

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

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

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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.

If you're an unpaid carer, there's a section for you too. It gives advice on how to look after your mental health during this challenging time.

This booklet has 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.

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 difficulties with mental health 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, such as:

- emotions you might feel
- concerns about body image
- its impact on your 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 – you might find these useful again now.

You can also use some of our suggestions in this booklet as a starting point.

What will work best?

When it comes to finding your own coping mechanisms, it might involve some trial and error. But 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 can 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.

Anthony Nolan has a free Telephone Emotional Support service that you may find useful:

[anthonynolan.org/tess](https://www.anthonynolan.org/tess)

If you're able to spend some extra money, you can also see a therapist privately. The British Association for Counselling and Psychotherapy (BACP) provides a list of their registered therapists online. You can find contact details for both organisations in **Other useful contacts** on p61.

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 feel worried, times when you feel 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.

Everyone who has a stem cell transplant experiences a wide range of emotions before, during and after their transplant. Some of your thoughts and feelings will be difficult to deal with. Not everyone will go through these feelings in the same order or for the same amount of time. It's important to remember that:

- you are not alone
- your feelings are totally normal
- there is 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

What you might be feeling

Depression

It's completely understandable if the uncertainty of your stem cell transplant and concerns for the future leave you feeling low. Usually these feelings pass in due course. But it could be a sign that you're experiencing depression if the feelings:

- interfere with your life
- don't go away after a couple of weeks
- come back over and over again for a few days at a time.

Anger and sadness

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

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 quite a 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. For specific information and advice about this stage of your recovery, see our booklet on **Preparing for hospital isolation.**

Anxiety

You might feel anxious about not being able to plan for the future or feeling like you're not in control of your situation.

Hope

If there are setbacks, it's not unusual to feel hopeless at times. But it can feel great when your treatment is going well. This feeling 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. If you're going home, you may also worry about losing the medical support you had in hospital.

Determination

Self-managing parts of your recovery, like 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's plenty of information to help you. Your medical team should be able to give you specific advice or put you in contact with their hospital welfare officer. Citizen's Advice also offers support on their website.

For more information, please visit the **Recovery: Life** section of our website at: anthonymolan.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 difficult feelings you had before your transplant may come back, perhaps even stronger than before.

You may not be able to have further treatment to fully cure your condition – 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 and understand all of your options
- have time to think through the options
- speak to your family and friends, or people close to you.

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 ways to cope. As a starting point we've made some suggestions on p28. You could also talk things through with a therapist, which you can find out more about on p46.



Family, friends and home life



Having a stem cell transplant can be an intense and stressful time for everyone involved – this includes your partner, family and friends. You might feel that people treat you differently and the dynamics of your relationships could change. It's also common to see a shift in the roles and responsibilities within your home life.

You will probably go through a period where you need to rely on the help and support of others. Getting used to this lack of independence can be hard, particularly if you can no longer support others like you used to. You might find it more difficult to deal with other people's problems during this time – but that's completely normal and understandable.

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 their relationship.

It will be important for you both to talk about how you're feeling so there are no misunderstandings. If your partner seems 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 feel concerned about your relationship and you need some help, have a chat with your medical team about your problems. They'll be able to put you in contact with a therapist you can talk to, either with or without your partner.



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. Years on, I worry.

Victoria, whose husband Alex had a stem cell transplant to treat CML

For information and advice for anyone who is having concerns after their transplant, see our **Sex and relationships** webpage: anthynolan.org/relationships

Family

Your family routines are likely to change a lot during your time in hospital and while you recover at home:

- you might not be able to do all the family activities together that you used to
- people might need to take on responsibilities they haven't done before.

Help make everybody feel included, by involving them in discussions about how things might change and how they can help.

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.



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, who had a stem cell transplant

Friends

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

Some of your older 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 of them 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 them 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

Wider support network

You'll probably find that you can't do as much as you once could. You might need to try being realistic about what you can manage. Having a strong support network of people around you, who you can rely on for both practical and emotional support, will help make things easier. This could be particularly important if you live alone.

Relatives or close friends might be able to help out in the place you live, especially with jobs like emptying the bins which could be an infection risk to you. They may also be able to help with childcare from time to time, so you can get some rest.

If you can afford it, paying for a cleaner would also give you more 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 local services.



