

THE SEVEN STEPS THE NEXT STEPS

A handbook for long-term recovery after a
blood stem cell or bone marrow transplant



ANTHONY
NOLAN

saving the lives
of people with
blood cancer

A handbook for recovery

Written by Michelle Kenyon and Dr Bronwen Shaw

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Finally, we would like to express our sincere thanks to Anthony Nolan for their support in the development, production and distribution of this booklet.

Ordering more copies

If you'd like to order more copies of The Next Steps, please get in touch with Anthony Nolan on **patientinfo@anthonymolan.org** and they will send them to you.

Need information or support?

The Patient Experience team can help you before, during and after transplant. You can reach them on **0303 303 0303** or **patientinfo@anthonymolan.org**. For more information, visit the website at **anthonymolan.org/patientinfo**

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What's in this booklet?

We wrote this booklet in response to feedback from many patients over many years, who felt that they weren't able to find enough information about their long-term recovery and the effects of their treatment. The information and tips in this booklet are based on our experience, current research and our discussions with our patients – people who've 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.

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 get in touch with the Patient Experience team at Anthony Nolan. You can reach them at patientinfo@anthohnolan.org or **0303 303 0303**.

Michelle Kenyon and Dr. Bronwen Shaw

Anthony Nolan take great care to provide up-to-date and accurate facts about stem cell transplant. The information here will help you to look after yourself. Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from your doctor and transplant team. Please speak to your transplant team for more details about your own situation as they will be able to give you personalised, specific advice.

Step 01

TAKING CARE OF
YOURSELF AFTER
YOUR TRANSPLANT

01

TAKING CARE OF
YOURSELF AFTER
YOUR TRANSPLANT

What's in this step?

What's in this step content

- Leaving hospital
- The road to the new you
- Getting out and about and seeing people
- Appetite, taste changes and food hygiene
- Managing fatigue
- Looking after your emotions
- Relationships and family life
- Managing your finances
- Returning to work...
- ...Or doing something different
- Healthy living
- Complementary therapies
- Travel insurance
- Keeping in touch with your team
- Contact with your donor
- Helping others

LEAVING HOSPITAL

‘When I was told that I could go home – I was excited but I was exhausted. My husband Adrian packed up everything around me and I just watched. People came in to say goodbye. The walk to the car seemed like miles.’

Fran, who had a transplant in 1995

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

You’ll have spent a number of weeks getting used to being a transplant recipient, learning the day-to-day routine of blood tests, observations and medications. And you’ll have been under the constant care of your team on the transplant unit.

You’ll have gained an understanding of the changes that can happen and an awareness of your own body that you may not have had before. But the prospect of being ‘let loose’ on your own can be daunting.

The reality is that you are never truly alone. The staff on the transplant unit 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.

The reality is that you are never truly alone.

The staff will make sure that you have instructions about what to do if you become unwell.

Here’s a 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 or 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 – so go easy on yourself and allow yourself time to recover.

THE ROAD TO THE NEW YOU

‘After the transplant a significant part of me went offline for a couple of years. But I’m now beginning to improve – the creativity is returning along with the occasional, exhilarating bursts of optimism.’

Daffydd, who had a transplant in 2012

As you move along the road to recovery, there may come a time when you start to take stock. 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 and feel different from before. This may only be a temporary change caused by losing weight or hair. Changes in the way you look and other changes in your life can take a bit of getting used to. It’s quite normal to need a little help and support in making adjustments.

Just as it takes time for your body and immune system to recover after your transplant, it also takes time for how you feel emotionally to get better. Many people say that their daily life changes after a transplant, although this doesn’t mean they aren’t satisfied with it.

You are likely to need some support along the way to recovery so please speak to your team. They may ask you about how you’re feeling and anything you need help with at your follow-up appointments, as well as monitoring your

‘We limited our visitors to a few close friends and family who offered positivity and support.’

Una, wife of a transplant recipient

physical health, and they can point you in the direction of support services and further treatment if you need it. Find out more on page 141 about how to get support.

If you ever feel like you need some support along the way, speak to your team.

GETTING OUT AND ABOUT AND SEEING PEOPLE

Aim to start going out again as soon as you feel up to it – this is an important part of your recovery. This may mean something as simple as walking to the end of your garden or street, to begin with.

Aim to start going out again as soon as you feel up to it – this is an important part of your recovery.

At first this will be daunting, and after spending time in hospital, you may even feel uncomfortable with the 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. But it's also important to see people and do normal things as this will help you feel better. You might want to visit friends, for example. Or you may want to go shopping – and this is fine, too, as long as you go at quiet times.

You should avoid anyone with infections or who has been in contact with an infection during the early months after the transplant. It's OK to make physical contact but initially you should limit this to family and the people who are really close to you.

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

TOP TIP

Try visiting shops, restaurants, cafés or friends at quieter times of the day to start with. Start slowly, build up your strength and stamina, and your confidence will soon start to improve.

Regaining your confidence in social situations is just another part of your recovery. Start with something familiar, like the school run or going to the corner shop. Be prepared that you may meet people who haven't seen you for a while and sometimes it can be difficult to know what to say. It can help to take someone along with you on your first outings. It's nice to have the company, and it's reassuring to have someone else there.

Regaining your confidence in social situations is just another part of your recovery.

At this stage, it's good to have the flexibility to be able to do things as and when you feel ready – rather than being committed to things before you feel you are really up to it. Use your common sense to guide you in making decisions.

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 we'd get more active. We decided to start walking up and down the drive, then to the end of the road, and then 25 yards to the park. We started visiting local shops and coffee bars – they became the new pubs! Mary was with me the whole time and she and my nurse practitioner really helped to motivate me.'

Peter, who had a transplant in 2012

APPETITE, TASTE CHANGES AND FOOD HYGIENE

Your appetite, weight and energy levels

Your appetite may not be as good as it was before the transplant for a long time, but it should get better. Losing your appetite and losing weight 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.

It's common for partners and carers to devote a great deal of time to preparing your favourite meals for you as they want you to eat well. But you may still feel quite fussy about your food and this can be frustrating for you as well as those around you. You may have grand ideas about meals that you would like, but by the time they are cooked and served, you may have gone off the idea altogether.

It's easy to fall into the trap of becoming obsessed with your food, particularly when eating can be difficult. Here are some top tips:

Try and make mealtimes as relaxed and calm as you can.

Try eating little and often, you don't have to stick to a three-meals-a-day routine. Make sure you have snacks and easy to prepare food on hand such as yoghurts, ice-creams and cereal bars.

Try having your food served on a small plate. Large meals often look too difficult to manage, and you can be put off as soon as you see it.

Choose foods that you can prepare quickly and easily. Don't be afraid of ready meals or convenience foods when you're feeling tired. As long as you follow the manufacturer's guidance and heat them up properly they're fine!

Try 'food fortifying' – add high-calorie, protein-rich foods to your meals or snacks, like butter and cheese in a baked potato or cream in your soup. Although you might normally follow a low-fat diet, adding these foods in for a short time will boost your calorie count and protein intake.

Go for foods that you really fancy and that are easy to eat.

Maybe you've been craving something while you've been in hospital – now's your chance! Have fun and experiment with different flavours and you'll eventually find something you enjoy.

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 (see page 31), but that can come when your weight and energy levels are up.

In general, advice about diet will change at different points during the transplant process – so it's good to be aware of that. Your dietitian can help you find ways to boost your appetite and energy levels, and to achieve a healthy weight.

Changes in taste and smell

It's common for food and drink to taste different for some time after your transplant. This is because treatments such as chemotherapy, infections, mucositis and medication can affect your taste buds. You may find that the textures of food in your mouth will also feel different for a while.

The changes tend to gradually go back to normal, and your sense of sweet taste is often the one that comes back first – a good excuse to treat yourself and add extra sugar! Talk to your dietitian about what tastes different and what can help.

Try these ideas to help with taste changes:

- If food tastes a bit like cardboard or cotton wool, you could opt for tart foods like citrus fruits
- If food tastes metallic, this could be down to the iron in red meat, so try switching to different sources of protein like chicken, turkey, fish or lentils
- If your food seems tasteless, then opt for stronger flavours that will heighten your sense of taste

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

- 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

You may also experience some changes in your sense of smell. Cold foods tend to smell less than hot foods, so if smells make you feel nauseous or put you off eating, try it cold.

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

Food hygiene

In the early stages of your recovery in hospital, your team may have advised you about eating a clean diet, or neutropenic diet, to help prevent getting an infection 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.

MANAGING FATIGUE

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

It's common to feel fatigued after your transplant. In fact, fatigue is one of the most common problems that people report. It can help to know you're not alone.

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

Fatigue can be caused by a combination of things related to your treatment, particularly conditioning therapy. Other causes of fatigue are much more individual – for example, 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 there is anything that may be affecting your energy

levels, and advise you on how to improve the way you feel.

What helps?

You might find that you have lots of energy one minute and feel exhausted the next. Try to pace yourself and balance rest with activity. It's important not to do too much when you're having a good day, and it's just as important to get out of bed and do a couple of really small things if you're having a bad day.

Exercise may feel like the last thing you want to do, but research shows that a bit of light-to-moderate exercise can help reduce treatment-related fatigue and improve your physical strength. See page 32 for ideas.

If you were sick and not very active during treatment, it's normal for your fitness, endurance, and muscle strength to decline. It's important to exercise at a level that's manageable for you now. Just start small, and build up gradually.

There are many things you can do to help improve fatigue.

- Make sure that you're getting exercise and rest in balanced amounts (see page 32)
- Eat a balanced and healthy diet
- Drink plenty of fluids
- Try not to overdo it when you're feeling good, so you don't use up all your energy and wind up feeling more fatigued
- Have rests during the day if you need to
- Try to get a good night's sleep.

Studies have shown that people who follow an exercise programme adjusted to their individual needs feel better physically and emotionally, and cope better, too. If you are concerned about fatigue, please discuss it with your team. You may be able to get an exercise prescription or referral to be able to use a gym or have sessions with a personal trainer or physiotherapist. Some centres organise, or may be able to refer you to, an exercise group. You can read more about exercise on page 32.

You can find lots of suggestions and tips from other people who've had a transplant in our booklet, *Managing Fatigue After a Bone Marrow or Stem Cell Transplant*, including tips on balancing your energy levels, being active, and getting a good night's sleep.

LOOKING AFTER YOUR EMOTIONS

Recovery after a transplant often feels like a very long rollercoaster ride. It can be difficult to cope with the feelings of uncertainty, which can make it difficult to plan from day to day.

Recovery after a transplant often feels like a very long rollercoaster ride.

People can feel low, distressed or worried while recovering. It's not surprising – you've been dealing with a massive event in your life. Some people find they're surprised at these difficult emotions – you may have never expected to feel sad, angry or anxious after making it through the treatment.

These feelings can hang around at first, but please be reassured that this does get better with time for most people, although some find they need some help along the way.

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

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

NHS Choices has more information on low mood and when to seek help in their Moodzone at [nhs.uk/moodzone](https://www.nhs.uk/moodzone)

It's important to remember that you're going through a learning process and dealing with changes to your body

and your life, so go easy on yourself. Sometimes all you need is someone to reassure you that other people feel this way after a transplant too.

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What helps?

Talking to people and getting support

Recovering from a transplant can take over your life at times. Some people can find it very difficult to keep telling their story, or talking about their treatment or emotions, even to those around them. Others find that it helps to talk about their experiences. There's really no right or wrong.

It's sometimes hard to speak to those closest to you because you don't want to worry them. It can help to talk to someone you don't know.

Connecting with others – for example at a local support group or by asking your team if there are other patients you can talk to – is a very useful way of sharing experiences and ideas with people who've had a transplant. It's an opportunity to talk to people who can relate to your experiences, and reassure you by talking about their own.

Ask your team or hospital about support groups in your area or if there are other patients you can talk to. Some transplant centres have a transplant survivorship group, and Macmillan Cancer Support and Maggie's Centres also have information about local support groups. See page 141.

You can also visit our online transplant community and connect to other transplant recipients at anthonymolan.org/transplantcommunity

Psychological therapy like counselling can help people with emotional and health problems deal with how they're feeling. Therapists are trained to listen and can help you find your own ways to deal with things. There are different types of counselling, and if it's not working out with one counsellor, you could try a different approach with another.

