

# YOUR MENTAL HEALTH AND **STEM CELL TRANSPLANT**



**ANTHONY  
NOLAN**

saving the lives  
of people with  
blood cancer



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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# YOUR MENTAL HEALTH AND STEM CELL TRANSPLANT



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**ANTHONY NOLAN**  
PATIENT SERVICES

# WHAT'S IN THIS BOOKLET?

Your stem cell transplant is likely to affect many aspects of your life, including the way you feel. There are likely to be many highs and lows that will have an impact on your mental health. This booklet highlights some of the issues you might experience and gives advice on how to come to terms with them.

It's been written with guidance and advice from our remarkable patients and healthcare professionals. They have shared their experiences with us to help you see that other people have come through similar difficulties.

There is information for carers, too, to help them look after their mental health during this challenging time.

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** or on **0303 303 0303**.

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# KEY QUESTIONS

## IS IT NORMAL TO FEEL LIKE THIS?

Having a stem cell transplant will probably be one of the most challenging experiences you will have to face, and there's no right or wrong way to feel. Everybody's recovery is unique, and all patients go through a wide range of emotions at different times on their transplant journey.

Many of our patients talk about how their mental struggles still come up months and even years after their transplant.

## HOW CAN THIS BOOKLET HELP ME?

This booklet focuses on how your stem cell transplant could affect your mental health, including the emotions you might feel, concerns about body image and its impact on family life.

It offers help on talking about difficult problems, and explains how a therapist can work with you to make them easier to cope with. It also highlights other ways charities and organisations can help you with your mental health.

## HOW WILL I COPE?

It can be difficult to know the best ways to cope with the challenges you might face. Many people use a variety of different techniques that work best for them. You might want to have a think about the things you did to help you through other difficult times in your life

– they may be useful again now.

We have also made some suggestions in this booklet as a starting point for you.

## WHAT WILL WORK BEST?

It might involve some trial and error but when it comes to finding your own coping mechanisms, you should trust your instincts. You might also find that different things work better at different times.

## HOW WILL I KNOW WHEN TO ASK FOR EXTRA HELP?

You don't have to wait until something is wrong before asking for help. Talking about what's on your mind will help you come to terms with your situation and might stop something turning into a bigger issue.

## HOW DO I FIND A THERAPIST?

If you would like to talk to a therapist, you can get a referral from your GP or medical team. If you live in England, you can also refer yourself through the Improving Access to Psychological Therapies (IAPT) scheme.

If your situation allows, you can also see a therapist privately. The British Association for Counselling and Psychotherapy (BACP) provides a list of their registered therapists online. Links for both organisations are available in the **other useful contacts** section on p60.

# YOUR MENTAL HEALTH – BEFORE, DURING AND AFTER TRANSPLANT



There's no right or wrong way to feel during your transplant journey. 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.

All stem cell transplant recipients experience a wide range of emotions before, during and after their transplant, and some will be difficult to deal with. Not everyone will go through these feelings in the same order or for the same amount of time. The important thing to remember is that you're not alone, your feelings are totally normal, and there's support available for you.

*'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 2006



## WHAT YOU MIGHT BE FEELING

### Depression

It's completely understandable if the uncertainty of having a stem cell transplant and concerns for the future leave you feeling low. Usually these feelings pass in due course but if they come back regularly for a few days at a time, it could be a sign that you're experiencing depression.

### Anger and sadness

Both feelings are part of the grieving cycle we go through before we can accept a situation and move on. Grieving doesn't have to involve the loss of a person – after a life-changing event like a transplant, people grieve for the life they used to have. Every patient has asked themselves, 'Why me?' at some point.

### Isolation

Feeling as though nobody understands what you're going through can lead to feelings of isolation. Living alone, having family members who are out for most of the day, or having a relatively small social group can lead to similar feelings.

Your stay in protective isolation directly after transplant can be a very difficult and challenging time, too. Please see our *Preparing for Hospital Isolation* guide for specific information and advice about this stage of your recovery.

### Anxiety

Not being able to plan for the future or feeling like you're not in control of your situation can make you feel anxious.

### Hope

If there are setbacks, it's not unusual to feel hopeless at times – but when your treatment is going well, it can feel great. This sense of progress can lead to thoughts of hope and positivity for the future.

### Loss

You might feel like you've lost the freedom you had before your diagnosis, or that you don't have full control of your situation. These feelings could be especially strong if you've not yet returned to work or had to give it up. You may also worry about losing the medical support you had in hospital.

### Determined

Self-managing parts of your recovery, such as your diet and exercise, can help you feel as if you're regaining control of your situation.

