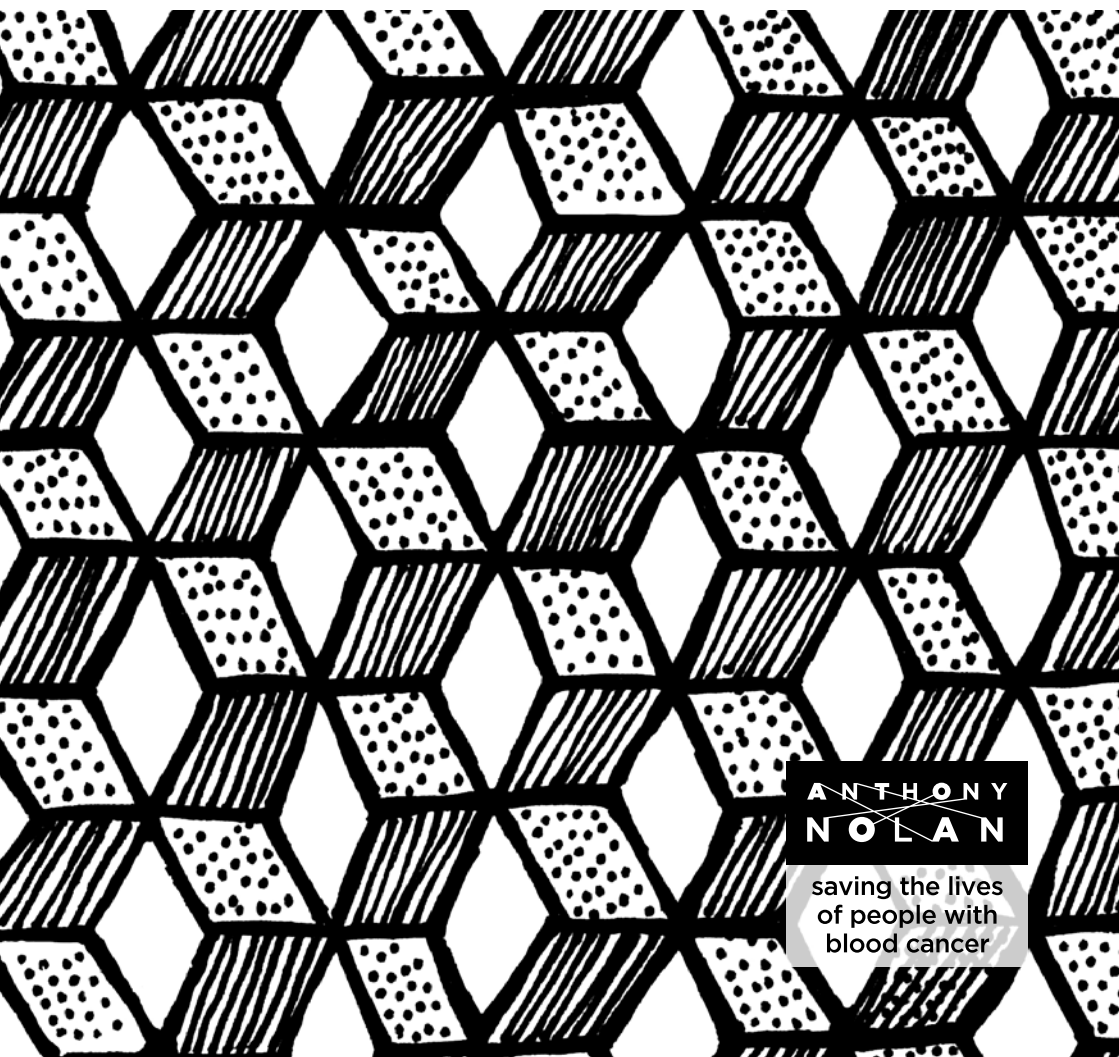
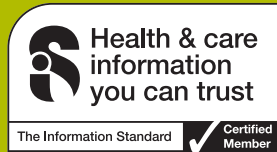


# MANAGING FATIGUE AFTER A STEM CELL TRANSPLANT



**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer



**Patient information awards**  
Highly commended

At Anthony Nolan we take great care to provide up to date and accurate facts about stem cell transplant. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

#### Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)

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The information contained in this booklet is correct at the time of going to print (June 2019). We plan to review this publication within three years. For updates or the latest information, visit [anthohnolan.org](http://anthohnolan.org)

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# MANAGING FATIGUE AFTER A STEM CELL TRANSPLANT



saving the lives  
of people with  
blood cancer

**ANTHONY NOLAN**  
PATIENT SERVICES

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# WHAT'S IN THIS BOOKLET?

We've put together this booklet to help you manage fatigue during and after a stem cell transplant.

It's been written with guidance and advice from our remarkable patients and healthcare professionals, to help you come to terms with your current situation and what can be done to help.

Your friends and family might also like to read through it to get an understanding of what fatigue is and how they can support you.

If you need to ask us any questions, or you would like some more advice, please get in touch with the Anthony Nolan Patient Services team at: [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org) or **0303 303 0303**

The booklet is decorated with intricate, hand-drawn doodles. When you need a moment of calm, colouring one of them in might help you relax and take your mind off things.

# KEY FACTS

**1** Fatigue is an expected side effect of a stem cell transplant. Up to 80% of patients will experience it in the first few months of recovery, and some for much longer.

**2** Fatigue can be caused by a combination of factors including pre-transplant conditioning therapy, Graft vs Host Disease (GvHD), anaemia (low red blood cells) and your medication.

**3** Fatigue and your mental health are closely linked and can affect each other.

**4** Managing fatigue is a balancing act. Try to not overdo it on a good day but more importantly, try to do a little bit on what might feel like a bad day too.

**5** Keep a diary of your energy levels and activities. It will help you see when fatigue affects you most, so you can plan ahead.

**6** Living a healthy lifestyle that includes a balanced diet, sleeping well and regular exercise will reduce the impact of fatigue and aid your recovery.

