

The Seven Steps

The Next Steps

A handbook for
long-term recovery after
a stem cell transplant

**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



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ANTHONY NOLAN
PATIENT SERVICES

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Written by Michelle Kenyon

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We would like to gratefully acknowledge all the patients and their carers we've met over the years whose experiences have inspired *The Next Steps*. Their ideas and suggestions are the foundations upon which this booklet has been created.

We're thankful to the patients and members of the BSBMT executive and EBMT (UK) NAP who gave their time generously to comment on the various drafts of the first edition. We're also grateful to the members of the Anthony Nolan Patient and Families Panel for their help with this edition. While developing the booklet with the help of patients, we learned a lot about their individual needs and experiences after transplant.

What's in this booklet?

The information and tips in this booklet are based on our experience, current research and our discussions with our patients – people who have been where you are now.

We hope it will help you understand more about the long-term effects of a bone marrow or stem cell transplant – and make your journey to recovery a little easier. Your family and those close to you might also want to read it so that they can learn a little more about your recovery.

Use this book as you wish. You might want to read it all the way through or look at the Steps you think will answer your questions.

For many patients, a stem cell transplant offers not only the chance of a cure, but also the chance of a normal quality of life. The road to recovery is different for everyone. You might find that you recover well without too many problems. Or you may find things more difficult and demanding – physically and psychologically.

Both of these experiences are normal and help is available for everyone, even those who may not appear to need it.

In this guide you'll find information about the side effects and complications you might come across, what treatments and support can help, and what you

can do to manage some of these things.

For a small group of people, the long-term and late effects of the transplant can have a very serious impact on their general health and wellbeing. As some of the problems we discuss may be life-changing or even life-threatening, you may find some of the information upsetting and hard to read.

This guide covers most possibilities – but it doesn't mean that you'll get all of these side effects. Getting information about what to expect can help you feel more prepared to cope with the challenges that may lie ahead. Remember your transplant team will be monitoring you closely and you can always go back to them if new things crop up.

You might recognise some of the topics discussed from *The Seven Steps* booklet, available from Blood Cancer UK. In this booklet, we hope to address some of these in more detail to help you understand more about your transplant journey.

If you ever need to ask any questions or would like to discuss anything in this booklet, please don't hesitate to get in touch with your transplant team. You will have a key worker who will be happy to provide information or support. Or contact the Patient Services team at Anthony Nolan – you can reach them at **0303 303 0303** or by email: patientinfo@anthonymolan.org

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Step One

Taking care of yourself
after your transplant

1

What's in this step?

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- Keeping in touch with your team
- Contact with your donor
- Helping others

Leaving hospital



Leaving the hospital couldn't come soon enough, and recovery was frustrated by my own will to get better.

Simon, who had a stem cell transplant in 2014

When you leave the hospital for the first time after your transplant, there can be a sense of nervous excitement and anticipation. It can also be quite scary.

You'll have spent a number of weeks learning the day-to-day routine of blood tests, observations and medications while you have been under the constant care of your transplant team. So the process of going home can be an anxious time for some.

In reality, you are never truly alone. Your transplant team will make sure that you leave the hospital with instructions about what to do if you become unwell. They will also give you the names and numbers of people to contact if you have any questions at all.

Checklist of things you may need before you go home:

- A list of contact numbers for the transplant centre.
- Arrangements for taking care of your central venous catheter (CVC – this may be a Hickman line, central line or PICC line) or advice about how to look after it yourself.
- Advice about nutrition and your diet.
- Medication and information on how to take it.

- Appointments for outpatient blood checks, outpatient clinic and investigations such as bone marrow tests.

Although you're ready to leave hospital and an important phase of your transplant process is complete, there are still some months of recovery ahead.

If you are finding it difficult to manage at home or are feeling more unwell than you did in the hospital, please speak to your healthcare team.

The road to the new you



We're told life is a journey - well how fortunate am I, because of my stem cell transplant, to get the chance to do the journey again!

Carole, who had a stem cell transplant in 2014

As you move along the road to recovery, you may start thinking about the experience you've had and the journey so far. You may also start to think about what happens next.

Having a transplant is a life-changing event, either in the short-term, long-term or both. Even when you feel settled into everyday life again, many people find that their values have changed or their approach to life is different.

You might look or feel physically different from before. Further readmissions to hospital are common and you may experience other complications that impact on your physical recovery. This can be emotionally

challenging. It's quite normal to need help and support in adjusting.

You might feel more anxious or less motivated than you did. Please tell your team how you are feeling so that they can talk to you about available emotional and psychological support. This is an important part of your care and recovery, and we have further information on our website (anthonymolan.org/mind).

Many people say that their daily life changes after a transplant, although this can still mean they feel satisfied and fulfilled.

Getting out and about and seeing people



I started with 10-minute walks just to get out of the house and then progressed to longer walks. Getting exercise definitely helped me to keep positive.

Mel, who had a stem cell transplant in 2017

You may feel uncomfortable with noise and stimulation of the world around you. It's best to avoid crowds and public transport at peak times for a few months while your immune system recovers. You should also avoid anyone with infections or who has been in contact with an infection during the early months after the transplant.

If you're not sure what's safe to do, ask your team for advice. It's better to adjust goals than to take risks or end up doing nothing at all.

What helps?

- Try to have the flexibility to do things when you feel ready – rather than being committed to things before you feel up to it.
- Aim to start going out again as soon as you feel up to it – it's an important part of your recovery. To start, do something as simple as walking to the end of your garden or street. Start making plans to see people and do normal things. This will help you feel better. You might visit friends, for example, or you may go shopping – and this is fine, too, as long as you go at quiet times.
- You may meet people who haven't seen you for a while. It can be difficult to know what to say but it can help to take someone along with you. It's nice to have the company, and it's reassuring to have someone else there.
- Limit physical contact initially to family and those really close to you to control the number of close contacts you have.
- To regain confidence in social situations, try starting with something familiar, like the school run or going to the corner shop. This can help you become surer of yourself and what you feel able to do.

Use your common sense to guide you in decision-making. Set yourself step-by-step goals, like Peter did:



After my transplant, I could hardly walk to the gate and someone had to help me get into the car. But with encouragement from the medical team, my wife Mary and I decided to start walking up and down the drive, then to the end of the road, and then 25 yards to the park. Mary and my nurse practitioner really helped to motivate me.

Peter, who had a stem cell transplant in 2012

Appetite, taste changes and food hygiene



For the first six weeks after leaving hospital, I was very weak and struggling to eat properly. But after that I noticed progress every day.

Mel, who had a stem cell transplant in 2017

Food hygiene

In the early days of your recovery, your team may have advised you about eating a 'clean' or 'neutropenic' diet to help prevent infections from bacteria in food.

Once your blood counts have recovered, you don't need to stick to this advice, but take care to cook foods thoroughly, wash your hands and fresh foods

well, and keep the kitchen clean to protect yourself from infection. You can talk to your team about this if you're unsure.

Appetite

Your appetite may not be as good as it was before the transplant for a long time. Appetite and weight loss can make you feel tired. You might not feel like eating much, but during your transplant and the recovery phase, your body needs more nutrients to renew and repair cells and tissue.

Partners and carers often spend time preparing your favourite meals. But you may feel quite fussy about your food which can be frustrating for you as well as those around you. It's easy to fall into the trap of becoming very focussed on food, particularly when eating can be difficult.

If you're taking cyclosporine, you should avoid grapefruit and any products that contain grapefruit.

What helps?

- Try to make mealtimes as relaxed and calm as you can.
- Try having your food served on a small plate.
- Try eating little and often – snacks such as yoghurts, ice-creams and cereal bars.
- Choose foods you can prepare quickly and easily – ready meals or convenience foods are useful when you're feeling tired.
- Try 'food fortifying' – add high-calorie, protein-rich foods to meals or snacks, butter and cheese in a baked potato or cream in soup.

- Go for foods that you really fancy and are easy to eat.
- Keep experimenting with different textures and flavours to find foods that work.

Some of this advice might seem to turn your normal diet on its head. You'll probably need to change back to a lower fat diet later on when your weight and energy levels are more stable.

Advice about diet is individual and will often change during the transplant process.

Changes in taste and smell

It's common for food and drink to taste, feel and smell different for some time. Taste and texture experiences vary widely with some describing all foods as tasting bland or greasy or favouring sweet over savoury and vice versa.

This is because treatments such as chemotherapy, infections, mucositis and medication can damage and affect your taste buds.

The changes tend to gradually go back to normal; many patients report that the sense of sweet taste is often the one that comes back first.

Please talk to your transplant team about what tastes different or what can help. Ask to see the dietitian at your transplant centre who can suggest ways to boost your appetite and energy levels, as well as how to work towards achieving a healthy weight.

Try these ideas to help with taste and smell changes:

Issue	Suggestion
<ul style="list-style-type: none"> ■ food tastes like cardboard or cotton wool 	<ul style="list-style-type: none"> ■ opt for tart foods like citrus fruits
<ul style="list-style-type: none"> ■ food tastes metallic 	<ul style="list-style-type: none"> ■ this could be iron in red meat (try switching to different protein sources like chicken, turkey, fish or lentils) or your medication (please speak to your transplant team)
<ul style="list-style-type: none"> ■ food seems tasteless 	<ul style="list-style-type: none"> ■ opt for stronger flavours to heighten your sense of taste
<ul style="list-style-type: none"> ■ food smells increase nausea 	<ul style="list-style-type: none"> ■ try cold foods which smell less than hot

Take care of your mouth to keep it feeling fresh and get rid of stale tastes:

- Rinse your mouth with salty water, or bicarbonate of soda dissolved in water.
- Chew sugar-free gum or mints.
- Brush your teeth regularly.
- Drink plenty of fluid to prevent dehydration and keep your mouth clean.

Managing fatigue

It's common to feel tired or fatigued. In fact, fatigue is one of the most common problems that people talk about after transplant.

Fatigue is more than the usual feeling of tiredness after lots of work or a bad night's sleep. It doesn't go away or stay away with sleep or rest. It can make you feel both physically and mentally drained, and you can find it hard to concentrate on simple things.

Fatigue can be caused by a combination of things related to your treatment, particularly conditioning therapy, your cancer or blood disorder itself, any side effects you may have, and their treatments.

Fatigue can be a short-term effect of treatment that gets better over a few months. Others still experience fatigue beyond the first year after their transplant. It can help to know you're not alone.

It's important to talk to your transplant team so they can see if anything is affecting your energy levels and advise you on how to improve the way you feel.

What helps?

- Try to pace yourself and balance rest with activity, and rest during the day if you need to.
- When you're having a good day, try not to do too much.
- If you're having a bad day, try to do a couple of really small things.
- Eat a balanced and healthy diet.
- Drink plenty of fluid.

- Try to get a good night's sleep (see *Sleep* on p21).

Exercise

Exercise may feel like the last thing you want to do, but research shows that light-to-moderate exercise adjusted to your needs, can help reduce treatment-related fatigue. It can improve your physical strength and emotional well-being.

It's normal for your fitness, endurance, and muscle strength to decline so it's important to exercise at a level that's manageable for you now.

You may be able to get an exercise prescription or referral to use a gym, or have sessions with a personal trainer or physiotherapist. Some centres organise an exercise group, or may be able to refer you to one.

You can find lots of suggestions and tips from other people who have had a transplant at [anthonynolan.org/fatigue](https://www.anthonynolan.org/fatigue) and in our booklet *Managing Fatigue After a Stem Cell Transplant*, including tips on balancing your energy levels, being active and getting a good night's sleep.

Sleep

Getting enough rest is an important part of staying healthy. After transplant, people often talk about difficulty getting the right amount of sleep and this can persist for many months or even longer. Some find that they are sleeping much more than usual. Other people talk about insomnia (inability to get enough sleep to feel rested).

Excess sleep, too little sleep, daytime sleepiness, restlessness and increased dream activity or nightmares can impact on your ability to feel well and manage day to day activities. For some, this disruption in sleep can be distressing. Feeling too tired or fatigued from treatment and having sleep problems sometimes go hand in hand.

Please talk with your team if you're feeling affected by sleep changes. There are treatments and support services that can help.

Macmillan and Cancer.Net have more information about coping with sleeping difficulties and tips for improving your rest. The Royal College of Psychiatrists also has a helpful factsheet that can be accessed online at [rcpsych.ac.uk/mental-health/problems-disorders/sleeping-well](https://www.rcpsych.ac.uk/mental-health/problems-disorders/sleeping-well)

Relationships and dealing with change

Having a transplant can be an intense and stressful time for everyone involved – including partners, family and friends. After several weeks in hospital and the challenges of treatment and recovery, there can be a lot of changes in all your lives.

You may find it helpful to bring your partner, friend or relative to your appointments. They can be involved in your recovery, help to take in the information that is given to you, and think of questions to ask.

As you start to put your treatment behind you, you may feel less dependent on others. You may experience changes in your relationships with them, and it's common to find your roles and responsibilities change. With time, you may find you're ready to start taking on some of these responsibilities again.

What helps with relationships?

Here are a few things that other people have found useful:

- Making time together.
- Planning and working through problems together.
- Taking things step-by-step and being flexible.
- If you have children, keeping them involved in the same routine as before.
- If you're in a relationship, it may help to develop a routine, and have things you do together – make time for dinner, time to relax, and schedule in times when you'll speak to other family members and friends or respond to their emails. This can help things feel more secure and predictable.