If you're an unpaid carer

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

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

Try some of our advice and tips:

- **Talk to your loved one about how you feel.** Many carers feel guilty about admitting to their stress because they think they should always be strong for their loved one. But it's perfectly ok to talk to them about feeling this way. It will benefit your wellbeing in the long term.
- **Find time and space to enjoy things on your own.** This might be phoning a friend for a chat or taking up an old hobby. Nobody will judge you for taking some time for yourself. Doing this can give you fresh energy to tackle the challenges ahead.
- **Keep your body healthy.** You 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 to feel better.

- **Seek support from other places.** 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 might find our Telephone Emotional Support service useful: anthohnolan.org/tess. It might also help to share your story with people going through a similar experience. Your hospital and various charities organise local support groups you can join. You can also get advice online from the **Anthony Nolan Patients and Families Forum**.

More information about how to support your loved one practically is available on our website: anthohnolan.org/parentsfamilyfriends



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 stem cell transplant to treat ALL

Body image



Soon after having a 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. You might also worry that any slight change, blemish or odd feeling 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.

Over time, you should hopefully feel less worried about something more serious developing. But you may still have concerns about how your body looks, and how it 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.

Whether you're preparing to start conditioning therapy before your transplant or recovering afterwards, changes in your body are an important part of your journey.

There could be times when you're not happy with parts of your physical appearance. Or you might worry about how people will react when they see you. These physical 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 to treat AML

Why has my body changed?

Your body has probably gone through many changes during conditioning therapy and in the time after your transplant. You might have expected some of them, as they affect most patients, but others may feel like a surprise and could 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 all sorts of reasons, eating enough food to stay at a healthy weight can be difficult, especially in the first few weeks after transplant.
- **Skin changes** – Some people experience graft vs host disease (GvHD) after a stem cell transplant. GvHD can cause skin to become dry, blotchy or develop a rash. Some treatments can also cause scarring.
- **Weight gain** – Your doctor might give you long-term steroids to treat GvHD, which can cause weight gain.

Some of these changes are only short term and many patients quickly begin to feel like their normal self again. However, some body changes can be very upsetting and have a big impact on your future plans. For example, some people experience fertility issues and early menopause.

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 the physical effects of a stem cell transplant is available on our website:

anthohnolan.org/body

Regaining your confidence

When our confidence and self-esteem are low, we tend to only think about things that we feel are bad or wrong. We forget about the things we like about ourselves, or things that are going well.

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

Preparing yourself for how people might talk to you will help you feel more confident and able to 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 scary. Start off by seeing a few close friends in a place where you feel comfortable. You can 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 when you aren't comfortable talking about certain things and change the subject to something else. You're in charge.
- **Use humour.** If you feel comfortable making a joke of your situation, it can often make things feel less awkward.

- **Be ready for strange questions.** Someone, especially a young child, could ask an inappropriate question at some point about the way you look. Have a think now about how you might want to respond, so that you don't feel surprised at the time.

Organisations that can help

Charities like **Look Good Feel Better** offer a range of services like online tutorials and makeover workshops for people living with the effects of cancer treatment. You can visit their website at:

lookgoodfeelbetter.co.uk

If you decide you'd like to try wearing a wig, you might be able to get one through your hospital, free of charge. **The Little Princess Trust** also provides free wigs to children and people up to 24 years old. You can visit their website at:

littleprincesses.org.uk

Taking control of your recovery and living well



Being away from the security of the hospital makes some people feel anxious. You might feel helpless and not in control of your 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 getting some independence back and helping you settle into your new version of normality.

Recovering from a stem cell transplant comes with a unique set of challenges. To give you the best chance of feeling both mentally and physically stronger, try to live a healthy lifestyle with regular exercise, plenty of sleep and a good diet.

You probably feel like you already have lots of things to think about when it comes to your recovery. To help you feel more in control, record your information in a diary or in our **My Transplant Tracker app**. Find out more about it our website: anthohnolan.org/patientapp

Setting goals

Breaking down your big recovery targets into smaller, more manageable goals might make it easier to feel in control. When you can see daily improvement, it builds your confidence and self-esteem. Your early goals might be simply having a shower, 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 or goal. But this might leave you feeling like you're always fighting to achieve something, without 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. You need to feel comfortable about what you can manage. 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
- improve self-esteem.

Try not to do too much, as your fitness levels will have reduced during your treatment. Set yourself reachable goals, like going for a short walk. You can build on them gradually over time.