Many centres have a counsellor or people that they can refer you to for further help and support. Please ask your team if you think that this would be useful for you. The British Association for Counselling and Psychotherapy will also have information about counsellors in your area.

Finding the right information

Finding out more about life after transplant can be really useful and help you feel more in control.

There's a lot of information available online, but sometimes it can be hard to judge whether it's accurate or not. Ask your team to point you in the right direction for reliable information. You can also visit the Patients and Families section of the Anthony Nolan website, or get in touch with the Anthony Nolan Patient Experience team.

Ask your team to point you in the right direction for reliable information.

Looking after yourself

Macmillan Cancer Support, The Expert Patients Programme, Maggie's Centres and Penny Brohn Cancer Care also offer free courses on subjects such as managing stress, side effects of treatment, and relationships. Have a look at the complementary therapies section on page 33 for other ideas.

RELATIONSHIPS AND FAMILY LIFE

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

You may find it helpful to bring your partner, friend or relative to your appointments so that they can be involved in your recovery. It also helps to have another pair of ears to take in the information that is given to you, and to help think of questions to ask.

As you start to put your treatment behind you, you may feel like you don't need to depend on your partner or family as much. You may even 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?

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

- Making time together as a family
- Planning and working through any problems as a family
- Taking things step by step and being flexible
- If you have children, keeping them involved in the same activities as before you became ill

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.

Make time for dinner, time to relax, and time to speak to family and friends.

Getting support can help, either by yourself or with your partner and family. Look out for group sessions or courses at your local hospital or cancer support centre, or speak to your GP about a referral.

Getting some help at home can also take the strain. If you could do with extra help, get in touch with your local authority's social services department or your GP to see if they can give you advice or assistance. You can ask social services for an assessment to see whether your loved one or you (if you are providing them with care) need any services. This could include:

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

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 try also 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, anthonymolan.org

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 some 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. You can ask them for information about financial assistance, or speak to a financial or benefits advisor, or visit your local Macmillan centre.

It's important to get the right support so you can focus on your health

Benefits and financial guidance

It's important to find out if you're entitled to any benefits, including sick pay, personal independence payments and incapacity benefit. You may be entitled to help towards the cost of equipment, adaptations to your home, or heating through your local authority.

Have a look at gov.uk for more information on their benefits pages. The website has a 'benefits calculator' to help you work what benefits you may be eligible for

and how you can claim. You can also contact your local Citizen's Advice Bureau, who offer free, confidential and impartial advice.

Macmillan Cancer Support provides financial guidance and access to benefits advisers for people affected by cancer. You can access their services online or call them on **0808 808 0000**.

Grants

Anthony Nolan Grants are available to people affected by a transplant who have limited savings. Grants are typically under £150 and can help to meet a wide range of practical needs arising from a stem cell transplant. You can download the Anthony Nolan Grants Advice form to find out more, and email patientinfo@anthonymolan.org if you'd like to apply for a grant.

Macmillan Cancer Support 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 Bureau, or the charity Turn2us which offers a list of the various UK grants.

Other tips:

- Find out if your hospital does a parking season ticket, or if they have concessions available for people with cancer or other illnesses – this could 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 you're an older person or you're disabled, you can get a freedom pass. There's also help available for other local transport costs around the country
- Don't forget – carers can get financial support as well
- You should be able to get free prescriptions because you have had a transplant which is considered a cancer treatment, even if you weren't diagnosed with cancer. Please ask your GP or transplant team for a 'FP92A' which is the form you need to send away to get your

prescription exemption card. Each card will last for 5 years so make sure you renew it when that time is coming to an end

RETURNING TO WORK...

There are no hard and fast rules about when you should return to work – whether you work full or part time, if you go out to work, or if you look after a home or children. As a rough guide, we've found people who've had an autologous transplant tend to need about three months off work to recover. For donor transplants, this extends to four to six months but can be as long as a year.

If possible, you should not consider committing yourself to the pressures of work until you feel fully able to cope. Generally, it's fine to return to work whenever you feel ready, but you should discuss it with your doctor first. It might be that you need to return to work for financial reasons.

These things can help make your return to work easier:

- Let your employer know about the full impact of having a stem cell transplant. If you don't feel like talking about it in person, you could give them some of our publications to read.
- Talk to your HR department or occupational health service if your company has one. You could also contact your union.
- Your team may be able to help you access information about your employment rights; for example, there might be a welfare or benefits advisor or information centre at your hospital.
- Go to your employer with suggestions about what would help you. For example: taking extra breaks, working from home, working flexible hours, working part time to start with, or changing your job role or duties for a while.

If you have a physical or mental impairment that has a substantial and long-term effect on your ability to do normal daily activities, then you are covered by the Equality Act 2010. If you live in Northern Ireland, you'll have protection under the Disability Discrimination Act. Under

these laws, your employer has a duty to make 'reasonable adjustments' to where and how you work, and to make sure that you get the same chances as the people you work with.

Macmillan Cancer Support and the Citizen's Advice Bureau have helpful information and advice about your rights at work, and information for employers.

...OR DOING SOMETHING DIFFERENT

After a transplant, it's not uncommon for people to take stock and think about doing something different and making changes in their life. Take time to make these decisions and discuss your thoughts and feelings with your family. You can also speak to your team. Try not to change everything at once, as it's important to have some stability and consistency.

Take time to make these decisions and discuss your thoughts and feelings with your family or your team.

You may want a new sense of purpose or challenge, especially if you're no longer working. Have a look at the section, **Helping others**, on page 36.

HEALTHY LIVING

'I think that exercise is a great way of helping me relieve stress and stopping me thinking about the past and all the treatment I've been through. It doesn't get rid of it completely –but it makes the whole thought process about the illness and what I've been through a lot easier.'

Harun, who had a transplant in 2003

You may have reached a point in your recovery where you are starting to make choices to help you stay healthy and feel as well as you can. You might find you want to eat

better or get more exercise, or 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 worry you most, and ask for help with those that are harder for you.

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

It's a good time to think about making changes that can have a positive impact on the rest of your life.

The World Cancer Research Fund have these tips for a healthy diet and lifestyle, there's lots of practical information on all of these things on their website 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

NHS Choices has lots more information about a healthy balanced diet, including what all the major food groups are and why they're important.

You may not feel like eating, and lose weight when you don't want to. On the other hand, it can be hard to break habits that you acquire during your recovery. Once you start to regain weight, it can be difficult to control or lose. Remember that this can all settle down with time. Ask your team about seeing a dietitian who can help you deal with any problems.

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 or Tai Chi

There are lots of different ways to get active – you don't have to join a gym!

When you're recovering from a transplant, it's important to start slowly and gradually work up to doing more. You can ask your team or your GP to refer you to a physiotherapist for advice about what you should aim for and how to exercise safely.

You can also speak to your team or GP about getting access to a local gym or exercise classes for free, or at a reduced cost. You may be able to get an exercise prescription for free sessions with a physiotherapist or personal trainer. Some gyms have 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

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.

An important part of your recovery is about taking time for yourself.

Some people find complementary therapies help provide a complete kind of care, helping with side effects of treatment, and improving your overall sense of wellbeing.

Complementary therapies can be used alongside conventional treatments, but they 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, for example:

- Acupuncture
- Aromatherapy
- Healing and reiki
- Homeopathy
- Herbal medicine
- Hypnotherapy
- Massage
- Reflexology
- Yoga
- Relaxation and meditation

Complementary therapies are sometimes available for free or at a 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 or Penny Brohn Cancer Care.

If you'd prefer to find your own therapist, the Complementary and Natural Healthcare Council can help

you make sure they're properly qualified and belong to a professional body. Be aware that the cost can vary greatly.

Mainstream treatments are carefully tested to show that they work, to check for safety, and to highlight side effects. It can be difficult to judge how well complementary therapies work, because there is less reliable research about them.

There isn't much research in this area, but there is some scientific evidence showing that for people who're going through or have had a transplant:

- Hypnosis and relaxation exercises such as breathing exercises may help reduce pain, anxiety and feelings of sickness, and improve quality of life
- Massage therapy may help with fatigue, feelings of sickness and anxiety in the short term, and can make you feel more comfortable
- Meditation programmes have helped improved people's psychological and physical symptoms while they were 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 will almost certainly need to get special travel insurance cover. There are several companies that can provide insurance after transplant, but it may be more expensive. If you travel without appropriate insurance and then become unwell, you run the risk of having difficulties accessing lifesaving treatment, or running up expensive hospital bills.

You can ask your team for details, and 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, and often a yearly check is all you need.

Please bear in mind that their door is always open. If you have any questions or concerns between appointments, don't hesitate to contact your team at the transplant centre who will happily advise you.

Don't hesitate to contact your team at the transplant centre, their door is always open.

CONTACT WITH YOUR DONOR

You may be able to exchange letters or cards anonymously with your donor. A number of people decide to get in touch with their donor anonymously soon after their transplant. Often this exchange of letters or cards naturally ceases after a year or so, but sometimes people keep in touch over many years.

Others prefer to wait or not to contact their donor at all – you don't have to make contact, and your donor doesn't have to reply. It's not always possible to pass on your letter to your donor, so please don't be too disappointed if we can't send your letter. Be aware that there's certain things that you can't include, for example, your name, contact details, photos or gifts.

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 get you in contact with your donor. Alternatively, you could check with your transplant centre that you're not expecting any further transplants or donor lymphocyte infusions, then contact Anthony Nolan and they'll help. You can request contact with your donor by emailing donor@anthonymolan.org

The rules about contact are different depending on whether you're in the UK or another country. There are more details about this and getting in touch with your donor at anthonymolan.org

HELPING OTHERS

As you travel on your post-transplant journey, some recipients feel a desire to give something back.

You may wish to talk to others about your treatment and recovery to help them to overcome some of their anxieties. It also helps them to get to grips with some of the things that are difficult to understand from information books. You may feel you want to help at your hospital, or you may find you want to do something completely unrelated to your transplant.

The act of helping can be beneficial to you as well, helping to improve your mood. Just be sure to think about how much time you want to commit while you're still recovering.

If you're interested in volunteering with Anthony Nolan, there are lots of ways you can support and help. Have a look at the website or contact volunteering@anthonymolan.org You can also visit the volunteering section of ncvo.org.uk to find other volunteering opportunities to suit you.

Step 02

EARLY RECOVERY AFTER TRANSPLANT

This section covers some of the appointments, medical care, possible complications and their treatments that you might have in the early stages after your transplant. Some of the problems discussed in this chapter can be easily treated, while others are more serious, and some could lead to loss of life. It can seem overwhelming, but this chapter includes different possibilities and not everyone will go through all of these things and some people won't experience any.

Along your road to recovery, your team will need to make adjustments to your treatment and support. Knowing what to expect and what signs and symptoms to look for can be useful.

02

EARLY RECOVERY
AFTER TRANSPLANT

What's in this step?

What's in this step content

- 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
- TTP
- Liver problems
- Bleeding

APPOINTMENTS

When you leave the hospital, you will be given a number of appointments. You may wish to keep a diary for these. After your transplant, your team will monitor your health closely. This involves regular blood tests as well as medical reviews.

In Step Five, we explain the tests and check ups you'll have in the long-term to see how you're doing. In Step Six we explain the tests you'll have to assess the outcome of your transplant.

How often you have appointments depends on how long it's been since your transplant and how you're progressing. At first, it's normal to have an appointment as often as twice a week to see your doctor and have blood tests. You might need appointments more often if you need extra treatments, or your doctor wants to keep a closer eye on your progress.

Having to go to the hospital a lot can become very tiresome, particularly during the first weeks, or if you have to go in often over a long period of time. Your team will review how often you need to come in and will keep your visits to a minimum. Regular monitoring is important for making sure any new problems are found early and treated quickly. This is to maximise the chance of the transplant being successful.

Where will my follow-up appointments be?

Depending on the services in your area, you might need to go to the clinic at your local hospital, as well as your transplant centre. Your local hospital may even be your transplant centre. You might also need to see other specialists elsewhere if you need treatment for any side effects.

You may need these types of appointments:

- Outpatient appointments – local hospital.
- Outpatient appointments – transplant centre.
- Appointments for follow up investigations (such as bone marrow tests or scans).
- Appointments for pentamidine nebuliser if you need it.

This is a drug you inhale that helps prevent chest infections while your immune system is recovering. It's usually given monthly until your blood counts go back to normal, when it may be replaced with Septrin tablets.