Getting information and emotional support can help, either by yourself or with your partner, family or friend. Look out for group sessions or courses at your hospital or cancer support centre or speak to your GP about a referral. You'll find further advice at [anthonynolan.org/sex-and-relationships](https://www.anthonynolan.org/sex-and-relationships)

Managing at home

For some people, getting a little help at home with chores such as routine housework or cleaning can be a useful way to keep on top of things until you feel stronger.

If you are in a situation where you are having difficulty managing at home and could do with more help, your local authority's social services department or GP might be able to advise.

You, or someone caring for you, can contact social services for a formal assessment to see whether you need any services. This could include:

- Equipment, or adjustments to your home.
- Help at home: for example, with getting dressed, cooking, housework or shopping.
- Breaks away from home, either for you or the person caring for you.

Partners and family members

If you're a partner or family member of somebody who's had a transplant, then having access to some support for yourself may help you look after your own health and wellbeing. You can speak to the transplant team, and you could also try activities such as exercise, massage, yoga and meditation.

If you've had a transplant yourself, it can be useful for your partner or family members to get information about what to expect – that way, any side effects won't come as a surprise.

We have more information and support for partners and family members on our website at anthohnolan.org/patients-and-families

Managing your finances

Many people find that having a transplant has a significant impact on their finances. It will take time before you're ready to return to work, and you may need someone at home to look after you some of the time. You may need advice to help manage your finances and access information on mortgages and insurance.

It's important to get the right support so you can focus on your health. Your team will be able to point you in the right direction for help and advice.

Benefits and financial guidance

You may be entitled to benefits, including sick pay, or state benefits such as Universal Credit. You may be eligible for help towards equipment costs, adaptations to your home, or heating through your local authority.

Have a look at gov.uk for more information on their benefits and Universal Credit pages. The website has a 'benefits calculator' to help you work out what benefits you may be able to claim.

Grants

Anthony Nolan Grants are available to people affected by a transplant who have limited savings. Grants are typically under £200 and can help to meet a wide range of practical needs arising from a stem cell transplant. Further information is available on anthohnolan.org/grants or by emailing patientinfo@anthohnolan.org

Macmillan Cancer Support (macmillan.org.uk) also offers grants, which you may be eligible for. Grants from other charities or organisations are available too. Speak to your key worker or contact your local Citizen's Advice (citizensadvice.org.uk) or the charity Turn2us (turn2us.org.uk) which offers a list of various UK grants.

Free prescriptions

You should be able to get free prescriptions because you have had a transplant which is a cancer treatment, even if you weren't diagnosed with cancer. Ask your GP or transplant team for a 'FP92A' form which you need to send away to get your prescription exemption card. Each card lasts five years so make sure you renew it before the expiry date.

What helps?

- Find out if your hospital does a parking season ticket, or if they have concessions for people with cancer or other illnesses to save on parking costs.
- You might be eligible for a disabled badge for parking (the Blue Badge Scheme).

- If you're living in London and are an older person or disabled, you can get a Freedom Pass. There's also help available for other local transport costs countrywide.
- If you're claiming benefits, you may be able to reclaim your travel expenses associated with your hospital appointments such as train fares. Ask your key worker for more details on how to claim.
- Carers can often get financial support as well – the agencies listed on p25 will have further information.

Returning to work or education



I was able to manage my return to work gradually. I still underestimated how tired I would get and overdid it!

Mel, who had a stem cell transplant in 2017

There are no hard and fast rules about when you should return to work or education – whether you work or study full or part time, go out to work or look after a home or children.

There are wide variations in when people actually go back to work, with some not returning to work at all.

If possible, you should not consider committing yourself to work pressures until you feel fully able to cope physically and emotionally. However, you may need to return to work earlier than you would choose for financial reasons.

Initially you may feel more tired and find it hard to concentrate for long periods of time at work. This

generally improves but it's still important to get adequate periods of rest.

Generally, it's fine to return to work whenever you feel ready, but you should discuss it with your doctor first.

For those returning to education, speak with your school or university so that you can agree the best time to return and on what basis, whether part-time or full time. They will also be able to provide guidance to help you catch up with subjects you have missed and study tools that can be helpful during your recovery.

When returning to education, there must be flexibility so that your education needs can be met whilst also allowing for ongoing recovery and appointments where needed. The school nurse and leads for pastoral care can support your well-being during this time.

What helps?

- Let your employer or education establishment know about the full impact of having a transplant. If you don't feel like talking about it, you could give them a supporting letter from the hospital or some of our publications to read.
- Talk to your HR or occupational health department if your company has one. You could also contact your union. For those returning to education, the school nurse is a good contact point.
- Give your employer, school or university suggestions that would help you, such as taking extra breaks, working or studying from home, or flexible hours. Working part time to start with as a 'phased return', or changing your job role or duties for a while can also be helpful.
- Allow extra time at first to get ready for work or school and travelling.

- Your medical team may be able to help you access information about your employment rights, and there might be a welfare or benefits adviser or information centre at your hospital.

As someone with blood cancer or a blood disorder, your employee is protected under the Equality Act 2010 in England, Scotland and Wales, or the Disability Discrimination Act 1995 in Northern Ireland. This means that it's illegal for them to be discriminated against at work or to be treated less favourably for reasons relating to their ill health. Under these laws, your employer has a duty to make 'reasonable adjustments' to where and how you work, and to make sure you get the same chances as the people you work with.

Citizen's Advice offers free, confidential and impartial advice about your rights at work, information for employers and support for benefits. Macmillan Cancer Support provides financial guidance, access to benefits advisers for people affected by cancer as well as return to work advice and support. You can access their services online or call them on **0808 808 0000**

We have further information on returning to work or education, for employers as well as employees, on our website at anthonymolan.org/work and in our booklets *Going Back to Work After Your Stem Cell Transplant* and *Work & Stem Cell Transplant: Information for Employers*.

...or doing something different



I took the difficult decision to leave the job that I had so looked forward to returning to. Things had changed, I had changed and my previous perfect job just wasn't for me anymore. I wanted to do something for myself.

Nilush, who had a stem cell transplant in 2013

After a transplant, it's not uncommon for people to think about working differently, doing something different for work or making changes in other areas of their life.

Quite often, in the immediate period after treatment, the financial impact of not being able to work for a while can get in the way of your search for more meaningful, suitable or enjoyable work. For instance, you may decide to stay in your job for now because you can work around hospital visits, adjust your hours, and find the environment and your colleagues supportive. It may help to create short-term and long-term plans to put in place once your time post-transplant and confidence increases.

Take time to make decisions and discuss your thoughts and feelings with those around you. You can also speak to your transplant team. You might be able to access career counselling or coaching, or attend workshops with sessions specifically designed for people returning to education or employment after cancer treatment, which are often available through your hospital.

You may want to find a new sense of purpose or challenge, especially if you're no longer working. Have a look at our *Helping Others* section on p36.

Try not to change everything at once. It's important to have some stability and consistency.

Healthy living



Don't be just satisfied with saying, "Oh I'll do the same as I did last week." Always try to do that little bit more. Whether it be walking, or walking up the stairs, go that little bit further.

David, who had a stem cell transplant in 2015

You may have reached a point in your recovery where you are starting to make choices to stay healthy and feel as well as you can. You might want to eat better, exercise more, drink less alcohol or stop smoking. It's a good time to think about making changes that can have a positive impact on the rest of your life.

You could start by working on the things that concern you most, and ask for help with those that are harder for you.

Once you put these changes and new habits in place, you may be surprised at the benefits. They can improve your physical fitness, emotional well-being, levels of fatigue and your overall health, as well as lower the risk of other health problems including some types of cancer.

The NHS website ([nhs.uk/livewell](https://www.nhs.uk/livewell)) has lots of information on the key healthy living messages to help you understand why these are important and how you can go about adopting the advice to become healthier.

The World Cancer Research Fund has these tips for a healthy diet and lifestyle, with lots of practical information on their website ([wcrf-uk.org/uk](https://www.wcrf-uk.org/uk)):

- stay in shape
- keep active
- eat plenty of vegetables, fruits and wholegrains
- avoid high-calorie foods and drinks
- drink less alcohol
- eat less red meat and cut down on processed meat
- eat less salt.

Healthy eating

The NHS website ([nhs.uk/livewell](https://www.nhs.uk/livewell)) has information about a healthy balanced diet.

You may not feel like eating and may lose weight when you don't want to. On the other hand, it can be hard to break habits that you learn during your recovery. Once you start to regain weight, it can be difficult to control or lose.

Ask your team about seeing a dietitian who can help you to manage your diet and weight after treatment.

Getting active

Activity can improve your physical and emotional health in a number of ways:

- it improves the health of your heart and circulation
- combined with a good diet, it will help you get to, and stay at, a healthy weight
- it makes your muscles stronger
- it improves fatigue and helps you have more energy

- it can help lower anxiety and depression
- it can make you feel happier
- it helps you feel better about yourself.

There are lots of different ways to get active – you don't have to join a gym! Examples of activities you could try include:

- walking
- swimming or water aerobics
- riding a bike on flat ground or gentle slopes
- gentle exercises you can do at home, such as squats
- yoga, Pilates or Tai Chi.

Some gyms have specific programmes for people who have had cancer or other illnesses.

Once you're on the road to recovery, aim to follow NHS guidelines about how much activity you should do to stay healthy. Find out more at [nhs.uk/livewell](https://www.nhs.uk/livewell)

Our *Essential Guide to Diet & Physical Activity* booklet contains further information and advice.

Complementary therapies

An important part of your recovery is about taking time for yourself. We often think about physical recovery, but it's also important to think about your recovery as a whole person.

Some people find complementary therapies help with side effects of treatment, and improving your overall sense of wellbeing.

Complementary therapies can be used alongside conventional treatments, but shouldn't be used instead

of them. Your doctors may advise you to avoid some therapies because they could interact with your treatment. For example, some herbal remedies can stop your medications working properly. It's always best to check with your team that your chosen therapy is safe for you.

Complementary therapies include a huge variety of approaches and are sometimes available for free or at reduced cost through GPs, hospitals and hospices. You may also be able to access them through support centres and charities such as Maggie's Centres, Macmillan Centres or Penny Brohn Cancer Care.

If you'd prefer to find your own therapist, the Complementary and Natural Healthcare Council has properly qualified therapists who belong to a professional body. Be aware that the cost can vary greatly.

Mainstream treatments and medicines are carefully tested to show they work, are safe, and to highlight side effects. It can be difficult to judge how well complementary therapies work, because there is less reliable research. However, there is some scientific evidence showing that for people who are going through or have had a stem cell transplant:

- Hypnosis and relaxation exercises such as breathing exercises may help reduce pain, anxiety, feelings of sickness, and improve quality of life.
- Massage therapy may help with fatigue, feelings of sickness and anxiety in the short term, and improve comfort.
- Meditation programmes have improved people's psychological and physical symptoms while in hospital.

Travel insurance

While it may be many months before you feel ready to plan a holiday, when the time comes, you should discuss any travel plans with your doctor.

You should get travel insurance cover that takes account of your diagnosis, treatment, current physical health and medication. There are companies that provide insurance after transplant and cancer treatment, but may be more expensive. If you travel without appropriate insurance and become unwell, you risk having difficulties accessing lifesaving treatment or expensive hospital bills.

You can ask your team for details and advice. Macmillan Cancer Support or the British Insurance Broker's Association can help you find insurance brokers.

Keeping in touch with your team

Your transplant centre will monitor you indefinitely. As you recover, your appointments will become less frequent.

If you have any questions or concerns between appointments, please contact your team at the transplant centre.

Contact with your donor

If you had a transplant from an unrelated donor you may like to exchange letters or cards. Some people get in touch with their donor in this way very soon after their transplant, while others wait or don't make contact at all.

The rules about contact are different depending whether you're in the UK or another country, and also the country that your donor is from. It's not always possible to send a letter to your donor, so please don't be too disappointed if this is the case.

If contact is permitted, in the first two years after transplant this contact can only be anonymous – so things you cannot send include your name, contact details, photos or gifts. Often the exchange of letters or cards naturally ceases after a year or so, sometimes people keep in touch over many years.

Occasionally, if you and your donor agree, you may be able to have full contact with them – exchanging names, contact details and even meeting in person. At least two years must have passed since your last transplant or lymphocyte infusion, and you should be in good health.

Your transplant centre will be able to help get you in contact with your donor. Alternatively, you could confirm with your transplant centre that you're not expecting any further transplants or donor lymphocyte infusions, then contact Anthony Nolan for help. You can request contact with your donor by emailing our Donor Follow-Up team: donor@anthonymolan.org

Helping others

Moving forward, some people feel a desire to give something back. Although the act of helping can be beneficial to you as well, you may need some time to process your own experience before you are ready help others. Be sure to think about how much time you want to commit if you're still recovering.

You may decide to talk to others about your treatment and recovery to help them to overcome some of their anxieties. You may decide to volunteer at your hospital, start a fundraising challenge, or do something completely unrelated to your transplant.

If you're interested in volunteering with Anthony Nolan, have a look at our website: [anthonynolan.org](https://www.anthonynolan.org) or contact volunteering@anthonynolan.org. You can also visit the volunteering section of [ncvo.org.uk](https://www.ncvo.org.uk) to find other volunteering opportunities to suit you.



2

Step Two

Early recovery
after transplant

2

What's in this step?

- **Appointments**
- **Central venous catheter (CVC)**
- **Medication**
- **Transfusions of blood and platelets**
- **Going back into hospital**
- **Dealing with setbacks**
- **Nausea and vomiting**
- **Diarrhoea**
- **Infections**
- **Protecting yourself against infection**
- **Kidney problems**
- **Thrombotic Thrombocytopenic Purpura (TTP)**
- **Liver problems**
- **Bleeding**

This section covers appointments, medical care, possible complications and treatments during the early months. Many problems are easily treated, but others are more serious, could be life threatening and some could lead to loss of life. It can seem overwhelming, but this chapter includes different possibilities.

