

Hospital isolation after a stem cell transplant

A Guide



At Anthony Nolan we take great care to provide up-to-date and accurate facts about stem cell transplants. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide. It isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

Ordering more copies

If you'd like to order more copies of this guide, or to request it in an alternative format, please get in touch with us at patientinfo@anthohnolan.org

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

The information contained in this booklet is correct at the time of going to print (December 2024). We plan to review this publication within three years. For updates or the latest information, visit anthohnolan.org

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What's in this booklet?

We've put together this booklet for anyone about to have a stem cell or bone marrow transplant. It will help you prepare for your stay in one of the protective isolation units in your hospital or transplant centre.

This information aims to give you a better idea of what to expect, and help you come to terms with your current situation.

It's been written with guidance and advice from our remarkable patients who've been where you are now, as well as specialist healthcare professionals.

If you need to ask us any questions, or you would like some more advice, please get in touch with the Anthony Nolan Patient Services team at patientinfo@anthohnolan.org or on **0303 303 0303**.

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Patient Information Forum



ALEX WHO HAD A STEM CELL TRANSPLANT TO TREAT CML

Contents

Key questions	6
What is protective isolation?	9
Preparing for isolation	10
During isolation	13
Keeping in touch with loved ones	17
Young patients and protective isolation	20
Protective isolation and your emotions	22
Anthony Nolan contact details	26
Other useful contacts	27

Key questions

Why do I need protective isolation?

When you receive your new stem cells from your donor, it can take a little while for your new immune system to develop. During this time, you'll be at risk of catching an infection, so precautions need to be taken to avoid this.

How long will I be in isolation for?

It can vary from person to person, but most people will stay in isolation for at least a couple of weeks. You may need to stay for longer. This depends on your situation and how long it takes for your blood cell counts to increase. The doctors and nurses will check your blood counts daily to make sure everything's OK.

Can I have any visitors?

Your hospital or transplant centre will probably allow a few named visitors to come and see you. They may have to wear protective equipment, such as a gown and gloves, and take certain precautions to reduce the risk of infection spreading. Children may be able to visit, but check with your ward about their specific policy – see page 17.

What am I allowed to do?

Initially you'll have to stay in your room all the time. So, it's a good idea to take lots of activities with you to keep you busy – we've made some suggestions on page 13. After your transplant there may be times when you don't have much energy or you find concentrating difficult, so make sure there's something to do that doesn't need you to make a lot of mental or physical effort.

When can I start to leave my room?

Once your blood cell counts start to increase you'll be allowed to venture out of your room, and possibly outside, for a short time. Some hospitals may allow you to leave your room while your blood counts are low or recovering, at quieter times, when fewer people are around. Your medical team will make the decision, so ask them about your progress regularly.

REMEMBER: every isolation unit has its own set of rules and procedures. Check with your medical team or ward about what you can and cannot do.



RUPERT WHO HAD A STEM CELL TRANSPLANT TO TREAT MYELODYSPLASIA

ANTHONY NOLAN

What is protective isolation?

You'll be placed into protective isolation on the day of your stem cell transplant, if not before. If you have a blood cancer you may have experienced isolation after you had chemotherapy. Although the set-up and rules can vary between hospitals, the purpose is to keep you in a germ-free environment while your blood cell counts are low.

If you're having your transplant as an outpatient, without overnight stays (ambulatory care), your hospital team will tell you when you'll be admitted into protective isolation. They'll also tell you how to minimise your infection risk when you're outside the hospital.

Once you're in isolation, you'll spend most of your time in your own room. You'll have a bed, sink, shower, and toilet, as well as an emergency button in case you need immediate help. There will probably be a filter system to keep the air clean and sterile and, for this reason, the door and windows will always be kept closed. Typical protective isolation rooms are shown in the pictures in this guide.

Your bedding will be changed and your room cleaned daily. Your personal possessions will also need to be wiped clean on a regular basis. These measures kill germs and reduce your risk of getting an infection. All medical staff and visitors will have to clean their hands with alcohol wash when entering your room. They may also have to wear protective clothing such as gloves, a plastic apron and face mask.

In the first few weeks you may be put on a 'safe' diet that reduces the chance of getting an infection from your food. It will not include foods that are rich in bacteria (such as unpasteurised soft cheeses or yoghurts).

