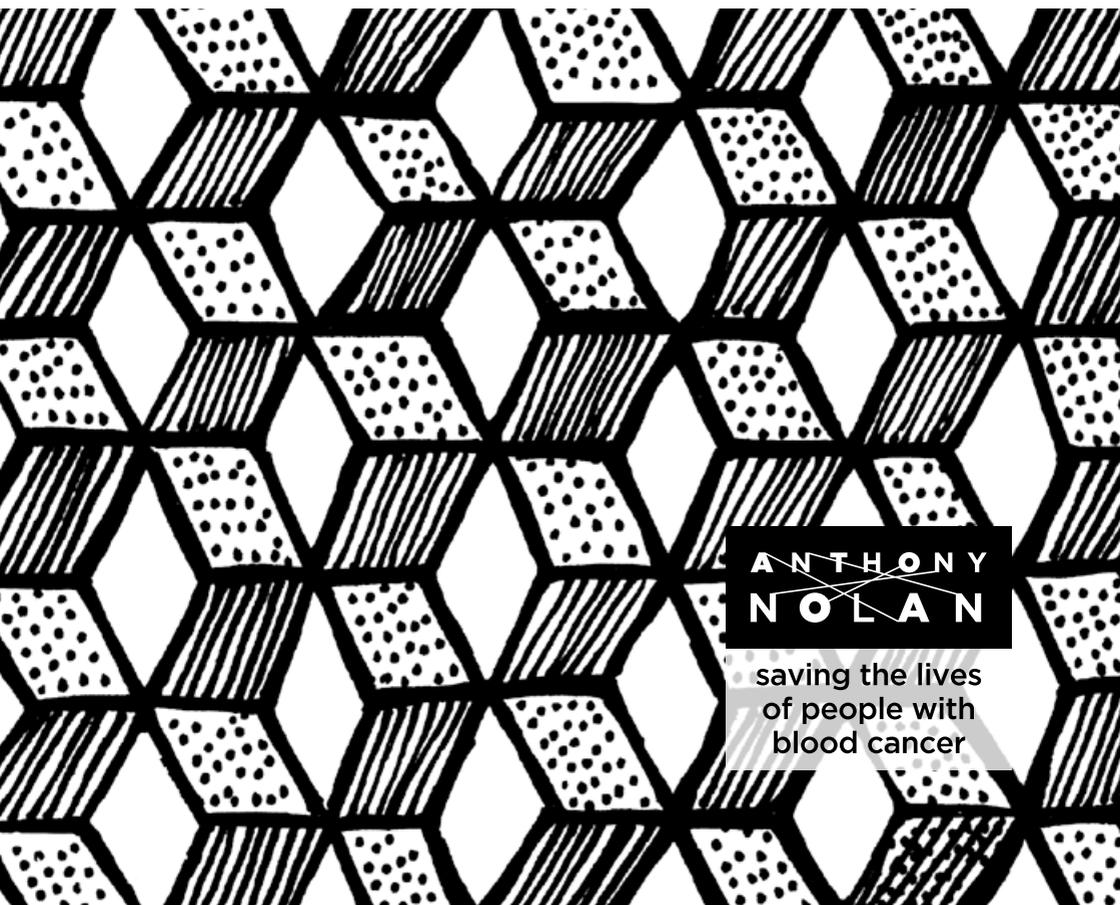


# MANAGING FATIGUE

## AFTER A BONE MARROW OR STEM CELL TRANSPLANT



**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer

# MANAGING FATIGUE

## AFTER A BONE MARROW OR STEM CELL TRANSPLANT

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# WHAT'S IN THIS BOOKLET?

We've put together this booklet to help you manage fatigue during or after a bone marrow or stem cell transplant. We've included the latest medical research and guidance from specialist healthcare professionals, and shared tips from patients who've been where you are now. We hope you find it useful.

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

The booklet is decorated with intricate, hand-drawn doodles. If you're feeling like you need a moment of calm and an activity to take your mind off things, why not colour them in as a simple relaxation exercise?

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

# WHAT IS FATIGUE?



'Fatigue is a normal part of your recovery. It can come and go. So don't be too hard on yourself - give yourself time to recover.'

*Hayley, Anthony Nolan Post-Transplant Clinical Nurse Specialist*

Fatigue is a common problem after a bone marrow or stem cell transplant. It's more than the usual feeling of tiredness after lots of work or exercise, or a bad night's sleep, and doesn't go away with sleep or rest. It can make you feel both physically and mentally drained, leaving you with very little energy or motivation, and it can be hard to concentrate even on simple things.

Fatigue can have a big impact on your everyday life - making it hard to carry out your normal activities, such as hobbies or work, and affecting your social life and relationships.

You might find your fatigue makes you feel extremely tired in the daytime, making it difficult to stay awake. This is called somnolence.

It's important for you, and the people around you, to recognise that your fatigue is different to just being tired, and more complicated.

'Seemingly simple tasks like unloading a dishwasher are exhausting, and putting on a coat feels unusually heavy. This is not the kind of tiredness that one experiences after hard work or lack of sleep.'

*Pavlos had a transplant in 2010*

### **When does it start and how long does it last?**

Depending on what treatment you've had for your blood cancer or disorder, you may already be feeling low on energy before your transplant takes place. Conditioning therapy given at the very beginning of your transplant (see page 13) can make you feel fatigued.

You may well feel fatigued during the first few weeks while you're in hospital and your white blood cell count is at its lowest. And you might really notice it when you go home and find you're not able to do all your normal day-to-day activities.

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.

Fatigue can develop at any time after a transplant, but usually within about a year, and it can sometimes be hard to find out what's causing it.

*'In my first few weeks back at home, the routine of getting up, showered and dressed was as much as I could manage some days.'*

*Peter had a transplant in 2012*

### **Is there anything that can be done about it?**

The good news is that there are treatments for the causes of fatigue, and ways you can manage it to make the most of the energy you have.