- Appointments for blood or platelet transfusions, or infusions of fluid or electrolytes by drip. There might be times when you need to wait in clinic for a few hours for different infusions, for example if you need medications or electrolytes which can only be given by drip rather than as a tablet.

It helps to make sure that your next appointment is booked at each visit.

Your transplant centre will continue to monitor you indefinitely. As you recover, you'll have appointments less often, and a yearly check might be all you need eventually. But their door is always open. If you have any questions or concerns in between your appointments, contact your team at the transplant centre who will happily advise you.

CENTRAL VENOUS CATHETER (CVC)

Your central venous catheter (CVC) will have been very useful during your treatment. CVC can include different devices such as a Hickman line (central line) or a PICC line. Your Hickman line is the tube that goes through the skin near your collarbone, into the large veins leading to your heart. You may have had a PICC line instead. This is similar to a Hickman line but is inserted into a vein in your arm.

Your transplant team will have used your CVC to take blood samples, give you medicine, blood transfusions, and the transplant itself.

Your CVC, or any other tubes going into your veins, are a potential source of infection. So it will usually be removed as soon as it's no longer needed, or if it becomes infected.

Removing the line is a simple procedure and is usually done in the outpatient or day unit. You will be given an injection of local anaesthetic around the area so that you won't feel anything. You'll probably need a stitch (suture) to help the site to heal, which will be taken out around a week later.

Although it can be a little daunting to think about having

‘Mary was with me the whole time and she and my nurse practitioner really helped to motivate me.’

Peter, who had a transplant in 2012

the line removed, especially if you've had one for a long time, it is an important step towards independence.

MEDICATION

You'll need to keep taking all your prescribed medicines, including creams, lotions and mouthwashes, until your team advise you to stop. You will need to take some of the medications for at least a year. Certain drugs such as penicillin, which help to protect you from infections, are lifelong treatments.

This can be difficult for some people, especially if your transplant was several years ago. You might also feel that these drugs are no longer needed when you're feeling well. But some of the damaging effects of your treatment are permanent and these drugs play an important part in protecting you from complications that can be life-threatening.

You may still need to keep taking immunosuppressive drugs such as cyclosporine (or tacrolimus). Take these medications as often as your team have advised you to. Your team will monitor the doses they give you so that you get the benefits but with minimal side effects. This is important because if the drug levels are too low, they won't work properly. If they're too high, they can cause damage to your kidneys or result in more infections.

TRANSFUSIONS OF BLOOD AND PLATELETS

Some people need transfusions of blood and platelets (blood cell fragments that help blood to clot) after they go home. These can often be arranged with your local hospital, or combined with other appointments at the transplant centre.

There are a number of reasons why you may need transfusions. Your team will explain these to you.

If you had a transplant from a donor, any blood products you receive will need to be irradiated (you might hear this called 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 need to go back to hospital after a transplant, and it's possible you'll need to go in more than once. We've found that as many as about 8 out of 10 people need to be readmitted to hospital in the first month after transplant. This does not mean that your transplant hasn't worked, it's quite common to have some glitches and challenging times while you recover.

As there are a number of possible problems that can happen after a transplant, which we discuss in this chapter, the reasons for readmission are very varied.

You might be admitted to your transplant centre or to your local hospital – your team will explain this to you before you go home after your transplant. How long you need to stay will depend on the problem that needs to be treated. Some people come in with one problem and then develop others and end up staying in for longer than for the transplant, while others come in only for a few days.

Readmission to hospital can be very challenging to your confidence and morale. Even knowing that readmission is a possibility might not make it any easier. It can be a time of great uncertainty, and it can be hard to accept that you feel unwell again after you have worked so hard and achieved so much during the first stages of your transplant.

You may find that you feel well despite developing problems, so it's frustrating having to spend more time in hospital. It can help to get support from your family, friends and transplant team.

After your transplant your immune system is vulnerable, and your body will be physically recovering from the demands of the treatment. The first few weeks are an important time, because some problems can be complex and difficult to treat, and can lead to serious illness in a relatively short time. For some, they can even be life-threatening.

Although it's possible that serious problems can develop at any time after your transplant, the chances become lower as time goes on and your immune system recovers. It can be reassuring to know that your transplant team will be monitoring you and will tell you what signs and symptoms to look out for.

High dependency and intensive care

There are times when you may need specialist care on a high dependency or intensive care unit (ICU or ITU). These units offer essential care, support and close observation if you become very unwell. Staff on these units are trained in using special equipment, machines and medications to monitor and treat your condition.

The types of treatment and monitoring you might have in ICU include:

More 'lines' (like your CVC or Hickman line) to monitor specific areas of the body. For example, a urinary catheter may be used to record the amount of urine that's being made, or a line may be inserted into an artery to monitor the amount of oxygen in your blood

Special drugs, which may be used to either treat the problem or make you feel more comfortable

Machines to help to take care of your kidneys if they're not working properly

Machines to help if you're unable to breathe for yourself (ventilators).

Being transferred to the high-dependency or intensive care unit can be a frightening and challenging time for you and your family. It can seem strange that at such an important time you are separated from the environment and staff that are familiar, and moved to an area that looks, feels and sounds very different.

The people who will be looking after you during your stay will work very hard to make sure that you settle in as quickly and smoothly as possible. Remember you can talk to your team about any concerns you might have.

The people looking after you will work very hard to make sure that you settle in as quickly and smoothly as possible.

You may need to be unconscious while on ITU and might not be able to communicate with family members and loved ones. This can be distressing, and it isn't always possible to have enough time to talk to your family before being transferred to ITU. If this is the case, the doctors will discuss this with you or your family, and try to answer any questions as fully as they can.

DEALING WITH SETBACKS

Recovery from serious problems often takes a long time, and can mean an extended stay in hospital. This is so that your team can keep a close eye on your progress and how you're feeling.

Do remember that only a few patients develop such serious problems. Although it's important to be aware that these problems can happen, for most people, readmission means little more than an inconvenience or an interruption to progress and improvement.

For most people, readmission means little more than an inconvenience or an interruption to progress and improvement.

Although this time can be unpredictable and sometimes frightening, it is part of your recovery after your transplant. The doctors and nurses who are looking after you will keep you as informed as possible about your progress. Use the tips and advice in Step One to help take care of yourself and get the support you need.

In the following sections we have described some of the possible complications. Remember that these are things that can happen, but you might not experience any of them.

NAUSEA AND VOMITING

It's not unusual to feel sick, with or without vomiting, after your transplant. This can go on for a number of weeks and, in some cases, months. There are several possible causes for

this which might include medication, infections and GvHD.

As nausea usually affects your appetite and what you eat, it's important to let your team know so they can organise the right treatment and tests.

DIARRHOEA

Diarrhoea after your transplant can be a troublesome symptom. If it goes on for some time it can cause weight loss and malnutrition because you won't be absorbing all the energy, vitamins and minerals you need. As with nausea and vomiting, there are several potential causes and it's even possible that the diarrhoea is caused by more than one problem at the same time. Let your team know about any new or ongoing diarrhoea so that they can take action quickly.

INFECTIONS

After your transplant, it can take a year or more for your immune system to recover. So it's quite common to pick up infections after a transplant. If you have ongoing GvHD or you're still taking medication to suppress your immune system, then you may still be at higher risk of infection, even after a year.

Infections can sometimes be serious so it's important to know what to look out for. Below, we have described some of the most common types and explained how you can protect yourself from infection.

Viral infections

These types of infections are a common reason for needing to go back into hospital after a transplant.

CMV

CMV (cytomegalovirus) is a very common and usually harmless virus, over half of people have had it at some point. It can have symptoms but sometimes has no symptoms, though it can be detected by blood tests. CMV can cause infection almost anywhere in the body.

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

If you've had CMV in the past, it can be reactivated. This is known as CMV reactivation. The virus can be detected at very low levels so you can be monitored for CMV reactivation, and many hospitals carry out weekly blood tests. CMV reactivation needs to be treated and can sometimes clear up within weeks.

It is also possible to pick up a CMV infection rather than reactivation. This can be more serious and is harder to treat, but this is less common.

Significant progress has been made in preventing CMV infections and reactivation. A number of treatments are available and given either as a tablet or a drip, twice a day, for at least two weeks. You might need to be in hospital for this treatment even though you might still feel well.

Most CMV reactivations occur during the first few months after the transplant, although some can occur later. Occasionally, patients experience repeated reactivations and may require treatment on and off for a number of months. This can be frustrating because it needs treating even though you might feeling well.

Respiratory viruses

Some viruses can feel like a common cold or flu-like illness, and symptoms include a runny nose or sore throat. They can cause inflammation to your airways and even lead to pneumonia. It's important to contact the hospital if you develop a runny nose or sore throat even without a fever. They will tell you if you need to have any tests done. A common test for these is a nose and throat swab.

Any treatment depends on which virus you have, if any. Sometimes no treatment is needed other than monitoring your symptoms. If you need treatment, it might be given as a tablet, through a drip, or through a nebuliser (a device used to give medication in the form of a mist that you inhale into the lungs). You might need to be admitted to hospital for the treatment of some respiratory viruses.

EBV (Epstein-Barr Virus)

This is the virus that causes glandular fever. It can be inactive in your body and become active again after a transplant. This viral activity is often picked up on a routine blood test when you feel quite well.

Most people don't need treatment at all. However, some people need an antibody treatment (Rituximab) which you can have through a drip as an outpatient. Occasionally, EBV can cause a more serious illness, with swelling of the lymph nodes. This might need extra treatment, sometimes in the form of chemotherapy.

BK virus

BK virus usually causes cystitis, which is inflammation of the wall of the bladder. This means you will feel the need to urinate often, and it will be painful. You may notice that your urine might have blood in it.

Tests include urine tests, and if the virus is detected, it will often be present for a number of weeks, or sometimes months. If your symptoms and discomfort don't improve, your doctor may refer you to another specialist who will carry out further investigations. There are a number of treatments available for BK virus and the one that's suitable for you will depend on your symptoms. If your symptoms are severe or you are unwell, you may need to stay in hospital until you start to feel better.

Bacterial infections

Bacterial infections are also a common reason for readmission to hospital. One of the most common bacterial infections can come from the CVC or Hickman line.

Hickman line infections are often, although not always, associated with chills or fever after the line has been used. This tends to happen within a few hours or even minutes. Whatever the cause, bacterial infections can make you very unwell very quickly.

Contact the hospital immediately if you have a temperature above 38°C, or if you suddenly feel unwell even without a temperature. There is always someone at the other end of the phone who will be able to give you advice.

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 when you have an infection.

If you have a bacterial infection, you may need medicines such as antibiotics.

Fungal infections

These infections tend to occur in the chest or sinuses but can also be present elsewhere.

Fungal infections can't be fully diagnosed on a normal X-ray. If your doctor thinks that you might have a fungal infection, then they might arrange for you to have a CT scan. A CT scan produces very detailed images which can be used to diagnose and monitor a variety of conditions.

Fungal infections usually happen when blood counts are low, but can occur later on, after the blood counts have recovered. Most people are given medication when they go home to prevent fungal infections and you'll probably be able to stop taking this a few months later.

If you need to carry on taking medication to suppress your immune system after this, or if you have Graft versus Host Disease, you may need to continue with the medication for longer, as there's still a higher risk of picking up an infection.

Signs of infection

You know your body best, so you're the best person to look out for signs of infection. Tell your transplant team about anything unusual so you can be diagnosed and treated quickly. Here are a few things you can do:

- Follow your transplant team's advice for taking your temperature regularly, and whenever you're feeling ill, or have chills, or a fever. It's vital that you contact the hospital immediately if you have a temperature above 38°C, or if you suddenly feel unwell even without a temperature. You might have been given a hotline number to call, or you could 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.

- Look out for other warning signs, including severe fatigue, bleeding, coughing, shortness of breath, chest pain, and severe headaches.
- Contact your transplant team straight away if you notice any of these signs or symptoms. Don't worry about it being a false alarm. Early treatment of infections can make a significant difference to your long-term recovery.

Having some bumps along the road with infections and feeling unwell is a normal part of recovery. The nurses and doctors supporting you are very experienced in dealing with infections, so it's good to trust in their care. It's natural to feel anxious about infection after your transplant, but it's important to try and balance this with getting back to a normal life.