Preparing for isolation

Pack your bag

Some people like to take their own pillow or bedding into the hospital to make it feel more like home. Alongside more practical things – like your wash bag, clothes and nightwear – you'll also need items to keep you occupied. You might want to consider taking personal items like photos and toiletries, but also things to keep you busy like books, magazines, a tablet, and crafts or other hobbies. Headphones and an eye mask or ear plugs are also helpful – trying to sleep in unfamiliar surroundings can disrupt your normal sleep pattern.

A list of further recommendations for your hospital bag is available on our website at anthohnolan.org/preparing

Ask for help

Many people worry about who will look after everyone else while they are in hospital. Ask friends and family for support with your children, pets or home – people are often more than happy to help. Sometimes people want to help you out but are unsure how to. Try asking for their help with very specific things – like driving you to an appointment, picking up your children from school or sorting things around the house.

Plan a visit

Find out if you can visit one of the isolation units you will stay in beforehand. This will help you form a mental picture of what your stay will be like. Hopefully, this will remove the unexpected and reduce the chance of unnecessary surprises.

Hospitals and transplant centres have different rules and procedures. So, a visit will let you find out the details that will apply to you.

Ask questions

Any situation can be daunting if you don't feel like you know what's going on. Concerns around smaller things can build up quickly, so take control of the situation by finding things out.

For example:

- Is there Wi-Fi so I can stream my favourite programmes?
- Where can my visitors park?
- What can I expect from the hospital food?

Your transplant team will be happy to answer any questions you might have.



JO WHO HAD A STEM CELL TRANSPLANT TO TREAT HODGKIN LYMPHOMA

During isolation

Routine

Many of our patients recommend getting into a daily routine during your stay. They found giving structure and meaning to each day makes life feel more normal. And it doesn't have to be anything complicated. You can make a huge difference to how you feel when you find the strength to:

- get out of bed
- take a shower
- put on fresh comfy clothes.

On some days, this will be difficult. When that happens, try to get out of bed for mealtimes at least.

Entertainment

Keeping entertained is an important way to pass the time in hospital. So, bring in anything that will help distract and relax you. Subscribe to a streaming service and get lost in your favourite films, dramas, or comedy. Also consider music, podcasts or audiobooks. Listening is a great option when you don't feel up to reading.

“As much as the isolation wasn't easy, I always tried to make the best of it because I knew that I had to do it.”

JIMMY WHO HAD A STEM CELL TRANSPLANT TO TREAT LYMPHOMA

Internet

Your smartphone, or other similar device, is the simplest way to keep in contact with the outside world. You can catch up with friends and family on social media or keep up to date with world events. Find out if your hospital offers free Wi-Fi and check on the 4G coverage and data usage of your phone contract.

Creativity

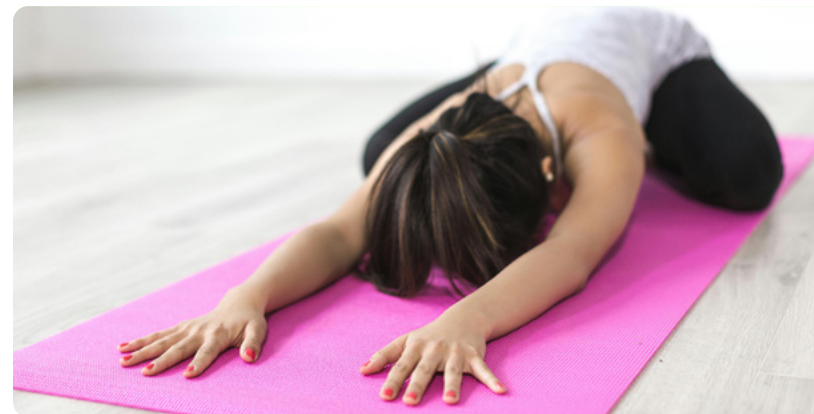
Letting yourself be creative can be very enjoyable during isolation. It can allow you to express your emotions in ways that are difficult to put into words. And there are many ways to be creative – doodle with coloured pens, pick up your knitting needles, make a model, write music. You might not always have the energy to concentrate. But it's great to have a hobby with you when you feel up to it.