*'The first step in dealing with fatigue is to speak to your transplant team as they may recommend some tests and treatment, and can offer advice and help you manage it.'*

*Paul, Anthony Nolan Medical Officer*

# BE PREPARED

**‘CHAT TO YOUR EXPERT MEDICAL TEAM AND DO SOME OF YOUR OWN RESEARCH TO FIND OUT MORE ABOUT FATIGUE.’**

‘Everything tasted wrong after my transplant and I had serious problems eating. But someone suggested children’s meals that you can buy from any supermarket; small tasty portions that were full of goodness and no additives.’

**‘IF FAMILY AND FRIENDS OFFER HELP, LIKE LIFTS TO THE HOSPITAL, LET THEM! THEY REALLY WANT TO, AND THEY CAN BECOME PART OF THE SUPPORT AND RECOVERY PROCESS.’**

‘Explain to people what fatigue is. Manage their expectations so they know that it doesn’t necessarily go away after just a few months. Being upfront may lead to greater understanding and even deeper friendships.’

## TALK TO OTHERS

‘Go easy on yourself. It’s OK if you need to go to bed when people are around. It’s OK to go dinner and have a starter and then go home. It’s OK to ask someone just to come around for a shorter time than usual, even if you haven’t seen them for a while.’

‘Ask your friends and family to do “smaller” social activities that won’t involve you travelling too far. Maybe they could pop in and see you for an hour?’

## PLAN YOUR DAY

‘Set small tasks and build things up slowly: for example, “Today I’m going to go for a five-minute walk”, “Today I’m going to get up and have a shower”.’

‘Choose your activities according to the time of day; do things that need concentration early in the day if that’s when you feel better. Write lists and set reminders on your phone.’

**‘HAVE A STRUCTURE TO YOUR DAY AND A REGULAR ROUTINE - THIS CAN HELP YOU KEEP THINGS UNDER CONTROL AND REDUCE YOUR STRESS.’**

# WHAT CAUSES FATIGUE AND WHAT HELPS?



Fatigue can be caused by a combination of factors related to transplant. Some will affect most people to some extent, particularly conditioning therapy. Others are much more individual – for example, your cancer or blood disorder itself, any side effects you may have, and their treatments. We explain more in the next few pages.

Your general health and wellbeing can also affect how fatigued you are. For example, your level of fitness, any other health problems you're dealing with, what treatments you've had in the past, and your age – older people are more likely to experience fatigue.

It's important to talk to your transplant team so they can investigate exactly what may be affecting your energy levels, and how they can help. They might refer you to another health professional who specialises in fatigue or the late effects of transplant.

## CONDITIONING THERAPY

Before you have your transplant, your bone marrow and immune system need to be prepared to make way for the new cells. This is done with chemotherapy, sometimes in combination with a type of radiotherapy called total body irradiation (TBI).

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 a small number it can go on for a long time, even years.

During your conditioning therapy and hospital stay you may have lost weight or become less mobile, especially if you've been in isolation for some time. This can add to your fatigue as it means you lose strength – meaning that tasks that were simple before now seem exhausting.

'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 had a transplant in 2012*

### **Chemotherapy**

Most people who have chemotherapy experience fatigue to some extent, particularly if they're receiving it in high doses.

### **Radiotherapy**

You're more likely to feel fatigued during and after radiotherapy if you have a series of fractions or doses, rather than a single dose. A higher total dose is also linked to fatigue. One study found that about a third of people having radiotherapy before their transplant experienced fatigue during the treatment, while others show it could be as high as two thirds.

## **PROBLEMS EATING AND DRINKING**

### **Loss of appetite**

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. Chemotherapy can make you feel ill, or be sick, and food might taste different. This can make it harder to eat as much or the same things as usual.

This means you might not be taking on all the energy and nutrients you need, making you feel fatigued.

'I was shattered when I came out of hospital, but recovered pretty quickly once I started eating and drinking properly.'

*Martin had a transplant in 2014*

### **What helps?**

Your team will keep an eye on your weight, so that if you're losing weight they can look into what's causing it and help you manage it.

Taking on the food and water you need can help boost your energy. If three square meals a day seems like too much, try and eat little and often throughout the day, and choose whatever you fancy.

Aim to drink around two litres of fluid every day, or 7-9 glasses. Caffeinated drinks such as fizzy drinks, tea and coffee don't count, and neither does alcohol, but all other soft drinks do, including milk and fruit juice. If you are vomiting, it's important to try and replace some of the fluid you've lost by drinking more than this. Try sipping small amounts of fluid throughout the day.

If you're feeling nauseous, tablets called anti-emetics can help. You could try avoiding fried foods and foods with a strong smell, and some people find tea or sweets flavoured with ginger help.

If you have any of the problems discussed here, you can ask to be referred to a dietitian. They can recommend foods to eat or avoid and give you tips to help you take in enough energy, fluid and nutrients throughout the day.

### **Sore mouth**

Some people will have mouth sores or ulcers caused by mucositis, where the mouth becomes inflamed and painful. This can be caused by chemotherapy.

### **What helps?**

Your team will be able to suggest ways to ease this such as a mouth-wash solution called Corsodyl, protective mouth gels, and products to numb or moisten the mouth. You could try sucking on ice cubes, lollies or boiled sweets, and go for foods with a soft texture, such as yoghurts and mashed potato.

## **DIARRHOEA AND PROBLEMS ABSORBING NUTRIENTS**

During and after your transplant you may have episodes of diarrhoea, which can add to fatigue. This can be caused by conditioning therapy, Graft versus Host Disease (see page 18) or infection.

Some treatments, in particular radiotherapy, can damage the cells in the gut, meaning you can't absorb as much energy or nutrients.

### **What helps?**

It's important to work out what's causing diarrhoea to make sure you get the right treatment, so do talk to your team if you're experiencing it. In addition to treating the cause, you might be prescribed anti-diarrhoea medication like loperamide to help with the symptoms.

Try to drink more than two litres of fluid a day to avoid becoming dehydrated. You might need oral rehydration fluids – sachets that dissolve in water and replace the minerals you might have lost.

There could be certain foods which make your symptoms worse. Ask to speak to a dietitian for advice about the right foods to eat and avoid.