**7** If you have any concerns, talk to your medical team. They will be able to alter your medication and give advice on how to manage fatigue.

**8** Make sure your family, friends and employer understand what fatigue is so that they can support you. Fatigue is different to just being tired and needs to be managed appropriately.



When we talk about fatigue, we don't just mean feeling tired after working hard.

Fatigue is when you find it difficult to concentrate and have no energy, even after lots of rest and a good night's sleep. It can make you feel both physically and mentally drained, leaving you with very little motivation. It can be hard to concentrate, even on simple things.

## SIGNS OF FATIGUE

There isn't a standard set of rules that your medical team will use to decide if you have fatigue or not. Everybody's recovery is different, and it will affect them in different ways. This is why it's important to keep your team well informed about how you're feeling. If you have any of the following symptoms, it could be a sign of fatigue:

- Feeling tired regularly, especially when you wake up.
- Needing to nap during the day.
- Trouble sleeping during the night.
- Feeling low or depressed.

## WHEN DOES IT START AND HOW LONG DOES IT LAST?

You might have felt like you had very little energy before your transplant took place. A combination of your blood cancer or blood disorder and how it was treated could have left you feeling constantly tired.

Fatigue can develop at any time after transplant, but most patients start to feel fatigued during pre-transplant conditioning therapy. It usually happens while your blood counts are still low but as they pick up, your energy levels will rise too. You might also notice it when you go home and find you're not able to do your normal day-to-day activities, as you once did.

For some people, fatigue is a short-term effect of treatment that gets better over a few months. Or it might come and go for about six months to a year. Others might recover many years after their transplant, or it may never completely go away. This could mean that you need to make some permanent changes to your lifestyle so that it's easier to come to terms with.

**'I think on balance I will possibly always suffer with fatigue but it's a very small (but not insignificant) price to pay to be back enjoying my life.'**

**Carole**, who had a stem cell transplant in 2014

## IS THERE ANYTHING THAT CAN BE DONE ABOUT IT?

There may be times in your recovery when fatigue is unavoidable, but it's still possible to manage your situation and make the best of the energy you have. This can be done through a combination of medication and practical tips, including those in this booklet.

## WHAT CAUSES FATIGUE AND WHAT HELPS?



There are many potential causes of fatigue, some of which relate to your transplant. But your general health and wellbeing are also factors.

Fatigue tends to be a bigger concern for older patients and those who had a lower level of fitness before their transplant. Your type of blood cancer or blood disorder, and other health concerns, could also affect how fatigued you are.

On the following pages we have outlined the main causes of transplant-related fatigue alongside suggestions that should make it easier to manage. The more common causes are listed first but you may not experience all of them during your recovery.

If you have any concerns relating to fatigue, it's important to talk to your medical team so they can identify what's affecting your energy levels, and how they can help. They may refer you to other healthcare professionals, such as a dietician or physiotherapist, for further advice too.

## CONDITIONING THERAPY

Before your stem cell transplant happened, you will have had a course of treatment known as conditioning therapy that consisted of chemotherapy and possibly radiotherapy. It prepared your body for transplant by removing the cells of your immune system, including those causing your blood cancer or blood disorder. This created enough space in your bone marrow for your donor's cells to engraft and start making new cells.

Conditioning therapy is one of the main causes of fatigue after a transplant. You might find fatigue gets worse while you're having treatment, then passes. It can improve after weeks or months, but for some patients it can go on for a long time, even years.

**'My fatigue set in on about day five of my week of conditioning with chemo. I began to feel like a different person. It wasn't so much tiredness – it felt like my energy had been taken from me.'**

**Peter**, who had a stem cell transplant in 2012

### Why does it cause fatigue?

Conditioning therapy causes your blood cell counts to drop, and they stay low while your new immune system develops. During this time, you will have fewer blood cells that normally transport oxygen around your body, which is needed to release energy.

Radiotherapy can also damage the cells in your gut, making it more difficult to absorb nutrients and release energy from your food.

### What helps?

Unfortunately, conditioning therapy is an essential pre-transplant step so it's difficult to avoid the fatigue it causes. However, improving your general fitness prior to transplant has been shown to reduce the impact fatigue can have post-transplant.



## EATING AND DRINKING

It can take a while to get back to your normal diet after your transplant. You might find you don't have much of an appetite, and it might come and go during the first few months to a year. Certain foods might taste different to how they did before, and you might not like the foods you once did.

Chemotherapy damages the cells in the mucosal lining of your mouth. The skin can break down, which can cause painful ulcers to form inside your mouth and throat. Ulcers may also form further down your digestive tract, which can cause discomfort and make it difficult to eat certain foods. This normally occurs about a week after treatment and should clear up in a week or two.

**'I found myself unable to eat much, food had a metallic taste and I didn't enjoy an alcoholic drink. Once I came off my immune suppressant, a month or so later, things gradually returned to normal.'**

*Dave, who had a stem cell transplant in 2014*

### Why does it cause fatigue?

Food is the body's only fuel source so if eating certain foods becomes difficult, it could leave you feeling tired and low on energy. The body needs plenty of fluid and various vitamins and minerals to release the energy stored in food effectively.

### What helps?

- Three full size meals a day can feel daunting so try eating smaller portions more often.
- During your early recovery, focus on foods that you want to eat rather than what you think is the healthiest option. It's more important to get the energy you need than anything else at this stage.
- Soft foods like soups, mashed potato, and ice cream are easier to swallow if you have a sore mouth. Your hospital may also give you nutritional drinks to help.
- Ice lollies or ice pops can help relieve a sore mouth and adds to your fluid intake.
- Try to drink up to two litres of liquid each day. Ideally this should be non-caffeinated, but you can have weak tea or coffee alongside water, juice or cordial. You might find it easier to sip water throughout the whole day.
- Ask to speak to a dietician at your hospital, they will be able to give you further advice.