Not everyone will go through all of these issues and some people won't experience any. Knowing what to expect and look out for can be useful.

Before you go home from the hospital after your transplant, you should be told how to contact your transplant team if you have any questions or are experiencing problems or symptoms. Make sure you have these contact details written down or that they are in your mobile phone.

Appointments

When you leave the hospital, you will be monitored closely with regular blood tests and medical reviews. You may wish to keep a diary for these.

In Step Five, we explain long-term tests and check-ups. In Step Six we explain tests to assess the outcome of your transplant.

How often you have appointments depends on the time since your transplant and your progress. At first, it's normal to see your doctor and have blood tests twice a week. You might need more appointments for extra treatments, or if your doctor wants to keep a closer eye on your progress.

Going to hospital often can become tiresome, particularly during the first weeks, and especially if it's for a longer period of time. Your team will minimise your visits where possible. Remember that regular monitoring is important to make sure new problems are found early and treated quickly. This maximises the chance of the transplant being successful.

Where will my follow-up appointments be?

You might go to your local hospital, as well as your transplant centre. Additionally, you might see other specialists elsewhere if you need treatment for any side-effects.

You may need one or more of these:

- Outpatient consultations at your local hospital and/or transplant centre.
- Follow-up investigations such as bone marrow tests or scans.
- Supportive treatment such as blood or platelet transfusions, or intravenous infusions of fluid. You might need to wait in clinic for several hours for different infusions.
- Pentamidine nebuliser - this is a drug you inhale to prevent chest infections while your immune system is recovering. It's usually given monthly until your blood counts normalise, when it may be replaced with Septrin tablets.

Make sure to book your next appointment at each visit so you know when to come back.

Your transplant centre will monitor you indefinitely, but appointments will lessen and a yearly check might be all you need eventually. If you have any questions or concerns between appointments, contact your transplant team for advice.



I was able to discuss all my concerns (however minor) with the staff at the outpatients clinic and email and phone when something happened out of the blue. They have been a fantastic source of support to me.

Mel, who had a stem cell transplant in 2017

Central Venous Catheter (CVC)

Your central venous catheter (CVC) is used during your treatment to take blood samples, give you medicine, transfusions and the transplant itself. CVC includes devices such as a Hickman line (central line) or PICC (Percutaneous Inserted Central Catheter) line.

The line will need to be looked after. You should expect your transplant team to explain the arrangements for line care and advise you how to shower and bathe with your line.

Your CVC is a potential infection source. Around eight weeks after transplant it may be removed if no longer needed, or remain in longer depending on your needs. If it becomes infected, it may be removed sooner and your team will discuss with you if another one is needed.

Removing the line is a simple procedure, usually done in the outpatient or day unit. A local anaesthetic injection is given to numb the area. You'll probably need a stitch (suture) to help with healing, which will be removed around a week later.

Although it can be daunting to think about having the line removed, especially if you've had one for a long time, it's an important step towards recovery.

Medication

You'll take all prescribed medicines, including creams, lotions and mouthwashes, until your team advise you to stop. Some medications continue for at least a year. Certain drugs such as penicillin (or an alternative for people with penicillin allergies), which help to protect

you from specific infections, are lifelong treatments.

The amount and timing of medication can feel complicated. Keeping a medication record sheet can be helpful. Your centre or pharmacist might have one or you can make your own. Our free **My Transplant Tracker** app also has a medication section - just search for 'Anthony Nolan' or 'My Transplant Tracker' in the App Store.

You may also find that some medications make some foods taste different for some people. Do speak to your team if this happens.

It's really important to follow instructions for taking immunosuppressive drugs such as cyclosporine (or tacrolimus). The doses will be monitored with blood tests and adjusted by your transplant team. If the drug levels are low, they won't work properly. If they're too high, they can damage your kidneys or result in more infections.

Taking medication can be challenging. If your transplant was several years ago, and you're feeling well, you might feel that certain drugs are not needed. But some effects of your treatment are permanent and these drugs protect you from life-threatening complications.

Transfusions of blood and platelets

Some people need transfusions of red blood cells and platelets (if your blood cell or platelet counts are low) after they go home. These can be arranged with your local hospital, or combined with other transplant centre appointments. Your team will explain how often these are needed.

After a donor transplant, whenever you receive blood products they will need to be irradiated (irradiated blood), no matter how long it's been since your transplant.

Ask your doctor or nurse for an 'irradiated blood product' card to carry with you.

Going back into hospital

It's common to be readmitted to hospital, and this can happen sometimes more than once. We've found that roughly 8 out of 10 people are readmitted in the first month after going home.

Early complications can sometimes be treated without admission, and reasons for readmission vary widely. It's usual to experience problems and challenging times while recovering and this does not mean that your transplant hasn't worked.

Your team will explain the readmission process to your transplant centre or local hospital before you go home. How long you will stay depends on the problem and the treatment you require. Some people come in with one problem, but then go on to develop others and end up staying longer than the transplant, while others are home in a few days.

Not everyone feels ill when they first develop problems, but your immune system is weak and your body is physically recovering. These first weeks are important, and some problems become complicated and difficult to treat, leading to serious illness rapidly. For some, they can even be life-threatening.

Readmission to hospital can be frustrating and challenging to your confidence and morale. Knowing readmission is possible can feel worrying. It can be hard to accept that you may feel unwell again after the effort of the first weeks of your transplant. It can help to get support from your family, friends and transplant team.

Although serious problems can develop any time after transplant, the chances become lower as time goes on and your immune system recovers. Your transplant team will be monitoring you and will tell you what to look out for.

High dependency and intensive care units (ICU)

The following section describes what to expect if you have a serious life-threatening complication. This may be difficult to read. Most patients do not need specialist high dependency or intensive care, but it can be helpful if you and your family are aware of what to expect should this happen.

ICU offers support and close observation if you become very unwell. The staff are trained to use special equipment, machines and medications.

Types of treatment and monitoring in ICU include:

- 'Lines' (like your CVC or Hickman line) to monitor you - for example, a urinary catheter aids urine monitoring, or a line inserted into an artery can monitor blood oxygen levels.
- Special drugs to help treat the problem or make you feel more comfortable.
- Dialysis machines to support your kidneys (if they're not working properly).

- Ventilator machines to support your breathing.

You may be unconscious while in ICU and unable to communicate with family members and loved ones. This can be distressing, and there isn't always time to talk to your family before ICU transfer. If this happens, the doctors will explain this, and answer any questions as fully as they can.

Separation from the familiar transplant unit can feel difficult. The ICU looks, feels and sounds different, and can be frightening and challenging for you and your family.

However, the ICU staff will settle you in and you can still talk to your transplant team and share any concerns you have.

Dealing with setbacks



It took almost 12 months for my transplant to work - but then the GvHD kicked in and remission shortly followed. Never give up hope, it can take time, but life is worth it.

Steve, who had a stem cell transplant in 2012

Your recovery can be unpredictable and sometimes scary. Use the tips and advice in Step One to take care of yourself and get support.

Recovery from serious problems can take a long time. Your team will monitor your progress, provide physical rehabilitation if needed and offer support as you improve.

Do remember that only a few patients develop very serious problems. Although it's important to know that serious problems can happen, for most people, readmission is a bump in the road to recovery.

The following sections describe some possible complications. Although these are things that can happen, you might not experience them.

Nausea and vomiting

It's common to feel sick, with or without vomiting. This can continue for weeks and sometimes, months. Causes might include medication, infections and Graft versus host disease (GvHD) - see Step Three for more information.

Nausea usually affects your appetite, so it's important to let your team know and if needed, they can organise treatment, nutritional assessment and tests.

Diarrhoea

Diarrhoea can be troublesome. Continued diarrhoea can cause weight loss and malnutrition. Medication, infections and GvHD are potential causes. Let your team know about new or ongoing diarrhoea.

Infections

After transplant, immune system recovery can take a year or more. Early on, it's common to pick up infections as your immune system can't protect you. If you have GvHD or are taking immunosuppressive medication, you are more likely to get infections, even after a year.

Infections can be serious so it's important to know what to look out for. Below, we have described some common infections and how to protect yourself.

Viral infections

Viral infections are a common reason for hospital readmission.

CMV

CMV (cytomegalovirus) is a very common virus and is usually harmless. Over half of the general population have had it. CMV does not always have symptoms, even when it is detected by blood tests. If you've had CMV in the past, it can be reactivated (CMV reactivation) and usually needs treatment.

When your immune system is not working, CMV can be serious and, in some cases, life-threatening.

Less commonly, it's possible to develop **CMV infection** (rather than reactivation) which is harder to treat and can be more serious.

Tablet or drip treatment for CMV infection or reactivation is given twice a day, for at least two weeks. You might need to be in hospital for treatment even though you feel well.

Most CMV reactivations occur early after transplant, although it can happen later. Occasionally, patients

experience repeated reactivations requiring treatment on and off for months which can be frustrating.

Respiratory viruses

Some viruses feel like a common cold or flu-like illness. They can cause airway inflammation and pneumonia. It's important to contact the hospital with a runny nose or sore throat symptoms, even without fever. They will advise you if any tests such as a nose and throat swab, are needed.

If you have symptoms when you come to hospital you will need to be isolated.

Treatment depends on which virus you have. Sometimes no treatment is required other than monitoring your symptoms. Treatment might be a tablet, a drip or nebuliser (a device giving medication as a mist that you inhale into your lungs) and some viruses might need hospital treatment.

EBV (Epstein-Barr Virus)

This virus causes glandular fever. It can be inactive and become active again after transplant. Routine monitoring blood tests can pick up viral activity.

Most people don't need treatment. However, some need antibody treatment (Rituximab) through a drip. Occasionally, EBV causes more serious illness, with lymph-node swelling. This might need extra treatment, sometimes with chemotherapy.

BK virus

BK virus usually causes cystitis (bladder wall inflammation) with painful, frequent urination. You may notice blood in your urine.

If the virus is detected on urine tests, it may be present for weeks, sometimes months. If your symptoms

and discomfort continue, your doctor may refer you to another specialist for investigations. There are treatments available for BK virus. If your symptoms are severe or you are unwell, you may be in hospital until you feel better.

Bacterial infections

Bacterial infections are a common readmission reason. A frequent infection source is the CVC or Hickman line.

CVC infections are often associated with chills or fever after line use within minutes to a few hours. Whatever the cause, bacterial infections can make you rapidly unwell.

Be aware that you don't always develop a temperature with infections. Some drugs, such as steroids and paracetamol, stop your body's ability to develop a temperature with an infection.

Bacterial infections are treated with antibiotics as tablets or drips.

Fungal infections

These infections usually occur in the chest or sinuses but can develop elsewhere.

They are usually diagnosed on CT scan which produces detailed images.

Fungal infections happen with low white blood cell counts, but can occur later, after blood count recovery. Early after transplant, most people have medication to prevent fungal infections.

You may need to continue this medication while on immunosuppressive medication, or if you have GvHD, as these increase the risk of fungal infections.

Signs of infection

It is crucial to tell your transplant team about anything unusual immediately to speed up diagnosis and treatment. Early treatment of infections and complications make a significant difference to long-term recovery.

Here are a few things you can do:

- Follow your transplant team's advice to spot signs of infection.
 - Regular temperature checking, and whenever you're feeling ill.
 - Contact the hospital immediately if you have chills, or fevers, your temperature is above 38°C (even if you feel well), or you suddenly feel unwell even without a temperature.
- You might have a hotline number or can go straight to A&E for emergency treatment.
- Tell your team about any fever, diarrhoea, frequent or painful urination, blood in urine or stool, or abdominal pain.
- Contact your transplant team immediately if you notice any of these warning signs:
 - severe fatigue
 - bleeding
 - coughing
 - shortness of breath
 - chest pain
 - severe headaches.

Don't worry about false alarms. The nurses and doctors supporting you are very experienced, so it's good to trust them.

It's natural to feel anxious about infection, but it's important to balance this with getting back to a normal life.

Protecting yourself against infection

You should protect yourself from infection for at least the first six months after your transplant, and sometimes longer - you should take as much time as needed. There are some key areas to think about when protecting yourself:

Handwashing

- Washing your hands regularly is one of the most important precautions. This includes after entering your house, touching anything dirty, being in crowds or on public transport.
- Avoid touching household or animal waste.
- Ask visitors to wash their hands and remove footwear.
- Avoid people with coughs, colds or other infections.
- Avoid changing nappies (if possible, ask someone else to do this for you), gardening and construction sites.
- Practice safe sex. Use condoms to reduce risks of sexually transmitted infections.

Food

- Follow food safety guidelines.
- Avoid travel where food, water quality and sanitation are not of highest standards for 6-12 months after transplant.

There's further information in Step One's *Appetite, Taste Changes and Food Hygiene* section.

If you have pets

- Wash your hands after touching them.
- Avoid their litter and ask someone else to help you with this.
- Look after their health.
- Early after transplant, some people ask someone else to look after their pets.

You will have added protection against common diseases once your transplant centre advises you can receive your childhood vaccinations and an annual seasonal flu vaccine. Until then, be cautious particularly around unvaccinated children. See Step Five for details.

It's also important to try to keep fit and well by eating a healthy balanced diet and exercising. Step One's *Healthy Living* section has further advice.

Kidney problems

Your team will routinely monitor your kidney function for changes. You'll have blood tests and your weight checked at least once a week.