Sometimes these feelings are caused by practical problems that may or may not be in your control. If you're concerned about how your transplant could affect aspects of your day-to-day life, like returning to work or your finances, there are many sources of information that can help. Your medical team should be able to give you specific advice or put you in contact with their hospital welfare officer. **Citizens Advice ([citizensadvice.org.uk](https://citizensadvice.org.uk))** also offers support on their website.

For more information visit the Recovery section of our website: **[anthohnolan.org/life](https://anthohnolan.org/life)**

## WHAT IF MY TRANSPLANT DOESN'T WORK?

Despite your best efforts and the support of your medical team, family and friends, your stem cell transplant might not work. It's natural to feel worried, angry or sad about needing further treatment. All the feelings you had before your transplant may come back, perhaps even stronger than before.

You may not be able to have further curative treatment – the risk could be too high, or you might decide you don't want it. Whether you make this choice, or it's made for you, it can be really difficult to face. It's important that you know all your options, have time to think them through, and speak to your family and friends. Your medical team will support you at every step and answer any questions you might have.

During this time, you might benefit from developing your own coping mechanisms. As a starting point we've made some suggestions on p34. You also have the option of talking things through with a therapist (see p46).



# FAMILY LIFE



Having a stem cell transplant can be an intense and stressful time for everyone involved – including your partner, family and friends. People might react to you differently and the dynamics of your relationships could change. It's common to find the roles and responsibilities within your family environment shift, too.

You will probably go through a period where you need to rely on the help and support of others. Adjusting to this lack of independence can be challenging, particularly if you can't support others like you used to. It might be more difficult to deal with other people's problems during this time – but that's completely normal and understandable.

*'It's made us closer in many ways, which is positive. I'm a lot more protective over him though, which is probably annoying! I worry about him. Nearly two years on. I worry.'*

**Victoria**, whose husband Alex had a stem cell transplant in 2016

Our booklet *An Essential Guide to Sex and Relationships* has more information and advice for anyone who is having concerns after their transplant.



## YOUR PARTNER

The worry surrounding your stem cell transplant could make your relationship more complicated. For some couples, a situation like this brings them closer together as they support each other through their difficulties. But there could be times when the stress and anxiety that surrounds a transplant puts a strain on the relationship, too.

It will be important for you both to talk about how you're feeling so there are no misunderstandings. If your partner appears distant, help them open up about their feelings. They could be hiding their concerns because they don't want to burden you with extra worries.

If you are concerned about your relationship and feel like you need some help resolving your problems, have a chat with your medical team. They will be able to put you in contact with a therapist you can talk to, either with or without your partner.

## FAMILY

Your family routines are likely to change significantly during your time in hospital and as you continue your recovery back home. It might not be possible to still do some family activities together, and people might need to take on responsibilities they haven't done before. Involving everybody in discussions about how things are likely to change and how they can help will make them feel included.

Family members will also have fears about the future. Try to talk openly about your concerns and invite them to talk about theirs. It will help you support each other.

If you have young children or grandchildren, you may be unsure about how to talk to them about stem cell transplants and life afterwards. It's generally a good idea to let children know what is happening, but in language they will understand. That's why we've produced *Lucy and the Good Soldiers*, an illustrated storybook that explains stem cell transplants for children. You can order a free copy from our website: **[anthohnolan.org/booklets](http://anthohnolan.org/booklets)**

*'My children were at very vulnerable ages, eight and seven. It was important for me to explain that I was unwell, but that doctors were going to do what they could to make me better. They took it in their stride and they just continued with life as normal.'*

**Johnny**, stem cell transplant recipient

## FRIENDS

You're likely to become friendly with other stem cell transplant patients while you're in hospital and during your recovery. Often these friends support you in ways other friends and family might struggle with, because they're sharing the same experiences. Many people form deep, life-long friendships during this time.

Some friends will continue to make you laugh and support you, but others may find it more difficult. You might find that your relationships with some friends change and become a little awkward. This is often because they are uncomfortable with the situation and worry about saying the wrong thing. If you notice this and feel comfortable doing it, encourage your friends to be open and to ask questions about things they don't understand.

*'At first, I didn't want my friends to know, but now I understand that the community of people you are in is important too.'*

Kate, who had a stem cell transplant in 2015

## WIDER SUPPORT NETWORK

You will probably find that you can't do as much as you once could, and you need to be realistic about what you can manage. Having a strong support network around you, that can be relied on for both practical and emotional support, will help relieve the burden. This could be particularly important if you live alone.

