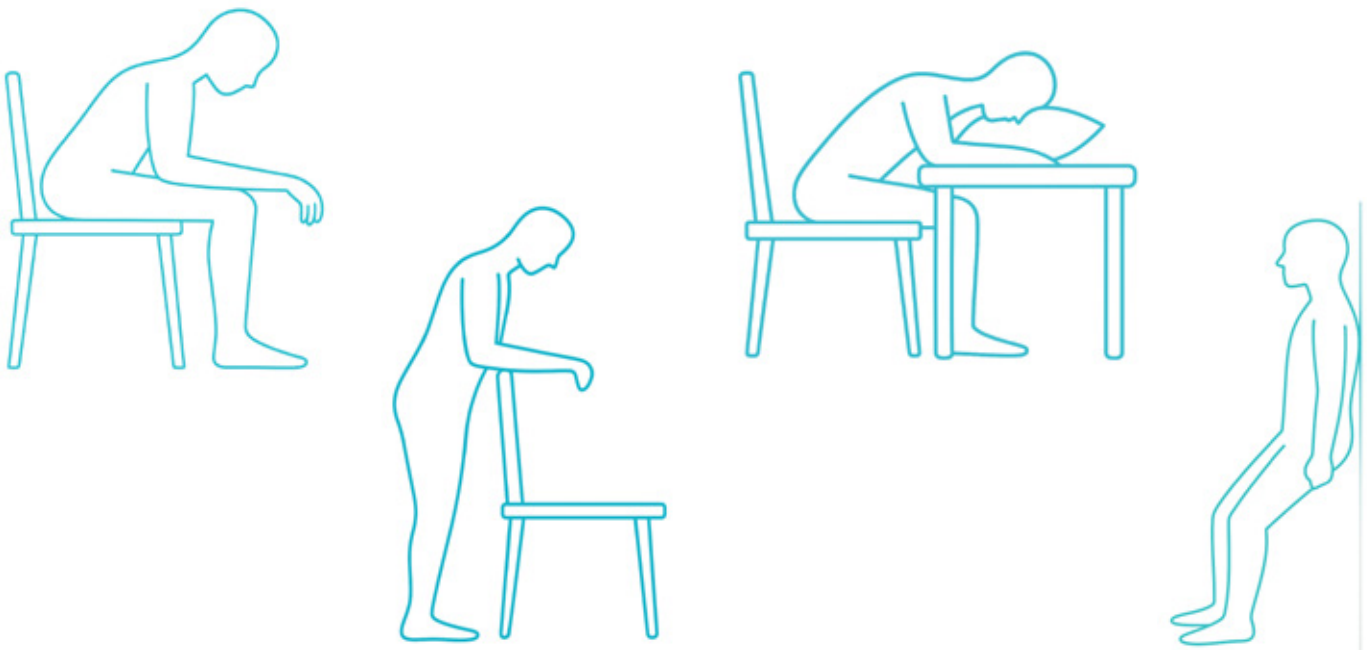
- It is important to only take in the air that you need, it is not about taking a deep breath.
- Breathe out gently through your mouth, like a sigh, not forced, through pursed lips if it helps, and let your tummy fall until the breath comes to its natural end.
- Always focus on the breath out; the breath in will take care of itself. This is especially important if you are feeling anxious.
- Gradually try to make the breaths slower.
- Closing your eyes may help you focus on your breathing and relax.

See link for video on breathing control:

<https://www.youtube.com/watch?v=k9-8AG3sUi4>

Positions of ease

There are also positions to help you recover when feeling breathless:



Resources:

If you have an altered breathing pattern see:

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

More on breathing activities:

<https://www.acprc.org.uk/media/gl3ma3wr/gl-02howtocopewithbeingsob-breathingex.pdf>

Week 5 Activity and Exercise

There are many advantages to increasing our activity levels / exercise levels including:

- Improves cardiovascular fitness
- Improves endurance
- Improves immune system
- Improves mental health
- Improves muscle strength and power
- Improves joint strength and power
- Improves metabolism
- Reduces/manages pain
- Reduces health risk e.g. heart disease, diabetes, stroke, cancer.