## GRAFT VERSUS HOST DISEASE (GvHD)

GvHD can happen if you've had a transplant using cells donated by another person (known as an allogeneic transplant, or allograft), and immune cells from your donor (graft) are attacking your own body (host).

GvHD can be painful or make you feel unwell, which will affect your appetite. It can have an impact on different parts of the body, including the digestive system. It can affect the mouth, oesophagus (food pipe), stomach, and liver, affecting how you feel and what you can eat. It can also affect the gut, causing diarrhoea. This can mean you lose weight, making you feel weak and fatigued.

### What helps?

Getting treatment for GvHD can improve your overall well-being as well as your symptoms. And treating GvHD of the digestive system can help you to absorb the nutrients you need and keep weight on, which could help with your fatigue.

There are different types of GvHD and your treatment will depend on which type you have, and where in your body it's affecting. Treatment can include a number of medicines such as steroids and medications to suppress your immune system.

Your team may offer you other medication to help treat your symptoms. For example, anti-diarrhoea medication (see page 17), painkillers and anti-sickness drugs.

## ANAEMIA

Almost everyone who has a transplant will have anaemia at some point in their treatment. This is because blood cancer and blood disorders either start in or affect your bone marrow, where blood cells are made, and treatments such as conditioning therapy can also reduce the number of red blood cells being made.

Sometimes other health problems can cause anaemia, such as vitamin deficiencies. A low folate level, for example, is common after transplant and folate is needed to produce red blood cells.

Oxygen is used by the cells in your body to release energy. It's carried from the lungs around your body by haemoglobin, which is found in red blood cells. If your haemoglobin levels become too low, your cells might not have enough energy. This can make you feel fatigued or short of breath – anaemia can have a big impact on your daily life and ability to do everyday activities.

### What helps?

Treatment for anaemia may help relieve your fatigue. Your transplant team will keep a close eye on your haemoglobin level through regular blood tests. They will use this, along with any other symptoms you might have, to consider whether you need a blood transfusion.

## PROBLEMS SLEEPING

It's common to have problems sleeping during and after transplant, particularly while you're in hospital. This is normally because you're feeling unwell or anxious. It might be noisy or too light on the ward, or the medical team may need to wake you to check your blood pressure, pulse and temperature in the night.

Another common time you might have trouble sleeping is when you go home after treatment. The environment you're in will be different and you'll have a new routine to get used to.

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

You should find that sleep problems get better over the first year, but around 20-45% of people may still struggle to get a good night's sleep.

### What helps?

For tips about sleep and looking after yourself while you're in hospital, read our leaflet, *Dealing with Isolation*. Taking ear plugs and an eye mask to hospital can help.

There's more about managing your sleep habits on page 34. It could be that once you've had time to adjust to your new routine and surroundings, you're able to sleep better.

A type of counselling called cognitive behavioural therapy (CBT) has also been used effectively to treat sleep problems in people with cancer. Find out more on counselling on page 22.

Occasionally you might be offered a mild medication if you're really struggling to sleep. As steroids can make you more energetic, avoid taking these in the evening if possible, but make sure you take them as prescribed.

## FEELING LOW, WORRIED OR STRESSED

During your time in hospital and after you go home it's not uncommon to feel low, distressed or worried – you're dealing with a massive event in your life. You might pick up infections and need to be readmitted to hospital, which can make you feel worn down and like you're not making progress.

When you go home you might find these feelings hang around at first. As time goes on and you adjust, they should gradually get better. Sometimes you just need someone to reassure you that what you're feeling is normal.

Feeling very low in mood is closely linked with fatigue after a transplant – it can be tricky to work out what came first. Fatigue can be a symptom of feeling very low, or depression, and feeling fatigued can make you feel down. Feeling anxious and worried all the time can be exhausting.

There are some signs that might mean you need more support to cope with how you're feeling. Let your transplant team know if:

- You've been feeling very low for two weeks or more
- You have little interest in things and can't find the motivation to do anything, even important tasks
- You feel unable to control your thoughts, or feel guilty or hopeless
- You respond to things differently, such as being irritable or tearful.

NHS Choices has more on low mood and when to seek help. See page 57.

### What helps?

For some people these difficult feelings can persist for a long time, sometimes even years, so it's important to seek help and take care of yourself.

## Counselling

Psychological therapy, including counselling, can help people with cancer and other health problems deal with how they feel, both psychologically and physically.

It's sometimes hard to speak to the people closest to you, because you don't want to upset them or show your emotions. Some people find it easier to talk to someone they don't know – which is where a counsellor or clinical psychologist might come in. They're trained to listen and can help you find your own ways to deal with things.

There are different types of counselling and therapy available, so if it's not working out with one counsellor, you could try a different approach with another. Your GP or transplant team can refer you to a counsellor, or you could find one yourself. The British Association for Counselling and Psychotherapy has information about counsellors in your area (see page 57).

**'Psychotherapy, which included art and photography, has helped me to manage my fatigue by learning to pace myself. It also helped me to revalue all my relationships and address some of my issues in dealing with people.'**

*Pavlos had a transplant in 2010*

You can read more about how Pavlos used photography to deal with his fatigue on page 44.

## Medication

There are medications that can help with anxiety and depression. These may contribute to fatigue, so your team will make sure you're prescribed the best treatment for you.

## Looking after yourself

Some research shows that relaxation training, meditation and breathing exercises can help with the physical and emotional effects of transplant, or when recovering from cancer treatment.

- Maggie's Centres, Penny Brohn Cancer Care and local hospices offer free courses on managing stress, including meditation and relaxation techniques. Find out what's available in your area using the contact details on page 57.
- Self Management UK also offer free self-management courses to help you take control of your health and well-being.
- Try keeping up with your usual hobbies and social activities, or try some new ones. Perhaps you could still do the things you used to but on a smaller scale, like seeing your friends but for a shorter time, or going for a walk but not as far.
- Get support from others. Research shows that this can improve your quality of life, lift your mood and improve your wellbeing. See page 54 for where to get support.
- Connect with other people who've been through a transplant. You can discuss things anonymously at our online community: **[anthonymolan.org/transplantcommunity](http://anthonymolan.org/transplantcommunity)**
- Our booklet, *The Seven Steps: The Next Steps*, has more information on life after transplant.
- Macmillan Cancer Support has a booklet called *What to do after cancer treatment ends: 10 top tips*, which has suggestions on where you can get support after treatment – it's useful even if you've been treated for something other than cancer.