The kidneys regulate calcium, water and other substances and also filter your blood, removing waste products via urine.

Medication, infection, or dehydration can affect your kidneys. Mild kidney problems are common, but occasionally readmission for medication and intravenous fluid is needed until your blood tests are normalising.

Rarely, the kidneys become damaged for longer. Readmission is not always needed but extra hospital visits for monitoring instead until the kidneys improve.

Thrombotic Thrombocytopenic Purpura (TTP)

Thrombotic thrombocytopenic purpura (TTP) is a rare condition. Small clots (thrombi) can form within the circulation and more platelets are used up, leading to a low platelet count (thrombocytopenia). You need platelets to seal cuts in blood vessels and stop bleeding.

Symptoms can include fever, headaches, diarrhoea and easy bruising. If the kidney vessels become affected your blood pressure can become high.

What causes TTP?

The exact cause of TTP is uncertain, but thought to involve a blood protein called von Willebrand Factor (vWF) which can stop working and become sticky. This causes platelets to clump together forming clots, particularly in small vessels supplying the brain and kidneys.

Some medications, such as cyclosporine, are linked to TTP, but few patients taking cyclosporine actually develop TTP. It has also been linked to certain infections and total body irradiation (TBI) treatment.

What treatment can I have for TTP?

The treatment of TTP requires specialist care. The doctors review all medications and may stop cyclosporine.

Possible treatments include daily plasma exchange (removing your blood plasma and replacing it with donor plasma) for five days or longer in some cases. This helps to replace sticky vWF protein with normal vWF protein.

Liver problems

Your liver is monitored with blood tests as occasionally it can stop working properly. Reasons include medication, infection, GvHD (see Step Three) or veno-occlusive disease (VOD).

VOD is where blood flow through the small veins of the liver is partially blocked. VOD usually occurs during the first weeks after transplant, but sometimes happens later.

VOD can cause yellowing of the eyes and skin (known as jaundice), abdominal swelling and fluid build-up. It's usually very mild and disappears quickly – often without you being aware of it.

Occasionally VOD can be serious. Available treatments have improved outcomes, and life-threatening disease is rarer than it was. Recovery is helped by your liver's ability to regenerate from the effects of diseases such as this.

Bleeding

You may have platelet transfusions after transplant, and still need them after discharge. Platelets help the blood to clot, and low platelet levels can cause bruising and bleeding.

Contact the hospital if you notice new bruising or bleeding – for example, blood in urine or stools, or persistent nosebleed. Although bleeding can occur later, it's not common so tell your team immediately.

Remember that these side effects don't mean that the transplant hasn't worked. It's quite normal to make adjustments to your treatment as you progress through your recovery. Please discuss any concerns you have with your team.

3

Step Three

Graft versus Host Disease (GvHD)

3 What's in this step?

- **What is GvHD?**
- **How common is GvHD?**
- **Who's at risk of GvHD?**
- **Types of GvHD**
- **Diagnosing and assessing GvHD**
- **GvHD by organ, and what helps**
- **Other treatments for GvHD**
- **Graft versus leukaemia (GvL)**
- **Living with GvHD**

This Step explains in more detail Graft versus Host Disease (GvHD) – a complex illness that can happen after your transplant.

Make sure you report any new physical changes or concerns to your transplant team as prompt assessment and treatment of GvHD is very important. Remember that you may find it helpful to refer back to some of these Steps later in your recovery.

Everyone's experience of GvHD is different, and this information should be used together with the care provided by your medical and nursing team.

What is GvHD?

Graft versus Host Disease (GvHD) can happen when you've had a transplant using donated cells from another person (an allogeneic transplant or allograft). Your donor may have been related or unrelated to you.

GvHD describes the reaction that can happen when cells from your donor (graft) attack your body (host). During this reaction, donor cells recognise your body is 'foreign' and mount an attack against it.

The cells that cause GvHD are called T-cells. They're a type of white blood cell, part of the immune system, and help us to fight infections. T-cells attack and destroy cells they see as foreign, such as bacteria and viruses.

Normally, your T-cells don't attack your body's own cells. This is because they can recognise proteins on the surface of cells, called HLA (human leukocyte antigens), as part of you, or 'self'.

Before a stem cell transplant, donors have blood tests to identify their HLA or tissue type, and this is compared to yours to see how closely the HLA matches. Generally, the closer your HLA matches your donor's, the lower your chance of GvHD.

T-cells can tell the difference between 'self' and 'non-self'. When the donor's bone marrow starts to make new blood cells after the transplant, the new donor T-cells see that the HLA proteins on your own cells are not exactly the same. This might make the T-cells attack your body's cells, and this is called GvHD.

GvHD can cause a wide range of mild to severe symptoms. If you have moderate to severe GvHD you'll often need much closer monitoring through blood tests and clinic visits and may be admitted back into

hospital more often and for longer periods of time with complications related to the GVHD.

GvHD can behave differently in different people. For some, GvHD can resolve completely. For others, it can be absent for long periods, then appear again in the same or different organs. Even with treatment, for some it may be a lifelong condition that is controlled but never fully cured.

How common is GvHD?

Up to 80% of allogeneic transplant patients will develop GvHD. GvHD is most common during the early months and years after transplant, but sometimes you can develop GvHD later on or experience GvHD returning after it has been absent for a while.

For a small number, GvHD can be serious and sometimes life-threatening or even fatal. It can have a big impact on how you feel physically and emotionally. For some, it can be a long-term or chronic issue.

GvHD can affect your quality of life and may mean you're unable to do some things you used to, such as going back to work, taking holidays, or exercising. Fortunately, for most patients GvHD is mild and causes few problems.

Who's at risk of GvHD?

There are a number of factors which can increase your risk:

Unrelated, cord or haplo-identical donor

The chance of developing GvHD is generally lower if your donor was your brother or sister rather than an unrelated, cord or haplo-identical donor. This is because your siblings have inherited their same tissue type from your parents. The genes (DNA) between the HLA molecules are more likely to be similar to yours than the other donor options.

HLA mismatch

Your doctors will choose a donor who's matched to your HLA type, but sometimes an exact match isn't possible. The more of a mismatch between you and your donor can increase your chances of developing GvHD.

Age

Some researchers have found that having a transplant when you're older (or if your donor is older) is related to a higher risk of chronic GvHD.

If you're a man and your donor is a woman

If you're a man and your donor is a woman who has had one or more pregnancies, there's a higher chance of GvHD.

Having acute GvHD

If you've had acute GvHD, you may be more at risk of developing chronic GvHD.

If you or your donor have tested positive for cytomegalovirus (CMV)

Some studies have shown that GvHD risk increases with CMV reactivation or infection. CMV is a very common and usually harmless virus. Being CMV positive means having had CMV in the past and now having CMV antibodies in the blood.

The chance of CMV reactivation or infection increases if either you or your donor is CMV-positive. Treatment for CMV can be complicated when you also have GvHD as the treatment for GvHD suppresses the immune system, which can in turn increase viral reactivations such as CMV.

Types of GvHD

GvHD is generally referred to as acute or chronic.

Acute GvHD

Acute GvHD can be mild to severe and can begin as your new bone marrow starts to produce blood cells. This is usually 2-3 weeks after transplant, but can also happen when immunosuppressive medication (such as cyclosporine) is lowered or stopped altogether.

Acute GvHD usually happens in the first 100 days after transplant, but some people develop 'late onset' acute GvHD. This has the same signs and symptoms but happens after 100 days.

Acute GvHD often affects skin cells. It may start with a rash on your palms or feet but can be more widespread. In severe GvHD, it may become blistered or peel.

Acute GvHD may also affect your gut and liver. This can cause diarrhoea, nausea jaundice, and tummy pain.

Acute GvHD can be quite frightening as it can develop rapidly. When you're in hospital and during your follow-up your medical team will be monitoring you for signs of GvHD.

It's important that you report any new or worsening problems as soon as possible - so that treatment can be started early.

Chronic GvHD

Chronic GvHD can follow acute GvHD or can happen without warning many months after transplant, even if you never had acute GvHD. It can last months or even years.

Like acute GvHD, chronic GvHD can affect your skin, gut and liver, but it can also affect other parts of your body such as your mouth, eyes, lungs, genitals and joints. Chronic GvHD may be mild, moderate or severe, and sometimes life-threatening.

Diagnosing and assessing GvHD

During your follow-up after the transplant, you'll be monitored for signs of GvHD. This is usually done by asking you about your wellbeing, taking blood tests and examining your body. If your team suspect that you have GvHD, they may arrange for more tests or ask other specialists to confirm that you have it.

Biopsy

One way of diagnosing GvHD involves taking a small sample of affected tissue. This is called a biopsy. The tissue is sent to the laboratory to be examined under a microscope. The results are usually available after a few days. Other tests might be done on the tissue sample to check for other causes such as infections.

Endoscopy

If you have symptoms of gut GvHD (see p71), the doctor may arrange for you to have an endoscopy. An endoscopy is a procedure where the inside of your body is examined using an endoscope - a long, thin, flexible tube that has a video camera at one end.

An endoscopy is usually carried out while you're awake. Before the procedure, you may be able to have a sedative (medication that has a calming effect) to help you relax.

Examination of the upper part of the digestive system, including the mouth, oesophagus (food pipe) and stomach is called a gastroscopy. For this, the endoscope is passed into your mouth.

Examination of the lower bowel is called a sigmoidoscopy or colonoscopy and the tube passes into your back passage.

It's usually necessary to prepare the gut for examination. You may need to stop eating for a few hours to make sure your stomach is empty. If your lower bowel is being examined, you may be given a medicine to help clear the bowel.

Biopsies taken during the endoscopy can be looked at under the microscope or tested for infections.

It's also common to feel worried about losing bowel control during an endoscopy. Speak to the endoscopy team if you have any concerns about the procedure so that they can reassure you.

Scans

You may have a CT scan to confirm GvHD and rule out other diagnoses. They'll usually be looked at by specialists within a couple of days.

Lung function tests

The way to assess if you have GvHD of your lungs is to test if your lung function has changed and how effectively your lungs are working in terms of their capacity, elasticity and ability to exchange gas.

Tests include:

- Spirometry – breathing into a device that measures how well you breathe in and out.
- Lung volumes – measuring the size of your lung by breathing into a mouthpiece.
- Gas transfer test – breathing in a harmless gas through a mouthpiece and holding your breath for about 10 seconds.



It's important to report any changes to your medical team. You know your body so watch out for unexpected changes and don't be afraid to ask silly questions.

Mark, who had a stem cell transplant in 2016

Grades of GvHD

Your team may talk about the 'grade' of your GvHD. Grading systems give a standard way of describing the level of GvHD and how severe symptoms are in different parts of your body. It's also helpful in keeping track of progress, as the grade can change.

Different grading systems are used for acute and chronic GvHD. This is because acute and chronic GvHD can have different symptoms, affect different areas of the body and may require different kinds of treatment.

GvHD by organ, and what helps

GvHD can affect different parts of the body, and more than one area at a time.

The areas most often affected include:

- skin
- gut
- mouth
- liver
- lung
- eyes
- muscles and joints
- genitals.

Treatment will depend on whether GvHD is acute or chronic, the grade, and part or parts of the body affected. Some treatments for different parts of the body are described in here, and we've described the other main treatments in the next section.

Skin GvHD



I've had GvHD but seem to have got away lightly to date, having just had it affecting my skin. A recent change in steroid cream and continuing photophoresis (light therapy) seems to be getting on top of it.

Steve, who had a stem cell transplant in 2013

GvHD can affect the skin – it can cause changes in appearance, affect the skin's ability to regulate body temperature and act as a protective barrier.

The symptoms of acute skin GvHD may include:

- Dry, itchy or red skin.
- A rash on the palms of your hands or soles of your feet.
- Difficulty keeping warm – the body can lose more heat.
- A rash that can become widespread, painful, itchy or prickly.
- Blisters and peeling in severe cases.

Chronic GvHD can have some of the same symptoms as acute GvHD. Symptoms of chronic skin GvHD may include:

- Dry, itchy or red skin.
- A rash, which can look like eczema or psoriasis.
- Build-up of fluid under the skin.
- Skin infections.
- Changes to the colour (pigmentation) of your skin – lighter or darker patches.

- Difficulty keeping warm and heat loss.
- Thicker and tighter skin, loss of elasticity, which sometimes makes it difficult to move your joints.
- Thin or brittle nails and hair, hair loss, hair thinning, greying or colour loss.



The GvHD on the soles of my feet made it feel like walking barefoot on broken glass.

Harry, who had a stem cell transplant in 2014

Treatment

Sometimes mild acute or chronic skin GvHD improves without treatment. For some, chronic skin GvHD can last for months or years, and treatment if needed, can be challenging and tiring.

Available treatments can improve GvHD symptoms, and there are also things you can do to help yourself, explained in the *What helps* section on p71.

Your haematology doctor will often ask a skin specialist (dermatologist) for their opinion. They may perform a skin biopsy and give advice on the best treatment.

For mild GvHD, you may need to apply moisturisers, or a steroid cream to the affected areas.

If your skin problems are moderate or severe, or aren't getting better with the help of these treatments, then your doctor may use immune-suppressive or steroid medication.

Other skin GvHD treatments includes extracorporeal photopheresis (ECP) (see p84).

What helps?

- Wear cotton clothes.
- Try to avoid temperature extremes – very hot or cold.
- Use plain, unperfumed soaps.
- Try not to rub your skin dry after bathing.
- Use moisturisers as advised.
- Ask for help with putting on moisturisers and lotions.
- Try wearing cotton gloves at night to prevent scratch marks.
- Always use high factor sunscreen (Factor 50) if you go out when it's sunny. The sun can trigger skin GvHD or make it worse.
- Cover your skin with light cotton clothing, even in spring and autumnal sunshine.