## SICKNESS AND DIARRHOEA

It's common to feel sick and be sick after your transplant because of your treatment, medication, a possible infection or GvHD. Nausea normally only lasts a week or two for most people. For the same reasons you may also experience diarrhoea.

### **Why does it cause fatigue?**

Prolonged sickness and diarrhoea can make it difficult to get the energy you need from food and potentially lead to weight loss. The discomfort they cause can also affect your sleep and mental wellbeing.

### **What helps?**

- Your medical team can give you anti-emetic (stops you feeling sick) and/or anti-diarrhoea medication.
- Identify the foods that make your symptoms worse and remove them from your diet.
- Replace lost fluids by drinking water regularly. Isotonic drinks or sachets of oral rehydration salts replace lost salts and sugars (electrolytes) that your cells need to stay healthy.

## ANAEMIA

Anaemia is caused by a low number of functioning red blood cells. Almost all stem cell transplant patients will have anaemia at some point in their treatment, and it's most likely to happen early on. This is because many blood cancers and blood disorders affect your body's ability to make blood cells properly. The conditioning therapy you had pre-transplant will also reduce the number of blood cells you make.

Anaemia can be caused by other factors too, such as vitamin deficiencies. Low levels of vitamin B12 or folate acid can both lead to anaemia post-transplant.

### **Why does it cause fatigue?**

Your red blood cells deliver oxygen from the lungs to all other cells in the body, where it's used to release energy. Red blood cells carry oxygen on a protein called haemoglobin and if you don't have enough of it, it can leave you feeling tired or short of breath.

### **What helps?**

Anaemia treatment will vary depending on what is causing it, so please check with your medical team before taking anything yourself. They will check your haemoglobin level regularly and monitor your other symptoms to decide the best treatment. It could be one (or more) of the following:

- Vitamin supplement tablets.
- Erythropoietin (EPO) injection – a hormone which stimulates your body to make more red blood cells.
- A blood transfusion.

## GvHD

After your transplant, there are still small differences between your donor's stem cells and your own cells. This means your new immune system may harm other cells in your body because it sees them as 'different'.

Some Graft versus Host Disease (GvHD) can be a good thing because it shows your immune system is active and can attack any remaining or returning disease. However, too much GvHD can cause side effects. GvHD could potentially happen anywhere in your body but often affects the skin, digestive tract and liver.

### **Why does it cause fatigue?**

If you have GvHD in parts of your digestive tract, it can make eating and drinking difficult but can also cause sickness and diarrhoea.

Coping with GvHD can be a painful and stressful process, and the discomfort could affect your sleep and mental wellbeing.

### **What helps?**

Your medical team will assess your GvHD and decide on the best medication for you. Generally, GvHD is treated using steroids and immune suppressants. However other treatments, such as anti-sickness or diarrhoea drugs, may also be given to treat the symptoms GvHD causes.

More information on GvHD is available in our *Essential guide to GvHD* booklet.

## PROBLEMS SLEEPING

Recovering from your stem cell transplant will be both physically and emotionally demanding. There may be times when you find sleep difficult through a combination of feeling unwell, stress and anxiety.

It's common to have problems sleeping while you're in hospital. It might be noisy or too light on the ward, or your medical team may need to wake you to check your blood pressure, pulse and temperature in the night. It can also be difficult to get used to a new environment and routine when you return home after treatment.

You should find that sleep problems get better over the first year, but some people still struggle to get a good night's sleep for longer.

### **Why does it cause fatigue?**

The quality of your sleep is as important as the amount of sleep you have. Having long naps during the day can disrupt your sleep/wake cycle and make it more difficult to fall asleep at night.

If your medications make you drowsy and you fall asleep during the day, this will affect your quality of sleep overnight.

### **What helps?**

- General tips for improving your quality of sleep are available on p34.
- A type of counselling called cognitive behavioural therapy (CBT) can be used to treat sleep problems in people with cancer. More information about counselling can be found in our *Your Mental Health and Stem Cell Transplant* booklet.
- If you're really struggling with sleep, your medical team may offer you mild sleeping medication to help.

## OTHER FACTORS

### **Hormone changes**

Depending on your situation, your stem cell transplant could lower the levels of certain hormones in your body, which can cause fatigue. This includes thyroid hormones, Vitamin D, and oestrogen and testosterone for women and men respectively. Your medical team will offer hormone replacement therapy (HRT) if you need it.

### **Medication**

During your recovery, it's likely that you will need to take lots of different medications. Some of them could make you feel drowsy and the effect could be greater when they are taken in combination with others.

### **Pain and discomfort**

You shouldn't have to put up with pain because it will have a negative effect on your mood, activity level and sleep.

If you have any concerns about the issues raised here, you should talk to your medical team. They will be able to change either the dose or type of medications you are taking in order to make your symptoms more manageable.



There may be times in your recovery when fatigue is unavoidable, but it's still possible to take control of your situation and make the best of the energy you have.

## MANAGE YOUR ENERGY LEVELS

Many patients find that their energy levels go through highs and lows during the day. It's very easy to overdo it when you get up in the morning and feel full of energy, only to need a nap in the afternoon. If you get into the habit of listening to your body and know how you're likely to react to certain activities, it will become easier to manage your fatigue.

Ask your GP, or medical team, to refer you to an occupational therapist who can help you plan your daily activities and maximise your energy levels and rest periods.

**'Everybody is different and there's no right or wrong for how much energy you should or shouldn't have. Listen to your body. Do the things you want to do if you feel able to. If you feel like your body needs to rest, then sit and rest.'**

**Mandy**, Bone Marrow Transplant  
Nurse Coordinator

## PACE YOURSELF

Pacing is a way of managing your activities throughout the day. This will help make the most of the energy you have and stop you doing too much.

Try to avoid getting into a routine where your energy levels rise and fall throughout the day. Decide when it's best to stop and rest – be flexible and understand your limits.

## PLAN AHEAD

Write a list of the things you want to do each day. Make sure you prioritise the things you either really enjoy doing or you really need to do. It can be very frustrating to think that you've wasted your energy and had to miss out on something important to you.

