ANTHONY NOLAN

Managing fatigue after a stem cell transplant

A Guide

At Anthony Nolan we take great care to provide up-to-date and accurate facts about stem cell transplants. 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. It 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, or to request it in an alternative format, please get in touch with us at patientinfo@anthonynolan.org

If you have any questions or comments about this resource, or would like information on the evidence used to produce it, please email patientinfo@anthonynolan.org

The information contained in this booklet is correct at the time of going to print (March 2026). We plan to review this publication within three years. For updates or the latest information, visit anthonynolan.org

Trusted Information Creator

Patient Information Forum

Anthony Nolan is a registered charity No 803716/SC038827

This publication was reviewed by:

- Orla McCourt, Specialist Physiotherapist, Haematology, University College London Hospitals NHS Foundation Trust
- Karen Nicholson, Clinical Nurse Specialist (Children & Young People), Anthony Nolan
- Anthony Nolan Patients and Families Network.

Author: Louise Jones

Editor: Rebecca Thomas

Designer: Jeremy Thompson

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@anthonynolan.org or on **0303 303 0303**.

XING WHO RECEIVED A STEM CELL TRANSPLANT

Contents

Key facts and tips

What is fatigue?

Fatigue is an expected side effect of a stem cell transplant. Up to 8 out of 10 patients will experience it in the first few months of recovery, and some for much longer.

What causes fatigue?

Fatigue can be caused by a combination of factors. These include pre-transplant conditioning therapy, graft vs host disease (GvHD), low red blood cells (anaemia) and your medication.

Can fatigue affect my mental health?

Yes, fatigue and your mental health are closely linked and can affect each other.

How can I manage fatigue?

Managing fatigue is a balancing act. On a good day, you need to try to not overdo it. But it's also important to try to do a little bit even on what feels like a bad day.

How can I monitor my fatigue?

Keeping a diary of your energy levels and activities will help you see when fatigue affects you most, so you can plan ahead. There's a fatigue diary you can use on **page 36**.

How can I reduce the impact of fatigue?

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

Who can I talk to about my fatigue?

If you have any concerns, talk to your medical team. They will be able to give the best advice for your individual situation on how to manage fatigue.

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

What is fatigue?

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's no standard set of rules 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
- feeling tired after small tasks or restful activities like watching TV
- 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?

Fatigue can develop at any time after transplant. But most patients start to feel fatigued during pre-transplant conditioning therapy. You might also notice it when you go home and struggle to do your normal day-to-day activities.

You might have felt like you had very little energy before your transplant took place. This early fatigue might have been due to your blood cancer or blood disorder and its treatment.

Fatigue can be a short-term effect that improves after a few months. But some patients still experience it more than a year after their transplant. Your experience of fatigue could be down to:

- your pre-transplant conditioning therapy
- your cancer or blood disorder
- side effects, such as graft versus host disease (GvHD), anaemia or hormone changes
- medications you're taking
- your age, general health and wellbeing
- feelings of anxiety, worry or depression.

For some people, fatigue may never completely go away. This could mean you need to make some permanent changes to your lifestyle so it's easier to cope 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 TO TREAT AML

What causes fatigue and what can I do about it?

Fatigue can have many causes. Some may be linked to your blood cancer or blood disorder and your transplant. But your general health and wellbeing can also make a difference.

> Fatigue tends to be a bigger concern for older patients and those who had a lower level of fitness before their transplant.

On the following pages we outline the main causes of transplant-related fatigue. We also include 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. 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 dietitian or physiotherapist, for further advice and support too.

Conditioning therapy

Before your stem cell transplant, you'll have had a course of treatment known as conditioning therapy. This consisted of **chemotherapy** and possibly **radiotherapy**. It prepared your body for transplant by removing the cells of your immune system. This included 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 healthy 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 a small number 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 TO TREAT AML

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'll have less of the red blood cells that normally transport oxygen around your body. This 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 can I do about it?

Unfortunately, conditioning therapy is an essential pre-transplant step so it's difficult to avoid the fatigue it causes. But improving your general fitness before 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 moist 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. This 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 TO TREAT AML

Why does it cause fatigue?