Gut GvHD

Gut GvHD can affect the whole digestive system, including your mouth, oesophagus (food pipe), stomach and bowel. It doesn't usually affect the whole system at once, and acute gut GvHD usually affects the bowel.

We have talked about mouth GvHD separately, on p74.

Symptoms of gut GvHD may include:

- Diarrhoea – a very common symptom. Your stools may look green, watery, or have a 'bitty' appearance.
- Undigested food in your stool, or mucous or blood.
- Cramping or bloating.
- A sense of urgency – needing to rush to the toilet.
- Indigestion.

- Loss of appetite.
- Feeling sick, and occasionally being sick.
- Becoming malnourished and losing weight.

Tests such as an endoscopy can help to work out the cause of your symptoms (see p65). You may be referred to a gastroenterologist (a doctor who specialises in the digestive system).

Treatment

If you have mild gut GvHD, you might not need any treatment. If symptoms make you feel sick and give you diarrhoea, it's important to drink enough fluid so that you don't become dehydrated.

If you have severe diarrhoea, it can be difficult to take in enough fluid, and you may need to have fluids through a drip in hospital.

Your team may offer medication to help with symptoms: anti-diarrhoea medication, painkillers to help ease cramps and stomach pains, and anti-sickness drugs if you feel sick.

If you have gut GvHD, it's important to see a dietitian. If you're unable to eat and are losing weight, it might be necessary to give you nourishment through your central line if you still have it, or through a feeding tube into your stomach. This will help to stabilise your weight loss and prevent you from becoming malnourished.

There are also treatments for gut GvHD which include steroids (general and targeted), immunosuppressive drugs and antibodies.

What helps if you have diarrhoea?

Changing your diet may not always help, but you could try the following:

- Eat small amounts of food regularly.
- Go for high calorie snacks and energy shakes.
- Rich foods could worsen symptoms. Cut down on oils, fats, rich sauces, and fried foods.
- Boil, grill or microwave your meals instead.
- Monitor your fluid intake and increase it if you can.
- Avoid fizzy drinks, chewing gum and sweets containing sorbitol (a sweetener).
- Use barrier creams to prevent the area around your bottom from becoming sore. You can get these from the chemist.
- If your bottom is already sore, try using flushable, soft toilet wipes.
- Tell your transplant team if you can't take your tablets or the frequency or consistency of diarrhoea increases.



Gut GvHD can make journeys to check-ups a major operation. We packed a makeshift toilet (bucket), spare clothes and antibacterial wipes.

Harry, who had a stem cell transplant in 2014

Mouth (oral) GvHD

If you have GvHD in your mouth (oral GvHD), it can become sore, blistered, ulcerated, dry, sensitive and sometimes difficult to open. You might notice lacy white patches inside the cheeks or on the tongue.

Your sense of taste may change, making it difficult to enjoy certain foods. There are tips about eating and drinking on p75.

Visit your dentist every six months if you have oral GvHD. There is a small increase in the risk of oral cancers with chronic oral GvHD. Let the dentist know about any changes you notice.

Treatment

There are a range of treatments for oral GvHD.

- Mouthwashes with antibacterial or soothing properties.
- Pastes.
- Mouthwashes containing steroids or immunosuppressive drugs.
- Antifungal rinses if required.

If you are struggling to eat, a dietitian may offer advice on foods to try.

What helps?

For a sore mouth:

- Avoid spicy, acidic foods and drinks.
- Avoid alcohol.
- Avoid toothpaste containing SLS (foaming agent).
- Use covering agents that form a barrier over ulcers.

For a dry mouth:

- Sip water regularly.
- Chew sugar-free gum.
- Avoid alcohol containing mouthwashes. Use mouthwashes and gels designed for dry mouth such as Biotene (or Biotene toothpaste).
- Avoid rough, dry, crunchy foods such as crisps and crusty bread. Go for soft foods that don't need chewing, such as yoghurt, mashed potato and rice pudding and foods with sauce or gravy.

For a healthy mouth:

- Brush teeth and gums twice daily with a soft brush and toothpaste with at least 1450ppm fluoride.
- Floss between teeth daily.
- Reduce sugary snacks.

Liver GvHD

Sometimes liver GvHD doesn't have any symptoms. The first sign may be an increase in your liver enzyme levels picked up through routine blood tests.

If your liver function worsens, you may become jaundiced – your skin and whites of the eyes become yellow, and your skin may itch. If your liver gets bigger, your abdomen can become swollen and uncomfortable.

The liver has lots of important roles, such as cleaning the blood by removing toxins. When chronic GvHD affects the liver, it can become damaged and might stop working properly, letting toxins build up. Your liver function tests can remain abnormal for quite a long time after the liver has started to recover.

Treatment

A number of treatments are used for liver GvHD including steroids and immune-suppressive drugs. You can read more about these on p83.

What helps?

- Take antihistamines to help reduce itching.
- Try to avoid extremes of temperature as itching may be worse if you are very hot or cold.
- Tell your doctor if you are prescribed any new medicines which may affect liver function.
- Reduce your alcohol intake – this can make your liver function worse.

Lung GvHD

If you have lung GvHD, your lungs can lose some flexibility. This can lead to a permanent condition which can make you feel short of breath, wheezy, prone to coughs and chest infections, and you may find exercising harder – this can happen gradually over time.

It's important to let your team know early if you notice any worsening in breathing so it can be investigated and treated if necessary at an early stage.

You'll need to have tests such as pulmonary (lung) function tests, chest X-rays, CT scans and sometimes bronchoscopies (a type of an endoscopy for looking at the inside of the airways) to find out what's causing your problems and rule out infection.

Treatment

You may need to see a lung specialist, and your treatment might include medications, such as immune-suppressive drugs. If you have very severe lung GvHD, oxygen therapy can help relieve your symptoms by increasing the amount of oxygen in your lungs and bloodstream. A machine or portable cylinder can provide you with oxygen if you need it at home.

NHS Choices and the British Lung Foundation have information on oxygen therapy and managing breathlessness.

Eye (ocular) GvHD

The symptoms of GvHD of the eyes include:

- Itchy, sore or uncomfortable eyes.
- Dry, gritty or painful eyes.
- Continuous watering.
- Sensitivity to bright lights.
- Difficulty opening your eyes in the morning because they're sticky.

In severe cases these problems can affect your vision.

Treatment

If you're having these symptoms your transplant team will refer you to an ophthalmologist to check your eyes and vision. Artificial tears, eye drops to lubricate the eyes, and medications to reduce inflammation or antibiotics can help. Sunglasses can protect your eyes from the sun.

What helps?

- Try a home humidifier to add more moisture to the air so tears evaporate more slowly.
- If possible, avoid air conditioners which reduce humidity and dry the air.
- Have regular breaks from visual tasks. Prolonged time at computer work, watching television and reading can make your eyes feel tired and achy.
- Take dietary supplements – omega-3 oil and flaxseed oil help to improve tear quality.
- Drink plenty of water – being dehydrated can exacerbate dry eye symptoms.

- Use non-preserved lubricants – preserves can change the tear composition and make your eyes more dry.
- Perform eyelid care regularly – warm compresses and maintaining eyelid hygiene will reduce bi-products and bacteria which can cause frequent infections and discharge.
- Consider moisture chamber glasses which can provide relief by preventing air from blowing on your eyes, as well as slow the evaporation of your tears. You can use clear, plain lenses if you don't usually wear glasses to see.

Musculoskeletal GvHD

GvHD can affect almost any area of the body including:

- Joints.
- Muscles.
- Tendons – the tough band of tissue that connects muscles to bones.
- Fascia – the connective tissue fibres that form sheets underneath the skin to attach and separate muscles and other internal organs.

If GvHD is affecting the fascia in your arms or legs it may lead to stiff joints as your muscles and joints are shortened. This can affect the range of movement in certain joints; for example, making it difficult to bend and straighten your arms and legs. It might affect the way you move around and activities such as driving and climbing stairs. This is rare, however.

Treatment

Medication to suppress your immune system, steroids and other medicines may help. Physiotherapy can also improve symptoms – particularly doing stretches and keeping your joints mobile – and you may be referred to a physiotherapist or have been given an exercise programme. Make sure that the exercise programme you are following is specific to your condition and level of ability.

Report changes you notice in your function or movement to your therapist or medical team promptly.

- Target a variety of muscle groups during your exercise session to maximise the benefit.
- Adjust the frequency, duration and intensity to your changing physical and medical condition (including your platelet and haemoglobin levels).
- Be aware of side effects from your medications and report any you experience to your doctor. Sometimes bone, joint and muscle-related symptoms can be managed by adjusting the drug prescription.
- Lymphatic drainage involving special massage can sometimes be helpful to move extra fluid from swollen parts of your body.

Genital GvHD

This can affect men and women.

In mild cases, women may experience vaginal dryness but have no other problems. In extreme cases, there may be vaginal strictures (when the vagina becomes narrow) and ulceration (sores). You may experience pain during sexual intercourse or find it difficult to insert a speculum for smear tests.

Male genital GvHD can cause inflammation and

sensitivity of the penis, a rash, or narrowing of the urethra (the tube you pass urine through). You may feel as though you don't want to have sex or are unable to get an erection.

Treatment

Women will normally be referred to a gynaecologist. They may offer you creams and gels to make your vagina less dry and sore. Hormone replacement therapy may also help, as some symptoms might be caused by early menopause (see p93). Topical ointments using immunosuppression or steroids may help with both GvHD of the vagina and the penis. Men who have GvHD of the penis will be referred to a specialist, usually a urologist.

Having genital GvHD can affect how you feel about yourself sexually, as well as your ability and desire to have sex. There is more information about this and getting support on p94.

What helps?

- If you are able to (and it is practical) maintain intercourse where possible. Lubrication may be required – use a water or oil based natural lubricant.
- Keep the delicate area lubricated – good quality coconut oil is a great moisturiser.
- Look or feel for skin changes, tightening, change of colour, lumps or bumps.
- Use water alone for washing, as lotions and soaps could cause irritation.
- Be mindful of an unusual discharge or pain.
- Maintain stretching of the penis and retracting the foreskin to prevent tightening – monitor for erectile problems.

- Use dilation for women – vaginal dilators to prevent tightening, but also fingers can help maintain some elasticity within the vaginal walls.
- Vibration may be helpful for women to increase blood flow and skin integrity/elasticity – pleasuresolutions.co.uk is an informative website that offers advice and devices for patients who have undergone cancer therapy.
- Most importantly: report any changes so that further investigation and treatment can be considered if required.

People often find it difficult to talk about sexual problems. However, they are very common and your team will be experienced in talking about them, so please ask for help.

Other treatments for GvHD

The treatment for your GvHD will depend on whether it is acute or chronic, its grade, and part of the body affected.

Most GvHD treatments aim to reduce the attack of the T-cells on your body. Many will weaken your immune system making you more vulnerable to infections. GvHD itself also suppresses the immune system, and so often people with GvHD will experience more infections.

Your team will be monitoring you and treating you for infections if they occur.

Medication to suppress your immune system

Your team will give you medication to suppress your immune system during and just after your transplant. This should help prevent GvHD, as it suppresses the activity of the donor T-cells that could attack your body. The most common medication is called cyclosporine. Tacrolimus or mycophenolate mofetil are sometimes used.

Avoid grapefruit juice or products which contain grapefruit when taking cyclosporine – it affects the way the drug works.

If you have chronic GvHD, you may need to have immunosuppressive treatment for some time, and the medications will be lowered very slowly to reduce the chance of GvHD returning. About half of people affected by chronic GvHD are still taking this medication after two years.

Steroids

Steroids are one of the main treatments for both acute and chronic GvHD. They reduce inflammation and suppress your immune system.

You can take steroids in various ways, depending on the grade and type of your GvHD. For example you can apply cream to your skin (called topical steroids) to treat skin GvHD, or use steroid mouthwash to treat oral GvHD.

You can also take them in tablet form, or by intravenous drip if your GvHD is severe or in lots of different places. The dose you'll need depends on the severity of your GvHD. Some people may need to have lots of courses of steroids or even stay on a small dose

of steroids for a longer time.

Like all medication, steroids have potential side effects. These include diabetes, high blood pressure, higher risk of infection, bone thinning and behaviour changes.

Because of these effects, your doctors will monitor you closely, with the aim of lowering the dose when the GvHD is responding to treatment.

Other drug treatments

There are some other treatments that may be offered to you to treat your GvHD that are not mentioned here.

Some transplant centres may be able to access other treatments through clinical trials. This may mean that their effectiveness in the treatment of GvHD is not yet fully known.

Please speak to your transplant team about clinical trials in GvHD.

Extracorporeal photopheresis (ECP)

Extracorporeal photopheresis (ECP) is used mainly for skin, liver or oral GvHD – both acute and chronic. The treatment works by ‘destroying’ some of the white blood cells that are causing the GvHD.

It’s usually suggested when you’ve had other treatments but your GvHD hasn’t improved. ECP is a complicated treatment and you may need to attend a hospital that has a skin specialist (dermatology) centre for it. It can take as long as six months for you to start seeing the benefits, especially if you have severe skin GvHD.

The treatment involves a nurse connecting you to a machine by a drip. Your blood goes through the machine where some of your white blood cells are separated off and treated with a drug called

methoxypsoralen (8-MOP) and exposed to ultraviolet light. The light helps activate the drug so it can destroy the white blood cells. After they’ve been treated, the white blood cells are given back to you through your vein.