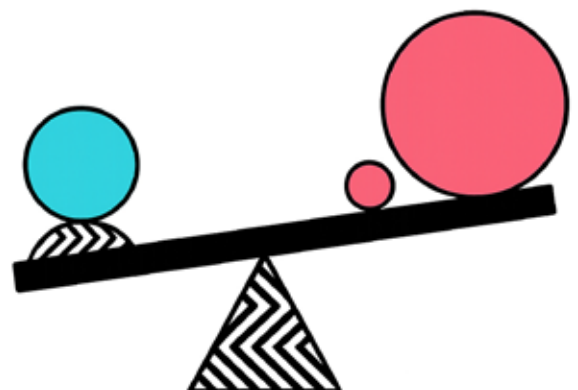
However, people living with a chronic condition also face many barriers to increasing activity and or exercise:

Pain

Pain is a common factor that can make you want to avoid exercise. For persistent pain, we know that exercise is the best thing for long-term outcomes of both pain and function. The key is to start slow, find exercises that are manageable and do not excessively flare up symptoms. As symptoms allow, you can gradually progress to different forms of activity, slightly more challenging exercises or increasing the time you exercise per week. It is important to make small adjustments at a time and see how this impacts on symptoms. Sometimes scaling things back slightly may be needed if pain is increased too much.

Fatigue

Similar to pain symptoms, the key with managing fatigue is balance. Too little activity leads to deconditioning, which makes daily tasks even harder and more tiring in the long-term. Too much exercise or activity can exacerbate symptoms, which is also not ideal. Finding the right balance of activity and exercise can help keep us healthier and reduce the risk of losing muscle strength and fitness. If you find after exercise that you are excessively tired the next day, this is a sign you have done too much and should reduce exercise/activity slightly. However, if your symptoms are stable and have not become worse on the



following days after exercise, this is a sign you did not over-exert yourself and could potentially progress things slightly. The key is making small increases at a time to reduce the chance of a setback.

Post Exertional Symptom Exacerbation

This is a worsening of your symptoms that maybe felt up to 72 hours after the increase in activity/exercise. The importance of pacing is crucial in managing this. If you suffer from PESE we advise you seek support from your clinician during your 1:1 in how you can increase your activity levels safely.

Heart palpitations

Palpitations can be caused by a number of factors (dysautonomia, emotions and psychological triggers, some medications, hormone changes, heart conditions, other medical conditions). In many cases they are not dangerous but if you have not had this symptom investigated you should see your GP for an ECG to be performed. This will screen for conditions that may require further treatment such as atrial fibrillation. You can have palpitations even with a normal ECG. These are not dangerous, should not prevent you from exercising and can even improve with better conditioning. If you have any concerns please see your GP.

POTS/orthostatic intolerance

You will have been screened for this at your first assessment. If you have these conditions you will likely have been informed. Some people will experience symptoms from prolonged periods of standing, such as dizziness or palpitations.

Some adjustments to exercise choice can be beneficial; try selecting recumbent (lying down or leaning back) exercises to begin with such as rowing, recumbent bike, Pilates, resistance band exercises and over time, you can gradually incorporate more upright/standing exercises as tolerated (mix of strength and cardio is ideal). Ensuring good hydration is also important.

Chest pain/tightness

There can be many causes of chest pains, many of which are not a risk to you. However, if you are experiencing chest pains and have not had this investigated, you should see your GP prior to commencing exercise. If you have had this investigated, you can be assured it is safe to exercise. Most of the time this pain will be due to weakness of the breathing muscles and surrounding soft tissue.

Call 999 if:

- You have sudden chest pain that spreads to your arms, back, neck or jaw
- Sudden pain, tightness or heaviness in the chest
- Sudden shortness of breath with sweating and feeling nauseous or vomiting.

