



Fatigue and auto-immune conditions

Welcome to our fatigue management course. We will work through this workbook over 6 sessions. Each session will have homework activities to help you learn and use the strategies outlined in the workbook. Give them a go, at whatever level you can manage.

Session 1: What is fatigue?

The NHS defines fatigue as a persistent, overwhelming tiredness that's not relieved by rest, making it hard to function and perform daily tasks.

Fatigue is common in many auto-immune conditions, with up to 80% (4 out of 5) people with rheumatoid arthritis (RA) experiencing some fatigue in the first year of disease. 20-40% (1-2 in 5) people will have ongoing fatigue that effects everyday life.

It presents differently from person to person and from day to day – common symptoms include:

- **Physical symptoms:** Waking up exhausted (un-refreshing sleep), heavy/weak limbs, headaches, stomach ache/body aches
- **Cognitive symptoms:** Poor concentration, forgetfulness, brain fog
- **Emotional / sensory symptoms:** Fidgeting or feeling irritable, feeling anxious, over-emotional or overwhelmed, lacking motivation

The first step to managing fatigue is being able to recognise the signs.

Have you noticed that you start to think, feel or behave differently when you are tired?

It may be useful to ask a friend or family member if they notice any changes in your behaviour when becoming increasingly tired?

Recognising triggers – what type of activity makes you most tired?

Everything you do is an activity.

- **Physical** activities are things like walking or everyday functional activities like getting out of bed, climbing the stairs, washing, shopping.
- **Cognitive** activities can include things like concentrating on reading, writing, typing or texting; giving instructions or teaching others, watching TV, playing video or online games.
- **Social** activities include things like talking to friends, going to a party or restaurant, eating with family.
- **Emotional** activities could involve discussing something that is worrying you, supporting others, looking at the news/social media.

Most activities are a mix of the categories listed above but it can be helpful to categorise them when thinking about what types of activity you find the most demanding. Remember that what you find demanding is unique to you (e.g. some people find reading a book a relaxing and

enjoyable hobby, while for others it is challenging task). **Activities that we find demanding and which lead to an increase in fatigue symptoms are known as 'triggers'.**

Other common triggers are:

- **Doing too many activities together** – common examples include:
 - doing too many activities without a break, then crashing;
 - doing too much in the morning, then crashing in the afternoon;
 - doing too many activities at the beginning of the week;
 - doing too much at the end of the week in order to keep weekends free.
- **Doing too little physical activity** – leading to de-conditioning. Weak muscles take more energy to move than stronger muscles do.
- **Poor sleep.**
- **Poor diet** – particularly an increase in sugary or highly processed foods.
- **Being in a busy environment** (too much for the brain to process).
- **Stressful or emotionally demanding events.**

Session 1 homework – identifying triggers (activities)

- ✓ Keep a diary of activities (include sleep patterns, mealtimes, daily activities, rests).
- ✓ Mark each activity as **low**, **medium** or **high** energy use.
- ✓ We will be looking at identifying what your triggers are in the next session.
- ✓ If you find this exercise too difficult, write a list of everyday activities and write down how tiring each one is on a scale of 0-10 (with 0 being not tiring at all and 10 being extremely tiring).

Session 2: Exploring your triggers in more detail (sleep and diet)

Sleep

Getting a good night's sleep is crucial to feeling more alert during the day. For ideas on improving sleep: www.nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-fall-asleep-faster-and-sleep-better,

If you struggle with getting to sleep due to a racing mind, it may be worth keeping a worry journal next to your bed or try using sleep apps. Free apps that can help with sleep include:

- Sleep sounds (rain, ocean waves etc).
- White Noise Lite – 50 pre-programmed sounds (has a timer to switch off).
- Meditation apps. Headspace offer a free trial.

All apps are available for Apple or Android.

If your sleep problems are long-standing and you feel you have got into a pattern of not sleeping, you can get a referral from your GP for cognitive behavioural therapy (CBT) or you can self-refer to Talking Therapies. If you live in Reading the self-referral link is:

www.talkingtherapies.berkshirehealthcare.nhs.uk

If you are not sleeping due to pain, please see your GP for pain management advice.