Even if you are having a really bad day, try to do at least one thing. It can be really difficult but achieving something will make you feel more positive and may lift your mood.

## LITTLE AND OFTEN

Break down your tasks into small and manageable goals, and make sure you get some rest in between. This will help top up your energy levels regularly and reduce the risk of becoming exhausted.

## KEEP A DIARY

You could start by keeping a daily diary for a week. Note down when you sleep, rest and the activities you're doing. Also jot down how tired you feel and the times you feel at your best. We have put together a fatigue diary on p52 that you can photocopy and use yourself.

## SET YOURSELF GOALS

It can help to set achievable goals that can also be expanded over time. For example, walking to the end of your street, then into town or for a length of time you set yourself. When you reach your targets, it will help you feel in control and that you're making progress in your recovery.

**'My dad suggested I write a diary. Not of how tired I was each day and when, but of my mini achievements that day. It might be really silly things, but as the weeks progressed they became more substantial and I could see a way out!'**

**Emma**, who has received two stem cell transplants

The Anthony Nolan **My Transplant Tracker app** allows you to set these goals and monitor your progress each week. It can be downloaded for free from the Apple and Google Play stores.

## PHYSICAL ACTIVITY AND EXERCISE

Exercise may feel like the last thing you want to do, but it can help reduce fatigue and improve physical strength. You will find that your fitness, endurance and muscle strength has reduced during your treatment. Keeping active and slowly building up towards structured exercise will be an important part of your recovery.

Getting plenty of exercise and fresh air will also release hormones called endorphins. They act as ‘feel good’ signals in your body that can lift your mood and reduce feelings of stress and anxiety.

### WHERE DO I BEGIN?

If your medical team agrees, you should be able to try a few very simple exercises in your hospital bed. If your hospital has a physiotherapist, they can give you some suitable exercises and stretches. As your recovery continues, your physio will work with you to increase your physical activity and progress your exercise programme.

Focus on maintaining functional movement to begin with, like walking and moving regularly, building up gradually. You will probably find it more manageable to break down activities into small chunks with some rest in between.

If you're really struggling with fatigue, or having a particularly bad day, physical activity may seem daunting. Sometimes even light physical activity can be a real challenge, but it's important to still do something and it could help you feel better. It might be as simple as moving regularly, aiming to break up long periods of sitting or lying down by getting out of bed, having a wash and moving around indoors.

**‘After my transplant I was very, very weak. I couldn’t get up the stairs without being really out of breath. As part of my recovery I was receiving some physiotherapy, and those daily exercises helped get some movement back in my routine.’**

**Ashling**, who had a transplant in 2012

## WHAT TYPE OF PHYSICAL ACTIVITY SHOULD I DO?

Physical activity can include exercises as part of a home or gym programme, playing organised sport or simply doing tasks around the house or garden. You don't have to join a gym or an exercise class if you don't want to. It's best to build physical activity into your everyday routine. It's often easier to stick to something you enjoy, that doesn't need much effort or planning.

As recovery progresses, a structured exercise programme should cover four key areas – aerobic, resistance, balance and flexibility:

### **Aerobic**

Anything that increases your heart and breathing rate. You could try walking, jogging, cycling, dancing or a team sport.

### **Resistance**

Carrying the shopping and doing housework will make your muscles stronger. You could also lift weights in the gym, but make sure you start gently and build up gradually.

### **Balance**

Activities such as yoga or tai chi will strengthen the muscles that help you balance. Even simple activities like standing on one leg can help too.

### **Flexibility**

Regularly stretching muscles and moving joints will make you more supple and reduce any aches and pains. Yoga, tai chi and Pilates will improve your general flexibility.

The NHS recommends adults should do at least 150 minutes of moderate physical activity or 75 minutes of vigorous physical activity each week. Strengthening activities that work most of the body should also be done on two days per week. It's also advised to reduce extended periods of sitting.

As a guide, moderate level activity includes things like brisk walking or cycling where you can still talk, but you can't sing the words to a song, whereas vigorous exercise makes you breathe hard and fast. If you're working at this level, you won't be able to say more than a few words without pausing for breath.

These guidelines may not be achievable at the start of your recovery, but that's understandable. They should be a long-term goal that you build up to gradually over time.

**'One thing that changed so much for me were parkruns. It was a breath of fresh air for me, it gave me motivation. I saw a lot of ill people doing it. So, I really recommend it when your strength is back a bit, as they are all over the country.'**

*Alex, who had a stem cell transplant in 2016*



## WHERE CAN I GET HELP?

Your medical team or GP might be able to help you access local exercise classes for free, or at a reduced cost. They may also refer you to a physiotherapist or prescribe free sessions with a personal trainer at your local gym. Some gyms have programmes for people who have had cancer or other long-term conditions.

Have a look at what's available through your local hospice and support centres, such as Maggie's Centres, too.

## WHEN IT'S NOT SAFE TO EXERCISE

In general, if you're recovering well, it's safe to do light or moderate exercise. There could be times, especially in your early recovery, when your blood counts are very low. It's probably best to focus on moving regularly during this time but your physiotherapist, or another member of your medical team, will be able to give you specific advice about when to introduce exercise.

Exercise should also be avoided if you start to feel unwell in any way. Possible signs of illness or an infection include:

- having a temperature
- nausea
- vomiting or diarrhoea
- a persistent headache
- aches and pains
- dizziness or feeling faint.

If you start to have any of these symptoms, you should discuss them with your medical team straight away.

## SLEEP WELL

Improving the quality and amount of sleep you get each night will give you more energy and help your recovery. However, you might find it difficult to sleep for a variety of reasons. If you can record your sleep patterns using a wearable fitness tracking device, or make a note of the hours you sleep, you can look back on when these problems occur. This will help your medical team spot patterns and work out how they can help.