Relatives or close friends might be able to help around the house, especially with jobs like emptying the bins which could be an infection risk. They may also be able to help with childcare from time to time, so you can get some rest. 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. Your clinical nurse specialist or hospital welfare officer can advise on the services available locally.

## IF YOU'RE A CARER

Helping someone through their transplant journey will probably become the most important thing in your life. Although you're probably happy to do it, it can still be difficult and demanding, especially if you also have to work and/or look after your family.

Just as patients have to get used to being less independent, it can take time for you to adjust to your new supportive role too. It's understandable if you find it hard to cope with this responsibility, while also worrying about if they're getting better.

Many carers feel guilty about admitting to their stress because they think they should always be strong for their loved one. However, it's perfectly ok to talk to them about feeling this way, and it will benefit your wellbeing in the long term.

Find time and space to enjoy things on your own. This might be simply phoning a friend for a chat or re-starting a forgotten hobby. Nobody will judge you for taking some time for yourself. It will reinvigorate you and give you fresh energy to tackle the challenges ahead. You also need to make sure you're physically looking after yourself as well as your loved one. If possible, try to maintain a healthy diet, sleep well and exercise regularly. It will help you feel better.

You might need emotional support, too. If you need to talk to somebody else about how you're feeling, there are options available. The medical team can put you in contact with a therapist, or you may benefit from sharing your story with people going through a similar experience. Your hospital and various charities organise local support groups you can get involved with. You can also get advice online from the **Anthony Nolan Patients and Families Forum**.

More information about how to support your partner practically is available on our website: **[anthohnolan.org](http://anthohnolan.org)**

*'I was lucky enough to get sessions with a counsellor, as I needed to talk to someone outside of what was happening to us. The sessions really helped me to cope with uncertainty. All the unknowns were such a struggle for me.'*

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

# BODY IMAGE



Soon after transplant, many patients focus solely on their health and whether their treatment has been successful. During this time, you might find you don't have a lot of confidence in your body and that any slight change, blemish or niggle is a sign of something more serious. As a result, you will probably become more in tune with your body and pay lots of attention to how it looks and feels.

These fears of something more serious developing will hopefully lessen over time, but you may still have concerns about how your body looks and responds to physical activity.



## WHAT IS BODY IMAGE?

Our body image is the way we think about ourselves and how we think we appear to others when we look in the mirror.

Whether you're preparing to start your conditioning therapy or recovering after your transplant, changes in body image are an important part of your journey. There could be times when you aren't happy with parts of your physical appearance or worried about how people react when they see you. The changes often mean different things to each person.

*'I had loss of hair, massive weight loss, and I looked quite frail. Friends and family just don't know what to say to you when they see you like that; you look so different to what they've known. But you are still you. I don't think I really prepared myself for the impact of it.'*

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

## WHY HAS MY BODY CHANGED?

Your body has probably undergone many changes during your conditioning therapy and in the time after your transplant. You probably expected some of them, as they affect most patients, but others may have come as a surprise and can be harder to get used to.

You may have already experienced:

**Hair loss** – Most patients lose their hair shortly after starting chemotherapy.

**Weight loss** – For a variety of reasons, eating enough food to sustain a healthy weight can be difficult, especially in the first few weeks after transplant.

**Skin changes** – GvHD can cause skin to become dry, blotchy or develop a rash. Some treatments can also cause scarring.

**Weight gain** – Long term use of steroids (used to treat GvHD) can cause weight gain.

Some of these changes are only temporary and many patients begin to feel more like their normal self quickly. However, some changes, such as those involving fertility and early menopause, can be very upsetting and have a big impact on your future plans. If you have any concerns, it's important to discuss them with your medical team so they can provide both practical and emotional support.

More information on how your stem cell transplant could affect you physically is available on our website: **[anthonymorgan.org/body](https://anthonymorgan.org/body)**

## REGAINING YOUR CONFIDENCE

When we're low in confidence, it's easy to dwell on the things that we think are wrong and forget about the things we like about ourselves, or that are going well.

It might not be obvious at first, but you will probably find that people who don't know you are less interested in your appearance than you might think.

Preparing yourself to be ready for how people might talk to you will make you feel more confident and help you stay in control of the situation. You may find some of the following suggestions useful:

**Don't push yourself** – It will take time to feel like you're getting back to normal. At times, the thought of seeing people and talking about what you're going through might seem daunting. Start off by seeing a few close friends in a place you feel comfortable, and then slowly build up to bigger social situations when you're ready.