Food is the body's fuel source. So if eating certain foods becomes difficult, you could end up feeling tired and low on energy. To release the energy stored in food properly, the body needs lots of fluid and various vitamins and minerals.

What can I do about it?

- Three full meals a day can feel daunting, so try eating smaller potions more often.
- During your early recovery, focus on foods 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. Though it's best to avoid caffeine, you can enjoy weak tea or coffee. Water, juice, or cordial are great options. You might find it easier to sip water throughout the whole day.
- Ask to speak to a dietitian at your hospital. They will be able to give you further advice.

Sickness and diarrhoea

It's common to feel sick and be sick and have runny poo (diarrhoea), after your transplant. This can be caused by your treatment, medication, a possible infection or GvHD. Feeling sick normally only lasts a week or two for most people.

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 can I do about it?

- Your medical team can give you a medicine that stops you feeling sick, called an anti-emetic, or anti-diarrhoea medication, or both.
- Identify and try to avoid any foods that make your symptoms worse.
- Replace lost fluids by drinking water regularly. Isotonic drinks or sachets of oral rehydration salts replace lost salts and sugars, called electrolytes, that your cells need to stay healthy.

Anaemia

Anaemia is caused by having 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 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. Not having enough haemoglobin to carry the oxygen can leave you feeling tired or short of breath.

What can I do about it?

Anaemia treatment will vary depending on what's 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 supplements
- 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'.

Having mild GvHD can be a good thing. It shows your immune system is active and can attack any remaining or returning disease, as well as your body cells. But too much GvHD can cause side effects and can be very serious. 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, stressful process. The discomfort could affect your sleep and mental wellbeing.

What can I do about it?

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 booklet **Graft versus host disease (GvHD): A Guide**.

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.

> **"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 HAD TWO STEM CELL TRANSPLANTS TO TREAT AML

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 can I do about it?

- General tips for improving your quality of sleep are available on **page 26**.
- 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 booklet **Your mental health and stem cell transplant**.
- 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. This can cause fatigue. These include thyroid hormones, vitamin D, oestrogen and testosterone. Your medical team will offer hormone replacement therapy (HRT) if you need it.

Medication – it's likely you'll need to take lots of different medications during your recovery. Some of them could make you feel drowsy, especially if you've got to take a few medications together.

Pain and discomfort – experiencing pain and discomfort can be very tiring. You don't have to cope with it by yourself. Speak to your medical team who can adjust any medications or find other ways to support you.

If you have any concerns about anything we've mentioned here, you should talk to your medical team. They might be able to change either the dose or type of medications you're taking. And they can support you in other ways, to make your symptoms more manageable.

How can I manage my fatigue?

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.

There are four main ways you can help reduce the effects of fatigue:

- manage your energy levels
- physical activity and exercise
- sleep well
- delegate daily tasks.

Manage your energy levels

Many patients find 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 have more energy, only to need a nap in the afternoon. Listen to your body. Knowing how you're likely to react to certain activities will make it easier to manage your fatigue.

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

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 you've wasted your energy and had to miss out on something important to you.

Even if you're having a bad day, try to do at least one thing. It can be difficult but achieving something may make you feel more positive.

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.

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

Keep a diary – make a note of the activities you do and how you feel afterwards. This will help you to spot patterns and make changes to your routine. We've put together a fatigue diary on **page 36** you can photocopy and use.

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 know you're making progress in your recovery.

Physical activity and exercise

Exercise may feel like the last thing you want to do, but it can help reduce fatigue and boost your physical strength. You'll find your fitness, endurance and muscle strength will have 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?

Exercise can feel tough for anyone, let alone someone who has had a stem cell transplant. Try to follow these steps:

1. 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.
2. As your recovery continues, your physio will work with you to increase your physical activity. Focus on maintaining movements you need for everyday activity, like standing from sitting and walking. You can build up gradually. You'll probably find it more manageable to break down activities into small chunks with some rest in between.
3. Once you've left hospital, try to keep a routine of manageable movement. Then try to increase your activity. You could aim to walk to the end of the road and back one week, then aim to walk to a nearby shop the following week.
4. Find an activity you enjoy, like swimming, yoga, or walking with friends. Exercise should be fun. If you've got a favourite sport, it could be time to start playing again, or you could try something completely new.