Each treatment takes several hours. For acute GvHD ECP is given for two days every week and for chronic GvHD, you’ll normally have it for two days every two weeks, for around 6-12 months.

ECP doesn’t have any serious side effects. Some people may feel a bit weak or dizzy during or after the treatment.

After the treatment, your skin and eyes may be more sensitive to sunlight for about 24 hours, so you’ll need to protect yourself from the sun and wear sunglasses.

Graft versus Leukaemia (GvL)

Graft versus leukaemia (GvL), or graft versus tumour effect, is a beneficial part of GvHD. People with acute or chronic GvHD after transplant tend to have lower risk of disease relapse. This is because the donor T-cells can cause a beneficial immune reaction by attacking any diseased cells in your bone marrow.

If your disease does come back after transplant, there are a number of ways to make the most of your donor’s immune system to help fight the disease. These can include an additional infusion of donor T-cells and sometimes performing a second transplant, possibly using a different donor. While both of these strategies may help to harness the GvL effect, they may also increase your chance of developing GvHD.

Living with GvHD

GvHD can feel like an unexpected and devastating effect of transplant – for you and for your family. It can have a big impact on quality of life, how you feel physically and emotionally, and your expectations of life after transplant. Despite the impact of GvHD, most people find they have relatively good quality of life and very few say they actually regret having their transplant.

There is help available for you and your family to support your treatment and recovery. Please speak to your team so you and your loved ones can get help if needed.

You can share your experiences and get support from others on the Anthony Nolan Patients & Families Forum ([anthonynolan.org/forum](https://www.anthonynolan.org/forum)). There are also local support groups around the UK you can join. Please speak to your transplant team for these details.

Other sources of help include your GP, Maggie's Centres, local hospice or visit Macmillan Cancer Support to see what's available in your area.

4

Step Four Other effects of treatment

4 What's in this step?

- **Emotional changes**
- **Infertility**
- **Premature menopause**
- **Sexual problems**
- **Skin changes**
- **Joints and muscles**
- **Eyes**
- **Mouth**
- **Teeth and gums**
- **Bone changes**
- **Thyroid and other glands**
- **Bowel**
- **Kidneys and bladder**
- **Liver**
- **Lungs**
- **Heart**
- **Memory changes**
- **Immune system and late infections**
- **Post-transplant cancer**

In this section we describe different effects that may occur months or years after the transplant. These are known as 'late effects' and while some are more common than others, your transplant team will know how to manage them and the treatments available. It's important that you know what to look out for, and how your team will monitor, screen for, and prevent these.

Before the transplant, your main focus is usually on the transplant itself. But it's important for you and your family to understand what can happen later so you're prepared for what life might be like after your transplant. It can also help to look at this booklet again when you're recovering, and life's beginning to settle down.

The most common problems are described first, with rarer problems later in the chapter. The chances of developing these effects depends on many factors, including the type of transplant, other drugs or radiotherapy you received, your age and gender.

Some late effects can't be predicted or prevented. But you will be regularly monitored and can contact your team with any concerns so problems can be picked up sooner and treated more easily.



It's easy (and natural) to worry about every little thing just after your transplant. But I've realised that worrying doesn't help. I trust the professionals around me and do what I can to keep fit and healthy – and happy!

Helen, who had a stem cell transplant in 2014

Emotional changes

It's common to feel worried and down before, during and after a transplant. The treatment itself can make you feel unwell, tired and low, and it's extremely disruptive to normal life. It can be frustrating to feel like you're not getting better quickly enough or can't do the things you used to. You might be worried about money or the future.

Often these feelings subside over time. In some people they hang around for longer, and we find it can take up to two years to adjust emotionally.

Not feeling like yourself can affect your mood. It's understandable that you may feel low, angry, anxious or depressed, but you don't have to deal with these feelings alone. It's important to speak to your team or GP and get the right support.

The challenges you face during transplant and recovery can leave you feeling emotionally vulnerable. We know that some people develop anxiety, depression, problems with sleep and sometimes feel very traumatised by the experience.

Because a transplant can have a big impact on emotional well-being and mental health, counsellors and psychological therapists can be important in your recovery. Talking things through with a trained mental health professional can really help, while for some, treatment with antidepressants or anti-anxiety medications can stabilise your mood while you work through the difficulties.

You'll find further information and advice in our booklet *Your Mental Health and Stem Cell Transplant* and on our website ([anthonynolan.org/mind](https://www.anthonynolan.org/mind)).

Infertility

The high-dose conditioning chemotherapy you have before your transplant means fertility problems are likely. Fertility preservation methods such as embryo storage and sperm freezing are described in *The Seven Steps* booklet, available from Blood Cancer UK.

Once you're recovering and thinking about life post-transplant, you may want to have a fertility assessment and explore available options. This might include using previously stored semen or embryos with assisted conception or fertility treatment. Your transplant team or GP can refer you to a fertility specialist or assisted conception unit. Infertility Network UK also has information and advice.

Some people wish to consider adopting a child. There's more information about adoption from [gov.uk](https://www.gov.uk), your local council or The British Association of Fostering and Adopting. If you're considering adoption, bear in mind that many adoption agencies want to know that you have been well for several years, and you're in remission. It could be as many as two to five years post-transplant before they're able to help you find a child. However, most agencies will be happy to talk things over and answer questions about the process beforehand. The adoption process involves a medical assessment by your GP. Your transplant team will probably be consulted too, with your consent.

Thinking about fertility can be hard, and it's an emotional subject. Talk things through with your partner, family and friends, as well as finding other ways to get psychological support (see p134).

It's important to know that occasionally, fertility can recover, sometimes for a short time. If you don't want to have children, it's important to use contraception.

Premature menopause

After transplant, women may experience premature menopause. This can be hard, especially if you weren't expecting your menopause for a long time. As well as finding out what medical treatments there are to tackle the physical symptoms, make sure you're looking after yourself and getting support.

Premature menopause can cause a range of symptoms, including:

- Irregular periods or periods stopping
- hot flushes and sweats
- vaginal dryness
- bladder problems
- mood changes
- difficulty concentrating
- low sex drive.

It can also affect your heart and bone health. Hormone replacement therapy (HRT) can help maintain your sex drive, sexual function and bone health.

Speak to your GP about your symptoms and the treatments available. You can be referred to a gynaecologist for specialist advice. They will do a full assessment and start treatment if needed. The Daisy Network is a charity that supports women who have experienced premature menopause.

Sexual problems

Almost everyone – men and women – who has a transplant will notice some changes in their sexual feelings or function.

Having a transplant can affect:

- how you feel about yourself sexually
- sexual desire (libido)
- sexual satisfaction
- ability to get an erection (erectile function) if you're a man
- ability to ejaculate and have an orgasm
- pain during sex, for example caused by GvHD or vaginal dryness (see p80)
- fertility
- appearance of your body
- sexual relationships.

It can feel difficult to talk about sex, but it's nothing to be ashamed of or embarrassed about. It's important to talk to your transplant team about your concerns to get the support you need. If you're finding it hard to broach the topic, you could take this booklet to your appointment.

Many people only start to notice or worry about sex once they're feeling better. For some people, sexual desire and function will return naturally after a period of time. However, for many patients with otherwise reasonable or good quality of life, sexual issues remain.

There are many reasons why sexual problems happen after transplant, for example:

- fatigue
- physical changes and body image
- hormones
- emotions
- side effects of transplant
- medications.

The cause is often a combination of factors.

Fatigue

Fatigue is very common after a transplant. It's difficult to feel enthusiastic about sex when everything else takes such a lot of effort! Finding ways to manage and improve fatigue may also help your sex life (see p19).

Physical changes

You can look and feel different early on post-transplant which can affect the way you see yourself. Changes may be caused by hair loss, weight changes or scarring from CVCs or Hickman lines.

GvHD can produce physical changes and GvHD involving the sexual organs (the vagina and the penis) will require specific treatment (see Step Three).

Weight changes are common, and you might feel less physically fit. Looking after yourself and taking up exercise can improve overall wellbeing. It's important to be kind to yourself. Ask your team for help in speaking to someone about body confidence and issues you might be experiencing around this.

Your hormone levels

Low levels of the main sex hormones (testosterone in men, oestrogen in women) are common after transplant and can affect sexual desire.

In men, low testosterone symptoms include lack of libido (sex drive) and difficulties getting or maintaining erections. In women, low oestrogen can lead to premature menopause, the symptoms of which are explained in Step Four.

Hormone replacement treatment can help with symptoms, so do discuss this with your team.

Your emotions

Relationships can change during serious illness – yours might become stronger or you might feel the strain of a lot of understandable stress. Some people say that the nature of their relationship changes. You might be less close physically, but closer emotionally.

Fears about the future can also be hard to deal with; if you're feeling anxious you might not want sexual contact, and uncertainty can be challenging if you're considering starting a new relationship.

In some cases, your partner may be reluctant to initiate sexual contact because they are worried about you physically, that they might hurt you or tire you out.

Emotional support

Understanding these are common problems with solutions can be a relief. Talking things through with your transplant team can start to address these difficulties and a referral to specialist professionals or clinics may be helpful.

Talking to your partner about your feelings can help. Macmillan Cancer Support has tips about relationships and communication. Relationship or psychosexual counselling, perhaps with your partner, is also something to consider. The charity Relate provides relationship counselling and other relationship support services. Sex therapy is available on the NHS or privately.

Your sex life might be different – but you don't have to give up on pleasure, closeness or fun. It might be helpful to try not to focus all of your attention on sex. Instead, spend some time nurturing yourself and your relationship. Go for a long walk. Get a little extra sleep. Kiss your partner goodbye before you head out the door. Make a date night at your favourite restaurant. If you're in a relationship, keeping physical closeness alive, in whatever ways possible, can protect or even improve your connection.

Medical treatment

Treatments are available for both men and women, and many centres have a specialist clinic. Macmillan Cancer Support has more information about treatments for sexual problems.

Men

Male testosterone levels may normalise with time, but testosterone replacement is available through injections, patches or gels.

Finding what works can be trial and error, if one treatment doesn't work, others may be available. Medicines called phosphodiesterase type 5 (PDE5) inhibitors can help men get erections. Some of these drugs are:

- sildenafil (Viagra®)
- tadalafil (Cialis®)
- vardenafil (Levitra®).

Women

Early menopause can cause sexual problems which may be improved by HRT, oestrogen cream to address low oestrogen levels and menopausal symptoms such as hot flashes, difficulty concentrating, fatigue, fluctuations in mood or depression. There are also creams or gels to treat vaginal dryness.

If you are able, regular sexual intercourse can help improve sexual function and prevent some problems. Resuming sexual activity within the first year post-transplant is linked to fewer long-term sex-related problems.

Consider a holistic approach to sexual problems by combining medical treatment with support for the

emotional impact of transplant on your relationship. You'll find further information at [anthonynolan.org/patients](https://www.anthonynolan.org/patients)

Skin changes

Your skin is a large and sensitive organ, which often changes post-transplant. GvHD frequently affects the skin and may need treatment (see Step Three). Even without GvHD, chemotherapy, radiotherapy and certain drugs can leave your skin drier and more sensitive. Skin thinning and hair loss can make you feel cold, although this usually improves.

Post-transplant sun protection is particularly important because of a higher chance of developing skin cancer:

- use high-factor (SPF 30-50 with UVA+UVB filter) sun creams or sunblock
- avoid direct sun and sunbathing
- cover up with long sleeves and brimmed hats.

Get to know the location and appearance of your moles and record them with photographs if that helps. Report new skin changes to your GP or transplant team to refer you to a dermatologist promptly if needed.

Avoiding sunlight completely can lead to vitamin D deficiency. If your vitamin D levels are low, you can take a supplement.

Joint and muscles

Loss of strength

Lack of activity, poor general health and poor nutrition can reduce muscle strength. GvHD can affect joints and muscles (see p79), and steroid treatment for GvHD can also reduce muscle strength.

Joint problems

Joint aches and pains can be common post-transplant and often settle down with time. You might be referred to a specialist or for investigations if these are troublesome.

Muscle cramps

Muscle cramps, especially in calves and hands, may occur post-transplant. Possible causes include lack of certain dietary vitamins and some medications; supplements may help, as well as quinine tablets. Always check with your team or pharmacist before taking supplements in case they interact with other medications.

Numbness and tingling

Numbness and tingling, usually in the hands and feet, can be due to nerve damage following certain chemotherapy drugs, and improves for most people over time.

How exercise can help

Exercise, and sometimes physiotherapy, is important for building muscle strength and stability.

Walking is a great foundation for increasing strength, stamina, balance and confidence – gradually increase your distance and maybe pace as your strength and confidence develop.

Improving strength and fitness takes time. Some people develop new enthusiasm for health and become fitter than before treatment. Others won't regain strength or stamina so choose different goals and challenges. Exercise is highly individual, and you should start slowly and build up gradually. You'll find further information in our *Essential Guide to Diet and Physical Activity* booklet.



It's curious that you can feel completely exhausted but a short 15-20 minute walk can actually make a huge difference. It also gives me the energy and motivation to tackle things I've been avoiding doing!

Mel, who had a stem cell transplant in 2014

Eyes

Your eyes can be affected in various ways after transplant. Vision naturally deteriorates with time, and regular checks are important. Your transplant team may also refer you to an ophthalmologist (eye specialist) for specialist investigations and advice.

Graft versus Host Disease (GvHD)

GvHD frequently affects the eyes (see Step Three), but even without GvHD, your eyes might feel dry, gritty or irritated. Simple eye drops can lubricate the eye surface reducing irritation.