**Be assertive** – Take control of the situation and only talk about things on your terms. If someone asks you how you are, be upfront and tell them what you would like to say. Try to have the confidence to say you aren't comfortable talking about certain things and change the subject to something else. You're in charge.

**Comedy** – If you feel comfortable making a joke of your situation, it can often help diffuse any awkwardness there might be.

**Strange questions** – Someone, especially a young child, could easily ask an inappropriate question about your appearance at some point. Have a think about how you would want to respond now, so it doesn't surprise you at the time.

## ORGANISATIONS THAT CAN HELP

Charities like **Look Good, Feel Better** ([lookgoodfeelbetter.co.uk](http://lookgoodfeelbetter.co.uk)) offer a range of services including online tutorials and makeover workshops for both men and women living with the effects of cancer treatment.

If you decide you would like to try wearing a wig, they're often available through your hospital, free of charge. **The Little Princess Trust** ([littleprincesses.org.uk](http://littleprincesses.org.uk)) also provides free wigs to children and young adults.

*'It's wrong to assume that men don't worry about hair loss, and that only women worry about their looks. Altered body image is important to men and women, so I always approach patients as individuals.'*

Hayley, Anthony Nolan Lead Nurse

# TAKING CONTROL OF YOUR RECOVERY AND LIVING WELL



Being away from the security of the hospital makes some people anxious. They can feel helpless and not in control of their situation. But if you're home, your recovery has begun and you're doing well. Now it's time to start 'owning' your recovery. It's the first step in regaining some independence in your life, helping you return to a new normal.

Recovering from a stem cell transplant will come with a unique set of challenges. Living a healthy lifestyle that includes regular exercise, plenty of sleep and a good diet will give you the best chance of feeling both mentally and physically stronger.

You probably feel like you already have lots of things to think about when it comes to your recovery. Recording your information in a diary or in our **My Transplant Tracker** app ([anthohnolan.org/patientapp](http://anthohnolan.org/patientapp)) will make you feel more in control.

## SETTING GOALS

Breaking down your big recovery targets into smaller, more manageable goals will make it easier to feel in control. When people can see improvement every day, it builds confidence and self-esteem. Your early goals might be simply having a shower and getting dressed, or taking your medication for a week without forgetting.

Remember to give yourself credit for the things you achieve. It's easy to always look ahead to the next step, the next goal. This might leave you feeling like you're always striving for something but not quite getting to where you want to be. Take time to notice what you have done and the progress you have made.

Feel free to set as many (or as few) goals as you want and are comfortable managing for now. Here are a few suggestions to get you thinking:

### Exercise

Being active and going outdoors improves your mental health as well as your physical strength. Regular physical activity has been shown to reduce stress, relieve anxiety and improve self-esteem. It's important to not overdo it as your fitness will have reduced during your treatment. Set yourself reachable goals, like going for a short walk, and build on them gradually over time.

More information is available in the **Exercise and keeping active** section of our website.

*'I think it's really important to constantly have some kind of goal, even if it's just to get out of bed that day.'*

Georgi, who had a stem cell transplant in 2015

### Sleep

Difficulties sleeping and mental health problems often go hand in hand. Many people know that stress and anxiety can make sleep more difficult. However, poor sleep can also contribute to a mental health problem starting or make an existing one worse.

Everybody feels better after a good night's sleep and it aids your recovery. If you record your sleep, you can look back at when problems occurred. This will help your medical team spot patterns and find ways to help.

Our *Managing Fatigue* booklet has more information on sleep hygiene.

### Diet

For many reasons, people often lose weight after transplant. But as you recover, your body actually needs more nutrients than usual to help your cells grow and repair. You might decide that you want to eat a certain number of calories per day or aim to eat five portions of fruit and veg. Eating healthily will help you feel both physically and mentally stronger.

### Fluids

It's important to keep yourself hydrated to aid your recovery. Your body's cells need water to work, and that includes your brain cells. Try to always drink one to two litres of non-caffeinated drinks every day. Keep a water bottle with you, it might be easier to drink smaller amounts more often.



## SET YOURSELF REMINDERS

There could be times when you find certain mental tasks more difficult than you once did – including remembering appointments, recalling the names of people, 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 feeling fatigued.

It's a good idea to come up with a strategy to help you keep on top of things, including:

**Appointments** – After your transplant, you will need to visit the outpatient department regularly to check that everything is going well and possibly tweak your medication. You'll also have regular blood tests to measure your blood count, liver and kidney function, and check for viruses.

**Medication** – Changes to medication will happen at times and adjusting to a new schedule can be hard. Putting reminders in your diary and storing the details will help make sure you don't miss any.