For more information, see our website section on Exercise and keeping active:

[anthonynolan.org/exercise](https://www.anthonynolan.org/exercise)



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 to treat ALL

Sleep

Sleeping problems and mental health problems are often linked. For example, stress and anxiety can make sleep more difficult. However, poor sleep can also contribute to mental health problems developing, or make existing problems worse.

We all feel better after a good night's sleep, but it also aids your physical recovery. If you record your sleep, you can look back at when you had problems. This will help your medical team spot patterns and find ways to help.

For more information on getting a good sleep, see our booklet on **Managing fatigue**.

Diet and weight

For many reasons, people often lose weight after transplant. But as you recover, your body needs more nutrients than usual to help your cells grow and repair. Eating healthily will help you feel both physically and mentally stronger.

For example, you might decide that you want to:

- eat a certain number of calories per day
- aim to eat five portions of fruit and vegetables.

Fluids

It's important to keep yourself hydrated to aid your recovery. Your body's cells need water to function – including your brain cells. Try to drink between one and two litres of non-caffeinated drinks every day. Carry a water bottle with you around the house or if you go out, as it can be easier to drink smaller amounts more often.

Setting yourself reminders

There could be times when you find certain mental tasks more difficult than you once did, like:

- remembering appointments
- recalling the names of people
- concentrating on things in general.

These problems are known as **cancer-related cognitive changes (CRCCs)** because they affect the way we recall and process information. You can often experience these alongside 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'll often need to visit the outpatient department. This is to check that everything is going well and possibly make changes to your medication. You'll also have regular blood tests to measure blood count, liver and kidney function, and check for viruses.

- **Medication.** Sometimes doctors will make changes to your medication, but getting used to a new schedule can be hard. Putting reminders in your diary or saving the details in your phone will help make sure you don't forget.

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

For more information on how your stem cell transplant could affect your memory and recognition, see our webpage:

[anthonynolan.org/cognition](https://www.anthonynolan.org/cognition)

Recording your progress

There will be days when you feel physically and mentally drained, but there will also be good days when you feel on top of the world. It can really help to record your emotional wellbeing in a diary. 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, plus 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 effects of your transplant. This is perfectly normal – it's something many people go through. Finding ways to manage difficult feelings will make things easier and help you be more resilient in the future.

We are all different, so it's impossible to say what will work best for you. Some things may work better at different times. Try to think about other tough points in your life, and what you did to help you get through. You might find that these methods come in useful again.

Take control

Find out more – Some people worry about the unknown. If you feel this way, finding out more about the challenges of recovery can make it easier to come to terms with.

Stick to information sources you know you can trust and try to avoid relying on web searches. If you have concerns, you can always ask your medical team for advice. Feel free to make notes about what they say, or ask someone to come along with you for support.

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

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, like 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

Relax

Take a 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, visit the **NHS Moodzone** website.

Try meditation – You might have heard 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.

Do exercises that help with wellbeing – Exercises like tai chi and yoga nidra combine gentle movements, stretching and breathing with elements of meditation. This helps you to focus your thoughts on the present and relax your mind.

Lift your mood

Have a laugh – We've all got something that always makes us laugh. Try watching your favourite comedy show, film or listening to a podcast. You could ask your friends for their recommendations too.

Listen to music – Make a playlist of your favourite songs that always make you feel happier.

Treat yourself – What you're going through isn't easy, so enjoy the little things in life. Buy that slice of cake if it tempts you, go out for a nice meal or do something you've always wanted to do. Whatever takes your fancy, do it.

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.

Try to focus on something else

See friends – Spend time with friends 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 – You can study a wide range of courses through night schools or online, like cookery, art and languages. You might even decide to re-train for a new profession. Distance learning courses can be a good way of doing this without the need to move or commute. Check the **Open University** website to see if there's anything you like the sound of.

Join 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, online or in your local library to see what's available in your area.

Express yourself

Blogging – It can feel beneficial 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 going through similar experiences.

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

Singing – Joining local choirs and other musical groups can be a great way to do something you enjoy and meet new people.



Talking about your mental health



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

Different people get different benefits from talking about their problems with other people:

- Sharing your concerns will help you feel supported. You might even get practical advice that you hadn't thought of before.
- Getting the opinions of other people may also help you make decisions. This could be about which treatments to have or other important life choices.

Some people 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 like you're too demanding** – they'll want to do what they can, or help you find another solution.

How to have difficult conversations

Many of us find that talking about mental health problems can be difficult. The hardest thing of all can be finding a way to start the conversation.