JULIA WHO RECEIVED A STEM CELL TRANSPLANT

If you're really struggling with fatigue, or having a particularly bad day, 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 aiming to break up long periods of sitting or lying down by getting out of bed, having a wash and moving around indoors.

Top tip: We have lots more information and support on exercise and stem cell transplant in our booklet **An essential guide to diet and physical activity** and on our website.

"After my transplant I was very, very weak. I couldn't get up the stairs without taking a break because I was very short 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 STEM CELL TRANSPLANT TO TREAT AML

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. Your physiotherapist, or another member of your medical team, will be able to give you specific advice about exercising if this is the case.

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
- feeling sick
- being sick or having runny poo (diarrhoea)
- a headache that doesn't go away
- 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

Getting a good night's sleep should give you more energy and help your recovery. This means sleeping for the right number of hours and making sure your sleep is of good quality.

If you struggle with your sleep, it's worth recording your sleep pattern. You can do this with a wearable fitness tracking device, or by making a note of the hours you sleep. You and your medical team can look back on this, spot any patterns and work out how to help.

When should I sleep?

Our bodies have a natural built-in clock. This allows us to wake up in natural daylight feeling refreshed. Then it 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. This means it's important to limit daytime naps. Extra sleep during the day will not make you feel better because it does not 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. This will help avoid night-time disruption.

Preparing to sleep

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

- Ear plugs and blackout 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 does not 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 your mind doesn't wander to more stressful thoughts. You can find out more on the Be Mindful, Calm and Headspace apps and websites, and search for more online.

Delegate daily tasks

Even simple day-to-day tasks can be difficult for someone with fatigue. If you've got a support network around you, consider how they can help relieve the burden.

Relatives and close friends might be able to help around the house, especially with jobs like:

- making dinner so you know you're getting a good meal
- cleaning the house and emptying the bins that could be an infection risk
- childcare from time to time, so 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. Social workers can help to support you at home. Get in touch with your local social services, or ask your medical team or GP to refer you.

If you don't have a personal support network at the moment, you can still find sources of support. See the other useful contacts on **page 40**.

Fatigue and your mental health

Your mental health is closely linked to fatigue after a transplant. Fatigue can affect how you're feeling, your ability to cope, and your mental processes like memory and concentration.

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 processing them. This is not always easy but there are many techniques, healthcare professionals and charities that can help you.

Memory and concentration

During your recovery there could be times when you find certain mental tasks more difficult than you once did. This could include finding it difficult to:

- remember appointments
- remember the names of people or objects
- concentrate in general.

These problems are known as **cancer-related cognitive changes (CRCCs)**. They often happen along with fatigue.

You can read our booklet called **Memory and concentration after a stem cell transplant** to find out more about CRCCs and tips to manage symptoms.

In the meantime, here are a few tips 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, on your phone or on sticky notes in easy-to-see places.
- Always keep important things, like your phone and keys, in the same place so they are easier to find.
- If you've got a task to do, find a quiet place with few distractions to help you concentrate on it. 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.
- Having a daily routine and sticking to it will make things more familiar and easier to remember.
- Crosswords, jigsaws and other puzzles exercise the mind, helping memory and concentration.

> **"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."**

RACHEL MILLER ANTHONY NOLAN LEAD NURSE

Your emotions

There's no right or wrong way to feel during your recovery. There'll probably be times when you're worried, times when you're scared and times when you want to cry – and that's OK. But experiencing all these feelings can be exhausting. So, finding ways to process and cope with how you're feeling is important.

Ways to cope

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

Lift your mood – what you're going through is not easy, so enjoy the little things in life. Buy that slice of cake when it tempts you. Go out for a nice meal. Visit somewhere you've always wanted to go. Choose what you want, because you want it! 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 other 'talking therapies' can 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. Or, 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 place for cancer patients to focus on their recovery. They are run by specially trained healthcare professionals who can help with many topics including fatigue, nutrition and emotional support. They also provide recreational classes, professional talks and support groups.