Borg Scale

- It can be helpful to think of exertion on a 0-10 scale and try to stick within a certain level of exertion during exercise.
- If you are starting exercise for the first time in a while, take things easy to start with and build up gradually.
- If your symptoms allow, you can increase the intensity and amount of exercise gradually.
- If you experience exacerbation of symptoms after exercise (including on the days after) you should reduce the amount and/or intensity.

0	Rest
1	Really easy
2	Easy
3	Moderate
4	Sort of hard
5	Hard
6	
7	Really hard
8	
9	Really, really hard
10	Maximal, just like my hardest race

The importance of nutrition with activity

- Maintaining a healthy, balanced diet ensures your body receives the fuel it needs while exercising.
- Eat regularly.
- Base meals around starchy carbohydrates.
- Carbohydrate rich foods include wholegrain foods such as bread, rice, pasta, cereal and potatoes.
- Adequate fluid intake is key to maintaining the body's health, energy and performance during activity.
- Protein is a building block used to help the body grow and repair during exercise. It can repair muscles and tissues and help to maintain strength — all of which are vital for staying active and mobile throughout life.
- Protein helps to preserve muscle stores and reduce muscle loss during exercise, allowing for quicker recovery afterwards. Studies show that the addition of 15-25g of protein to a post-workout meal or snack can reduce muscle soreness and promote muscle repair, making them stronger and more resilient. Good protein sources include chicken, tinned tuna, cottage cheese, eggs, beans, nuts and yogurt.

Exercise ideas

Gentle movement / flexibility	Cardiovascular	Strength
Yoga	Brisk walking	Body weight exercises
Stretches	Jogging	Hand weight exercises
Pilates	Swimming	Resistance band exercises
Tai Chi	Cycling/exercise bike	Resistance machines
Walking		

Resources:

POTS advice: <https://www.potsuk.org/managingpots/>

Exercising with POTS: <https://www.standinguptopots.org/livingwithpots/exercise>

Pain and exercise resources: <https://www.flippinpain.co.uk/resources/>

Week 6 Relaxation and Sleep

The Autonomic Nervous System

The autonomic nervous system controls functions in your body that you don't have to consciously think about such as breathing, blood pressure, digestion, etc.

It has 2 branches and can be viewed as a pair of scales:



The **Sympathetic** 'fight or flight' (sometimes freeze) side is activated when

your brain detects a threat. It prepares your body for action to get away from danger by increasing your heart rate, etc. It does not matter if the threat is real or perceived. Once the threat has gone, the scales reset and the **Parasympathetic** 'rest and digest' side

can be activated. The system works well when there is overall balance. However, the stress of living with a long-term condition can mean that the 'fight or flight' response is continually 'on' meaning that the mind and body can struggle to properly 'rest and digest' or recover.

How the body responds to stress

One way the body responds to stress is by creating tension. Imagine you are about to fight someone or run away from them. Your muscles get ready for action, they tense up. This tension/energy, when not released can be held in various parts of the body. Quite often you may feel it in your shoulders, and some people get tension headaches.

Activity

On a scale of 1-10 (1 is completely relaxed/no tension at all, and 10 is fully wound up, think to yourself - 'how am I feeling at this moment' and score/write below.



Think of which parts of the body are holding any tension and write them down.

Relaxation and sleep

Relaxation and sleep are both important in restoring balance to the autonomic nervous system. They are not the same and the quality and quantity of one can affect the other. It could be argued that both are essential for survival, it's just with a lack of sleep, you notice the impact much more quickly. When you don't relax enough, it can take days, months or years to realise.

Resetting the scales with active rest

Living with constant pain and fatigue or dealing with the uncertainty of fluctuating symptoms often results in chronic stress. Resetting the scales may seem impossible. If you feel unable to reduce anything from the 'fight or flight' side, it may be possible to add to the 'rest and digest' side through active rest.



Active rest is an important part of energy conservation and is key to managing fatigue, brain fog, stress, pain and other symptoms you may experience. Active rest is not doing 'nothing'. Doing 'nothing' does not actively boost your parasympathetic nervous system or top up your 'battery'. Examples of active rest may include being in nature, listening to relaxing music, doodling/colouring, meditation.