'I went to a local cancer care centre and joined an eight-week course of support, counselling and relaxation. It became a place to look forward to – making new friends, dressing up a little, getting out in the car and feeling some independence.'

*Peter had a transplant in 2012*

## **HORMONE CHANGES**

There are a number of ways a transplant can affect your hormone levels, which can cause fatigue.

### **Underactive thyroid**

After a transplant some people develop an underactive thyroid (hypothyroidism). This means the thyroid gland doesn't produce as much thyroid hormone as it should, and fatigue is a very common symptom. It tends to occur a year or more after transplant.

### **Early menopause in women**

Women who've had a transplant may experience premature menopause and lower levels of the female sex hormone, oestrogen. These can cause problems with sleeping and can contribute to fatigue.

### **Low testosterone in men**

After transplant, it's common for men to have low levels of their main sex hormone, testosterone, which can affect your energy levels.

### **Vitamin D deficiency**

You might also have lower levels of vitamin D in your blood after a transplant, which makes you feel tired.

## **What helps?**

Your transplant team should check for all of these hormone changes with regular blood tests, and they can be treated with hormone replacement therapy.

For example, an underactive thyroid can be treated easily by taking a tablet each day to replace the missing hormone. Testosterone levels in men may increase with time, but you may also be able to have testosterone replacement through injections, patches or gels.

## MEDICATIONS

It's normal to have a lot of different medications during your recovery. Some can cause or worsen fatigue, and sometimes it's the specific combination that causes it.

Some medications to tackle side effects or other problems can have a sedating effect and make you feel sleepy, such as anti-anxiety medications, anti-sickness tablets, anti-depressants and strong painkillers.

Steroids are often prescribed to help with GvHD. The side effects vary greatly from person to person. For example, they can make it hard to sleep. Speak to your team if you think they're affecting your fatigue.

### What helps?

The medications you take after a transplant are very important and closely monitored. You'll need everything your team prescribes.

Let your transplant team, or supportive or palliative care team, know if you think one of your tablets might be the problem – there might be an equivalent you can try.

Having a lot of different medications to take can be difficult to manage if you're fatigued. Find ways to help with this on page 49.

## PAIN

Sometimes the effects of a transplant can cause pain, such as GvHD of the mouth or gut. Living with pain for a long time can affect your mood, activity level and sleep which can lead to fatigue.

### What helps?

You shouldn't have to put up with pain. Let your transplant team or supportive or palliative care team know so they can investigate what's causing the pain and help you manage it.

As well as getting medical help, you can learn ways of dealing with long-term pain, such as meditation and relaxation techniques. Find out more on page 23.

# GET SUPPORT

## PLAN AHEAD

'Cook more than you need for one meal and freeze surplus, so you have some easy meals for when you can't be bothered because you're tired.'

**'DO YOUR SHOPPING ONLINE. YOU CAN BUY JUST ABOUT ANYTHING VIA THE INTERNET. WHY STRUGGLE?'**

'RECORD TV PROGRAMMES SO THAT IF YOU FALL ASLEEP WHILE WATCHING SOMETHING, YOU CAN WATCH THE BIT YOU MISSED!'

'In my experience, the fatigue seemed endless! But doing things in small steps, trying to slowly build up a little each week would also be my advice.'

## GO EASY ON YOURSELF

**'PSYCHOTHERAPY WAS REALLY HELPFUL FOR BEING MORE ASSERTIVE. IF I'M TIRED, I SAY NO TO THINGS!'**

'COULD YOU GET A CLEANER, OR ASK FAMILY AND FRIENDS TO HELP WITH BASIC HOUSEHOLD CHORES THAT TIRE YOU OUT?'

'Just listen to your body, even years down the line. When you're tired, take it easy. You can do that task tomorrow.'

'We go walking twice a week with a group organised for people affected by cancer and their carers. We've met new friends, exchanged experiences and support each other by listening and walking together. Instead of planning a foreign holiday, we've discovered some lovely and interesting places in England and Wales.'

'I enjoy the little things in life, so I can have many small pleasures instead of a few big ones.'

**'MOST IMPORTANTLY, BE KIND TO YOURSELF AND GIVE YOURSELF TIME TO HEAL.'**



## MANAGING YOUR ENERGY LEVELS

'I learnt to sit back and watch the sunlight shining on a plant on my balcony. This sounds very trivial, but I was always on the go before getting ill. This approach helps me to slow down and manage my energy exertion.'

*Pavlos had a transplant in 2010*

### **Pace yourself**

Pacing is a way of managing your activities throughout the day so you can make the most of the energy you have, while avoiding doing too much and getting more fatigued.

What often happens is that you wake up feeling great and full of energy, so you try and do everything you've been putting off. But this tends to mean you'll need a nap in the afternoon, which creates a pattern of disturbed sleep at night and feeling fatigued again the next day.

Try to avoid these peaks and troughs. Listen to your body and learn when to stop and rest – be flexible, and understand your limits.

'I slowly learnt to listen to my body and rest more to allow myself to recover.'

*Simon had a transplant in 2012*

### **Balance rest with activity**

While it's important not to do too much when you're having a good day, it's just as important to get out of bed and do a couple of really small things if you're having a bad day. Some people find not doing anything makes them feel worse and lose motivation.

### **Keep a diary and make a plan**

You could start by keeping a daily diary for a week. Note down when you sleep, rest and what activity you're doing. Also jot down how tired you're feeling and any other symptoms you have. After a week, have a look at your patterns of activity and how this relates to your tiredness. This should show you when you have the most energy.

Make a list of the key things you need to do each day, then plan how you can fit them in along with times of rest, based on your diary. Spread activities out across the week, and break tasks down into smaller parts. Planning like this can reduce how much fatigue interferes with your daily life.