**Medical team** – During your transplant journey you will be at the centre of a large medical team that's responsible for giving you the best possible care. It can be hard keeping track of everybody's name and what they do, so make a note of everyone in your team.

More information on how your stem cell transplant could affect your memory and recognition is available in our *Managing Fatigue* booklet.

## RECORDING YOUR PROGRESS

There will be days when you are physically and mentally drained, but there will also be good days when you feel on top of the world. There are great benefits to recording your emotional wellbeing. You gain a sense of progress, but it also highlights when you need extra support from friends, family or a professional.

You should also record how you feel physically, and clinical data like your blood cell counts, to get a better idea of how your recovery is going.



# WAYS TO COPE



There could be times when you feel down or find it hard to cope with the impact your transplant is having on you. This is perfectly normal and something many patients go through. Finding the best way to manage these feelings will make things easier and help you be more resilient in the future.

It's impossible to say what will work best for you and some things may work better 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.

## TAKE CONTROL

**Find out more** – Some people worry about the unknown, and finding out more information about the challenges of recovery can make it easier to come to terms with.

Stick to information sources you know you can trust and avoid simply relying on internet search engines. If you have concerns, you can always ask your medical team for advice as well. Feel free to make notes about what they say or ask someone to come with you for support.

**Get organised** – There are many things to remember during your recovery, so try to settle into a routine. You will have days when sticking to your plan is more difficult but if you feel like you're doing something positive and that you're in control, it will help.

**Talk to someone** – As the old saying goes, 'A problem shared is a problem halved.' Sometimes simply talking to someone makes a huge difference. You can also talk to your medical team or a member of the Anthony Nolan Patient Services team. Some people also find comfort in talking to people within the community, such as religious leaders.

*'Physically I feel much stronger, however there are still days where I feel low and overwhelmed by everything. Luckily, I am able to talk to my family and friends when I am low and sharing this always makes me feel better. It's ok not to feel great all the time!'*

Anna, who had a stem cell transplant in 2016

## RELAX

**Deep breath...** – It might sound simple but taking a deep breath can really help calm your nerves. Practising controlled breathing will also help you relax. For more information on how to do this, please visit the **NHS Moodzone** website ([nhs.uk/moodzone](https://nhs.uk/moodzone)).

**Meditation** – You might be familiar with the idea of mindfulness or other types of meditation as a relaxation technique. Meditation helps you become more aware of your feelings and accept them for what they are. This allows you to think more clearly and react in a calmer way when things get tough.

**Health promoting exercise** – Techniques like tai-chi and yoga nidra combine gentle movements, stretching and breathing exercises with elements of meditation. This helps you to focus your thoughts on the present and relax your mind.

## LIFT YOUR MOOD

**Have a laugh** – Everybody has something that always makes them laugh, so get your favourite DVD boxset or search the online streaming services. You could ask your friends for their recommendations too.

**Music** – Make a playlist of your favourite songs that always lift your spirits.

**Treat yourself** – 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.

**Travel** – Is there somewhere in the world you've always wanted to visit? Now might be the perfect time to go on that trip. You should check with your medical team that it's safe for you to travel before you go.



## FOCUS ON SOMETHING ELSE

**Friends** – Spend time with people whose company you enjoy to help take your mind off your current situation. Sometimes it can be easier to be around people who aren't quite as involved with your recovery as your immediate family.

**Learn a new skill** – A wide range of courses can be taken through night schools or online including cookery, art and languages. You might even decide to re-train for a new profession. Distance learning courses, such as those run by the **Open University (open.ac.uk)**, can be a good way of doing this without the need to move or commute.

**Social groups** – If you have a particular interest, there could be a local group set up for people to share your hobby. Have a look on social media or in your local library to find out what's available in your area.

## EXPRESS YOURSELF

**Blog** – It can be therapeutic to write about your experiences, both good and bad. Even if you don't want to share your thoughts with others, writing them down can help you process them. You may also find comfort in reading the stories of other people who are going through a similar experience.

**Art and hobbies** – Some people find it hard to express their thoughts and feelings with words but find it easier to use other creative outlets. Drawing, painting, sculpting, poetry and creative writing can all help with this process.

**Singing** – Local choirs and other musical groups can be a great way of doing something you enjoy and meeting new people.



# TALKING ABOUT YOUR MENTAL HEALTH



Even though you might not always feel like it, talking about the difficulties you face on your transplant journey could make a big difference to how you're able to cope.