## WHEN SHOULD I SLEEP?

Our bodies have a natural clock built in. Normally, it allows us to wake up in natural daylight feeling refreshed and makes us feel tired and fall asleep at the end of the day. This sleep/wake cycle is also called our circadian rhythm. When it becomes disrupted it can affect our mood and general wellbeing. It can also make it more difficult to fall asleep at night.

Night-time sleep is the most important for your overall wellbeing, and your general recovery, so limiting your daytime naps is really important. Extra sleep during the day won't make you feel better because it doesn't affect what's causing your fatigue. If you need to sleep during the day, plan it for late morning or early afternoon, and limit it to 45 minutes to avoid night time disruption.

## PREPARING TO SLEEP

If you are struggling to get a good night's sleep, you might find the following suggestions helpful:

- Ear plugs and black out blinds or curtains will help remove background noise and light.
- Avoid alcohol, caffeine and nicotine for four hours before sleep.
- Don't use devices with an electronic screen in the hour before bed.
- Write down anything that's worrying you before going to sleep.
- Start a relaxing pre-sleep routine, such as reading a book.
- Stick to a regular sleeping pattern – your body's natural sleep cycle will be more settled.
- Create a calm, dark and cool sleeping environment.
- Only go to bed if you feel truly tired – if sleep doesn't come, try to do something relaxing like reading or listening to podcasts.

**Mindfulness meditation can also help improve sleep and reduce fatigue. It helps to focus your thoughts on the present so that your mind doesn't wander to more stressful thoughts.**

You can find out more on the **BeMindful** website or download the **Headspace** app.

**'As much as you will need to sleep a lot, once you're asleep, your mind is off things. Whilst you're awake, keep your mind occupied by DVDs, laptop, games or puzzles. It does help.'**

**Jimmy**, who had a stem cell transplant in 2014

## DELEGATE DAILY TASKS

Even simple day-to-day tasks can be difficult for someone with fatigue – but having a strong support network around you will help relieve the burden.

Relatives and close friends might be able to help around the house, especially with jobs like emptying the bins that could be an infection risk. They may also be able to help with childcare from time to time, so that you can get some rest. This will give you more time and energy to focus on getting better and enjoying the things you like.

Other tasks, such as your weekly shopping, can be done online and delivered to your door so you don't have to worry about filling a trolley at the supermarket.

If you can afford it, paying for a cleaner would also free up your time to focus on your recovery. If not, asking for help from social services could be an option.

**'Having my family around was a great support. My mum and dad put the effort into the boring stuff for me. They would cook and clean, so I had the energy to go for a little walk, or see my friends. I wasn't wasting my energy on dull stuff, and I got more satisfaction from the day.'**

**Emma**, *who has received two stem cell transplants*



**Your mental health is closely linked to fatigue after a transplant. Fatigue can affect both how you are feeling and your mental agility.**

It can be tricky to work out what came first – your fatigue or feeling low. It can be exhausting and mentally draining to be anxious and worried about your future all the time. Similarly, if you feel too tired to do the things you want, it can leave you feeling down and even depressed.

Some patients try to focus on just the physical side of fatigue, but it's also important to consider the mental aspects too. You may find it much easier to relax and get a good night's sleep by addressing your feelings, and finding a better way to cope with your situation. This isn't always easy but there are many techniques, healthcare professionals and charities that can help you.

## MEMORY AND RECOGNITION

During your recovery there could be times when you find certain mental tasks more difficult than you once did. This could include difficulty remembering appointments, recalling the names of people or objects, and concentrating in general.

These problems are known as **cancer-related cognitive changes (CRCCs)** because they affect the way we recall and process information. They often go hand-in-hand with fatigue and many patients find they experience more CRCCs when their fatigue is also bad.

Research into CRCCs is ongoing but, despite some promising early results, there isn't any established treatment for it yet. However, there are many tips you can use to manage your situation. Here are a few to consider:

- Make lists of the things you need to do or important things that would be annoying to forget. This could be in a diary, your phone or on post-it notes in easy-to-see places.
- Always keep important things, such as your phone and keys, in the same place so they are easier to find.
- Find a quiet place with few distractions to help you concentrate on the task in hand. Turning off the TV or radio will also help you concentrate.
- Try doing harder tasks at the start of the day when you feel less tired.
- Getting into the same daily routine will make things more familiar and easier to remember.
- Crosswords, jigsaws and other puzzles exercise the mind and make it stronger.

**'There is a connection with mental agility and physical fatigue that we see in patients. It's really important to acknowledge and should be discussed with the same emphasis.'**

**Hayley**, *Anthony Nolan Lead Nurse*

## YOUR EMOTIONS

There's no right or wrong way to feel during your recovery. There will probably be times when you're worried, times when you're scared and times when you want to cry – but that's ok. Sometimes it's reassuring to hear that what you're feeling is completely normal.

It can be very easy to get lost in a circle of negative thoughts during your recovery – especially if you have one or two setbacks along the way. Try to also remember the positive times when things have gone well and when you felt in control of your situation. It will help give you a sense of progress that can lead to thoughts of hope and positivity for the future.

**'Mental health is often overlooked when going through a stem cell transplant. Mental health problems can occur when you least expect it, many years down the line. Be kind to yourself, take a break and know when to seek support.'**

**Sarah**, who had a stem cell transplant in 2016

## WAYS TO COPE

It's impossible to say what will work best for you, and some things may work better than others at different times. It might be a good idea to think about the things you did to help you get through other tough points in your life. You might find that they come in useful again during your recovery.

### **Lift your mood**

What you're going through isn't easy, so enjoy the little things in life. Buy that slice of cake when it tempts you, go out for a nice meal or do something you have always wanted to do, whatever takes your fancy. Many patients also use their favourite comedies, stand-ups or music to lift their spirits.

### **Relaxation techniques**

You might be familiar with the idea of mindfulness or other types of meditation as a relaxation technique. Activities like tai-chi and yoga also combine gentle movements with elements of meditation. These activities can help you become more aware of your feelings and focus your thoughts on the here and now. Even simply taking a deep breath can really calm your nerves.