*'Although I didn't keep a diary, my wife did, recording things like temperature, sleep, eating, physical activity, and any other issues. It was very useful at my weekly clinic visits, so I didn't forget anything of importance.'*

*Peter had a transplant in 2012*

### **Set yourself goals**

It can also help to set realistic goals. Break them down into small steps – things you want to achieve each day or week.

Over time, you could gradually make your goals slightly more ambitious. Keep a record of what you've achieved in a notebook or on your mobile phone. This can help you feel more in control and more positive.

*'Setting yourself goals is a good way to progress, and measure that progress.'*

*Peter had a transplant in 2012*

### **Where can I get help?**

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

## MANAGING YOUR SLEEP PATTERNS

The amount of sleep people need varies – most of us need about eight hours a night, while a few people can get by with only three.

### When is the best time to sleep?

Night-time sleep is the most important for your overall wellbeing, and even your 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 your rest interfering with your night's sleep.

### How can I prepare for a good night's sleep?

Some people find that having an evening routine helps them prepare for a good night's sleep. This might include spending a bit of time relaxing before going to bed; for example, taking a bath, reading, or listening to music. You could try writing down anything that's worrying you before you go to sleep.

Try to not have too much alcohol right before bed. Although this may help you fall asleep, your sleep is more likely to be disturbed.

Make sure your environment is right for sleeping. Keep light and noise to a minimum; for example with blackout blinds and ear plugs.

If you wake up in the night and can't get back to sleep, try doing something relaxing. After a while you might find you're tired enough to get back to sleep. It might help to keep a snack nearby, so you don't have to get up if you need to eat something in the night.

Mindfulness meditation can also help to improve sleep and reduce fatigue. This technique involves sitting and quietly paying attention to the sensations of breathing or other regions of the body, bringing your attention back whenever your mind wanders.

### Where can I get help?

Speak to your team if you're having real trouble sleeping. An occupational therapist or psychologist may be able to help you manage your sleep habits. Your doctor might also prescribe mild medications on a temporary basis.

Macmillan Cancer Support and The Royal College of Psychiatrists have more information about coping with sleep problems.

NHS Choices and the Mental Health Foundation have more information on mindfulness and accessing courses, books and audio guides. See page 57.

## PHYSICAL ACTIVITY

'I still suffer with sudden fatigue which overwhelms me, but I now just take it easy – rest or nap – and accept that this happens. I find regular exercise, yoga, Tai Chi, meditation and pacing myself have helped.'

*Sarah had a transplant in 2010*

Exercise may feel like the last thing you want to do, but there's a growing amount of research suggesting that a bit of light to moderate exercise can help reduce treatment-related fatigue and improve your physical strength.

It can also improve your quality of life and how you feel emotionally before, during and after your transplant.

Maintaining some muscle strength before and during your treatment will help you to keep doing the things that are meaningful to you and your family, such as taking a short walk together.

### How can I get more active?

'I'm a big believer in setting goals, and I'm a big fan of using a mobile phone app that measures and records my exercise and sleep.'

*Martin had a transplant in 2014*

Try these ideas to help you get started:

- Start by monitoring what you're doing every day for a week.
- Pick an activity that feels achievable now and do this every day. It can be very small – remember, this is your starting point. You could walk to the end of the drive, march on the spot for 30 seconds, or see the one-minute exercises on page 39.
- Have different options in mind, in case something gets in the way of one, such as bad weather.
- Build up what you're doing gradually over weeks or months. Increase frequency first (how often you do it), then duration (how long you do it for), then intensity (how hard you work).
- A good long-term target is 30 minutes of moderate-intensity exercise, five days a week.

Going for a short walk every day can be an excellent place to start. Using a pedometer is a great way to track your distance and time, so get in touch and we'll send you one for free to get you started.

### What type of activities should I do?

The type of exercise and activity you choose is up to you. In the long term you'll find it easier to stick to something you enjoy, or that doesn't need much effort or planning.

This could be exercise classes or using a gym, joining a local walking group or sports club, or simply walking instead of taking the bus and using the stairs instead of the lift. These might seem unachievable to start with, but by starting small you can gradually build up.

'I vividly recall walking out of the front door and down the drive. A real effort at the beginning, but I gradually extended the walk to a park about 40 metres away. I remember holding back tears. I thought I'd never get that far again. Gradually I extended the distance to the local shops for a newspaper or a coffee. It felt like a real achievement.'

*Peter had a transplant in 2012*

'Walking was a godsend because you can be outside enjoying the fresh air, you can pace yourself, and you can avoid crowds. At first I didn't go out alone so that I had someone to lean on if I got tired. This enabled me to walk a bit further because I felt safe and supported.'

*Sarah had a transplant in 2010*

'See who's around for support to keep you motivated - find cheerleaders! Often family and friends want to help out but don't know how, exercising together could be a good way.'

*Lucy, physiotherapist*

## ONE-MINUTE EXERCISES

Pick an exercise and repeat it at a steady pace for one minute, a few times a day. You could do an exercise when the adverts come on the TV, or whenever you feel you've been still for too long.

### One-minute exercises: from lying down

If you need to spend a lot of time in bed, try these Exercises to keep the strength in your muscles and movement in your joints. They all start from lying on your back.

**Ankle bends** - point your toes up to the ceiling, then straighten your ankles and point your toes away from you. Keep your knees straight to stretch your calf muscles.

**Knee bends** - bend one knee and pull it towards your chest, then lower your leg back down. Repeat on both sides.

**Leg stretches** - keep both legs straight, and use your leg muscles to pull back the toes of your right foot, push your knee down into the bed, hold for five seconds, and relax. Repeat on the other side.

**Leg raises** - lift up one knee so your foot is flat on the bed. Keep the other leg straight, toes pointing towards the ceiling, and lift it up about six inches, hold for five seconds, and lower it down. Repeat on both sides.

### One-minute exercises: from sitting

Try these once you're out of bed and able to sit. They all start from sitting in a chair or bed.

**Leg strengthening** - starting with both feet flat on the floor, straighten one knee slowly and smoothly to lift your foot up, then lower it back down. Repeat on both sides.

**Shoulder pushes** - hold both hands just in front of your shoulders, push one arm up towards the ceiling until it's straight, and bring it back down. Repeat on each side. Hold light weights to make this harder. You can also do this standing.