Relaxation exercises such as diaphragmatic breathing or 5 finger breathing may also help – see separate leaflets or view these videos from other NHS trusts:

<https://www.facebook.com/watch/?v=2142964259184058>

<https://www.youtube.com/watch?v=Bz7WZ5jS19I>.

Diet

Foods like sweets, white pasta/bread/rice and most cereals are fast release carbohydrates. This means that they may cause an initial increase in energy, but this is followed by a fall in energy 1-3 hours later.

Fruits, vegetables and wholegrain pasta/bread/rice are slow release carbohydrates. The fibre in these foods helps the body to process the natural sugar these food contain and release the energy slowly to maintain your energy levels for longer.

For more information on a balanced diet of slow releasing carbohydrates and proteins (dairy, fish and meat), see the National Rheumatoid Arthritis website (www.nras.org.uk) or their posts on YouTube on diet and Arthritis.

Session 2 homework – continue with your activity diary to recognise triggers with a focus on sleep and diet

- ✓ Write down when you slept and any breaks in sleep, with the reason for not being able to sleep.
- ✓ Write down what you ate at each meal and any snacks. Write down any changes in energy levels that you notice in the next 4 hours after eating.

Session 3: Pacing (planning)

A trigger many people have is doing too much or pushing through fatigue to try to get a task done. This is called 'boom' behaviour. It is usually followed by you having to stop and rest or sleep (known as 'bust').

It can be frustrating and upsetting not being able to do the things you want to do. Everyday life often pushes us to try to do too much. However, over time, '*boom and bust*' can lead to you feeling more exhausted. A way of managing 'boom and bust' is to use pacing.

Pacing

Is made of up of 3 basic steps to help achieve continuous energy levels throughout the day.

- 1) **Planning activities to ensure a balance of activities over the day and week.**
- 2) **Resting enough to recharge your energy resources.**
- 3) **Adapting activities to reduce the energy needed to complete the activity.**

Planning

This involves thinking about all the activities you do on a daily or weekly basis. Ask yourself the following for each task:

- If I do this task, will it increase my fatigue symptoms?
- Is this task essential or important?
- Can I delegate this task to someone else?
- Can I adapt this task to make it less tiring (Session 5 covers this in detail).
- Can I do this task less often?
- Do I enjoy this task? It is important to include activities that you enjoy – enjoyable tasks boost our mood and energy.

When you are unsure how you are going to feel, it is easy to stop doing activities that are important to you. This can lead to negative thoughts such as "I should be able to do this, I'm useless". It is important to:

- Acknowledge that you may not be able to do as much as you did before, but focus on what you can do. For example, can you still go for a walk but for a shorter time or at a slower pace?
- Try to focus on finding solutions. For example, I cannot physically manage the shopping but I can shop online.
- Try to think what you would say to a close friend or relative who was in your position to give them encouragement and apply this to yourself.
- Plan time to do activities you enjoy as well as work or daily living activities you have to do.
- Recognise when you do things well.
- Have 'Can do days' – these are days when you cannot do your normal activities but still achieve something by having a list of activities you can get done with only a little effort (e.g. if you are physically exhausted, can you sit up in bed and use your laptop or phone to get the dentist booked or check your emails?).
- Try to include a little gentle activity or movement, even on bad days.

Establishing a baseline

- Your baseline is the amount of activity you can do without making symptoms worse. You should be getting an idea of this from your diaries.
- If you are unsure of how much you can do of any task, start by doing less than you think you are able to do.
- Set a limit (e.g. 10 minutes) and stick to it. This might mean doing less on good days and a bit more on worse days so that activity levels are more consistent. For example, if you can walk for 30 minutes on a good day but only 5 minutes on a bad day, your baseline is 5 minutes. You could do an extra walk on a good day but stick to the 5 minutes and see if you can do it more regularly.

Session 3 homework – planning activity

- ✓ Choose 3 activities and complete the planning exercise for each task.
- ✓ For 2 activities that are essential for you to do and cannot be delegated, think about where your baseline for each activity is. Try completing each activity for that length of time. **Do not complete for longer if you are having a good day.**
- ✓ Identify one activity that you enjoy and make sure you plan this into your week.