Cataracts

Cataracts are common post-transplant, especially after total body irradiation (TBI) or steroids. Cataracts occur in just over half of TBI recipients, but less than 1 in 5 of those without. They usually occur 2-4 years post-transplant but can develop much later.

Cataracts are cloudy patches developing in the eye lens. They cause blurred or misty vision, difficulty with night vision especially while driving. Cataracts can be treated surgically if they're affecting daily life, providing your eyes are otherwise healthy. The Royal National Institute for the Blind (RNIB) has more information.

Mouth

Even without GvHD, it's common to have mouth symptoms for several months before they resolve. The effects caused by mucositis, infections and some medications can make your mouth dry, more sensitive and food and drink may taste different.

Artificial saliva and frequent sips of water can relieve your dry mouth, making chewing and swallowing food easier.

It's important to take care of your mouth. Try rinsing with salty water or bicarbonate of soda, chew sugar-free gum or mints, and brush teeth regularly. Even if you're not eating much, drink plenty of water.

Teeth and gums

Teeth and gums are affected by chemotherapy, drugs, radiation and malnutrition leading to increased tooth decay. A dry mouth may also make cavities more likely.

It's important to take care of your teeth and gums by:

- brushing regularly
- no smoking
- reduce sugary drinks
- visit your dentist regularly.

Bone changes

There are two main problems that can involve your bones.

Osteoporosis

Osteoporosis, or thinning bones, is common in general, but it is more common post-transplant, affecting both men and women.

Osteoporosis is more likely with age, low bodyweight, less activity, or steroid treatment. Osteoporosis is more common after menopause, so women tend to be more frequently affected.

Osteoporosis is generally painless, but as the bones are weaker, fractures are more common. A DEXA scan – a type of x-ray measuring bone density to assess your risk of osteoporosis, is usually arranged.

Physical activity, calcium and vitamin D supplements, and HRT if you're a woman, can help prevent and treat osteoporosis.

Osteoporosis is often reversible, and your doctor may prescribe medications called bisphosphonates.

Avascular necrosis

The second problem, avascular necrosis, is when bone in a joint breaks down, because of restricted blood flow. Often this happens in the hip, but sometimes it's knees, wrists or ankles. Avascular necrosis is less common but can happen after steroids, TBI, or GvHD. It can be painful, resulting in difficulty walking and other daily activities.

Pain medication can help but most people need surgery to regain good, pain-free mobility afterwards.

Thyroid gland

About a fifth of people develop an underactive thyroid gland post-transplant, and it's more common after TBI.

An underactive thyroid means you produce less thyroid hormone. Symptoms include fatigue, constipation, hair loss and weight gain. Your transplant team monitor thyroid gland function with blood tests. It's treated with tablets that replace the hormone.

Bowel

Your bowels may take time to normalise. Some people's bowel habits change after transplant and remain changed. Bowel movements may be looser, or you may get constipated more often.

Any new changes in bowel habits should be reported to your team as soon as possible.

Kidneys and bladder

TBI, GvHD, medications or infections during or after transplant can affect the kidneys and bladder and may sometimes be long-lasting.

Problems may show up as slightly abnormal blood tests during routine monitoring and you might not feel any symptoms. If tests suggest a chronic (long-term) kidney problem, you'll be referred to a specialist for more tests and treatment.

Liver

With chronic GvHD, it's common to have abnormal liver tests (see p76). Without GvHD, long-term liver damage is relatively rare but can be caused by long-term use of some medications, infections and iron from multiple blood transfusions building up in the liver.

Yellowing skin or whites of eyes (jaundice), or right-sided abdominal pain can be symptoms of a liver problem. Liver function is monitored with routine blood tests. Treatment if you need it depends on the cause and exact problem.

Lungs

Some people experience lung problems post-transplant. This can happen if you have chronic GvHD or had lots of infections. It can also be related to the transplant conditioning treatment.

Lung problems can cause symptoms, including:

- a persistent dry cough
- worsening breathlessness
- wheezing
- fever.

You may need X-rays, scans and lung function tests. Treatment depends on the problem, but might include steroids, other medications and maybe referral to a specialist.

You shouldn't smoke post-transplant due to higher risk of long-term lung problems and some cancers, including mouth and lung cancers. For help to stop smoking, please ask your team or contact NHS Smokefree.

Heart

Heart problems, especially hardening of arteries (atherosclerosis) are common in the general population, particularly with ageing. A transplant increases heart disease risk long-term.

Heart problems can cause:

- chest pain
- abnormal heartbeat
- swollen ankles
- breathlessness.

Some symptoms may be related to a 'floppy' heart where the weaker muscle can't pump blood around your body properly. Serious problems can result from heart disease; for example, atherosclerosis can lead to a stroke.

Follow-up tests are done yearly to monitor your heart health. You can reduce your heart disease risks by keeping active, eating the right foods (reduced salt and cholesterol) and not smoking.

Memory changes

Short-term memory loss and difficulties concentrating are common post-transplant. Things that can affect memory include your original disease, past treatment and transplant conditioning therapy. Simple things affecting memory and concentration include fatigue and lack of sleep. Some people have trouble with 'word-finding'. Doing puzzles like crosswords and quizzes can improve mental agility.

These difficulties are unlikely to be bad enough to affect your ability to work.

Making notes and lists often helps with memory issues and for most, this improves, getting better over the first year.

You could also ask for a referral to a psychologist or occupational therapist. Our booklet *Cognition: How Stem Cell Transplant Can Affect Your Memory and Concentration* has further information.

Immune system and late infections

Your blood counts should be back to normal, but your immune system takes up to two years to recover during which time, your risk of getting infections is raised.

Your immune system may never be as effective as before and your risk of infections continues when taking immune suppressive medication to treat chronic GvHD.

Your spleen is important for supporting your immune system, but it gets damaged by radiation and

transplant conditioning chemotherapy. This is why you may be asked to take an antibiotic such as penicillin lifelong. You will also be asked to have your childhood vaccinations again (see p120).

You can read about ways to protect yourself from infection on p48.

Post-transplant cancer

Even though you may be cured of your original illness after transplant, there is a higher chance of developing a cancer afterwards. This may be anywhere in the body, although it's more common in some organs such as skin.

The risk of post-transplant cancer is one of the reasons that lifelong follow-up is recommended. There's more on this in Step Five.

The risk of developing cancer depends on things, such as:

- total body irradiation (TBI)
- chronic GvHD and taking immune suppressive medication (particularly linked to mouth and skin cancer)
- younger age at transplant
- family history of cancer
- other risk factors such as smoking, alcohol and obesity.

Getting treatment early if you do develop a cancer increases the chance of success. It's important to know what to look out for and reduce your risks by using sun creams, not smoking, following a healthy lifestyle (see p30), and cancer screening (see p117).

Speak to your GP or your transplant team about any concerns. Support is also available from Macmillan Cancer Support and Maggie's Centres.

In some rare cases a blood cancer can develop after a transplant. The most common form is called PTLN (post-transplant lymphoproliferative disorder). It's usually caused by the Epstein Barr Virus (EBV), a very common virus. PTLN can be treated with antibody therapy, and if needed steroids and chemotherapy.

Developing PTLN, or another cancer, in the donor cells does not mean the donor has or will develop cancer. The changes usually happen to the donor's cells after transplant and it's most likely an effect of some of the medications. Similarly, your donor developing a cancer will not usually increase your chances of developing that cancer.

5

Step Five

Long-term health checks and wellbeing

5

What's in this step?

- **Blood tests, investigations and monitoring**
- **Screening for second cancers**
- **Which health professionals will I need to see?**
- **Immunisations**
- **Venesections**

Many people feel like they're starting to get back to normal and have good quality of life about a year after transplant. However, this varies between people, and recovery is an ongoing process.

It's important to continue clinic reviews with your transplant team and you will still need some tests and investigations.

As explained in Step Four, side-effects can occur months or even years after transplant. For some people, the idea of ongoing monitoring and tests can be worrying. However, picking up any side-effects early means they can be treated quickly before your health and quality of life are affected. Even if you feel completely well, you should continue follow-up visits long-term.

Ongoing follow-up appointments may not always be at the transplant centre and are usually less frequent than early post-transplant appointments. It's important that you understand what to expect and look out for between clinic visits. Your transplant team will be happy for you to contact them outside these appointments too and will direct you to the most appropriate source of help.

Blood tests, investigations and monitoring

Transplant centres follow international guidelines which list recommended tests and examinations, and how often they are done.

Here are some key investigations you'll have as part of your long-term care:

What's the test and how is it done?	What is it checking?	How often will I have it?
Blood count <ul style="list-style-type: none"> Blood tests 	That your blood counts are stable and in the normal range.	At each clinic visit.
Liver function <ul style="list-style-type: none"> Blood tests 	How well your liver is working – by looking at chemicals processed in the liver (bilirubin, ALT or AST, and alkaline phosphatase).	Usually at each clinic visit.
Renal (kidney) function tests <ul style="list-style-type: none"> Blood tests 	How well your kidneys are working.	Usually at each clinic visit. If your kidneys are not working as well as they should, you may have other tests such as urine tests, other blood tests, scans or biopsies.

Immunoglobulin (antibody) levels <ul style="list-style-type: none"> Blood tests 	Your immune system.	At 12 months, but sometimes earlier. They'll be repeated if they're abnormal.
Ferritin (iron) <ul style="list-style-type: none"> Blood tests 	Iron levels in your blood.	At 12 months but sometimes earlier and repeated if abnormal or if you're being treated for high iron level.
Respiratory (breathing) tests <ul style="list-style-type: none"> Pulmonary (lung) function tests Chest X-rays 	How well your lungs are working.	Usually only done if you've had abnormal results in the past, developed new symptoms or if you have ongoing GvHD. Some centres will do lung function tests routinely, for example 12 months after transplant.
Thyroid function (thyroid hormone) <ul style="list-style-type: none"> Blood tests A physical examination is sometimes performed (where the doctor feels your neck to check if the thyroid gland is enlarged) 	How well your thyroid gland is producing hormones.	Between 6 and 12 months after transplant, then yearly.

<p>Gonadal assessment (sex hormones)</p> <ul style="list-style-type: none"> ■ Blood tests 	<p>How well your sex organs are producing sex hormones like testosterone and oestrogen.</p>	<p>Between 6 and 12 months after transplant, then yearly.</p>
<p>DEXA scan (bone scan)</p> <ul style="list-style-type: none"> ■ A scan that uses low dose x-rays 	<p>Your bone density (how strong your bones are).</p>	<p>Usually at about 12 months after transplant. This is repeated after treatment if it's needed, or you might have a monitoring period.</p>
<p>Vascular (heart and blood vessel) screening</p> <ul style="list-style-type: none"> ■ Blood pressure ■ Your weight ■ Blood tests to check your blood cholesterol level 	<p>How well your heart is working and how healthy your blood vessels are.</p>	<p>Your blood pressure and weight are measured at every clinic visit.</p> <p>The blood test should be done yearly, and as your team thinks appropriate.</p>
<p>Screening tests for overall health and disease prevention</p> <ul style="list-style-type: none"> ■ Blood tests (for vitamin levels such as B12, folate and vitamin D) 	<p>Your vitamin levels, for example low B12 and folate can cause anaemia, vitamin D is important for bone health.</p>	<p>Vitamin B12 and folate should be measured at 12 months and repeated if abnormal. Vitamin D may also be checked.</p>

Screening for second cancers

As the risk of some cancers is higher after transplant, it's important to attend screening tests. Your team will explain which tests you need and how often.

Breast screening for women

This is an X-ray scan of your breasts (mammogram) but might be an MRI or ultrasound. If your conditioning therapy included TBI (total body irradiation), this starts either at age 25 or 8 years after transplant, whichever is earlier.

Cervical screening for women

Screening with a smear test picks up changes early so they can be treated to prevent cancer of the cervix (neck of the womb) developing. This is done yearly after age 21, or within 3 years of becoming sexually active. Find out more at [nhs.uk/conditions/cervical-screening/](https://www.nhs.uk/conditions/cervical-screening/) or speak to your GP.

Bowel cancer screening

You should have screening when offered on the national screening programme starting at age 60 (or age 50 in Scotland). The test involves giving a stool sample using a kit provided in the post. If there's any sign of a possible bowel problem, you'll be invited for further tests. Find out more at [bowelcanceruk.org.uk/about-bowel-cancer/screening/](https://www.bowelcanceruk.org.uk/about-bowel-cancer/screening/)

Checks for prostate problems in men

Men may have a yearly blood test measuring PSA level. This can indicate a possible prostate gland problem and if you need further tests. Find out more about the PSA test at prostatecanceruk.org

Mouth checks

You should see a dentist at least yearly or every 6 months if you have had GvHD to check for problems, including signs of oral cancer.

Being aware and checking yourself

Speak to your GP or transplant team about cancer awareness and how to check yourself. For example, signs of skin, breast, testicular, and mouth cancer. You can find out more at nhs.uk/conditions/cancer/symptoms/

Which health professionals will I need to see?

Everyone should see:

- Your GP: involved in many aspects of your care, including cancer screening, immunisations, and routine prescriptions.
- Your dentist: at least yearly to check for problems including signs of oral cancer. If you have GvHD, see them every 6 months.
- A gynaecologist: for advice on hormone replacement therapy (HRT) or other treatment for menopausal symptoms as well as sexual function issues.
- An ophthalmologist/optician: yearly to check your eyes.