**Elbow bends** – with your feet flat on the floor at hip width apart, keep your back straight and hold onto a bottle of water, palm up. Bend your arm at the elbow until your hand almost meets your shoulder. Repeat on the other side. You can also do this from standing.

**Tricep lifts** – hold a bottle above your head with your arm straight. Bend your elbow and slowly lower the bottle towards your shoulder, behind your head, keeping your elbow high. Then straighten your arm again. Repeat on both sides. You can also do this from standing.

### **One-minute exercises: from standing**

**Mini-squats** – stand with your feet at shoulder width apart, bend your knees as if you're going to sit down in a chair (just as far as you're comfortable) and come back up. You can hold onto a support in front of you, such as the back of an armchair or sofa.

**Step-ups** – stand on the floor in front of a staircase or step. Step up onto the first step with one foot then the other, then back down again with one foot followed by the other. Alternate which foot you step with first.

**Arm raises** – stand with your arms by your sides, palms facing behind you, and raise them up in front of you to shoulder height, keeping your arms straight. Then lower them back down.

**Heel lifts** – from standing, raise yourself up onto the balls of your feet, and back down.

**Sideways leg raises** – hold onto a support in front of you, such as an armchair or sofa, or place your palms against a wall. Put all your weight on one leg and raise your other leg up to the side, keeping your toes pointing forward, and bring it back to the middle. Repeat on both sides.

### **When isn't it safe to exercise?**

If you're recovering well, it's generally safe to do light or moderate exercise. If you're feeling unwell or still need to go to hospital for problems related to your transplant, or you have other health problems, ask to speak to a physiotherapist about what's safe for you to do.

Speak to your doctor and avoid exercise if you have any of these:

- Very low blood counts
- Bad skin reactions to radiotherapy
- New pain in your bones, neck or back
- Severe, persistent headaches
- Low platelet count or problems with blood clotting
- Pain in the chest, arm, or jaw
- Irregular heart rate
- Nausea, vomiting or diarrhoea
- Fever (a sign of infection)
- A sudden weakness in your muscles
- Recent pain or swelling in your joints
- Recent dizziness or fainting.

### **Where can I get help?**

Speak to your transplant team or GP about accessing exercise classes for free, or at a reduced cost. Your GP may be able to give you an exercise prescription for free sessions with a physiotherapist, or with a personal trainer at your local gym. Some gyms have programmes for people who have had cancer or other illnesses.

Have a look at what's available through your local hospice and support centres such as Maggie's Centres (see page 57).

Macmillan Cancer Support has a guide to getting more active called the *Move More* pack, and a 60-minute exercise DVD available on their website.



Macmillan Cancer Support has a very helpful booklet called *Coping with fatigue*, with practical tips for making day-to-day tasks easier – like shopping, cooking and looking after the house – as well as suggestions for ways to relax and get enough sleep. There's also advice on what to do if fatigue is affecting your work.

## EXPLAINING FATIGUE TO FRIENDS

'Other people often don't realise I'm tired, but it's invisible so why should they? I don't want to be going on about it all the time.'

*Anne had a transplant in 2011*

One of the big challenges of dealing with fatigue can be explaining it to those around you. Your friends, family and people at work may 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. On the other hand, your loved ones may be over-protective and not let you get on with things – which although well-meaning, isn't helpful.

It may help to show them this booklet, so they have understanding of what you're dealing with and what helps.

## LOOKING AFTER SOMEONE WITH FATIGUE

If you're close to someone who's going through a transplant, and if you're supporting them afterwards, it can be tough. If they're feeling exhausted you might find that you're helping around the home more or have to take on some of their activities. You can end up feeling tired and drained yourself.

Make sure you also take some time out to look after yourself. We have more information and support on our website at [anthonymolan.org/carers](http://anthonymolan.org/carers).

You might also find it useful to contact Carers UK and Macmillan Cancer Support.

# REAL STORIES

## PHOTO-THERAPY AND ME

For Pavlos, his camera helps him combat fatigue, giving him the motivation to get out and about, finding beautiful things to photograph near his home in London.

I had my transplant in 2010, but it wasn't for another two years that my fatigue started. It still continues, so I've found techniques to manage it.

I used to be a real adventurer, travelling around the world and taking photos as I went. After my transplant I began a form of psychotherapy which included photography. Now I use photography to express myself, focusing on things locally and photographing them as if I'm travelling.

I took the photograph of the green line on my way to the eye hospital where I have treatment for Graft versus Host Disease - it's there to guide people to the entrance.

The picture of the swan represents how I've learned to take life at a slower pace and just be, rather than being constantly on the go.

I know walking is good exercise for me, and going out with my camera motivates me to walk, even for a little bit. And having chronic fatigue doesn't mean I can't have a social life. My friends understand my boundaries and join me for walks or in some of the many cheerful cafes nearby. I enjoy photographing these times, as in the photographs with the daffodils and the glass.

Photo-therapy taught me I can still do the things I'm passionate about, like socialising and being creative, just on a smaller scale. It helped me stay positive and focus on the things I can do, not the things I can't.



## FINDING SUPPORT IN UNEXPECTED PLACES

When Peter felt he had to get his life back to normal, he found the motivation he needed in his family and local support groups.

A few months after my transplant in 2012 I spent a month in hospital with pneumonia, that was when my fatigue was at its worst. It was a struggle just to get up. I couldn't be discharged until I was able to walk down the hospital corridor. Somehow I made it, with the thought of seeing my new grandson, and a walking aid, to help me.

My wife Mary kept me going after that and made sure I kept up some kind of routine. And my consultant gave me a talking-to. He said "Peter, you're not yourself. Come on, you have to be motivated. You will get better". I knew I had to get back to normal.

Mary and I used to go away together so we booked a few days away in Wales. We make sure we escape for a few days of walking whenever we can. I joined a support group, which I never thought would be for me, but talking to a counsellor really helped. I joined a Macmillan walking group as well. There's good camaraderie; we help each other up the hills, and stop for a coffee at the end.