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

PROTECTING YOURSELF AGAINST INFECTION

During the first six months after your transplant you should try and take steps to protect yourself from infection (some people might need to follow this guidance for longer, so ask your transplant team if you're not sure):

Wash your hands regularly, particularly after touching anything dirty or after being in crowded areas or public transport.

Avoid people with coughs, colds or who might have infections or other bugs.

Avoid changing nappies, gardening and construction sites, and try not to touch household or animal waste (if you do, wash your hands!).

Practice safe sex using a condom to reduce the risk of catching sexually transmitted infections (these might be harder to fight off after you've had a transplant).

If you have pets, take extra care, wash your hands after

touching them, avoid touching their litter, and make sure you look after their health. Some people decide that someone else should look after their pets in the first few months after their transplant.

Follow food safety guidelines.

Avoid travelling to any countries or locations where food and water quality might not be up to the highest standards for the first 6 to 12 months after your transplant.

Unfortunately there's no magic potion for boosting your immune system. In general, you should try and keep fit and well by eating a healthy balanced diet and exercising. But there's nothing else 'special' you should be doing – other than making sure you get all your childhood vaccinations again as soon as your transplant centre recommends them.

KIDNEY PROBLEMS

After your transplant, as part of your regular follow-up, your team will monitor your kidneys. You'll have blood tests and your weight will be checked at least once a week.

The kidneys do a number of important jobs. For example they regulate the levels of calcium, water and other substances in your body. They also act as a filter for your blood, removing waste products via your urine. So it's important that they remain healthy.

There are a number of reasons why your kidneys might not be working so well after a transplant. Sometimes this can be related to your medication, an infection, or simply dehydration. Mild kidney problems are common, but occasionally it might be necessary for you to go into hospital for treatment until your blood test results become normal again. To treat kidney problems, your team might make adjustments to your medications and you may need extra fluids through a drip if you've become dehydrated.

In very rare instances, the kidneys can become damaged and may not work properly for quite some time. It's not always necessary to stay in hospital until the kidneys improve, but you may need extra visits to the hospital for monitoring.

‘I came home with eleven different drugs. Keeping it organised was a challenge and we made a tick box chart which was a big help.’

Martin, who had his transplant in 2014

TTP

Thrombotic thrombocytopenic purpura (TTP) is a rare condition which can happen after a transplant, where small clots (thrombi) can form within the circulation. This means more platelets are used up, leading to a low platelet count (thrombocytopenia). You need platelets in your blood to help seal cuts in blood vessels and stop bleeding.

The symptoms can include fever, headaches and sometimes diarrhoea and bruising easily. If the vessels of the kidney become affected it can lead to high blood pressure.

What causes TTP?

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

Some medications, such as cyclosporine, are linked to TTP, but very few patients who take cyclosporine actually develop this problem. TTP 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 are likely to review all your medications and may even stop the cyclosporine.

There are a number of possible treatments, including plasma exchange, which involves removing your blood plasma and replacing it with donor plasma. This helps to remove the sticky vWF protein and replace it with normal vWF protein. This is usually done daily for five days or more for it to be effective.

LIVER PROBLEMS

Your liver also needs to be monitored after your transplant, as occasionally it stops working properly. There are a number of reasons for this – it can be related to your medication, an infection, Graft versus Host Disease (see page x) or veno-occlusive disease (VOD).

VOD is where the blood-flow through the small veins of the liver is partially blocked. VOD can cause symptoms such as yellowing of the eyes and skin (known as jaundice), swelling or enlargement of the abdomen, and fluid build-up in your body. It's usually very mild and disappears quickly – often you won't even be aware of it.

VOD usually occurs during the first few weeks after the transplant, but in some cases it can happen later. It's generally more common in people who've had very high doses of chemotherapy before their transplant.

Occasionally VOD can be a serious problem, and treatment is aimed at minimising its effects. New treatments are available which have improved the outcome for patients with severe VOD, and life-threatening disease is rarer than it used to be. Recovery is helped by your liver's own great ability to recover and regenerate from the effects of diseases such as this.

BLEEDING

You may have had platelet transfusions during the time just after your transplant, and you may still need to have platelet transfusions after you go home. Platelets help the blood to clot, and when you have a low platelet level you are at risk of bruising and bleeding.

Contact the hospital straight away if you notice any new bruising, bleeding – for example, blood in your urine or stools – or a persistent nosebleed. Although bleeding can occur later on, this is generally not considered normal, so make sure you tell your team immediately so that they can investigate the cause.

There can be many possible reasons for bleeding. Remember that these 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.

Step 03

GRAFT VERSUS HOST DISEASE (GVHD)

Step Three describes what GvHD is, and some of the treatments available.

03

GRAFT VERSUS HOST
DISEASE (GVHD)

What's in this step?

What's in this step content

- What is GvHD?
- How common is GvHD?
- Types of GvHD
- Who's at risk 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. Everyone’s experience of GvHD is different, and this information should be used together with the care provided by your medical and nursing team.

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?

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) are attacking your own body (host). During this reaction, donor cells recognise that 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 and are part of the immune system, and they help us to fight infections. T-cells recognise, attack and destroy cells that they see as foreign and potentially harmful, 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 a part of you, or ‘self’.

HLA is a part of your DNA which can be matched to other people. Before a stem cell transplant, donors have blood tests done to identify their HLA or tissue type, and this is compared to yours to see how closely the HLA matches. When bone marrow donors are chosen, although the closest HLA match is often selected, there are still differences in the proteins on the surface of the cells. Generally, the more closely your HLA matches your donor’s, the lower your chance of GvHD.

T-cells are able to 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 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 symptoms, which can range from mild to severe. If you have moderate to severe GvHD you’ll often need much closer monitoring through blood tests and clinic visits. You may also need to be admitted back into hospital more often and for longer periods of time, as you are more likely to have complications related to the GVHD.

HOW COMMON IS GVHD?

Approximately half of patients who have an allogeneic transplant will develop GvHD.

For a small number of people, GvHD can be a serious and sometimes life-threatening, or even fatal illness that can have a big impact on how you feel physically and emotionally. GvHD can affect your quality of life and may mean that you’re not able to do some of the things that you used to, such as going back to work or going on holidays, or exercising in the same way. Fortunately, for the majority of patients GvHD is mild, causing very few problems.

Types of GvHD

Generally, GvHD is referred to as acute or chronic. This relates to the time after the transplant when GvHD starts.

Acute GvHD

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

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

Acute GvHD	this can start within 100 days of your transplant or when the immunosuppression is being lowered or stopped
Chronic GvHD	this can start later, after 100 days post-transplant, and may follow acute GvHD
Progressive GvHD	this is where acute GvHD progresses and becomes chronic
Overlap GvHD	this has some features of chronic and acute GvHD at the same time

Acute GvHD often affects skin cells. It may start with a rash on the palms of your hands and soles of your feet but can be more widespread. For some people the skin can be itchy and red. For others the skin may be dry or scaly. In cases of severe acute GvHD, it may become blistered or peel.

Acute GvHD may also affect your gut and liver. This causes diarrhoea which can be mild or excessive, nausea and yellowing of the skin and eyes (jaundice), and swelling or pain in the abdomen.

Acute GvHD can be quite frightening as the symptoms can change rather quickly. When you're in hospital and during your follow-up your medical team will be monitoring you for signs of GvHD, but it's important that you report any new or worsening problems as soon as possible – so that treatment can be started early.

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 your transplant, even if you never had acute GvHD. It can last for 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.

WHO'S AT RISK OF GVHD?

There are a number of factors which can increase your risk of GvHD after a transplant.

Having an unrelated donor

The chance of developing GvHD is generally lower if your brother or your sister was your donor than if you had an unrelated donor. This is because your brothers and sisters

‘I don’t normally get my arms or legs out but why try to hide it? I’ve won my war and I have the scars to prove it.’

Alexandra, who had two transplants and is living with GvHD

will have inherited their tissue type from your parents. The genes (DNA) between the HLA molecules are more likely to be similar to yours than if you have an unrelated donor.

HLA mismatch

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

Age

Some researchers have found that being older when you have your transplant is related to a higher risk of chronic GvHD, but not acute GvHD. This risk of GvHD also goes up with the age of the donor.

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 the risk of GvHD to be increased in patients with CMV reactivation or infection.

CMV is a very common and usually harmless virus with over 50% of people testing positive for it. This means that they have had CMV in the past and have detectable CMV antibodies in their blood – this is called CMV-positive.

If either you or your donor is CMV-positive, there is a risk of a CMV reactivation or infection after transplant. In this case there is a high chance of you needing treatment for CMV which can be very complicated and problematic when you also have GvHD.

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 general wellbeing, taking blood tests and examining your body. If your team suspect that you have GvHD, they may arrange for some more tests or ask other specialists to confirm that you have it. The tests and specialists involved will depend upon the area or areas of the body where you may have GvHD.

Biopsy

One way of diagnosing GvHD involves taking a small sample of the 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 (page 77), 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 light source and a video camera at one end. Images of the inside of your body are relayed to an external television screen.

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 by endoscopy is called a gastroscopy. For this, the endoscope is passed down your oesophagus.

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

It's usually necessary to prepare the gut for this examination. You may need to stop eating for a few hours

to make sure your stomach is empty. If your bowel is being examined, you may need to take a medicine which helps to clear the bowel before the test takes place. It's common for the doctors to ask for both types of endoscopy to be done to look at the upper and lower parts of the digestive tract.

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

Scans

You may need to have a CT scan of the lungs so the structure can be examined in better detail and other causes of your symptoms, such as infection, can be ruled out. You may need to have a number of scans as part of your assessment for GvHD, and 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 how well your lungs are working. It helps to see if your lung function has changed and how effectively your lungs work in terms of their capacity, elasticity and ability to exchange gas.

None of these tests should be painful, and they include:

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

Grades of GvHD

Your team may talk about the 'grade' of your GvHD. They use grading systems so that they have a standard way of describing the level of your GvHD and how severe symptoms are in different parts of your body. This helps them recommend the best type of treatment.

It's also helpful in keeping track of your progress, as the grade of your GvHD can improve and get worse.

GVHD BY ORGAN, AND WHAT HELPS

GvHD can affect different parts of the body, and can affect more than one area at the same time. The areas it most often affects include:

- Skin
- Gut
- Mouth
- Liver
- Lung
- Eyes
- Muscles and joints
- Genitals

Your treatment will depend on whether your GvHD is acute or chronic, what grade it is, and the part or parts of the body affected. Some of the 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

GvHD can affect the skin and can cause changes in appearance, and affect its ability to regulate body temperature and act as a protective barrier for your body.

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
- If your skin is very red, you may lose a lot of heat and find it difficult to keep warm
- A rash that can become widespread, and may be painful and itchy or prickly
- In severe cases your skin may blister and peel

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 may develop, which can look like eczema or psoriasis
- Build-up of fluid under the skin
- Skin infections
- Changes to the colour (pigmentation) of your skin – you may develop lighter or darker patches
- You may lose a lot of heat and find it difficult to keep warm
- Your skin may become thicker and tighter, losing its elasticity, which sometimes makes it difficult to move your joints
- Your nails and hair may also be affected and become thin or brittle. Some patients lose their hair then find that it doesn't grow back properly, or turns grey or white

Treatment

Sometimes mild skin GvHD, whether it's acute or chronic, requires no treatment at all and may get better on its own.

Chronic skin GvHD can last for months or even years, and if it needs treatment, this can be challenging and tiring. But as well as the treatments available which can improve your symptoms, there are things you can do to help yourself, explained in the top tips on page 77.

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 course of treatment. You may need to continue to see the dermatologist, particularly if the treatment for skin GvHD is ongoing.

For mild GvHD, you may need to apply moisturisers, or a steroid cream to the affected areas, or all over your body. If your skin problems are moderate or severe, or aren't getting better with the help of these treatments, then your doctor may decide to use medication to suppress your immune system or steroid medication which you can take as a tablet or through a drip.

Other treatments for skin GvHD include ultraviolet light treatment (explained below) and extracorporeal photopheresis (ECP) (explained on page 86).

Ultraviolet light treatment

Psoralen plus ultraviolet A, or PUVA, is a treatment that combines exposure to ultraviolet light with a medicine called psoralen. The psoralen makes the donor T-cells attacking the skin more sensitive to the light so that when the T-cells are exposed to the UVA light, they become less active. This treatment can help to clear the skin of the GvHD.