### **Counselling**

When we experience difficult times in our lives it can be easier to talk to someone we don't know. Counselling or 'talking therapies' help you come to terms with your feelings and change your behaviour, so you feel more in control of your emotions.

Your medical team or GP will be able to refer you to a counsellor. Alternatively, if your situation allows, you can pay to see someone privately.

## EXTRA HELP

Charities like Macmillan and Maggie's fund purpose-built cancer centres with the aim of supporting patients and their families. They provide a calm and tranquil place for cancer patients to focus on their recovery. They are run by specially-trained health professionals who can help with many topics including fatigue, nutrition and emotional support. They also provide recreational classes, professional talks and support groups.

On the **Anthony Nolan Patients and Families Forum**, you can read and talk about a wide range of topics related to stem cell transplants. You can take your time and be as involved in the discussion as you like. Some people take great comfort in reading about the experiences of other people without feeling like they need to contribute themselves.

More information is available on our website: [anthonymolan.org/mind](https://anthonymolan.org/mind) and our *Your Mental Health and Stem Cell Transplant* booklet.

**'It was a chore to talk to people sometimes and I knew full well I wasn't great company. I look back now and think, "How easy is it to reply to a text message?", but it was tiring to even think about it. That's how bad the fatigue was.'**

*Alex, who had a stem cell transplant in 2016*



## EXPLAINING FATIGUE TO FRIENDS AND FAMILY

Many patients underestimate how much an effect fatigue can have on their lives after their transplant. One of the biggest challenges you might face is explaining fatigue to friends and family. They might think that because you've had a transplant, you're now better and can get on with life as normal, when in reality you're still recovering.

**'I'd get up at 8:00 in the morning and by 10:30 I'd be snoozing on the sofa. You even ask yourself, "Am I milking this? Am I really this tired?" because I'd never had anything like this before.'**

*Rachel, who has received two stem cell transplants for AML*

There will be times when you need help from those closest to you. This could simply be helping with daily tasks like shopping and housework, but you will also need their emotional support. However, there could also be times when you're feeling down and don't really want to be sociable.

It can be difficult to balance how you're feeling and still show that you appreciate the help they're giving. It may help to show them this booklet, so they have an understanding of what you're dealing with and what helps.



## FATIGUE AND WORK

Depending on your situation, you might have to return to work while still managing your fatigue. This can be a challenging time but if you make your employer aware of your situation, they should be able to put a plan in place to help you. Many patients have a phased return to work, where either their responsibilities or time spent at work is steadily increased.

Anthony Nolan is currently working with a company called **Working Towards Wellbeing**. Their work support services and work focused health coaching help people to become more active. They help to manage fatigue and other symptoms, so people can stay at work or return to work.

You can find more information in our back to work guides for **patients** and **employers** at [anthonymolan.org/booklets](http://anthonymolan.org/booklets)

## LOOKING AFTER SOMEONE WITH FATIGUE

Helping your partner or relative through their transplant journey has probably become the most important thing in your life. Although you are probably happy to do it, it can still be physically and mentally demanding, especially if you also have to earn a living and look after your family.

It may take time for you to adjust to your new supportive role. It's understandable that you might find it hard to cope with this responsibility, while also worrying whether they're getting better.

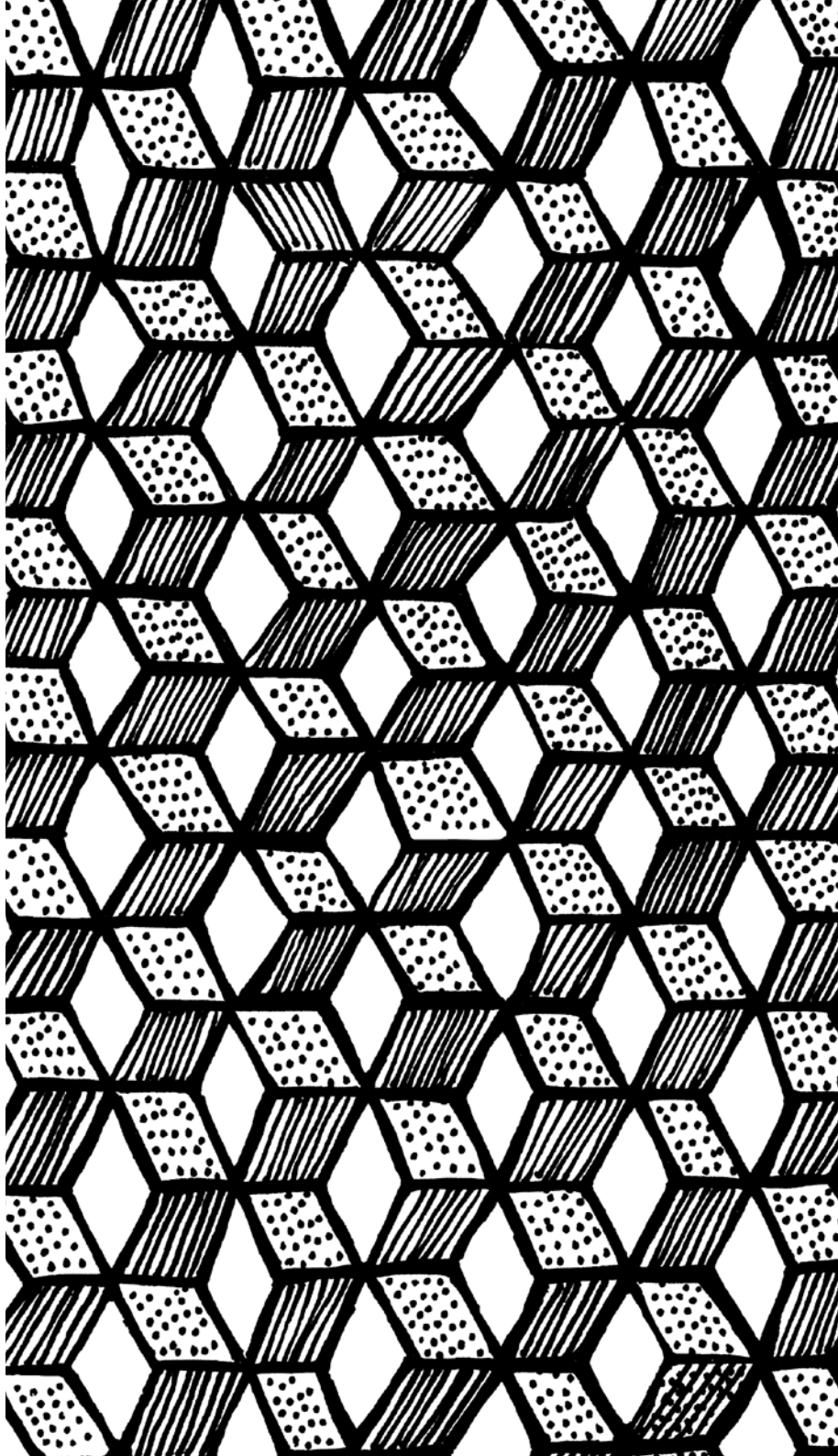
You can access help from a range of places including social services, government benefits and charities, as well as your social network of friends and family. Nobody expects you to do everything on your own. Many people will be happy to offer you support but you also need to have the confidence to ask for it when you need it.