Gradually I've found I've got back to normal, looking after the grandchildren and doing DIY. To anyone with fatigue I'd say - be patient and be positive, take it one day at a time, and you'll get there.

## LEARNING TO PACE MYSELF AND FIND BALANCE

Having always been very active before her transplant in 2010, Sarah now uses meditation, Tai Chi and yoga to stay strong, calm and healthy.

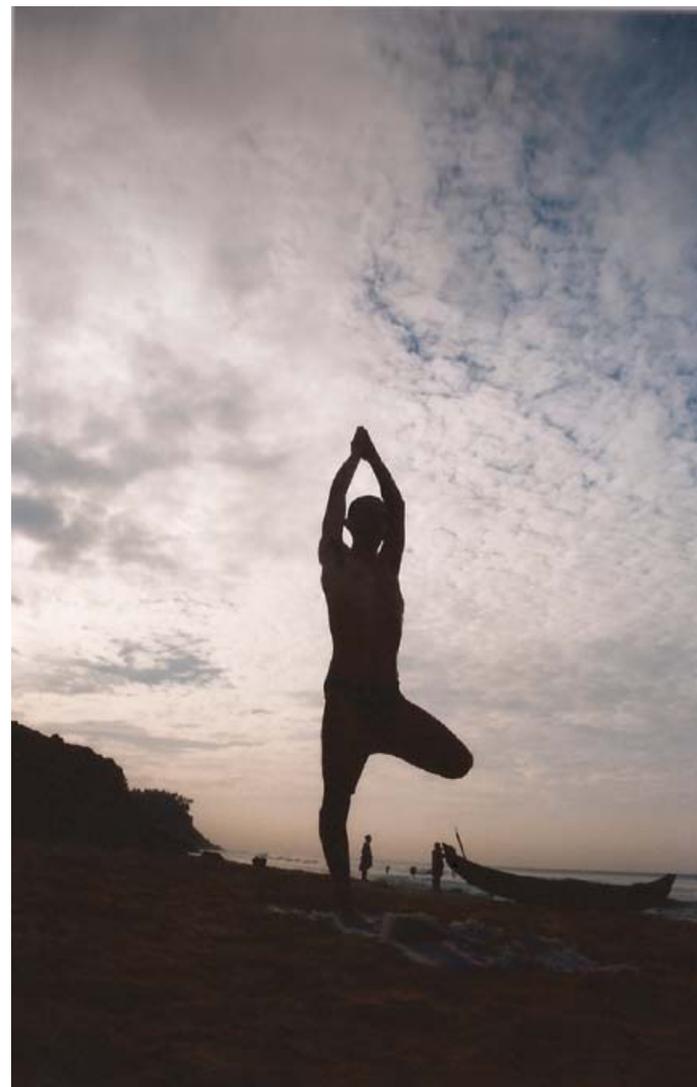
I was always very fit before my transplant, so it was a shock when I got home and couldn't make it up the stairs. For that first year I was in and out of hospital with infections and for lymphocyte infusions, and I couldn't eat much. That's where my fatigue came from.

It was walking that saved me. I pushed myself to walk every day. I walked to the hospital for my blood tests twice every week and climbed the six flights of stairs to the clinic.

Those days were exhausting but I didn't want to go to bed in the afternoon so I started doing guided meditation. Listening to the tapes did a lot of good. It was half an hour of just being calm.

A friend suggested I try a yoga DVD. The movements are slow, so I could build up my muscles really gently. Then my doctor recommended Tai Chi. It included elements of Chinese medicine which helped physically, mentally and with my wellbeing as a whole.

I'm not as fit as I was, but I recently ran 5K with my brother, my donor. I still get fatigue but I've come to accept it and pace myself. I don't feel like I have to finish everything on the to-do list, and I've learned to give myself permission to have a rest. It's about balance.





## MEDICATIONS PLANNER

To keep track of your medications, simply fill out the name of each of your prescribed medications down the left-hand side of the planner on the next page (and what they look like, if that's easier to remember) as well as the time of day you need to take them. You could set alarms at these times.

You can also buy containers (sometimes called dosette boxes) which allow you to separate your medications out into days of the week and times of day. You can buy them from pharmacies, or ask your transplant team or GP if you can be prescribed one.

Photocopy your chart or fill it out in pencil so you can update it each time your prescriptions change.

'Recovering from a transplant takes time. It can feel like you're not making any progress when in fact, slowly but surely, you are. Keep a diary and look back from time to time. See if you can see tiny improvements - you might be suprised by how far you've come.'