When it comes to talking about something that could be upsetting for you, think about who you're most comfortable talking to. For some people it's a family member or friend, but others 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 experience stress and difficulty in their lives that can make their mental health harder to cope with. So even if they haven't had a stem cell transplant, they could still have experience of dealing with similar feelings.

You might find it helpful if you try to:

- **Be prepared.** 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.
- **Be relaxed.** Find a relaxing and quiet place to talk, somewhere you feel comfortable and no one can get distracted.
- **Be ready for questions.** Expect to be asked questions about how you're feeling. You don't have to answer everything if you don't want to, but it helps the other person understand what you're going through.

Letting someone else know is the first step in getting help – it might feel good to open up to someone. But please remember that your difficult feelings could still come back. It might take some time before you feel like you can handle these feelings on your own.

Don't want to talk?

It might start to feel emotionally draining to be asked by people close to you, '*How are you feeling?*' While they're trying to show they care, the thought of saying the same thing over and over can feel stressful. It might help if you try to:

- Have the confidence to say you would rather not talk about certain topics.
- Direct the conversation to something you're more comfortable with.

Some people only share their progress with one or two close relatives or friends, then ask them to pass messages on to their wider circle of friends and family. In the same way, some people prefer to use social media as a way of keeping people up to date.

There could be times when you'd rather be alone with your own feelings and don't want to talk to anybody. While this can be a good way of processing your thoughts, you need to make sure you aren't bottling things up inside either.

It's important to not completely shut yourself off from others. You should 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 with your mental health. It's not always easy to tell when this is, especially if you're already feeling low. People around you or healthcare professionals may notice this behaviour before you do. They may want to talk to you about it.

If you start to experience some of the following for longer than a couple of weeks, you should talk to your GP or medical team. They can talk you through options like medication and talking therapies (see p46). If you:

- Have been feeling very low and not like your usual self.
- Cannot find the motivation to do anything, even important tasks.
- Regularly have trouble sleeping.
- Have lots of negative thoughts about yourself, the world and the future.
- Feel unable to control your thoughts and emotions.
- Feel much more anxious and on-edge than usual.

If you want to talk to someone right away, organisations like the Samaritans can help. You can call them for free on 116 123.



Talking therapies



Many people turn to family and friends for support when they experience poor mental health, but another option is talking therapy. A 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 give you the tools to make them easier to deal with.

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

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.

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 these professionals called therapists, counsellors or psychotherapists. Terms like these can also be used to describe certain types of talking therapies. They mean roughly the same thing – a session where we talk through our problems with someone.

In our booklet, we'll use the general terms **talking therapies** and **therapists**.

What happens in talking therapy?

A session with your therapist is usually a one-to-one conversation lasting about an hour. In each session, they should:

- Ask you how you're feeling and what makes you feel that way.
- Discuss how you react to these feelings.
- Work with you to help you change your behaviour in the way that you want.

Together with your therapists, you'll find ways to help you feel more in control of your difficult feelings.



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

How do I get the help I need?

If you would like to try a talking therapy, your medical team or GP can refer you to NHS mental health services. The NHS is likely to offer a course of between six and fifteen sessions. Each session should last about an hour. But this depends on your situation and how quickly you make progress.

In England, you might also be able to access 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.

There could be a long waiting list for NHS services, or you might decide you want to see someone for longer. If this happens, and you're able to afford it, you could consider paying for private therapy. You can find a registered therapist through the **British Association of Counselling and Psychotherapy (BACP)**.

If you'd like to see a private therapist but you're worried about costs, some therapists and organisations may offer:

- 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 people in full-time education.

Anthony Nolan has a free Telephone Emotional Support service that you may find useful, available for stem cell transplant patients and family members. You can talk about whatever's on your mind with wellbeing specialists Working To Wellbeing over a series of phone calls. Find out more at: anthodynolan.org/tess

Your place of work may offer counselling as an employee benefit, or be willing to contribute to therapy costs as part of your return to work. Ask your HR department to explain your options.

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

What types of talking therapies are there?

Different talking therapies help people in different situations. Most of the time, it's to help people through situations that could be either stressful or upsetting.

There's no right or wrong answer for which type will be best for you – everybody's situation is unique. Many therapists are trained in several different types. They can 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**
- how you react – **behaviour**.

We tend to react in a certain way to our negative thoughts, 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 parts of your life you can't control. For these reasons, people who have had stem cell transplants often find it helpful.