Different people will get different benefits from talking about their problems with other people. Sharing your concerns will help you feel supported and you could possibly get practical advice that you hadn't thought of before. Getting the opinions of other people may also help you come to a decision about which treatments to have or other important life choices.

Some patients worry about letting their family and friends know about what they're going through. Even if you feel like you should be protecting them, you need to let them know how they can help. Don't worry about feeling too demanding, they will want to do what they can or help find an alternative solution with you.

## HOW TO HAVE DIFFICULT CONVERSATIONS

Talking about mental health problems is often difficult and finding a way to start the conversation can be the hardest thing of all.

When it comes to talking about something that could be upsetting for you, have a think about who you're most comfortable talking to. For some people it's a family member or friend, but many people prefer to talk to someone they don't know as well. This could be a healthcare professional, a fellow patient or another member of their community.

Before you start, remember that many people have stresses in their lives that can cause struggles with their mental health. So even if they haven't had a stem cell transplant, they could still have experience of dealing with similar feelings.

You might find the following ideas helpful too:

- Try to gather your thoughts beforehand so you're clear about what to say. Writing notes might be helpful, especially if you're speaking to a healthcare professional.
- Find a relaxing and quiet place to talk, where you feel comfortable and no one is distracted.
- Expect to be asked questions. You don't have to answer everything if you don't want to, but it will help the other person understand what you're going through.

Letting someone else know is the first step in getting help and it will feel good to open up to someone. Please remember though that the difficult feelings might return, and it might take some time before you feel like you can handle your problems on your own.

## DON'T WANT TO TALK?

It can be emotionally draining to be asked, 'How are you feeling?' by everybody close to you. While they're trying to show they care, the thought of saying the same thing repeatedly can become stressful in itself. Have the confidence to say you would rather not talk about certain topics and try to direct the conversation to something you're more comfortable with.

Some patients decide to only confide in one or two close people and then ask them to relay messages to their wider circle of friends and family. Similarly, some patients use social media as a way of updating their progress.

There could be times when you would rather be alone with your own feelings and don't want to talk to anybody. This can be a good way to help process your thoughts, but you need to make sure you aren't bottling things up inside either. It's important to not completely shut yourself off from other people and to seek their help when you need it.

## SIGNS OF SOMETHING MORE SERIOUS

A time may come when you feel you need extra support to help you cope. It's not always easy to tell when this is, especially if you're feeling low. Your family may recognise this behaviour before you do and may want to talk to you about it.

If you start to experience some of the following, you should talk to your GP or medical team, who will talk you through various options including medication and talking therapies (see p48):

- You've been feeling very low and not like your usual self.
- You can't find the motivation to do anything, even important tasks.
- You regularly have trouble sleeping.
- You have lots of negative thoughts about yourself, the world and the future.
- You feel unable to control your thoughts.
- You're feeling much more anxious than usual.

Organisations like the **Samaritans** (freephone 116 123) can help too if you want to talk to someone right away.





# TALKING THERAPIES



Many people turn to family and friends for support when things get tough, but you might also benefit from trying a talking therapy. Your therapist will give you time and space to be heard and help you think about your situation differently. It might not make your problems go away but it should make it easier to deal with them.

You don't have to wait until you feel overwhelmed before seeking help. Talking therapies can help anybody at any time. Being able to recognise your feelings and process them in a controlled way might even help you avert a crisis before it begins.

Talking to a therapist can form part of your bigger strategy for looking after your mental health and living a healthy lifestyle.



## WHAT ARE TALKING THERAPIES?

When we experience difficult times in our lives, it can be easier to talk to someone we don't know. When we talk to a trained professional about our feelings and how we react to them, it's called a 'talking therapy'. You might hear this type of support called 'counselling' or 'psychotherapy'. They roughly mean the same thing – when we talk through our problems with someone. However, they can also be used to describe certain types of talking therapies.

Here we stick to the general terms 'talking therapies' and 'therapists'.

Each session with your therapist is usually a one-to-one conversation lasting about an hour. They will ask you how you're feeling and what makes you feel that way. They will discuss how you react to these feelings and work with you to help you change your behaviour in the ways that you want. This will help you feel more in control of your emotions.

*'I did some counselling with the Maggie's Centre. I really benefited from sitting down and talking to someone who was not personally involved. I had underestimated the value of that kind of therapeutic chatting. Sometimes you just need to take a step away from yourself.'*

Crispin, who had a stem cell transplant in 2013

## HOW CAN I GET THE HELP I NEED?

If you would like to try a talking therapy, your medical team or GP can refer you. In England, it's also possible to access free treatment through the **Improving Access to Psychological Therapies (IAPT)** programme. This NHS service allows people with stress and anxiety problems to refer themselves directly to services in their local area.