You'll normally have treatment twice a week, for a period of weeks to months. You'll need to stand in a special cabinet which gives off ultraviolet light for a few seconds to several minutes. It can take some months to see an improvement, and it's often used alongside other immunosuppressive medication which can be reduced once the PUVA starts to take effect.

As your eyes and skin will be more sensitive to sunlight after each treatment, you'll be advised to wear sunglasses and protect your skin.

‘My GvHD just affects my skin. A recent change in steroid cream and continuing photophoresis (light therapy) seems to be getting on top of it.’

Steve, who had his transplant in 2013

TOP TIPS

- **Wear cotton clothes**
- **Try to avoid extremes of temperature – very hot or cold**
- **Use plain, unperfumed soaps**
- **Try not to rub your skin dry after bathing**
- **Use the moisturisers as advised**
- **Ask for help with putting on the moisturisers and lotions**
- **Try wearing cotton gloves at night to prevent scratch marks**
- **Always use high factor sunscreen such as Factor 50 when you go out, especially when it's sunny, as sun can stimulate 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 of your digestive system, including your mouth, oesophagus (food pipe), stomach and bowel. It usually doesn't affect the whole system at the same time, and acute gut GvHD usually affects the bowel. We have talked about mouth GvHD separately, on page 79.

Symptoms of GvHD of the gut may include:

- Diarrhoea. This is a very common symptom. Your stools may look green and watery and may have a 'bitty', possibly porridge-like appearance
- Undigested food in your stool. Occasionally it may contain mucous or blood
- Cramping or bloating in the abdomen
- 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. The lining of your gut will be inflamed, and won't be absorbing nutrients from your food in the usual way

You may need to have tests such as an endoscopy to work out the exact cause of your symptoms (see page 70). 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 at all. But the symptoms may make you feel sick and give you diarrhoea, so it's important that you 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 go into hospital to have fluids through a drip.

Your team may offer you other medication to help with your 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 also important that you see a dietitian. There may be a dietitian in your medical team who has experience of oncology, haematology or GvHD. 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 a range of treatments for gut GvHD which include steroids (general and targeted), immunosuppressive drugs and antibodies.

TOP TIPS – IF YOU HAVE DIARRHOEA

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

- Try to eat small amounts of food regularly if possible
- Go for high calorie snacks and energy shakes
- Rich foods could make your symptoms worse. If that's the case, 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 doctors and nurses if you can't take your tablets and if you notice an increase in the frequency or consistency of your diarrhoea

Mouth (oral) GvHD

If you have GvHD in your mouth (oral GvHD), it can become sore and dry, and you may find you are not producing enough or any saliva. Your sense of taste may change, and you may get blisters or ulcers. Oral GvHD can be painful and it can be difficult to enjoy certain foods. There are tips about eating and drinking on page 19.

Visit your dentist every six months if you have GvHD in your mouth. As there is a small increase in the risk of oral cancers in people with chronic oral GvHD, let them know about any changes you notice. Your dentist will also be able to look for changes – so that they can examine any changes, so any problems can be treated early.

Treatment

There are a range of treatments for mouth GvHD. These include regularly using mouthwashes with antibacterial or soothing properties, pastes and sometimes mouthwashes

that can contain steroids, and immunosuppressive drugs. If you are struggling to eat enough you may be referred to a dietitian who can advise you on foods you could try.

TOP TIPS

- Go for soft foods that you don't need to chew, such as yoghurt, mashed potato and rice pudding
- Keep drinks handy to help make chewing easier
- Choose foods which are quite moist with lots of sauce or gravy as dry foods like bread and crackers can be difficult to eat

Liver GvHD

Sometimes liver GvHD doesn't have any symptoms, so the first sign is often an increase in the levels of your liver enzymes. This will be picked up through routine blood tests after your transplant. These tests can reveal early changes in the way your liver is working before any symptoms develop.

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

The liver has lots of important roles, such as cleaning the blood by removing certain toxins. When chronic GvHD affects the liver, it can become damaged and scarred to the extent that it 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

There are a number of treatments used for liver GvHD which include steroids, drugs to suppress your immune system and sometimes monoclonal anti-bodies. You can read more about these on page 86.

TOP TIPS

- **Take antihistamines to help reduce any itching**
- **Try to avoid extremes of temperature. The 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 as this can make your liver function worse.**

Lung GvHD

If you have lung GvHD, your lungs can lose some of their flexibility and elasticity. This 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. 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 be referred to a lung specialist, and your treatment might include medications, including drugs to suppress the immune system. If you have very severe lung GvHD, oxygen therapy can help relieve your symptoms. This is used to increase the amount of oxygen that flows into your lungs and bloodstream. You may have a machine or portable cylinder to 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

- Your eyes may water almost continuously
- Your eyes might sometimes be sensitive to bright lights
- Inflammation of the inside of your eyelids, the white parts of your eyes and the transparent front part of your eye (your cornea)
- Changes to the skin around your eyes
- 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. They may prescribe you artificial tears, eye drops to lubricate the eyes, and medications to reduce inflammation or antibiotics. You may find it helpful to wear sunglasses to protect your eyes from the sun.

Musculoskeletal GvHD

GvHD can affect almost any area of the body. This can include your:

- Joints
- Muscles
- Tendons – the tough band of tissue that connects your muscles to your 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 mean you have stiff joints and 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 impact activities such as driving and climbing stairs. This is rare, however, and affects less than one out of 100 people who've had a transplant.

Some people also find that extra fluid collects in different

parts of their body, making them swollen, although this is rare.

Treatment

Physiotherapy can improve your symptoms – particularly doing stretches and keeping your joints mobile.

You may also be able to have lymphatic drainage, which can involve massage to help move any extra fluid from swollen parts of your body. Medication to suppress your immune system, steroids and other medicines may also help.

Genital GvHD

This can affect both men and women after transplant.

In mild cases in females, you may experience symptoms of vaginal dryness but have no other problems. In extreme cases, there may be advanced signs of GvHD, including vaginal strictures (when the vagina becomes narrow) and ulceration (sores). You may experience severe pain during sexual intercourse or find it difficult or impossible to insert a vaginal speculum for smear tests.

Men may also have genital GvHD. This usually affects the penis – and can make it inflamed and sensitive. You may also have a rash, or a 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 that can be put into your vagina to make it less dry and sore. Tacrolimus ointment helps to reduce symptoms. Hormone replacement therapy may also help to improve your symptoms, as some of these might be caused by early menopause (see page 101). Use water alone for washing, as lotions and soaps could cause irritation.

If you have narrowing of the vagina, using dilators might help. These are plastic tubes of varying sizes that can be inserted by you or by a partner. The dilators prevent the two side-walls of the vagina from sticking together, and are used with lubricants. Macmillan Cancer Support has more information about this.

Steroid cream 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. People often find it difficult to talk about sexual problems after transplant. However, they are very common and your team will be experienced in talking about them, so if you are having difficulties, please ask for help. You could try taking this booklet with you to your appointments. There is more information about this and getting support on page 97.

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

A variety of treatments are available for GvHD. Your treatment will depend on whether your GvHD is acute or chronic, what grade it is, and the part of the body affected.

Some of the treatments for different parts of the body are described in the previous section, and here we describe the other treatments that are often used.

Most of the treatments for GvHD aim to reduce the attack of the T-cells on your body. Most will weaken your immune system, so can make you more vulnerable to infections. GvHD itself also suppresses the immune system, and so often people with GvHD will experience more infections. But 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, and 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 the GvHD coming back. About half of those affected by chronic GvHD are still taking this medication after two years.

Your doctor may adjust the dose to make sure you're not taking too much or too little. You'll have regular blood tests to check the levels of this medication and to monitor your liver and kidneys for side effects.

Steroids

Steroids are one of the main treatments for both acute and chronic GvHD. They work by reducing inflammation and suppressing your immune system.

You can take steroids in a variety of ways, depending on the grade and type of your GvHD. For example you can apply a cream to your skin (called topical steroids) to treat skin GvHD, or use a 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 period of time.

Like all medication, steroids have side effects. These include:

- A higher chance of infection
- High blood pressure
- Changes in your blood sugar level
- Irritated stomach lining
- Behaviour changes and mood swings, including difficulty sleeping and feeling more anxious
- Appetite changes and weight gain
- Bone thinning (osteoporosis)

- Needing to drink much more fluid than usual, and pass much more urine

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

For some people, steroids can give you a sense of wellbeing. You might have more energy, a better appetite and be in a better mood. If your dose is reduced, you may find your sense of wellbeing also lessens. Read about ways to look after yourself on page 25.

Monoclonal antibodies

Monoclonal antibodies tend to work by targeting specific proteins on the surface of certain cells, and then attacking and destroying them. There are a number of different monoclonal antibodies that can be useful in the treatment of GvHD. For example, you may be prescribed one called rituximab.

Many of these antibodies can have a lasting effect on the immune system, making you more vulnerable to infections. They are usually given intravenously by drip, either as a single infusion or as a course. Please talk to your doctor about the effects and side effects of monoclonal antibodies, as each one works differently.

Extracorporeal photopheresis (ECP)

Extracorporeal photopheresis (ECP) can be used for skin, liver or oral GvHD – both acute and chronic. It's usually suggested when you've had other types of treatment but your GvHD hasn't improved. It's a complicated treatment and you'll probably have to go to a hospital that has a skin specialist (dermatology) centre. It can take around 6 months for you to start seeing the benefits of this treatment, 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. Your blood (minus the white blood cells) is given back to you via your vein.

The white blood cells that have been collected are then treated with a drug called methoxypsoralen (8-MOP) and exposed to ultraviolet light. The light helps activate the drug so it can destroy the abnormal 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 to complete and you'll normally have it for two days every two weeks, for around 6-12 months. You may need to have a central line if your veins aren't very good. The treatment is not painful, but can be tiring and you may find it more difficult to continue working during ECP treatment due to the frequency of appointments.

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.

Other medications

Other treatments for GvHD might include 'topical' treatments that are applied or used directly on the affected area. This can include creams for the skin, eye-drops and mouthwashes. These treatments can be just as important in controlling your symptoms, and should be used as often as directed by your team to achieve the best effect.

Depending on where your GvHD is affecting and what treatments you've had, sometimes other medications that dampen down the immune response can be available. Your team will talk to you about these if you need them.

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 a transplant tend to have a lower risk of disease relapse. This is because the T-cells from the donor can also cause a beneficial immune reaction by attacking any diseased cells in your bone marrow.

If your disease does come back after your 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 even using a different donor. While both of these strategies may help to harness the GvL effect, they may also mean you're more likely to develop GvHD.

LIVING WITH GVHD

GvHD can feel like an unexpected and devastating effect of your transplant – for you and for your family. It can have a big impact on your quality of life, how you feel physically and emotionally, and on your expectation of life after transplant.

Despite the impact that GvHD can have, most people do find they have a relatively good quality of life and very few tell us they actually regret having their transplant.

There is help available for you and your family to support you in your treatment and recovery. Share your experiences and get support from others on the Anthony Nolan transplant community

[anthonynolan.org/transplantcommunity](https://www.anthonynolan.org/transplantcommunity) There are also local support groups all around the UK you can join. Speak to your team or GP or visit Macmillan Cancer Support to see what's available in your area, you could also visit the nearest Maggie's Centres or hospice. Or contact the Anthony Nolan Patient Experience team for more support at **patientinfo@anthonynolan.org** or **0303 303 0303**.

See page 140 for more ways you can get support.

Step 04

OTHER EFFECTS
OF TREATMENT

04

OTHER EFFECTS
OF TREATMENT

What's in this step?

What's in this step content

- 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
- Emotional changes
- Immune system and late infections
- Second cancers

There are a number of side effects you might expect during and after the transplant. Although some of these effects may not occur during the transplant, they can still happen months or years later. You may hear these called 'late effects' and some are more common than others. It's important that you know what to look out for, and also how your team will monitor, screen for, and prevent these effects from happening.

Unfortunately some late effects can't be predicted or prevented, but as you'll be regularly monitored, they can be picked up sooner and treated more easily.

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During the months leading up to the transplant, you may find that you can only focus on the transplant process itself and the chance it will cure you of your disease. It can be very difficult to concentrate on problems that might occur months or years afterwards. But it's important for you and your family to understand what can happen after the transplant – so that you can consider all the factors when making up your mind, and so you're prepared for what life after your transplant might be like.

You might also find it helpful to have another look at this booklet after you've started to recover and life's beginning to take shape and get back to normal.