Anthony Nolan offers a free Telephone Emotional Support Service (TESS) you may find useful. It's run by Working to Wellbeing, a team of wellbeing specialists with years of experience supporting stem cell transplant patients, so you'll be able to talk about whatever's on your mind. To find out more, call us on **0303 303 0303** or visit anthonynolan.org/tess.

On the Anthony Nolan Patients and Families Forum, you can read and talk about a wide range of topics related to stem cell transplant. 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: anthonynolan.org/recovery and our booklet **Your mental health and stem cell transplant**.

> **"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 TO TREAT CML

Living with fatigue

Explaining fatigue to friends and family

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. But really, you'll be recovering for quite a while.

> **"It's been difficult accepting that it's going to take a really long time before I feel like myself again. It's also hard for my family. My partner was expecting me to come home and have a couple of weeks recovery like many other surgeries and then life would go back to normal. It's been almost a year and I'm still having difficulties."**

BIANCA WHO HAD A STEM CELL TRANSPLANT TO TREAT APLASTIC ANAEMIA

You'll probably need help from others sometimes during your recovery. This could be helping with daily tasks like shopping and housework, but you'll also need their emotional support.

There may 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 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 how they could help.

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 your employer 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.

Top tip: We have a booklet called **Work and stem cell transplant: Information for employers** which can help to inform and support your workplace.

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

You can find more information in our booklet **Going back to work after your stem cell transplant**.

Looking after someone with fatigue

Helping your loved one through their transplant journey has probably become the most important thing in your life. Although you're likely happy to do it, it can still be physically and mentally demanding, especially if you've got other responsibilities. It may take time for you to adjust to your new supportive role.

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. Though many people will be happy to offer you support, 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 STEM CELL TRANSPLANT TO TREAT ALL

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 support your own mental and physical health and give you fresh energy to tackle any challenges ahead.

More information is available in the **Support for Parents, Family and Friends** section of the Anthony Nolan website.

Weekly fatigue 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 this page so you can fill in your diary week by week, if you like. You could also record this information on your phone, or use a tracker app, if you prefer.

	Morning	Afternoon	Evening	Night
Monday Date:				
Tuesday Date:				
Wednesday Date:				
Thursday Date:				
Friday Date:				
Saturday Date:				
Sunday Date:				

Anthony Nolan contact details

Where can I get more information and support?

If you or a loved one is affected by a stem cell or bone marrow 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@anthonynolan.org

Get connected

Find support from other patients and their families by joining our **Patients and Families Forum** at anthonynolan.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 anthonynolan.org/patientinfo

Other useful contacts

5k your way

5k your way.org

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

British Association for Counselling and Psychotherapy

bacp.co.uk
01455 883 300

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.

Citizens Advice

citizensadvice.org.uk
Adviceline (England): 0800 144 8848
Adviceline (Wales): 0800 702 2020

Advice on a wide range of issues, including financial and legal matters. Online chat available.

Couch to 5K

nhs.uk/better-health/get-active/get-running-with-couch-to-5k

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

Macmillan Cancer Support

macmillan.org.uk
0808 808 0000

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

Maggie's

maggies.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
Infoline: 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.

NHS Talking Therapies

england.nhs.uk/mental-health/adults/nhs-talking-therapies

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

parkrun

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 UK

pennybrohn.org.uk
Helpline: 0303 3000 118

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

Samaritans

samaritans.org
Helpline: 116 123

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

Teenage Cancer Trust

teenagecancertrust.org
020 7612 0370

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

Working To Wellbeing

working2wellbeing.com
0330 0552903

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

Young Lives vs Cancer

younglivesvscancer.org.uk
Helpline: 0300 303 5220

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

Notes

> **“It is very hard to feel so tired and not able to do normal things – but it does improve, and soon you are able to do so much more.”**

PETER WHO HAD A STEM CELL TRANSPLANT TO TREAT AML

This material was co-funded through a grant from Johnson & Johnson, who have had no control or influence over the content, information or design.

For further patient information:

anthonynolan.org/patientinfo
facebook.com/anthonynolanpatients
patientinfo@anthonynolan.org
0303 303 0303

Trusted Information Creator
Patient Information Forum

anthonynolan.org

ANTHONY NOLAN