The NHS is likely to offer a course of roughly 6-15 one hour sessions, but this could vary greatly depending on your situation and how quickly progress is made. There could be a long waiting list on the NHS or you might decide to see someone for longer. If this happens, and your financial situation allows, you may want to consider paying for private therapy. You can find a registered therapist through the **British Association of Counselling and Psychotherapy (BACP)**.

If you would like to see a therapist privately but you're worried about costs, therapists and organisations may offer the following:

- A free taster session so you can be more confident it's the right option for you.
- Reduced rates for people on low incomes.
- Reduced rates for students.
- Your work may offer counselling sessions as an employee benefit or be willing to contribute as part of your return to work. Your HR department will be able to discuss your options with you.

You can apply to charities and other organisations for funding, including our **Anthony Nolan grants**. Charities like **Macmillan** and **Maggie's** also offer talking therapy sessions and other types of emotional support.

## WHAT ARE THE DIFFERENT TYPES OF THERAPY?

Many talking therapies have been developed to help people in different situations that could be either stressful or upsetting. There's no right or wrong answer for which type will be best for you because everybody and their situation is unique. Many therapists are trained in several different types and will tailor their approach to best suit your needs.

### Cognitive behavioural therapy (CBT)

On the simplest level, CBT has two main focuses – what you think about (cognitive) and how you react (behaviour).

When we have negative thoughts, we tend to react in a certain way, which can in turn make us feel worse. CBT is about working with your therapist to identify and challenge unhelpful or inaccurate thoughts. It focuses on the things you can change, while also helping you accept the elements of your life you can't control. For these reasons it can be very helpful for stem cell transplant recipients.

Your therapist will help you recognise when you're having negative thoughts and develop coping strategies with you, so you can act in a more balanced way. At first these new strategies may feel unnatural, and it can take effort and commitment to start using them more regularly. Your therapist may set you goals to work on between sessions.

### Counselling

In a counselling session, your therapist will listen to your concerns and how you're feeling without judgement. They won't tell you what to do to make things better, but they will work with you so that you can find your own solutions to the problems.

Counselling can help you cope with a variety of situations including depression, anxiety or difficult medical complications that you might be experiencing, such as fertility or body image.

Counselling doesn't have to be done face-to-face, it can be done over the phone or online if you prefer.

### Support groups

Sometimes simply being around other people going through something similar is reassuring. It helps you realise that how you're feeling is completely normal and can put your experiences in context of other people's. You might also pick up some tips about coping with your condition that you hadn't thought of before.

Local support groups are often set up by hospitals or through charities and organisations.

## FINDING THE RIGHT PERSON TO TALK TO

Just as your situation is unique, so is the relationship with your therapist. You will find you get on better with some therapists than you do with others. Talking therapies are of most benefit when you are comfortable enough to trust and talk openly with your therapist.

Research has shown that patients benefit most when their relationship with their therapist is stronger. This means it's important that you have the confidence to speak out when you think it isn't working. There's nothing wrong with asking to see someone new if it helps you more. Your therapist may even suggest it themselves if they think someone else would be better suited to you.

## WHAT IF THERAPY ISN'T FOR ME?

Although talking therapies have helped many stem cell transplant patients, they aren't for everyone. Some people try them and find no real benefit. There's nothing wrong with this and it certainly isn't your fault. It could have simply been that the timing wasn't right or that another approach suits you better.

There are various alternatives to talking therapies that you might want to consider, including medication. However, medications can also have side effects, so make sure you get all the information you need first and talk through your options with your medical team and close family before deciding.



# FURTHER SOURCES OF SUPPORT

Nobody expects you to deal with everything on your own. There are lots of charities and other organisations that offer support in a variety of ways to help you during your transplant journey.

We have outlined some of the services provided by us and other national charities, but there are many others organised locally. Your medical team can give you information on the services in your area.



## PEER SUPPORT

Patients can often feel isolated because their immediate family and friends aren't going through the same experience as they are. Although they will be as supportive as they can, it's not the same as talking to someone who is going through the same thing.

Talking to other patients about your concerns, and hearing how they deal with theirs, will help you put your situation in context. You can give each other support and encouragement.

Macmillan's **In your area** webpage ([macmillan.org.uk/in-your-area](https://macmillan.org.uk/in-your-area)) signposts to similar services that support patients with any type of cancer, including blood cancers.