In this section we describe the different late effects that may occur in the main organs of your body. We also explain what to look out for and the treatments available. The most common problems are described first, with the rarer problems at the end of the chapter.

Remember that the chances of developing these effects depends on many factors, including the type of transplant you had, other drugs or radiotherapy that you received, and your age and gender. You should discuss these with your transplant team.

Graft versus Host Disease (GvHD), a common effect of donor transplant, can affect any organ in the body.

Although some of those symptoms will be mentioned below, it's also important to read Step Three (page 60) to understand what may happen and what to look out for.

The next section, Step Five (page 112), explains the tests and investigations that your transplant team are likely to suggest as part of your routine, the reasons for them, and the long-term follow-up care involved.

INFERTILITY

Unfortunately, the high-dose chemotherapy you'll have had before your transplant means it's likely you'll experience fertility problems. We discuss many of the issues related to infertility in The Seven Steps.

Once you're recovering and thinking about life after transplant, you may want to find out for certain whether you're fertile or not, and explore what options are available to you. Your transplant team or GP can refer you to a fertility specialist or an assisted conception unit. Infertility Network UK also has information and advice.

Some people may wish to consider adopting a child. There's more information about adoption from **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 will want to know that you've been well for several years, and that you're in remission from your original disease. It could be as many as two to five years after the transplant before they will be able to help you to find a child. However, most agencies will be happy to talk things over and answer any questions about the process beforehand.

The adoption process involves a medical assessment by your GP. Your transplant team will most probably need to be consulted as well, with your consent.

Thinking about your fertility can be hard, and it's an emotional subject. Talk things through with your partner, family and friends, or find other ways to get psychological support (see page 24). It may be reassuring to know that many patients have successfully adopted children after their transplant.

‘After my transplant I was very, very weak. I couldn’t get up the stairs without being really out of breath!’

Ashling, who had a transplant in 2012

It is very important to be aware that very occasionally, fertility can recover, sometimes for a short time. So if you don't want to have children at all, it's still important to use contraception.

PREMATURE MENOPAUSE

Women who've had a transplant may experience premature menopause. This can be hard, especially if you weren't expecting to go through 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 the support you need.

Premature menopause can cause your periods to stop and you may have hot flushes and sweats, vaginal dryness, bladder problems, mood changes, difficulty concentrating, and low sex drive. It can also affect your heart and bone health. Hormone replacement therapy can help maintain your sex drive, sexual function and bone health.

You can be referred to a gynaecologist for advice. They will be able to do a full assessment and start treatment if it's needed. **The Daisy Network** is a charity that supports women who've experienced premature menopause. You can read more about the symptoms and the treatments available in *The Seven Steps*, in the main booklet and in appendix B.

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
- Your desire to have sex (libido)
- Your sexual satisfaction
- Your ability to get an erection (erectile function) if you're a man
- Your ability to ejaculate and have an orgasm

- Pain during sex, for example caused by GvHD or vaginal dryness (see page 101)
- Your fertility
- The appearance of your body
- Your sexual relationships

It can feel difficult to talk about sex, but it's nothing to be ashamed of or embarrassed about and it's important to talk to your transplant team about anything that's bothering you. They can make sure you get the support you need. If you're finding it hard to broach the topic, you could take this booklet into the appointment with you and show them this section.

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 who feel that they have otherwise reasonable or good quality of life, sexual issues remain.

There are many different reasons why you might have sexual problems after your transplant: for example, physical changes, changes in body image, side effects of transplant, or medications you're taking, and fatigue. In reality the cause is often a combination of factors.

Fatigue

Fatigue is very common after a transplant. For some people it can go on for months or even years, and can make you feel physically and mentally drained. It's often difficult to feel enthusiastic about having sex when everything else takes such a lot of effort! Finding ways to manage and improve your fatigue may also help your sex life (see page 21).

Physical changes

People often find that they look and feel quite different in the early months after a transplant. This can affect the way you see yourself. Some of the changes may be caused by things such as hair loss, weight changes or scarring from CVCs or Hickman lines.

Some people develop GvHD which can cause some physical changes, as can some of the treatments for it. Some patients may also develop GvHD involving the sexual organs (the vagina and the penis can be affected) and this will require specific treatment (see Step three).

It's common to lose or put on weight during and after a transplant, and for a while, you might be less physically fit than before. Looking after yourself and taking up physical activity could help you feel more confident in your body.

Your hormone levels

It's extremely common to have low levels of the main sex hormones (testosterone in men, oestrogen in women) after your transplant.

In men, the symptoms of low testosterone include lack of libido (sex drive) and difficulties getting or maintaining an erection. There's more about the symptoms of low oestrogen in women in the section about premature menopause on page 97; these can affect your desire for sex.

Hormone replacement treatment can help with these symptoms (read more on page 83).

Your emotions

Many relationships change during a serious illness – you might find that yours becomes stronger, or that stress has been placed upon it. Some people say that the nature of their relationship changes. You might be less physically close, but closer emotionally.

In some cases your partner may be the one who is reluctant to initiate sexual contact because they are worried about how you are physically and if they might hurt you or tire you out.

Fear about the future often contributes to these feelings. If you're feeling anxious you might not want sexual contact, and the feeling of uncertainty can be challenging if you're considering starting a new relationship.

Emotional support

Simply talking things through with your transplant team or a health professional is a good place to start on the road to recovery. They should be able to refer you to specialist professionals and clinics. Understanding that these are common problems and that there are solutions can be a relief.

Talking to your partner about how you're feeling can help. Macmillan Cancer Support has tips about relationships and communication on their website. You might find it helpful to talk to a relationship or psychosexual counsellor, perhaps with your partner. The charity **Relate** provides relationship counselling and a range of other relationship support services. Sex therapy is available on the NHS or privately.

Your sex life might not be the same as it was before you had a transplant – but you don't have to give up on pleasure, closeness or fun. If you're in a relationship, keeping some kind of physical closeness alive, in whatever ways possible, can protect or even improve your connection.

Medical treatment

There are treatments available for both men and women, and many centres have a specialised clinic that they can refer you to.

If you're a man, you may find that your testosterone levels increase back to normal with time, but you may also be able to have testosterone replacement through injections, patches or gels.

There are also a number of treatments you can try. Finding what works for you can be a process of trial and error, if one treatment doesn't work, there are often others available. A group of medicines called phosphodiesterase type 5 (PDE5) inhibitors can help men get erections. The names of some of these drugs are:

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

Finding what works for you can be a process of trial and error, if one treatment doesn't work, there are often others available.

If you're a woman, sexual problems may be linked to early menopause. These symptoms may be improved by hormone replacement therapy, oestrogen cream, or creams or gels to help with vaginal dryness.

If you are able, regular sexual intercourse after transplant can help to improve or regain sexual function, and prevent some problems. And we know that those patients who resume sexual activity within the first year after a transplant tend to experience fewer sex-related problems in the long-term.

Macmillan Cancer Support has more information about treatments for sexual problems.

Whether you're in a relationship or single, a good approach may be to combine medical treatment for sexual problems with support for the emotional impact of a transplant or your relationship.

SKIN CHANGES

Your skin is a very large and sensitive organ, and there are often changes to the skin after transplant. Graft versus Host Disease (GvHD) most frequently affects the skin and may need particular treatment (see Step Three). Even without GvHD, your skin is likely to be drier and more sensitive, to sunshine for example, for a long time after the transplant.

This is an effect of the chemotherapy and radiotherapy, but certain drugs (such as antifungals) could also add to this. Thinning of the skin and loss of hair follicles can also mean you feel the cold much more than usual, although this usually gets better with time.

It's very important for you to protect your skin in the long-term. Use high-factor sun creams or sunblock, avoid direct sun and sunbathing, and cover up by wearing long sleeves and a brimmed hat. This is particularly important as you'll have a higher chance of developing skin cancer after your transplant. Get to know your 'mole map' and if you notice any new changes to your skin, let your GP or transplant

team know so they can refer you to a dermatologist as soon as possible.

JOINTS AND MUSCLES

Loss of strength

GvHD can affect your joints and muscles (see page 82), and the steroids used to treat GvHD can cause your muscles to lose strength. Lack of activity and being unwell for long periods of time, as well as problems with eating and drinking, can also affect your muscle strength.

Joint problems

It's common to have some joint aches and pains following a transplant, but these will often settle down with time. If they are very troublesome you might be referred to a specialist to investigate this further.

Muscle cramps

Muscle cramps, especially in the calves and hands, may occur for months or even years after a transplant. There are many possible causes, including a lack of certain vitamins in your diet, and some medications. Some supplements may help, as can taking quinine tablets, although the cramps will continue to occur from time to time. Always check with your team if it's safe to take any supplements in case they have an effect on your other medications.

Numbness and tingling

You might have numbness and tingling, usually in the hands and feet. This may be due to nerve damage following certain types of chemotherapy, and in most people it improves over time.

How exercise can help

Exercise, and in some cases physiotherapy, are very important to build up muscle strength and stability. Walking is one of the best ways of starting to increase your strength, stamina, balance and confidence – start small and gradually increase the distance and maybe pace as you become stronger and more confident.

Walking is one of the best ways of starting to increase your strength, stamina, balance and confidence.

Building up strength and fitness takes time. Some people will develop a new appetite for health and may even become fitter than they were before treatment. Others unfortunately won't regain their physical strength or stamina and will need to work towards different goals and challenges. This is highly individual and when you do start exercising you should always start slowly and gradually build up.

EYES

There are a number of ways that your eyes can be affected after the transplant. Even without a transplant people's vision may deteriorate with time, but it's important to have regular checks. 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 if you don't have GvHD, your eyes might feel dry, gritty or irritated. Simple eye drops such as hypromellose (or liquid tears) may help to lubricate the surface of the eyes and reduce the irritation.

Cataracts

Cataracts are common following a transplant, especially if you've had total body irradiation (TBI) or steroids during the treatment. Research shows cataracts occur in just over half of those having TBI, but less than 1 in 5 of those without. They usually occur within the first 2-4 years after a transplant, but could develop as late as 10 years afterwards.

Cataracts are cloudy patches that develop in the lens of your eye. They can cause blurred or misty vision and it may be more difficult to see at night. People often notice that they have difficulty when driving. Cataracts can generally be easily treated with surgery if they're having a big impact on your daily life, providing that your eyes

are otherwise healthy. The Royal National Institute for the Blind (RNIB) has more information.

MOUTH

It's common to have symptoms in your mouth for several months after the transplant, even if you don't have GvHD. In most people these symptoms will resolve in time. Your mouth may be very dry and the taste of food and drink may have changed. This can also be caused by a particular medication, but in many cases a specific cause can't be found.

Artificial saliva helps some people and frequent sips of water can help relieve your dry mouth, and make chewing and swallowing food easier.

Take care of your mouth – keep it refreshed and get rid of stale tastes. Try rinsing it out with salty water or bicarbonate of soda, chew sugar-free gum or mints, and brush your teeth regularly. Even if you're not eating as much as usual, make sure that you drink plenty of water.

TEETH AND GUMS

Your teeth and gums can also be badly affected by chemotherapy, drugs, radiation and malnutrition – you may have more tooth decay than usual. Having a dry mouth may also make cavities more likely.

As well as taking care of your mouth (see above), it's important to take care of your teeth and gums by brushing regularly, not smoking and reducing sugary drinks. Make sure you also visit your dentist regularly.

BONE CHANGES

There are two main problems which can involve your bones.

Osteoporosis

Osteoporosis, or thinning of the bones, is a common problem for people who haven't had a transplant. After a transplant osteoporosis is even more common, for both men and women.

You're more likely to get osteoporosis if you're older, have a low body-weight, are less active, or if you've had steroid treatment for a long time before your transplant or to treat GvHD afterwards. Osteoporosis is more common after menopause, and as transplant can lead to early menopause, women are more likely to be affected.

Although osteoporosis is generally not painful, the bones are much weaker and, as a result, fractures are more common. A special type of X-ray called a DEXA scan can be used to look at the density of your bones to see whether you're at risk of osteoporosis.

The good news is that osteoporosis is often reversible. Being physically active, taking calcium and vitamin D supplements, and having hormone replacement therapy if you're a woman, can help prevent and treat osteoporosis. If you're diagnosed with osteoporosis and your bones are losing density, your doctor may prescribe you medications called bisphosphonates.