Session 4: Pacing (rest)

Rest

It can sometimes be helpful to think of fatigue like a battery. Some factors mean our battery isn't as big as it previously was (e.g. poor sleep, poor diet, illness) or that it drains more quickly (e.g. some medications can make you tired, being de-conditioned or overweight means our bodies have to work harder). If the battery gets too empty, it stops and takes a long time to re-charge. If you stop and recharge before the battery is empty, it is much easier to top up the energy levels.

1) Adequate rest.

It is important to build rest breaks into your day and take breaks before you even notice the signs of fatigue increasing.

Top tips for resting:

- Schedule short 10-15 rest breaks morning and afternoon and stick to them.
- Set alarms on your phone, watch or computer to remind you to rest.
- Try not to nap during the rest breaks, as this can affect sleep.

2) How to rest

- Make sure you have a quiet place with few or no distractions (noise cancelling headphones can be useful).
- Match your rest to the preceding task. For example, if you have been doing a physical task, make sure you sit down for your rest break. Or if you have been studying or working at a computer, take a short walk break in the fresh air.
- Find activities that help **you** relax (e.g. listening to music). Bear in mind what is relaxing for some people, isn't for others.
- Practising relaxation techniques may be beneficial in finding a way to totally relax in your breaks. Deep breathing (5 finger breathing or diaphragmatic breathing – see page 3), Tai Chi and mindfulness are examples of relaxing techniques.

There are a number of free apps available, such as:

- Headspace – run a free trial for a week (then a monthly fee if it works for you).
- Apple also do their own free meditation app Calm (go to the iTunes store) www.calm.com.

3) DO NOT FEEL GUILTY for taking rests

Feeling guilty or lazy is often a barrier to resting sufficiently. Remember, that employers have a legal duty to make 'reasonable adjustments' for employees with long-term health conditions. Changes in working schedules to include breaks and provision of a quiet area for breaks are examples of 'reasonable adjustments'.

Session 4 homework - planning your relaxation times

- ✓ Try to identify two things that you find relaxing.
- ✓ At work or during your normal day, make sure you include a morning and afternoon 10-15 minute rest break. What did you do to relax during this break?
- ✓ Document how you feel following the break and what you were able to get done for the next two hours following the break.

Session 5: Pacing (activity analysis and adaptation)

Learning to simplify activities can be really useful for saving energy. There are many ways to reduce the demands of an activity. Below are a few ideas, but more information is available at:

www.nras.org.uk and www.papaa.org.uk – both have leaflets on fatigue

www.versusarthritis.org – has section on useful gadgets and home adaptations.

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

Reducing physical demands

1) Reduce the strength needed:

- Use manual aids, e.g. wider grip handles (on pens, toothbrushes, cutlery, kitchen utensils) so you don't have to hold as tightly. Use electric items (e.g. can/jar openers, food processors to chop). Use sprung scissors to cut open packets. Lever taps rather than knobs (adaptors can be fitted).
- Use lighter materials (e.g. lightweight cutlery, travel size kettle, a washing bag rather than a basket. Use a cooking basket within a pan or a plastic steamer for cooking vegetables).
- Add wheels to objects (e.g. use a shopping trolley rather than a carrier bag).
- Do you need to stand? Use a perch stool at a worktop or in the shower. Sit at a table in a chair with a supportive back and leg support when preparing food.
- Use non-slip matting to help stabilise plates or give a better grip.
- If you use a keyboard a lot, try voice activated software. AbilityNet can help with advice to you or your employer.

2) Improve your body position or posture:

- Lift with both arms and slightly bend your legs, avoiding strain on your back. Keep the load close to your body.
- Slide items rather than lifting.
- Try to avoid bending or reaching too much. Arrange commonly used items on a worktop or in a cupboard within easy reach. Use long-handled dustpans, shoe horns, sponges (to wash your back or feet).
- Push objects with your body (use your legs rather than arms or use your hip or shoulder instead of your hand to push a door open or close a drawer).
- Use a bath/shower board to sit to use an over the bath shower.

3) Break tasks into smaller steps:

- Prepare a meal over the day – e.g. in the morning, decide what you are having for dinner and get items out of the freezer, chop vegetables at lunchtime, cook in the evening (or cook at lunch and re-heat in the evening).
- Plan rest breaks in a task that you know exhausts you. Take a rest as soon as you feel symptoms of fatigue coming on.