**'People are so generous, always asking, "How can I help? What can I do?" and you get overwhelmed, because life doesn't stop just because this thing has happened to you both. So sit down and write a list. If you need your garden waste collected and taken to the dump, put it on the list.'**

**Mariacristina**, whose husband, **George**, had a transplant in 2014

Make sure you continue to do the things that are important to you too. Nobody will judge you for taking some time for yourself. It will reinvigorate you and give you fresh energy to tackle the challenges ahead.

More information is available in the **Support for parents, family and friends** section of the Anthony Nolan website.



## WEEKLY FATIGUE AND ACTIVITY DIARY

Tracking your energy levels in a weekly diary will help you see when fatigue affects you the most.

It's important to record the times when you feel good or something positive happens. If you just focus on when things are difficult, it can be harder to see the progress you're making in your recovery.

You might want to consider noting:

- the times when you had more energy, as well as when you felt fatigued
- your activities and exercise
- hospital or GP appointments
- any goals you would like to achieve
- how much sleep you got
- how you felt emotionally.

Photocopy the pages 52-53 so you can fill in your diary week by week, if you like.

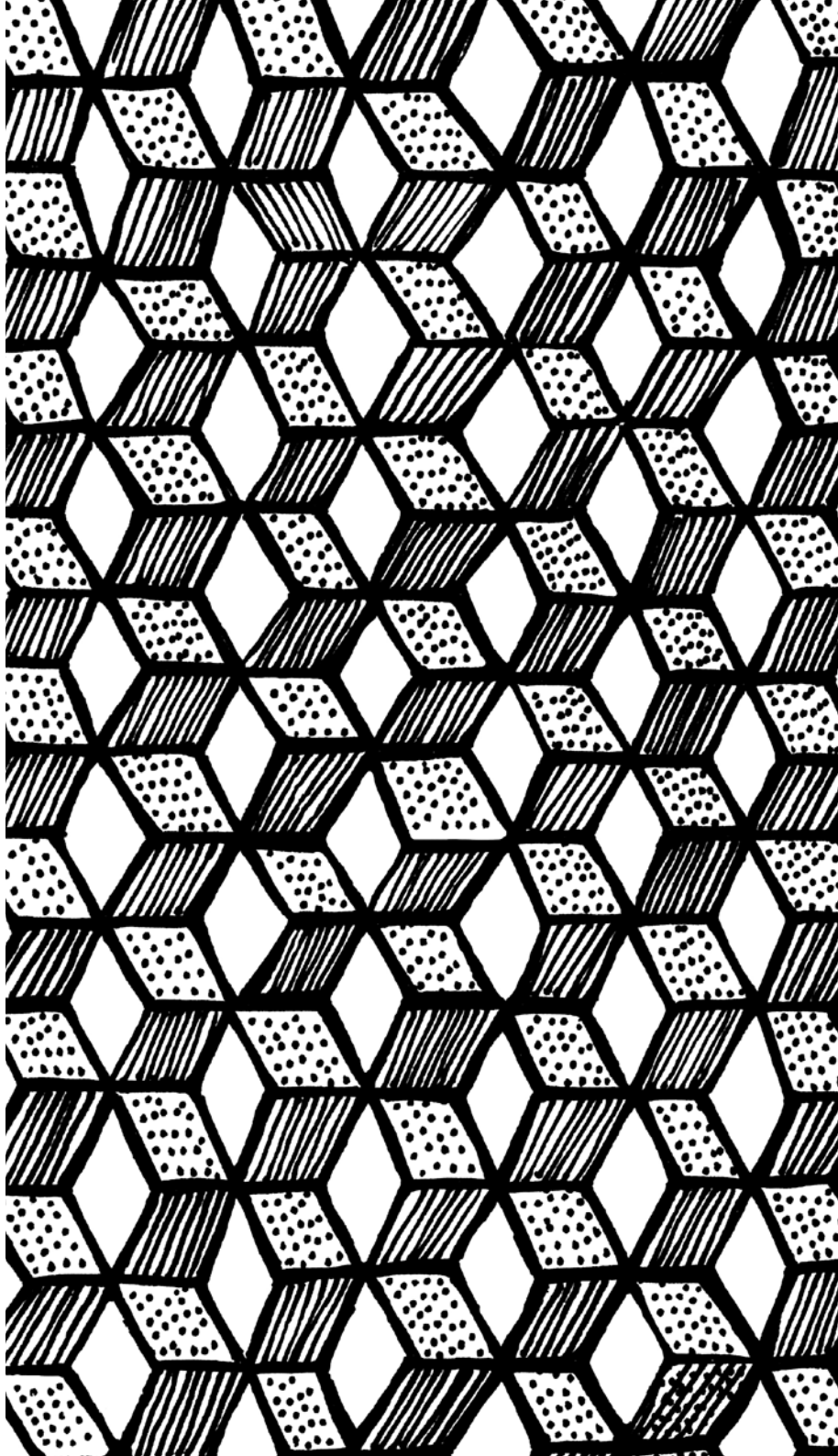
## WEEKLY FATIGUE AND ACTIVITY DIARY

DATE	MORNING	AFTERNOON	EVENING	NIGHT
MONDAY date:				
TUESDAY date:				
WEDNESDAY date:				
THURSDAY date:				
FRIDAY date:				
SATURDAY date:				
SUNDAY date:				