Avascular necrosis

The second problem, avascular necrosis, is when the bone breaks down due to a restricted blood flow, usually in one joint. Often this is the hip, but sometimes it can be the knees, wrists or ankles. This is less common, but can happen in those who have had a lot of steroids, TBI, or who have GvHD. Avascular necrosis can be very painful and result in difficulty with walking and other daily activities.

Medication can help with the pain but most people with avascular necrosis will need surgery. Many people will return to good mobility with no pain following surgery.

THYROID AND OTHER GLANDS

Up to about a fifth of people can develop an underactive thyroid gland after a transplant, and it's more common in those who've had TBI.

An underactive thyroid means you produce less of the thyroid hormone. The symptoms include fatigue, constipation, hair loss and weight gain. Your transplant team will monitor you for an underactive thyroid with

blood tests. It can be easily treated with tablets that replace the hormone.

It's also common for the glands that produce your sex hormones (oestrogen and testosterone) to be affected. It's far less common for other glands or hormones to be affected.

BOWEL

Your bowels may take quite some time to get back to normal. Some patients find their bowel habits change after a transplant and remain changed. Your bowel movements may be looser or you may find you get constipated more often.

If you have any new changes in bowel habits, you should report this to your team as soon as possible.

KIDNEYS AND BLADDER

Your kidneys and bladder may have been affected by total body irradiation (TBI), GvHD, medications or infections during or after your transplant. In some cases, the effects may be long lasting. Your transplant team will be monitoring your kidneys.

Any problems may show up as a slightly abnormal blood test – you might not feel any symptoms. If tests show you could have a chronic (long-term) kidney problem you'll be referred to a specialist for more tests and treatment.

LIVER

If you have chronic GvHD, it's common to have abnormal liver tests (see page 66). But if you don't have GvHD, long-term damage to the liver is relatively rare. There can be damage from the long-term use of some medications, infections, or from iron building up in the liver – as iron from multiple blood transfusions can build up in the body.

Yellowing of your skin or the whites of your eyes (jaundice), or pain under the ribs on the right side can all be symptoms of a problem with the liver. Your liver function will be monitored at your follow-up appointments

with blood tests. If you need treatment, it'll depend on the cause and exact liver problems you have.

LUNGS

Some people experience lung problems after a transplant. These can happen if you have chronic GvHD, if you've had a lot of infections during or after your treatment, and can be related to the conditioning treatment you had before your transplant.

If you have lung problems you may have symptoms such as a dry cough that won't go away, breathlessness that gets worse, wheezing and fever. You may need to have some lung function tests, and other tests such as X-rays and scans. Any treatment will depend on the exact problems but you might have steroids or other medications. If you have GvHD you will be referred to a specialist.

You should not smoke after a transplant because you'll be at higher risk of long-term chest problems and some types of cancer, including mouth and lung cancers. If you would like help to stop smoking, please ask your team or contact NHS Smokefree.

HEART

Heart problems, especially hardening of the arteries, known as atherosclerosis, are common in the general population, particularly as you get older, and the risk of getting heart disease in the long-term is higher after a transplant.

Heart problems can cause chest pain, an abnormal heartbeat, or symptoms related to a 'floppy' heart – where the heart muscle becomes weaker and can't pump blood around your body as well as it should – such as swollen ankles and breathlessness. They can also cause more serious problems in the long-term; for example, atherosclerosis can lead to a stroke.

You should have follow-up tests once a year to keep an eye on your heart health. You can help to reduce the risks of developing heart disease and look after the health of your heart by keeping active, eating the right foods

(reduced salt and cholesterol) and not smoking. Other family members who haven't had a transplant may already be doing the same!

MEMORY CHANGES

Short-term memory loss and difficulties concentrating are common after a transplant. This might be related to the conditioning therapy you had before your transplant, but there might be other things that affect your memory, such as your original disease and any treatment you've had in the past. There are also simple things that can affect memory and concentration, such as fatigue and lack of sleep.

These difficulties are unlikely to be bad enough to affect your ability to work, but some people have more trouble than others (the crossword often takes longer!). Some people say they have trouble finding the word they want, but doing puzzles like crosswords and word searches can actually help.

Making notes and lists often helps with memory issues and for most people these symptoms improve with time, getting better over the first year. You could also ask for a referral to a psychologist or occupational therapist.

Making notes and lists often helps, and for most people these symptoms improve with time.

EMOTIONAL CHANGES

It's common to feel worried and down before, during and after a transplant – you're dealing with a massive event in your life. The treatment itself can make you feel unwell, tired and low, and your normal life will have been disrupted. It can be frustrating to feel like you're not getting better quickly enough or can't do the things you used to, and you might be worried about money or the future.

It's common to feel worried and down before, during and after a transplant – you're dealing with a massive event in your life.

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. If you don't feel like yourself and it's affecting your mood, for example if you feel low, angry, anxious or depressed, it's important to speak to your team as help is available. As some people develop anxiety or depression in the longer term, counselling and treatment with antidepressants or anti-anxiety medications can help. See page 24 for more information.

If you don't feel like yourself and it's affecting your mood, it's important to speak to your team as help is available.

IMMUNE SYSTEM AND LATE INFECTIONS

Even though your blood counts should be back to normal, your immune system may take up to two years to fully recover, meaning your risk of infection is raised. In some ways it may never be as effective as before. You may be at higher risk for longer if you're taking medication to suppress your immune system because you have chronic graft versus host disease (GvHD).

Problems with your immune system might be a result of the damage that the radiation and chemotherapy have done to your spleen. This is why you may be asked to take an antibiotic such as penicillin for the rest of your life. You will also be asked to have your childhood vaccinations again (see page 122).

You can read about ways to protect yourself from infection on page 49.

SECOND CANCERS

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

The higher chance of second cancers is one of the reasons that we recommend lifelong follow up for everyone who has had a transplant. There's more on this in Step Five.

The risk of developing a second cancer can depend on other things, such as:

- Whether your conditioning therapy involved total body irradiation (TBI)
- Having chronic GvHD and taking medication to suppress your immune system (this is particularly linked to cancer of the mouth and skin)
- Being younger when you had your transplant
- Whether you have a family history of cancer
- Other, universal factors that put you more at risk of cancer, such as whether you smoke or drink alcohol, or whether you diet

The most important way to deal with this is by knowing what to look out for. You can also reduce your risks: for example, by using sun creams, not smoking and following a healthy lifestyle (see page x), screening (see page x), and getting treatment early if you do develop a second cancer. In many cases second cancers can be successfully treated, although it depends on the specific type of cancer.

In some rare cases a different blood cancer can actually develop. The most common form is called PTLD (post-transplant lymphoproliferative disorder). It's usually caused by the Epstein Barr Virus (EBV), a very common virus. PTLD can be treated with combinations of chemotherapy, steroids and antibodies.

Developing PTLD, or any other cancer, in the donor cells does not mean that the donor has cancer or will develop a cancer. The changes will usually happen to the donor's cells after they are already transplanted and it is most likely an effect of some of the medications. Similarly, your donor developing cancer will not usually increase your chances of developing that particular cancer.

Step 05

LONG-TERM HEALTH
CHECKS AND WELLBEING

05

LONG-TERM HEALTH
CHECKS AND
WELLBEING

What's in this step?

What's in this step content

- Blood tests, investigations and surveillance
- 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 a good quality of life about a year after their transplant. As with all aspects of the treatment though, this varies for different people, and it's important to remember that your recovery is an ongoing process.

It's important for your transplant team to continue to review you in clinic and you will still need to have a number of tests and investigations.

As explained in Step Four, there are side effects that can occur months or even years after the transplant. For some patients, the thought of ongoing monitoring and tests can be daunting and may raise concerns or questions. But if your team can pick up on these late side effects early, they can treat them quickly before they affect your health and quality of life. So even if you feel completely well, you should continue to have follow-up visits in the long-term.

These long-term follow-up appointments may not always be in the transplant centre, and are much less frequent than appointments early after transplant so it's important that you also understand what to expect and what to look out for. The team at your transplant centre will be happy for you to contact them between these appointments and will be able to direct you to the most appropriate source of help.

There is an international guideline used by transplant centres worldwide which lists all of the tests and examinations recommended, and how often they should be done.

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 called 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 need to 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 one year, 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 one year and repeated if abnormal or if you're being treated for a high or iron level.
Respiratory (breathing) tests <ul style="list-style-type: none"> · Pulmonary (lung) function tests · Chest X-rays 	How well your lungs are working.	These are usually only done if you've had abnormal results in the past, you've developed new symptoms or if you have ongoing GvHD, though some centres will do lung function tests routinely, for example at one year
Thyroid function (thyroid hormone) <ul style="list-style-type: none"> · Blood tests 	How well your thyroid gland is producing hormones.	Between six months and one year after your transplant, and then once a year.
Gonadal assessment (sex hormones) <ul style="list-style-type: none"> · Blood tests 	How well your sex organs are producing sex hormones like testosterone and oestrogen.	Between 6 months and 1 year after your transplant, then once a year.
DEXA scan (bone scan) <ul style="list-style-type: none"> · A scan designed to look at the health of your bones 	Your bone density (how strong your bones are).	Usually at about 1 year after transplant. This should be repeated following treatment if it's needed, or you might have a monitoring period.
Vascular (heart and blood vessel) screening <ul style="list-style-type: none"> · Blood pressure · Your weight · Blood tests to check the amount of cholesterol in your blood. 	How well your heart is working and how healthy your blood vessels are.	You'll have your blood pressure and weight measured at every clinic visit. The blood test should be done once a year, and as your team thinks appropriate.
Screening tests for overall health and disease prevention <ul style="list-style-type: none"> · Blood tests (for vitamin levels such as B12, folate and vitamin D). 	Your vitamin levels, for example low B12 and folate can indicate anaemia, and any other signs, and vitamin D is important for bone health.	Vitamin B12 and folate should be measured at one year and repeated if abnormal. Vitamin D may also be checked.

BLOOD TESTS, INVESTIGATIONS AND SURVEILLANCE

Here are some of the main investigations you'll have as part of your follow-up care:

SCREENING FOR SECOND CANCERS

As the risk of some cancers is higher after a transplant, it's important that you go for screening tests. Your team will talk you through which tests you need, these will probably be done every year and are likely to include the following:

Breast screening for women. This is done with an X-ray scan of your breasts, called a mammogram, but it might also be an MRI or ultrasound. If you had total body irradiation as part of your conditioning therapy this will start at the age of 38, or 8 years after your transplant, whichever is earlier.

Cervical screening for women. Cervical cancer affects the neck of the womb, or cervix, in women. Screening is done to prevent cancer developing by picking up on any changes early, and treating them. The test is called a smear test.

This should be done every year after the age of 21, or within three years of becoming sexually active. Find out more about smear tests at cancerscreening.nhs.uk/cervical/about-cervical-screening.html or speak to your GP.

Bowel cancer screening. Men and women should have a screening test every three years from age 60. This simply involves giving a stool sample, and if there are signs there could be a problem with your bowel you will be invited for further tests. Find out more at bowelcanceruk.org.uk

Checks for prostate problems in men. Only men have a prostate gland. Men will have a blood test to measure something called a PSA level every year in clinic. The PSA level can indicate if there is a problem with the prostate gland and if you need further tests. Find out more about the PSA test at prostatecanceruk.org

Mouth checks. You should see a dentist once a year, they can check for any problems including signs of oral cancer.

Thyroid tests. You will also have blood tests and sometimes a physical examination – where the doctor feels your neck – once a year in clinic to check for signs of thyroid problems including cancer.

Being aware and checking yourself

It's also a good idea to speak to your GP or your transplant team about being aware of signs of cancer and how to check yourself. For example, for signs of skin, breast, testicular, and mouth cancer. You can also find out more at nhs.uk/be-clear-on-cancer/

WHICH HEALTHCARE PROFESSIONALS WILL I NEED TO SEE?

Everyone should see:

- Your GP: your transplant team will ask your GP to be involved in many aspects of your care, including screening for cancers and immunisations
- Your dentist: you should see your dentist at least once a year. If you have GvHD you will need to see them every six months. They should also examine your mouth for signs of oral cancer.
- A gynaecology service: most women will need to see a gynaecologist for advice on hormone replacement therapy (HRT) or other treatment for menopausal symptoms.
- An ophthalmologist/optician: you need to see them once a year to check your eyes.