Activity

Have a think about how you rest or relax throughout your day or week.

What activities do you already do? Do they give you more energy than they use up?

Which active rest activities will you try/do more of to help support with your health and wellbeing? (see the active rest checklist for ideas)

Using active rest during the night if having sleep issues can help calm the system too, e.g. if you find it difficult to fall asleep or get back to sleep if you wake up in the night. If you are having difficulty sleeping, being able to rest well is still beneficial.

Sleep

Sleep can be adversely affected by several things: pain, needing the toilet, insomnia, spending more time than usual inside, too much caffeine, alcohol, noise, temperature (too warm or too cold), mood (anxiety/depression), PTSD and flashbacks.

It is important to acknowledge that sleep is individual, and people are affected differently by certain factors, e.g. caffeine. However, here is a typical 'checklist' of things to consider that can support your sleep. Commonly this is known as 'sleep hygiene'. For some people, making changes to these fundamental things can make a significant difference to their sleep.

- **Routines** – your body responds well to familiar patterns of sleep, and to cues whether it is wake or sleep time.
- **Exposure to natural light** – this can be by a window if you struggle to get outside. Some people find light boxes/SAD lamps in winter helpful.
- **Physical activity** – the key here is what you do and at what time, so you aren't overstimulated for sleep or feel physically uncomfortable.

- **Medications:** some medications can disturb sleep or can increase lethargy during the day. A medication review is advised if you are having sleep problems and take medication. Always mention what supplements/natural remedies you are taking too.
- **Screen time:** blue light emitted from screens including TVs and mobile phones can block melatonin, the sleep hormone. Try to avoid screen time for at least an hour before bed and consider leaving your tablet/mobile phone in another room.
- **Time to unwind:** put aside the concerns of the day before bedtime as best you can. Build in a buffer time between when you finish for the day and when you go to bed. This can help you get in the right frame of mind for sleep. If you can't fall asleep, try to do something relaxing or calming rather than remaining awake in bed.
- **Keep the bed for** sleeping, intimacy and relaxing.
- **Create a good environment** for sleep where possible, e.g. noise, light, temperature, comfortable bedding.

Hyperarousal

For some people, their sleep issues continue even with good sleep hygiene measures in place. Sleep itself can become a worry, which is not conducive to good sleep.

You may experience feeling 'tired but wired'. Feeling tired is different from feeling sleepy. You may feel exhausted but that you can't sleep – like you are too switched on (busy brain, feeling restless).



When we are aroused, our body has an increase in hormones and chemicals that are not supportive for a sleep state. Doing things you find calming, enjoyable, soothing and feeling happy helps different hormones and chemicals for sleep. This is both in the evening/night times and during the day – being 'wired' during the day can be harder to come down from.

Nutrition and sleep

It is important to recognise how diet and nutrition can have an impact on your sleep. Substances like caffeine interfere with the process of falling asleep and prevents deep sleep. Alcohol may help you to fall asleep initially, but it will disrupt your sleep later in the night. Try not to have alcohol within 3 hours of bedtime. Instead, have a warm, milky drink or herbal tea in the evening.

It is important to stay adequately hydrated; however, people are often woken up by their bladders through the night. Try to spread fluid intake out during the day and

don't have too much to drink just before bed. Too much food or fluid, especially late at night, can interrupt your sleep patterns.

Improving sleep can improve abdominal symptoms ('rest and digest'). There is a lack of evidence about specific foods that are good for sleep. However, eating a well-balanced diet during the day can help contribute to a good night's sleep. Try to include food from all the food groups every day and reduce your intake of foods high in sugar and saturated fats. Feeling hungry or thirsty at bedtime can distract you from falling asleep and can wake you up during the night. Research has found that food intake is increased when sleep is restricted.