Our **Peer Support Service** enables patients to talk to other transplant recipients on a one-to-one basis over the phone. You can talk about any subject you want and get advice on how to deal with it.

You can refer yourself to the service through your clinical nurse specialist or directly via email: **[patientinfo@anthohnynolan.org](mailto:patientinfo@anthohnynolan.org)**





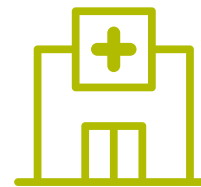
## ONLINE SUPPORT

Online forums could be more suitable if you would prefer to not talk about your concerns out loud. 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.

On the **Anthony Nolan Patients and Families Forum** you can read and talk about a wide range of topics related to stem cell transplants. More general subjects on living with cancer and cancer treatments are discussed on the **Macmillan** online forum.

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

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



## CANCER CENTRES

Various charities, such as **Macmillan** and **Maggie's**, fund purpose-built cancer centres with the aim of supporting patients and their families. They are often found in the grounds of hospitals and 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 you with many topics including nutrition, financial advice and emotional support. They also provide recreational classes, professional talks and support groups.

Maggie's also provides valuable online support for people who don't live close to one of their centres.

Please note, most cancer centres are only able to support patients who have had a stem cell transplant to treat a blood cancer. If you had a transplant to treat a blood disorder, unfortunately these services won't be available.

*'When I persuaded my husband to go a local Maggie's Centre he finally started to feel better inside himself. His mental state had taken a considerable battering and that was something that I couldn't help with. Maggie's Centre were brilliant and he came away feeling more confident and calm – things that we all as a family benefited from!'*

**Kate**, whose husband had a stem cell transplant in 2011

# USEFUL CONTACTS

## ANTHONY NOLAN PATIENT SERVICES

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@anthonymolan.org**

### GET CONNECTED

Find support from other patients and their families by joining our **Patients and Families Forum** at: **anthonymolan.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: **anthonymolan.org/patients-and-families**

### PEER SUPPORT

Our peer support service is provided over the phone by a trained volunteer who has been through a stem cell transplant at least two years ago. **anthonymolan.org/peer\_support**

## CLINICAL NURSE SPECIALISTS

Anthony Nolan funds, recruits and supports specialist nurses based in UK transplant centres, to raise the standard of post-transplant care around the country. We want patients and families to have equal access to services and support at all stages of recovery, for as long as it's needed.

## CLINICAL PSYCHOLOGISTS

Anthony Nolan also funds several clinical psychology posts based in UK transplant centres to help patients come to terms with the emotional impact of their stem cell transplant.

## RECOMMENDED RESOURCES

**How Are You Feeling? The Emotional Effects of Cancer** Macmillan Cancer Support

**A Young Person's Guide to Stem Cell Transplant Journey** Anthony Nolan

**Life After Transplant: An Essential Guide to Sex and Relationships** Anthony Nolan

**Looking After Someone With Cancer** Macmillan Cancer Support

**Bereavement and Stem Cell Transplant** Anthony Nolan

# OTHER USEFUL CONTACTS

## BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY (BACP)

**bacp.co.uk**  
**01455 88 33 00**

Information about counselling and therapists in your area. Local services can be searched at the following link **bacp.co.uk/about-therapy/how-to-find-a-therapist/**

## IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES (IAPT)

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

Allows patients to self-refer to NHS funded counselling and therapy services available in their local area. Local services can also be searched using the following link **nhs.uk/service-search/Psychological-therapies-(IAPT)/LocationSearch/10008**

## MACMILLAN CANCER SUPPORT

**macmillan.org.uk**  
**0808 808 0000**

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

## MAGGIE'S CENTRES

**maggiescentres.org**  
**0300 123 1801**

Maggie's helps anyone affected by cancer. You can talk to and get support from a range of professionals in any topic related to your treatment or recovery.

## MIND

**mind.org.uk**  
**0300 123 3393**

Provides information and support for any mental health related issue.

## RELATE

**relate.org.uk**  
**0300 100 1234**

Information, advice, relationship counselling and sex therapy.

## SAMARITANS

**samaritans.org**  
**116 123**

Offers a confidential free helpline where you can talk about anything that is concerning you, 24 hours a day.

# NOTES

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‘PHYSICALLY I FEEL MUCH STRONGER, HOWEVER THERE ARE STILL DAYS WHEN I FEEL LOW AND OVERWHELMED BY EVERYTHING. SHARING ALWAYS MAKES ME FEEL BETTER. IT’S OK NOT TO FEEL GREAT ALL THE TIME.’

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



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



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