4) Reduce the number of steps in a task:

- For example, use a towelling robe to dry rather than using a towel then putting on a dressing gown.
- Use a sheet between the duvet and yourself to reduce frequent changing/washing of the duvet cover.

Reducing cognitive demands

- **Use checklists** – e.g. shopping lists, to do lists, daily planners to help remind you what you need to do and so your brain doesn't have to hold things in your working memory.
- **Use visual reminders** – e.g. flow diagrams for work tasks rather than written steps.
- **Create folders** on your phone or manually so you don't have to look for commonly used information (e.g. passwords, addresses etc).
- **De-clutter your workspace** – physical clutter leads to mental micro-decisions.
- Plan **demanding tasks for quieter times of day.**
- **Split work so you change tasks frequently** – if you have been on a cognitive task for 30 minutes, change to a physical task or social task (e.g. get a cup of tea, or make a phone call).
- **Do one task at a time** (avoid multi-tasking). Avoid checking your phone or emails as a 'quick check' burns more brain power than you think.
- **Keep consistent routines, schedules and environments** – a familiar thing is much easier to remember.

Reducing sensory demands

- Noise control – use noise cancelling headphones or earplugs to reduce distractions.
- Ask to sit in a quieter area (away from printers, doors, communal spaces).
- Close your office door (if you have one) or use desk dividers if appropriate.
- Use soft furnishings/plants to absorb noise (if allowed).
- Turn off email and message notifications to avoid distractions.
- Use visual cues like a 'do not disturb' sign.
- Light/screen adjustments – reduce screen glare with filters or reposition your monitor.
- Adjust overhead lighting to ensure you can see well. Use a desk lamp for softer brightness, if needed.
- Have screen breaks – use the 20-20-20 rule. Every 20 minutes, look away from your screen to 20 feet away, for 20 seconds.
- Adjust the temperature – a comfortable temperature is usually 20-24 degrees.

Reducing emotional demands

- **Modify expectations** – set realistic goals, avoid perfectionism.
- **Use support systems** – share the workload, ask for help, talk through stressors.
- **Change the context** – complete tasks in a calm environment (see above).
- **Incorporate relaxation techniques** before, during and after tasks (as needed).
- **Positive reinforcement** – focus on progress, not just completion.

Example: Cooking a meal:

- **Physical** – sit while chopping (or use frozen/pre-sliced vegetables), use lightweight cookware (use microwave, air-fryer rather than an oven), prepare the meal over a day. Use ready-meals on bad days. Use a trolley to transfer meals to the table.
- **Emotional** – choose simple recipes to avoid feeling overwhelmed, avoid cooking big family meals until you feel less fatigued.
- **Cognitive** – use a recipe card with step by step instructions, use a timer for each stage, reduce distractions in the kitchen. (e.g. noise/other people), stick to familiar recipes.

Session 6: Increasing activity

Once you have established a manageable and stable routine, you can start thinking about building up your activity again.

Golden rules:

- Stability before progress – only increase activities when you have at least 2 stable weeks.
- Never push through fatigue.
- One change at a time – use your priorities/goals to decide on the activity you want to increase first.
- Don't forget to look at your overall activity when starting to build up, e.g. if you have a work deadline that is cognitively and emotionally draining, this might not be a good time to start back at the gym.
- Remember – physical activity includes daily functional tasks not just exercise, so be aware of your daily tasks when adding in more exercise.
- If you are increasing physical activity, start with an enjoyable activity. It is normal for muscles to ache and this should settle as your body adjusts. If muscles remain sore over a day later, you need to reduce the activity. You can increase the activity by weight (how much you are carrying/lifting), length of time or frequency of activity. **It is better to build time or frequency before intensity** (e.g. increase how often you are walking, before trying to increase the speed or carrying a rucksack whilst walking). **START LOW, GO SLOW!!**
- If you are increasing a cognitive activity, it may be helpful to start by trying to increase the length of time you can concentrate. Set a timer to ensure you stop on time. Maintain the changes to the environment, e.g. noise reduction. Once you can do the task for the length of time you want, e.g. an hour, slowly use less cognitive prompts such as lists. Practise trying to remember or summarise information you have just read (either verbally to someone else or make bullet point notes).

GOOD LUCK and don't forget to ask us if there is anything you don't understand in the sessions.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Rheumatology (Occupational Therapy), January 2026

Next review due: January 2028