When to seek more support

Speak to your clinician or doctor if you notice that insomnia lasts more than a few nights and/or if it starts to affect your daily routine, tasks and activities. You should also talk to them if you notice the following:

- Sleepiness during your waking hours that is hard to resist.
- Brief instances where you fall asleep during waking hours (these are known as microsleeps), especially if they happen while you're working or driving.
- If you have other conditions, including mental health conditions or concerns, that affect how much or how well you sleep. This could be difficulty breathing, recurrent nightmares, or other things.

Resources:

Sleep problems/mental wellbeing: <https://www.nhs.uk/mental-health/self-help/guides-tools-and-activities/mental-wellbeing-audio-guides/>

Pain good sleep guide: <https://www.northerncarealliance.nhs.uk/patient-information/patient-leaflets/pain-service-good-sleep-guide>

Pain service/ relaxation: <https://www.northerncarealliance.nhs.uk/patient-information/patient-leaflets/pain-service-relaxation-what-it-and-why-it-important>

Sleep better sleep guide: <https://www.sleepschool.org/>

Hyperarousal: <https://sleephub.com.au/what-is-hyperarousal/>

<https://my.clevelandclinic.org/health/symptoms/hyperarousal>

Occupational Therapy sleep advice: <https://www.rcot.co.uk/learn-about-occupational-therapy/ot-advice/lift-up/sleep>

Sleep Charity: <https://thesleepcharity.org.uk/information-support/adults/>

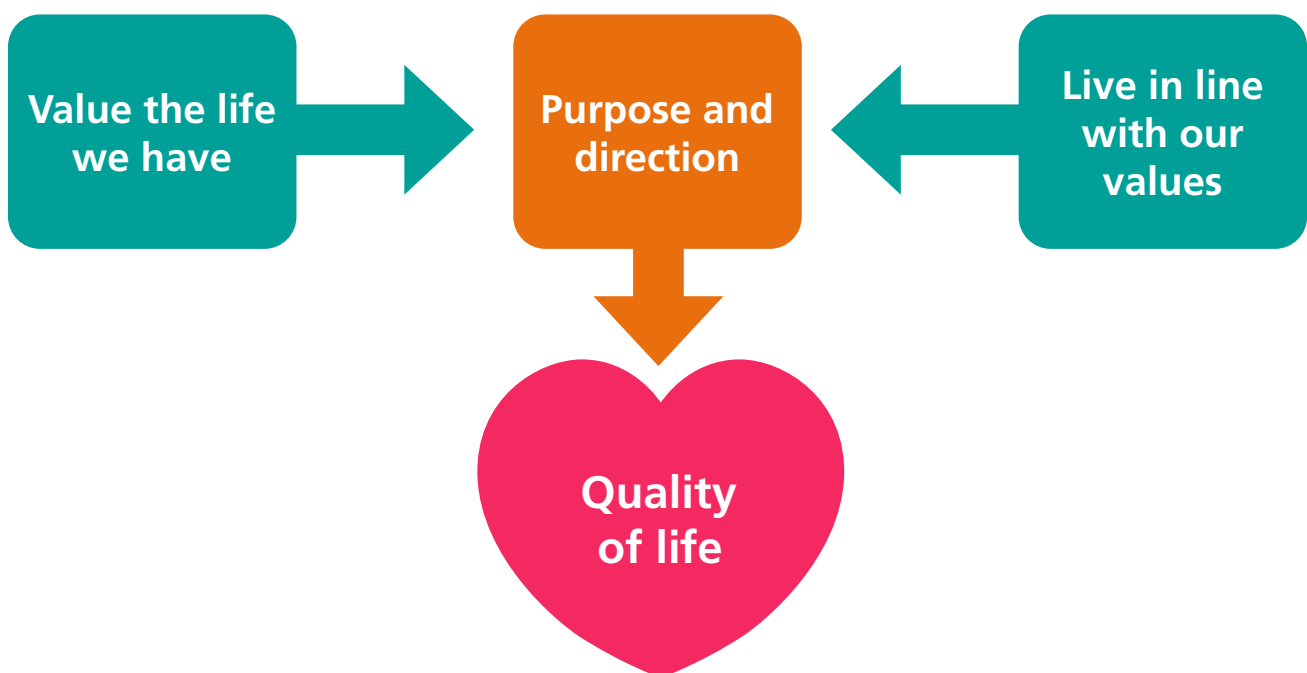
Week 7 Moving Forward

What matters to you?