Photocopy this page so you can fill in your diary week by week, if you like.

You might want to consider noting:

- the times when you had more energy, as well as when you felt fatigued
- your activities and exercise
- hospital or GP appointments
- any goals you would like to achieve
- how much sleep you got
- how you felt emotionally.



## WHERE CAN I GET MORE INFORMATION AND SUPPORT?

If you or a loved one is affected by a stem cell transplant, there are many ways we can support you:

### NEED TO TALK?

The Patient Services team at Anthony Nolan is here for you. Call us on **0303 303 0303** or email: [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)

### GET CONNECTED

Find support from other patients and their families by joining our **Patient and Families Forum** at: [anthohnolan.org/forum](http://anthohnolan.org/forum)

### FIND INFORMATION

Our website has lots of helpful information about what it's like to go through a transplant. Download or order our booklets for free, and find links to other places where you can get support at: [anthohnolan.org/patientinfo](http://anthohnolan.org/patientinfo)

## OTHER USEFUL CONTACTS

### 5K YOUR WAY

**5kyourway.org**

An initiative set up to help people recovering from cancer to run regularly.

### BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

**itsgoodtotalk.org.uk**

**01455 88 33 00**

Information about counselling and therapists in your area.

### CARERS UK ADVICE

**carersuk.org**

**helpline: 0808 808 7777**

Information and support for people looking after their loved ones.

### CITIZEN'S ADVICE

**citizensadvice.org.uk**

**helpline: 03454 04 05 06**

Advice on a wide range of issues, including financial and legal matters. Online advice is available at: **adviceguide.org.uk**

### CLIC SARGENT

**clicsargent.org.uk**

**helpline: 0300 3300 0803**

Offers a range of services for children affected by cancer and their families, including a helpline for emotional support and practical advice.

### COUCH TO 5K

**nhs.uk/live-well/exercise/couch-to-5k-week-by-week**

A nine-week programme of three runs per week designed to get people more active. Each run has an accompanying podcast too.

### EXPERT PATIENTS PROGRAMME

**expertpatients.co.uk**

**0800 988 5550 or 01925 320 000**

Free self-management courses to help you take control and manage your condition.

### IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES (IAPT)

**england.nhs.uk/mental-health/adults/iapt/**

Enables patients to self-refer to NHS-funded counselling and therapy services available in their local area.

### MACMILLAN CANCER SUPPORT

**macmillan.org.uk**

**0808 808 00 00**

Practical, financial and emotional support for people with cancer, their family and friends.

### MAGGIE'S CENTRES

**maggiescentres.org**

**0300 123 1801**

A network of drop-in centres for cancer information and support. Includes an online support group.

### THE MENTAL HEALTH FOUNDATION

**mentalhealth.org.uk**

Provides information on mental health, including mindfulness and mindfulness meditation.

### MIND

**mind.org.uk**

**helpline: 0300 123 3393**

Mental health charity which offers information, advice and support to anyone going through stressful situations or experiencing a mental health problem.

### NHS CHOICES

**nhs.uk**

**helpline: 111**

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

## **PARKRUN**

**[parkrun.org.uk](http://parkrun.org.uk)**

Free, organised 5k runs held every Saturday at 9am throughout the country for people of all fitness levels and abilities.

## **PENNY BROHN CANCER CARE**

**[pennybrohncancercare.org](http://pennybrohncancercare.org)**

**helpline: 0303 3000 118**

Free courses and support for people with cancer and their families.

## **SAMARITANS**

**[samaritans.org](http://samaritans.org)**

**helpline: 116 123**

The Samaritans are available 24 hours a day to listen and provide help for any problem you would like to talk about.

## **TEENAGE CANCER TRUST**

**[teenagecancertrust.org](http://teenagecancertrust.org)**

**020 7612 0370**

Support to improve the lives of teenagers and young adults with cancer.

## **WALKING FOR HEALTH**

**[walkingforhealth.org.uk](http://walkingforhealth.org.uk)**

Find a walk scheme in your area.

## **WORKING TOWARDS WELLBEING**

**[workingtowardswellbeing.com](http://workingtowardswellbeing.com)**

**01284 748207**

Provides wellbeing and rehabilitation services, supporting employees with physical health, mental health and long-term conditions.

'I FELT EXHAUSTED ALL THE TIME.  
YOU DON'T EXPECT TO FIND IT  
HARD TO JUST STAY UPRIGHT  
WHILE YOU'RE WAITING FOR  
THE KETTLE TO BOIL! WHEN I GOT  
HOME I FOUND THAT I COULDN'T  
GET UP THE STAIRS.

IT WAS A SHOCK, BUT I DIDN'T  
GIVE UP, I SET MYSELF GOALS  
AND I PUSHED MYSELF.  
ONE STEP AT A TIME.'

**Sarah**, *who had a stem cell transplant in 2014*



**saving the lives  
of people with  
blood cancer**



**[anthonymolan.org/patientinfo](http://anthonymolan.org/patientinfo)  
[facebook.com/anthonymolanpatients](https://facebook.com/anthonymolanpatients)**

**[patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)  
0303 303 0303**

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