In CBT, your therapist will help you recognise when you're having negative thoughts and develop coping strategies with you. These new strategies may feel unnatural at first – it can take effort and commitment to start using them more regularly. Your therapist may set you goals to work on between sessions. In time, CBT aims to help you to react in a more balanced way.

Counselling

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

Counselling can help you cope with a variety of situations, like:

- depression
- anxiety
- difficult medical issues 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, video call, or by online messaging if you prefer.

Support groups

You might feel reassured by simply being around other people going through something similar. It can help you in different ways:

- You might start to realise that how you're feeling is completely normal.
- You can put your experiences in context of other people's.
- You might 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 with others. You might find that talking therapy is more effective when you feel comfortable enough to trust and talk openly with your therapist.

Research has shown that people 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 else if it helps you more. Your therapist may even suggest it themselves if they think another person 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 could consider, including medication. However, medications can also have side effects, so make sure you get all the information you need first. Talk through your options with your medical team and close family before deciding to start taking medication to help with your mental health.

Further sources of support



Nobody expects you to deal with everything on your own. Many charities and other organisations can offer support in lots of ways to help during your transplant journey.

We've listed some of the services that we provide, as well as other national charities, but there are many others organised locally. Your medical team can give you information on the services in your area, or you can try searching online.

Peer support

People who have stem cell transplants can often feel isolated because their immediate family and friends aren't going through the same experience. Although they're trying to be as supportive as they can, it's not the same as talking to someone who understands the experience.

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, known as **peer support**.

You could get this support from:

- **Macmillan**. Visit the **In your area** webpage at: [macmillan.org.uk/in-your-area](https://www.macmillan.org.uk/in-your-area). Find a list of signposts and information about local services that support patients with any type of cancer, including blood cancers.

Online support

Online forums could be better if you'd rather not talk about your concerns out loud. You can take your time and be as involved in the discussion as much or as little as you'd like. Some people take great comfort in reading about the experiences of others without feeling like they need to contribute themselves.

You could get this support from:

- **The Anthony Nolan Patients and Families Forum**, where you can read and talk about a wide range of topics related to stem cell transplants. Visit: [anthonynolan.org/forum](https://www.anthonynolan.org/forum)
- **The Macmillan online forum**, where you'll find discussions of general subjects on living with cancer and cancer treatments. Visit: community.macmillan.org.uk



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

Cancer centres

Charities like **Macmillan** and **Maggie's** fund purpose-built cancer centres with the aim of supporting patients and their families. They're often found in the grounds of hospitals. These centres:

- Provide a calm and tranquil place for cancer patients to focus on their recovery.
- Are run by specially trained health professionals who can advise you on topics like nutrition, finance and emotional support.
- Can provide recreational classes, professional talks and support groups.

Maggie's also provides 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

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@anthohnolan.org

Telephone Emotional Support

Our Telephone Emotional Support service is available free for stem cell transplant patients and family members. You can talk about whatever's on your mind with wellbeing specialists Working To Wellbeing. Find out more at:

[anthohnolan.org/tess](https://www.anthohnolan.org/tess)

Get connected

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

Find information

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

[anthohnolan.org/patients-and-families](https://www.anthohnolan.org/patients-and-families)

Clinical nurse specialists

Anthony Nolan funds, recruits and supports specialist nurses based in UK transplant centres. By doing this, we aim 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. These psychologists help patients come to terms with the emotional impact of their stem cell transplant.

Other useful contacts

British Association for Counselling and Psychotherapy

bacp.co.uk

01455 88 33 00

Information about counselling and therapists in your area. You can search for local services by visiting: **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 in England to self-refer to NHS-funded counselling and therapy services in their local area.

You can search for local services by visiting: **nhs.uk/service-search/mental-health/find-a-psychological-therapies-service**

Macmillan Cancer Support

macmillan.org.uk

0808 808 00 00

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

Maggie's Centres

maggiescentres.org

0300 123 1801

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

Mind

mind.org.uk

Helpline: 0300 123 3393

Mental health charity offering information, advice and support to anyone experiencing a mental health problem. Includes an online forum for peer support.

Relate

relate.org.uk

0300 100 1234

Information and advice about relationships, including counselling and sex therapy.

Samaritans

samaritans.org

Helpline: 116 123

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



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 always makes me feel better. It's ok not to feel great all the time.

Anna, who had a stem cell transplant



anthonymolan.org/patientinfo

facebook.com/anthonymolanpatients

patientinfo@anthonymolan.org

0303 303 0303



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