Some people might need to see

- Endocrinologist – these are doctors who specialise in diseases of the glands and hormones. All children who have had a transplant should see an endocrinologist as their glands are still growing, but adults often don't need to see one.
- Chest specialist – for problems with the lungs
- Liver specialist
- Kidney specialist
- Nerve specialist

‘After a long struggle post transplant, I am now well enough to enjoy a wonderful life with my family.’

Julie, who had a transplant in 2009

- Physiotherapist
- Dietitian
- Psychiatrist, psychologist or other mental health professional
- Urologist – these are doctors who specialise in problems of the male and female urinary tract and the male reproductive organs.
- Assisted conception unit (ACU) /fertility service: please let your team know if you would like to speak to someone about fertility issues or having a family after transplant. They can refer you to an ACU or fertility service so that you can get expert advice on the options available to you.

IMMUNISATIONS

During the transplant, your own immune system is destroyed or damaged, and replaced with your donor's immune system. But because of some of the medications you'll be taking after the transplant, such as cyclosporine, the immunity of your donor cells against infections won't be perfect. Even if the donor has been vaccinated, their cells will behave slightly differently in your body.

Because of this, you'll need to have a number of vaccinations to protect you from infections and illnesses, this includes the vaccinations you had as a child. You'll have these several months to a year after the transplant. You might need to have some of the vaccines more than once.

Live vaccines, such as MMR (measles, mumps and rubella), contain live viruses that have been weakened or altered so you won't get the actual illness. They're not recommended until at least two years after the transplant, or longer if you have GvHD.

Your transplant team will have a schedule they can give you, and often your GP will be asked to give you the vaccinations. There are international guidelines which make basic recommendations for your team to follow, although the vaccinations you're recommended may differ depending on where you live and your age. You can ask your transplant team about this.

You might have some of these vaccinations:

- The influenza ('flu') vaccine. This is given every autumn, starting six months after transplant. This might be earlier if advised by national or local policy, for example during an outbreak of flu.
- General immunisations. These include the vaccinations usually given in childhood, they're normally started 6-12 months after a donor transplant (allograft).
- Pneumovax. This is started from about 6 months to protect against infections such as pneumonia and meningitis.
- Vaccination against human papilloma virus (HPV) may be considered for certain patients based on national guidelines.
- MMR, which varies with each individual, but no earlier than two years after a transplant.

VENESECTIONS

Iron can build up throughout your body during your treatment, as you get a lot of iron from blood transfusions. In general, the body isn't very good at getting rid of this extra iron. If your iron levels remain high for a long period of time, for example a number of years, iron can settle in many of your organs and cause damage.

Your transplant team will test for a protein in your blood that stores iron, called ferritin. If you have a high ferritin (usually more than 1,000) your team will recommend venesections to reduce the amount of iron being carried around in your blood.

Having a venesection is essentially the same as giving blood – as a pint of blood is removed from your vein using a large needle. The blood is then discarded. This can be done every few weeks or months until your ferritin levels are in the normal range. Venesections aren't usually started until your haemoglobin has got back up to normal after your transplant, 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.

Step 06

MONITORING YOUR
DISEASE, AND HAVING
MORE TREATMENT

06

MONITORING YOUR
DISEASE, AND HAVING
MORE TREATMENT

What's in this step?

What's in this step content

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

DISEASE ASSESSMENT

In Step Five, we explained that whenever you come to the clinic, you'll have blood tests and other investigations to see how you're doing. There will also be one or more times when you have a more formal assessment to see whether your disease is still in remission.

This might include a bone marrow test and/or CT, PET or other scans. How and when this is done will vary depending on what your illness was, and where you're being treated. Most people will have a disease assessment after one year, and you might not have another formal assessment after this unless something changes – for example, if your blood counts drop or you become unwell.

CHIMERISM ANALYSIS

After the transplant, your bone marrow and blood are replaced by the donor's bone marrow and blood.

Because your genes (your DNA) are different to your donor's genes, your blood or bone marrow can be tested to see what proportion of the blood or bone marrow is yours, and what proportion is from your donor.

After a transplant, many people's blood and bone marrow will become 100% donor. But some people will have what's called mixed chimerism, when both your blood and bone marrow cells, and your donor's, exist together.

Mixed chimerism doesn't mean that the disease has returned. It just means that some of your blood cells have survived or grown after the transplant.

Mixed chimerism doesn't mean that the disease has returned. It just means that some of your blood cells have survived or grown after the transplant.

It doesn't always need treatment – sometimes mixed chimerism will improve on its own over time.

If you're still taking medication to suppress your immune system, such as cyclosporine, this might be stopped or lowered to allow the proportion of donor's blood cells to increase. If treatment for mixed chimerism is required, 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%. If there were lymphocytes (white blood cells) left over from your transplant, they will have been stored, so they can be used at a later date.

If there were no donor cells left after your transplant, the 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 would say no or be unable to donate.

Collecting lymphocytes for DLI is easier for the donor than when they first donated, because they don't need any injections to increase the number of cells, and the cells are always taken from the blood rather than bone marrow.

Once the cells are collected, they can be given to you in the outpatients department through a cannula. You won't need any special lines like a CVC (for example a Hickman line or line), but if you do still have one, the cells can be given through it. You're unlikely to need any chemotherapy or other drugs if the DLI is being given for mixed chimerism.

The main risk or side effect linked with DLI is that you might develop graft versus host disease (GvHD, see Step Three for more information about this). Your doctor will talk to you about the risk in your case. To lower the chances of GvHD, a very small number of cells are usually given in each DLI dose.

If a single dose of cells 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 original disease will come back. This is incredibly hard for you and your family, especially if a long time has passed since your transplant.

In general, the risk of relapse is highest in the early stages

after your transplant, and reduces after about two years. It's much more unusual for the condition to come back after five years have passed, but it can sometimes happen.

If you do relapse, this might be picked up on by your team at a clinic visit, for example through an abnormal blood test or a swollen gland, or it might be that you seek medical advice if you're feeling unwell. It's important to look out for changes in your body or any new symptoms so that you can seek medical advice as soon as you can.

It's important to look out for changes in your body or any new symptoms so that you can seek medical advice as soon as you can.

Further tests such as a bone marrow biopsy or CT scan are often needed to confirm whether the original condition has come back.

More treatment may be available if you want it. This will depend 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 your loved ones about whether further treatment, and what type of treatment, is right for you.

FURTHER TREATMENT OPTIONS

Most treatments for disease relapse after transplant are aimed at getting the donor immune system to work harder at keeping the disease away. If you're still taking medication to suppress your immune system, your transplant team may lower or stop this. They may also suggest other treatments. This will depend on the type of transplant you've had, your disease, your age and how long it's been since you had your transplant.

Treatments include:

Chemotherapy

Chemotherapy can be very effective in getting the disease into remission again, but on its own it won't usually keep the disease away in the long-term. If you do have chemotherapy, it is often given with DLI or possibly before a second transplant (see below).

You will probably be familiar with the risks and side effects of chemotherapy, but you should talk these through with your team and loved ones again before making your decision.

Donor Lymphocyte Infusion (DLI)

DLI can be an option if your disease has come back. The procedure is similar to the one for mixed chimerism.

There are two main differences. One is that the DLI for relapsed disease is often given after chemotherapy or other types of medications to help the DLI work better. DLI used alone in this situation will often not be effective at reducing the number of cancer cells. The other is that the dose of cells might be higher, and this means that 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

For some people, the only chance of a cure is having a second transplant. In some cases the same donor might be used as for the first transplant, but the transplant will be done in a different way.

Your team will try to achieve a graft versus leukaemia (GvL) effect, where the donor T-cells attack the cancer cells. This is described on page 87. GvL often goes along with GvHD, and so you will be at a much greater risk of developing GvHD after the second transplant. In fact, your doctor may explain that they will try to cause GvHD to keep the disease away.

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

**‘I would love all donors
to see how appreciative
we are to live a normal,
bolder life and to live
life to the full.’**

Nicky, who had a transplant in 2012

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 either with or without DLI. These can be extremely effective, with low risk of side effects for most people.

In some cases drugs such as these may be used after a transplant as a way of keeping the disease away, even when there's no sign of disease.

There may be other options for further treatment, depending on what your original condition was. Researchers are looking at future treatments, such as new types of chemotherapy, targeted medication and different ways of harnessing your immune system.

PALLIATIVE CARE

In some cases it might not be possible or advisable to have further treatment. This could be because the risk to you is too high and 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 that you know all your options, and that you've had time to think them through and talk to your transplant team and your family and friends.

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

During the palliative phase of your care, you may still receive transfusions and antibiotics. You should be referred to a palliative care or supportive care team. They are 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 are often called to help manage some of the side effects associated with chemotherapy.

GETTING SUPPORT

It's natural to feel worried, angry or sad about having further treatment. It can be hard knowing your original condition has come back – all the feelings you had when you were first diagnosed can come back as well, maybe even stronger than before.

Ask your medical team for practical information about treatment options which might help ease your worries. It's also important to get support for yourself and your family during this time if you need it. Your key worker in your transplant team will be there to provide support and information, and you can find other organisations who can help on page 141.

Step 07

LOOKING AHEAD

What's in this step?

What's in this step content

- Getting support
- Other organisations that can help

Having a transplant is a difficult and complex treatment, and you may have setbacks during your recovery.

Life after transplant may not be the same as it was before. But the further you are from the transplant, the more confident you'll feel, and hopefully life will begin to settle into a familiar pattern and routine. Be proud of the journey you've travelled – 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 to get there, 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.

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 you shouldn't feel guilty if you're still adjusting. It can take time to really feel comfortable with the new you, and it's natural to feel uncertain or have questions or concerns.

Please discuss any concerns you have with your transplant team, who will always be happy to help you. Talk to your key worker if you need more support or information, and you can also get in touch with the Anthony Nolan Patient Experience team at patientinfo@anthohnolan.org or **0303 303 0303**.

GETTING SUPPORT

Anthony Nolan – Here To Help

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

Get connected

Find support from other patients and their families by joining the online transplant community at anthohnolan.org/transplantcommunity

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

Peter, had a transplant in 2012

You can also share stories and find out more about the important and interesting work on the Patients and Families Facebook page:

[facebook.com/anthohnolanpatients](https://www.facebook.com/anthohnolanpatients)

Find information

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

Need to talk?

Before, during and after transplant, the Patient Experience team at Anthony Nolan are here for you. Call on **0303 303 0303** or email patientinfo@anthohnolan.org

Share your thoughts

Anthony Nolan work with a panel of people who've been affected by transplant to make sure they offer the best services and information. If you'd like to join them – from sharing your experiences to coming up with new ideas and giving feedback on resources and services – your ideas and insight are very valuable. If you're interested in joining the panel, just get in touch!

Tell your story

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

OTHER ORGANISATIONS THAT CAN HELP

Bowel Cancer UK

bowelcanceruk.org.uk

Information about bowel cancer symptoms and screening.

British Association for Counselling and Psychotherapy

itsgoodtotalk.org.uk

Phone **01455 88 33 00**

Information about counselling and therapists in your area.

The British Association of Fostering and Adopting

baaf.org.uk

Everything you need to know about fostering and adopting.

British Insurance Broker's Association

biba.org.uk

Phone **0870 950 1790**

Find an insurance broker online or by calling their helpline.

British Lung Foundation

Helpline **03000 030 555**

blf.org.uk/

Support and information about lung problems.

Citizen's Advice Bureau

citizensadvice.org.uk

Online advice: **adviceguide.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

Phone **020 3178 2199**

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

The Daisy Network

daisynetwork.org.uk

Providing support for women who've experienced premature menopause.

Expert Patients Programme

expertpatients.co.uk

Phone **0800 988 5550** or **01925 320 000**

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

Gov.uk

gov.uk

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

Leukaemia and Lymphoma Research

leukaemialymphomaresearch.org.uk

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

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

maggiescentres.org

Phone **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 screening.

NHS Choices

nhs.uk

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

Penny Brohn Cancer Care
pennybrohncancercare.org
Helpline 0845 123 23 10

Helping people and their families to live well with cancer.

Prostate Cancer UK
prostatecanceruk.org
Phone 0800 074 8383

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

Relate
relate.org.uk
Phone 0300 100 1234

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

RNIB
rnib.org.uk
Support and information for people with sight loss.

Turn2us
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

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

Acknowledgements
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saving the lives
of people with
blood cancer