*Hayley, Anthony Nolan Post-Transplant Clinical Nurse Specialist*



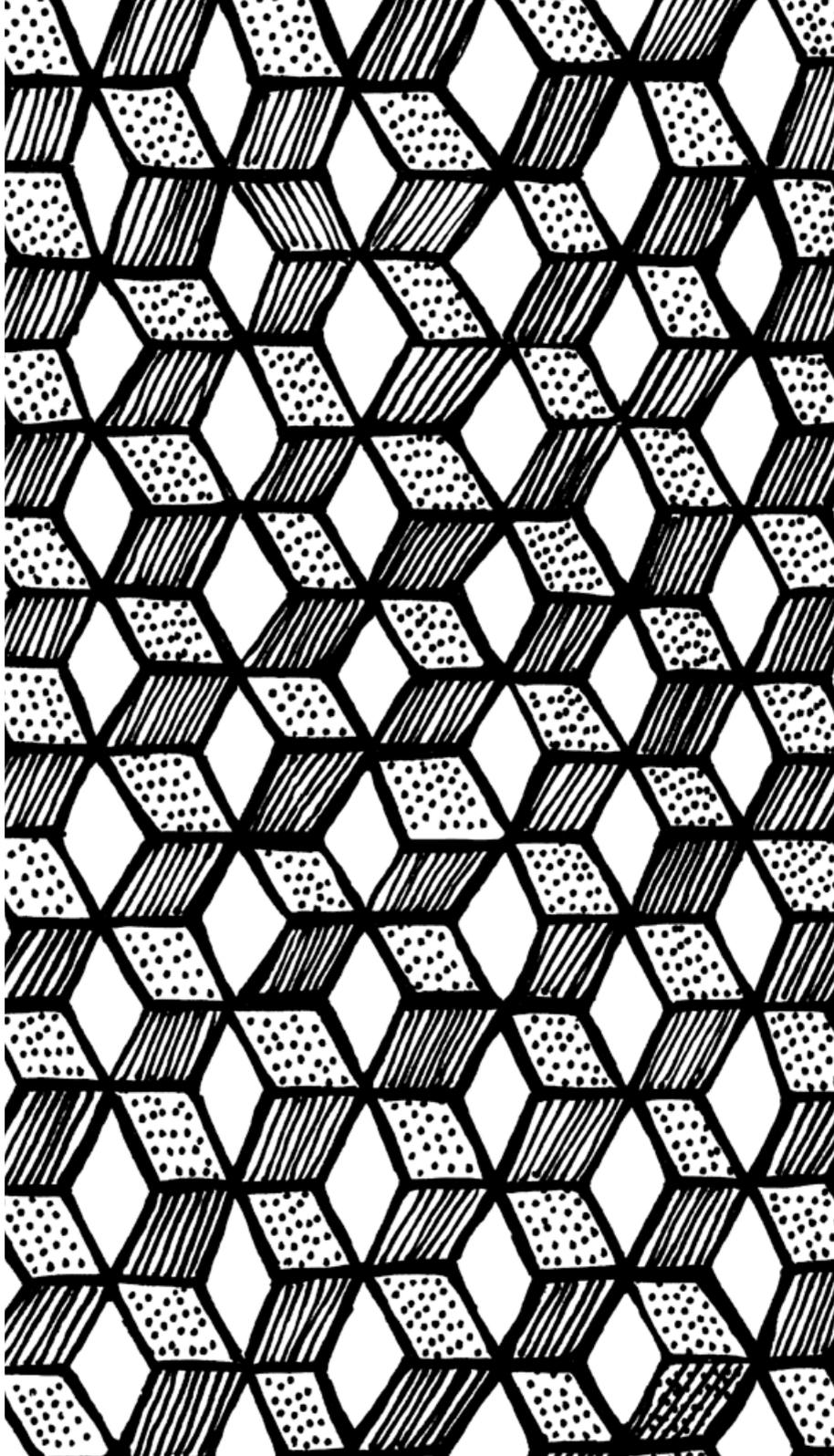
# WEEKLY FATIGUE AND ACTIVITY DIARY

*Photocopy this page so you can fill in this diary week by week.*

Use this diary to note down things like:

- how fatigued you feel
- your activities
- any symptoms you have
- how well you slept at night and if you slept in the day
- how you're feeling emotionally
- medicines you're taking or changes in medicines
- anything you would like help with.

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



## WE'RE HERE TO HELP

If you or a loved one are affected by bone marrow or stem cell transplant, there are many ways we can support you.

### Get connected

Find support from other patients and their families by joining our online transplant community at [anthohnolan.org/transplantcommunity](http://anthohnolan.org/transplantcommunity)

'I've had a lot of satisfaction from joining the Anthony Nolan online community. It has definitely helped in my recovery process to know there are others I can share my experiences with who understand. I would recommend it to everybody - patients, family and carers.'

*Peter had a transplant in 2012*

You can also share stories and find out more about our work on our Patients and Families Facebook page: [facebook.com/anthohnolanpatients](https://facebook.com/anthohnolanpatients)

### 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)

### Need to talk?

Before, during and after transplant, the Patient Experience team at Anthony Nolan are here for you. Call us on 0303 303 0303 or email [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)

### **Share your thoughts**

We work with a panel of people who've been affected by transplant to make sure we get our services and information right. And we'd love you to join them.

From sharing your experiences to coming up with new ideas and giving feedback on our resources and services: we need your ideas and insight. If you're interested in joining the panel, just get in touch!

### **Tell your story**

Nothing inspires people to help like hearing the story of someone affected by blood cancer. If you'd like to share your story, please contact us to find out more.

## **OTHER ORGANISATIONS THAT CAN HELP**

### **Active Scotland**

NHS Health Scotland's website which lets you search for nearby exercise activities (from easy to extreme).

**[www.activescotland.org.uk](http://www.activescotland.org.uk)**

### **British Association for Counselling and Psychotherapy**

Information about counselling and details of therapists in your area.

**Phone 01455 88 33 00**

**[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)**

### **Carers UK**

Advice, information and support for people looking after their loved ones.

**Phone 0808 808 7777**

**[www.carersuk.org](http://www.carersuk.org)**

### **Macmillan Cancer Support**

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

**Helpline 0808 808 00 00**

**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

### **Maggie's Centres**

A network of drop-in centres for cancer information and support. Includes free courses, emotional and practical support and an online support group.

**Phone 0300 123 1801**

**[www.maggiescentres.org](http://www.maggiescentres.org)**

### **The Mental Health Foundation**

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

**[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)**

### **NHS Choices**

Information about health conditions and treatments, including mindfulness and treatments for stress and low mood.

**[www.nhs.uk](http://www.nhs.uk)**

### **Penny Brohn Cancer Care**

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

**Helpline 0845 123 23 10**

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

### **The Royal College of Psychiatrists**

The College produces a range of materials for mental health professionals and the public – including information about sleep.

**[www.rcpsych.org](http://www.rcpsych.org)**

### **Self Management UK**

Free self-management courses in England (and online in parts of Wales) to help you manage your condition and take control of your health and wellbeing.

**Phone 03333 445 840**

**[www.selfmanagementuk.org](http://www.selfmanagementuk.org)**

### **Walking for Health**

Find a walk scheme in your area.

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

### **This publication was reviewed by:**

- Mandy Ellis, BMT Nurse Coordinator, Oxford University Hospitals NHS Trust
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- Professor John A Snowden, Consultant Haematologist & Director of BMT, Sheffield Teaching Hospitals NHS Foundation Trust & University of Sheffield
- The Anthony Nolan Patient and Families Panel

### **Ordering more copies**

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

The information contained in this booklet is correct at the time of going to print (September 2015)  
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To be updated September 2018

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.

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of people with  
blood cancer