Being aware of what matters to you is important to help live a meaningful life. It may be that you have to consider doing things differently to how you've done them previously. By recognising what is most important to you and thinking about how you can do things differently to still meet your values can help with your general wellbeing and resilience.



Acceptance and Commitment Therapy (ACT)



Accepting where you are now and learning to live with the symptoms that you are experiencing can be one of the biggest challenges. Being able to accept that life may be different, but still having value and purpose can lead to having a good quality of life. It can take time to process and get to this stage. For example, relationships with family and friends, career progression and employment, health and physical wellbeing.

Thinking about these values and completing this exercise may provide you with some clarity and help you think about where to focus the energy that you have.

Trying to maintain that balance between adopting the strategies we include on this course that are designed to help you manage your health, whilst avoiding some of the potentially difficult knock on effects is really challenging. The best advice we can give here is to be realistic about what you can achieve and manage and not set yourself goals or standards that feel too much. Not all the strategies we suggest will be helpful or even practical to adopt in their entirety, we want you to think about what is do-able for you, to help you maintain that balance point as best you can without feeling like you're either needing to make too much effort, or leaving yourself at too much risk of loss. This will take time to figure out, but it could be something to discuss further when we see you in clinic.

Activity

Have a think about what matters the most to you and what you value. Have a go at writing these down - 1 being the most important.

- 1.
- 2.
- 3.
- 4.
- 5.

Work, education and benefits

Decisions regarding work and returning to education are very individual, we are here to support you in your one-to-one sessions with either remaining in education or work, returning to education or work, or support you in any caring responsibilities you may have. We can offer advice on benefits you maybe entitled to. We also recommend if completing any requests for benefits to contact Welfare Rights for advice prior to submitting any claims.



Resources:

Places to seek advice and support about getting back to work:

- Line manager or supervisor
- Occupational Health and/or Human Resources
- Your union, if you are a member
- Citizens Advice Leeds www.citizensadviceleeds.org
- Welfare Rights Leeds City Council: 0113 376 0452 welfare.rights@leeds.gov.uk
- Gov.uk website – search for the information you need
- Acas (Advisory, Conciliation and Arbitration Service) employment advice service www.acas.org.uk
- Federation of Small Businesses www.fsb.org.uk
- Equality Advisory and Support Service (EASS) www.equalityadvisoryservice.com

Monitoring your health and taking control

What works for you to monitor your health and progress is very individual, some examples of ways to monitor your health and progress are:

- Technology – i.e. smart watches / fitbit
- Gratitude journals - to track your progress and reflect on your journey
- Diaries – i.e. activity diaries
- Friends, family and colleagues may notice and feedback changes
- Returning to hobbies and interests
- Spending time to recognise how your body feels
- Borg Scale
- Goal setting

Goals

Goals give you a sense of structure, purpose and positive reinforcement. They can help you feel more motivated despite the limitations that you are experiencing.



Goals can be as small as you want them to be, the smaller the better! You can set goals for the next hour, afternoon, day, week or month. Break each goal down into the smallest micro steps. A sense of achievement can be gained by completing the smallest goals. This helps build up confidence and creates momentum.

Goal example:

My goal/aim/focus	Benefits of goal	What/when/how
Get washed and dressed by 11:30am. Make a cuppa and listen to my favourite radio show at noon.	Helps my mood and routine, gives me structure. I enjoy listening to the speakers on the show.	Set a final alarm for 11:15am. Hang out the next day's clothes on an evening.
Have a 10 minute telephone conversation with my sister every week.	I won't feel guilty declining her calls anymore. She knows my situation. Enjoyed speaking to her previously.	Ask my sister to set a regular 10-15 minute weekly time to chat. Take it in turns to call each other.
Message one friend every week and meet them for a cuppa in one month.	Messaging friends will help me to build up to meeting them.	Have a set day/time to message. Give it a fair try to see if it helps.
Do my active rest for 45 minutes every day.	Helps me recharge my emotional and physical energy battery.	Communicate to my family what I'm doing and why.