Some people might need to see:

- Psychiatrist, psychologist or other mental health professional.
- Endocrinologist: for problems with the endocrine system (glands and hormones).
- Chest specialist: for problems with the lungs.
- Liver specialist.
- Kidney specialist.
- Nerve specialist.
- Physiotherapist.
- Dietitian.
- Urologist: for problems of male and female urinary tract and male reproductive organs.

- Assisted conception unit (ACU)/fertility service: let your team know if you'd like to speak to someone about fertility issues or having a family. They can refer you to an ACU or fertility service for expert advice on the options available to you.

Immunisations

During transplant, your immune system is replaced with your donor's immune system. However, your donor cells' immunity against infections won't be adequate, even if the donor was vaccinated.

Therefore, you'll need vaccinations to protect you from infections and illnesses, including vaccinations you had in childhood. You'll have these several months to a year after transplant. You might need some vaccines more than once.

Live vaccines, such as MMR (measles, mumps and rubella), contain weakened live viruses. They're generally not recommended until at least two years after transplant, or longer if you have GvHD.

Your transplant team will give you a schedule and will ask your GP to give the vaccinations. There are international guidelines with basic recommendations for your team to follow, although the vaccinations you're recommended may differ depending on where you live and your age. Always ask your transplant team before having any immunisations after transplant.

Your schedule may include these vaccinations:

- The influenza ('flu') vaccine: recommended every autumn, starting 6 months after transplant. This might be earlier if advised by national or local policy, for example during a flu outbreak.
- General immunisations: including the vaccinations usually given in childhood, normally starting 6-12 months after transplant
- Pneumovax: from about 6 months to protect against infections such as pneumonia and meningitis.
- Human papilloma virus (HPV) vaccine: may be considered for certain patients based on national guidelines.
- MMR: varies between individuals. Usually no earlier than 2 years after transplant.
- Any new vaccines required, e.g. COVID-19 vaccination. For further information on COVID-19 and stem cell transplant please speak to your transplant team. We have further information at anthohnolan.org/covid

Venesections

Iron levels can increase during treatment, as you get a lot of iron from blood transfusions. If your iron levels remain high for a long time, for example several years, iron can settle in your organs and cause damage.

Your transplant team will test for a protein in your blood that stores iron (ferritin). The body isn't very good at reducing the iron on its own, so if yours is high (usually more than 1,000 ng/ml) your team will recommend venesections to reduce the level.

The venesection process is similar to donating blood – a pint of blood is removed through a large needle in your vein and then discarded. This can be repeated every few weeks until the ferritin target range is reached. Venesections aren't usually started until your haemoglobin is normal, so you don't become anaemic. Most people feel fine during and after a venesection, although some people may feel faint and need to rest for a few hours.

6

Step Six

Monitoring your disease, and having more treatment

6 What's in this step?

- **Disease assessment**
- **Chimerism analysis**
- **Donor lymphocyte infusion (DLI)**
- **What if my disease comes back?**
- **Further treatment options**
- **Palliative and supportive care**

Disease assessment

Whenever you come to clinic, you'll have blood tests and other investigations to see how you're doing. You will also have more formal assessments to check whether your disease is in remission. This might include a bone marrow test and/or CT, PET or other scans.

How and when this is done varies depending on your illness, and where you're being treated. Most people will have a disease assessment after one year. After that you might not have another formal assessment unless something changes – for example, if your blood counts drop or you become unwell.

Chimerism analysis

After the transplant, your bone marrow is replaced by the donor's bone marrow. Because your genes (your DNA) are different to your donor's genes, your blood or bone marrow can be tested to see what proportion is you, and what proportion is your donor (chimerism analysis).

After transplant, many people's blood and bone marrow become 100% donor. But some people will have mixed chimerism – a mixture of both your blood and bone marrow cells, and your donor's, existing together. Mixed chimerism doesn't mean the disease has returned. It just means that some of your blood cells have survived or grown after transplant.

It doesn't always need treatment – sometimes mixed chimerism will improve on its own over time. If you're still taking immune suppressing medication, such as cyclosporine, this might be stopped or lowered to

allow the donor's blood cells to increase. If treatment for mixed chimerism is needed, it's usually with donor lymphocyte infusions (DLI).

Donor Lymphocyte Infusion (DLI)

A donor lymphocyte infusion (DLI) is when you're given more cells from your original donor to strengthen the donor cells and push the chimerism levels up towards 100%.

Your donor will be contacted to ask if they are willing to donate again. Donors are usually very committed once they've made a donation – it's extremely unusual that they are unable to donate.

Collecting lymphocytes from the donor's blood for DLI is easier than the stem cell collection because the donor doesn't need injections to increase the number of cells.

Once the cells are collected, they can be infused in the outpatient department through a cannula or your CVC (for example Hickman or PICC line). You're unlikely to need chemotherapy or other drugs if DLI is given for mixed chimerism.

The main side-effect of DLI is graft versus host disease (GvHD, see Step Three). Your doctor will talk to you about the risk in your case. To lower the chances of GvHD, a small number of cells are given in each DLI dose. If a single dose of DLI does not improve the proportion of donor cells, further doses can be given.

What if my disease comes back?

Despite having a transplant, some patients will relapse and their disease will come back. This can feel incredibly hard for you and your family.

In general, the risk of relapse is highest early on after transplant and reduces after about 2 years. Relapse after 5 years is more unusual, but it can sometimes happen.

A relapse might be picked up by your team at a routine clinic visit, for example through an abnormal blood test or swollen gland, or you might seek medical advice if you're feeling unwell. It's important to notice changes in your body or any new symptoms and seek medical advice as soon as you can.

Further tests including a bone marrow biopsy or CT scan are often needed to confirm a possible relapse.

More treatment may be available if you want it. This depends on how long it's been since your transplant, your general health, whether you have GvHD, and other factors related to the illness. You should have an honest discussion with your doctor and loved ones about whether further treatment, and what type of treatment, is right for you.

Getting support

It's natural to feel worried, angry or sad. It can be hard knowing your original condition has returned – the feelings you had at initial diagnosis can return as well, maybe stronger than before.

It's important to get support for yourself and your family if you need it. Your key worker in your transplant team will provide support and information, and there are other helpful organisations (p134).

Further treatment options

Most treatments for disease relapse after transplant aim to get the donor immune system to work better at keeping the disease away. If you're still taking immune suppressive medication, your team may lower or stop this. They may also suggest other treatments depending on your transplant type, your disease, age and how long it's been since your transplant.

Treatments could include:

Chemotherapy

Chemotherapy can be very effective in achieving remission again but won't usually keep the disease away long-term. Chemotherapy is often followed by DLI or possibly a second transplant (see below).

You'll probably be familiar with chemotherapy risks and side-effects, but you should discuss these with your team and loved ones again before deciding.

Donor Lymphocyte Infusion (DLI)

DLI can be an option if your disease has relapsed. The procedure is similar to the one for mixed chimerism with two main differences:

- DLI for relapsed disease is often given after chemotherapy or other types of medications to help the DLI work better. DLI alone in relapse will often not reduce cancer cell numbers sufficiently
- the dose of cells might be higher, meaning the risk of getting GvHD is also higher.

DLI can be very effective in some diseases including chronic myeloid leukaemia (CML), but works less well in others such as acute lymphocytic leukaemia (ALL).

Talk to your team about whether DLI is a good option for you.

Second transplant

A second transplant may be the only potentially curative treatment for certain cases. Your transplant team may opt to use the same donor as for your first transplant or they may find a new donor, but the transplant will be done differently.

Your team will try to achieve a graft versus leukaemia (GvL) effect, where the donor T-cells attack the cancer cells (see p85). GvL often goes along with GvHD, so there is often greater risk of GvHD after a second transplant. Your doctor may explain how GvHD might be triggered to help keep the disease away.

The amount of GvHD is unpredictable. Some patients may have very bad GvHD after a second transplant, which can be life-changing or life-threatening. Talk to your team very carefully, take your time, and get support in weighing up whether the treatment is right for you.

Other drugs

Depending on your original condition, your transplant team may recommend other types of medication: for example, Imatinib or Dasatinib for chronic myeloid leukaemia (CML). These can be used alone or with DLI, be extremely effective and with low risk of side-effects for most people.

Occasionally, drugs like these may be used after transplant to prevent relapse, even when there's no disease evident.

There may be other treatment options, depending on your original condition.

Researchers are continually investigating future treatments, such as new chemotherapy types, targeted therapies, or cell therapies such as CAR T-Cell therapy and different ways of harnessing the immune system.

For some patients it might be possible to join a clinical trial, where a new treatment, or treatment regime is being tested. Your consultant will be able to discuss your options with you. You can read more about clinical trials on our website: [anthonynolan.org/clinicaltrials](https://www.anthonynolan.org/clinicaltrials)

Palliative and supportive care

For some, it might not be possible or advisable to have further treatment. This could be because the risk to you is too high, the treatment is unlikely to help, or that you don't want more treatment.

This can be really difficult to face, even if it's your own choice. It's important to know your options, have time to think them through and talk to your transplant team, your family and friends.

If you're not having further treatment, you may hear the term palliative care. Palliative care aims to help with symptoms you might experience such as pain or nausea. It can also provide you with emotional, physical, practical and spiritual support.

During this phase, you may still receive transfusions and antibiotics. You should be referred to a palliative care or supportive care team, specialists who will be able to support you and your family during this time. You might even have met the palliative care team during your treatment as they often help manage some side-effects from chemotherapy.

7

Step Seven Looking ahead

7

What's in this step?

- **Getting support**
- **Other organisations that can help**

A transplant is difficult and complicated, and you may have setbacks during your recovery. Life after transplant may feel different. But the longer it is since the transplant, the more confident you'll feel, and hopefully life will settle into a familiar pattern and routine.

Be proud of your journey – after all, you've come a long way.

Keep looking ahead. There are lots of positive things that can happen after transplant. Although it takes time, some people say they feel renewed, with a greater sense of purpose and ambition. Others tell us that they feel as though they have a new life and a new beginning.

It can be an opportunity to look at life differently and take on new challenges, or just enjoy the way things are.

Everyone is different and adjusting can be challenging. It can take time to feel comfortable with the new you, and it's natural to feel uncertain, have questions or concerns.

Please discuss any concerns you have with your transplant team, who will always be happy to help. Talk to your key worker for more support or information.

Getting support

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. We also offer a free Telephone Emotional Support service. Call us on **0303 303 0303** or email: **patientinfo@anthonymolan.org**

Get connected

Find support from other patients and their families going through a stem cell transplant 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/patientinfo**

Other organisations that can help

Blood Cancer UK

bloodcancer.org.uk

Information about all types of blood cancer including leukaemia, lymphoma and myeloma.

Bowel Cancer UK

bowelcanceruk.org.uk

Information about bowel cancer symptoms and screening.

British Association for Counselling and Psychotherapy

bacp.co.uk

01455 88 33 00

Information about counselling and therapists in your area.

British Insurance Broker's Association

biba.org.uk

0370 950 1790

Find an insurance broker online or by calling their helpline.

British Lung Foundation

blf.org.uk

Helpline 03000 030 555

Support and information about lung problems.

Citizen's Advice

citizensadvice.org.uk

Advice on a wide range of issues, including financial and legal matters. Find your nearest Citizen's Advice Bureau on their website or in the phonebook.

Complementary and Natural Healthcare Council

cnhc.org.uk

020 3327 2720

Details of complementary therapy practitioners who meet national standards of competence and practice.

coramBAAF

corambaaf.org.uk

Everything you need to know about fostering and adopting.

The Daisy Network

daisynetwork.org

Providing support for women who have experienced premature menopause.

Gov.uk

Information about UK government services, including benefits, employment and money matters.

Leukaemia Care

leukaemiacare.org.uk

08088 010 444

Information about leukaemia plus support including a 24-hour careline and live chat.

Macmillan Cancer Support

macmillan.org.uk

Helpline 0808 808 00 00

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

Maggie's Centres

maggies.org

0300 123 1801

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

NHS Cancer Screening Programmes

cancerscreening.nhs.uk

Find out more about the NHS Cancer Screening Programmes for breast, cervical and bowel cancer.

NHS

[nhs.uk](https://www.nhs.uk)

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

Penny Brohn Cancer Care

[pennybrohn.org.uk](https://www.pennybrohn.org.uk)

Helpline 0303 3000 118

Helping people and their families to live well with cancer.

Prostate Cancer UK

[prostatecanceruk.org](https://www.prostatecanceruk.org)

0800 074 8383

Provides information and support about the signs and symptoms of prostate cancer.

Relate

[relate.org.uk](https://www.relate.org.uk)

0300 003 0396

Information, advice, relationship counselling and sex therapy. In Scotland, contact

[relationships-scotland.org.uk](https://www.relationships-scotland.org.uk)

RNIB

[rnib.org.uk](https://www.rnib.org.uk)

Support and information for people with sight loss.

Turn2us

[turn2us.org.uk](https://www.turn2us.org.uk)

Helpline 0808 802 2000

Provides help with accessing money that's available through benefits, grants and other support.

World Cancer Research Fund

[wcrf-uk.org](https://www.wcrf-uk.org)

Information about ways to reduce the risk of cancer and leading a healthy lifestyle.



We're told life is a journey - well how fortunate am I, because of my stem cell transplant, to get the chance to do the journey again!

Carole, who had a stem cell transplant in 2014



Patient Information Forum

anthonymolan.org/patientinfo
facebook.com/anthonymolanpatients

patientinfo@anthonymolan.org
0303 303 0303

Reg Charity no 803716/SC038827
1981PA 0721



saving the lives
of people with
blood cancer