Activity

Set one goal now in preparation for your one to one appointment with your clinician:

Setting your goals:

Goal:

What does this goal mean to me?

How close am I to meeting this goal currently?

Half way

Goal not met all **0 1 2 3 4 5 6 7 8 9 10** Goal reached

Review of goals:

How close am I to meeting this goal currently?

Half way

Goal not met all **0 1 2 3 4 5 6 7 8 9 10** Goal reached

How close am I to meeting this goal currently?

Half way

Goal not met all **0 1 2 3 4 5 6 7 8 9 10** Goal reached

Dealing with setbacks

Knowing that you are likely to have setbacks at times and planning how you will deal with them often makes them less scary when they happen. Accepting that you might need to pace or plan differently for a while should help you cope should things start to worsen.

The first place to start is knowing what's most helpful to you, and how you use these techniques to help you maintain progress. This could be breathing exercises, going to bed earlier, talking to someone about how you feel, or a combination of things. Identifying which 'tools' are beneficial to you and using them regularly, even when you are feeling reasonably well, means you can more readily select the right tool for the job when it feels like things are going wrong.

Seeking support can make setbacks much more manageable so if you feel able to do this we would advise you to do so. If you would go to friends or family, maybe think about talking to them about the fact you might call on them should you have a setback. Some people will feel so much better knowing there might be something they can do to help you.

Activity

What's in your toolbox to support you in managing your setbacks?

Appendix

- Additional activity diaries
- Additional goal logs
- Outcome measures log
- Notes pages

Activity and Fatigue Diary

Day	6-9am		9-12pm		12-3pm		3-6pm		6pm - bedtime		Sleep quality/hrs (Sun night)
	Activity	Score	Activity	Score	Activity	Score	Activity	Score	Activity	Score	
<i>Mon</i>											(Mon night)
<i>Tues</i>											(Tues night)
<i>Wed</i>											(Wed night)
<i>Thurs</i>											(Thurs night)
<i>Fri</i>											(Fri night)
<i>Sat</i>											(Sat night)
<i>Sun</i>											(Sun night)

Activity and Fatigue Diary

Day	6-9am		9-12pm		12-3pm		3-6pm		6pm - bedtime		Sleep quality/hrs (Sun night)
	Activity	Score	Activity	Score	Activity	Score	Activity	Score	Activity	Score	
<i>Mon</i>											(Sun night)
<i>Tues</i>											(Mon night)
<i>Wed</i>											(Tues night)
<i>Thurs</i>											(Wed night)
<i>Fri</i>											(Thurs night)
<i>Sat</i>											(Fri night)
<i>Sun</i>											(Sat night)

Activity

Set one goal now in preparation for your one to one appointment with your clinician:

Setting your goals:

Goal:

What does this goal mean to me?

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

 Goal reached

Review of goals:

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

 Goal reached

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

 Goal reached

Activity

Set one goal now in preparation for your one to one appointment with your clinician:

Setting your goals:

Goal:

What does this goal mean to me?

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

 Goal reached

Review of goals:

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

 Goal reached

How close am I to meeting this goal currently?

Half way

Goal not met all

0	1	2	3	4	5	6	7	8	9	10
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 Goal reached

Notes

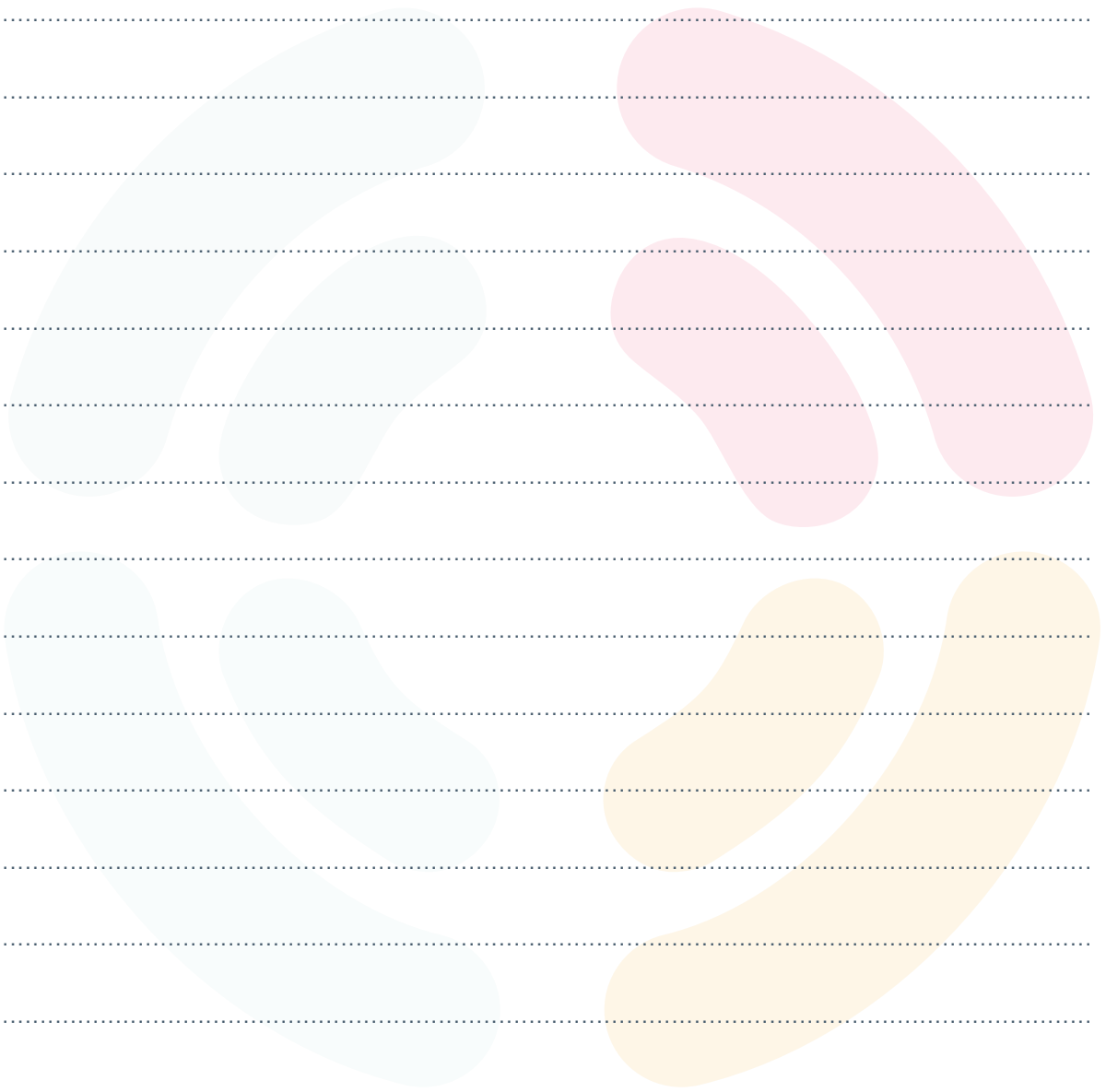
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Help us get it right

If you have a complaint, concern, comment or compliment please let us know by speaking to a member of our staff. We learn from your feedback and use the information to improve and develop our services.

If you would like to talk to someone outside the service contact the **Patient Experience Team** on **0113 220 8585**, Monday to Friday 9:30am-4:30pm or email lcht.lch.pet@nhs.net

We can make this information available in Braille, large print, audio or other languages on request.



Leeds Community Healthcare Trust

**MULTISYSTEM
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