Expectations

There'll be times when you don't have the energy to concentrate on some of the things you enjoy doing. Try to not worry about it – some days will be harder than others. It's OK if all you feel like doing is watching TV. But on the days you have more energy, take advantage of them and do something you really enjoy.

“I found it hard to read. I've always been an avid reader but I think it's hard to concentrate; you've got a lot going on mentally and emotionally.”

RACHEL WHO HAD STEM CELL TRANSPLANTS TO TREAT AML



Exercise

You might not feel like doing much at all, but even a small amount of activity can help reduce fatigue and improve your physical strength. Moving around in your room will also stop you feeling stiff. Ask to speak to a physiotherapist. They can give you some specific advice about exercises you can do safely during your recovery. This will probably be a series of low-impact stretches and yoga poses. You might also be given some simple breathing techniques to do daily. This will reduce the chance of you developing a chest infection.

Day/night cycle

It can be difficult to sleep in unfamiliar surroundings, and your sleep may be disrupted by your medical team checking on your progress every few hours. However, it's still a good idea to keep your curtains open and let natural light in during the day. It will keep your day/night cycle in sync, so you are more awake during the day and ready to sleep at night.

For more information and handy tips on how to get a better night's sleep, visit anthohnolan.org/fatigue



RUPERT DURING HIS STAY IN PROTECTIVE ISOLATION
WITH HIS BROTHER HECTOR

Keeping in touch with loved ones

Visitors

Most hospitals will let you select two or three people who can enter your room and be with you for most of your time in isolation. They will also be able to bring things in from home that you may have forgotten, or that you decide you need during your stay. Other friends and family will be able to come and see you too, once your blood counts start to recover. They may or may not be allowed into your room, but you can talk to each other on your mobile phones.

It's perfectly normal if there are times when you don't feel like seeing visitors. Remember, you are not letting someone down, though it might feel like that. Your wellbeing is the most important thing – they will understand that you need to put your recovery first.

Infection risk

The potential risk of infection from seeing friends and family can be a source of worry and anxiety for many patients. This shouldn't be a problem if your visitors are honest about how they are feeling and follow the unit's infection control rules.

But you've got every right to have concerns and be cautious. So, challenge your visitors about their health if you feel you have to.

Staying connected

You can connect with your wider circle of friends and family through social media, a WhatsApp group or even by writing an online blog. It's also easier to update everyone on your progress in one go. You may find it very therapeutic to write about your experiences, both good and bad.

Our Patient and Families Forum is also a great way to connect with other stem cell transplant recipients online. You can sign up at anthonymolan.org/forum

Or you could ask a few people close to you to update your friends and family on your behalf. This allows you to keep in touch with everyone but removes the pressure of having to re-tell the same story repeatedly, which can become draining.

“I used social media a lot, particularly Facebook, and built up quite a community of friends who were very much there for me day or night.”

RACHEL WHO HAD STEM CELL TRANSPLANTS TO TREAT AML

Children visiting

Unfortunately, some isolation wards don't allow children into the patient rooms. This is because of the infections that children might be carrying from mixing with others at their nursery or school. Rules can vary, so check your hospital's policy on children visiting.

Video calling can also be a good alternative, enabling you to see children face-to-face every day.



Young patients and protective isolation

Help your child understand

Protective isolation can be very difficult and stressful for children of all ages, as well as their parents and carers. They will be anxious of the unknown, the future and staying in an unfamiliar hospital.

So, if you can:

- Take time to explain what's going to happen.
- Try to not overload them with too much at once.
- Encourage them to ask questions so you can fill in the gaps.

Infection control rules are important post-transplant. But your child might find them hard to understand and follow. Or they might not want to!

If this becomes a problem, try making it silly or fun – a more child-friendly experience. At the end of the day, you know your child better than anyone else. You know what makes them happy and how they are likely to respond.

Our Anthony Nolan activity books are a useful way to help children understand what is happening during their stem cell transplant. We also have a guide for parents called *Helping your child through their stem cell transplant*. You can find them at anthonymolan.org/booklets

Plan ahead

Many parents find being prepared for their child's transplant helps them cope.

If possible, try to visit the hospital ward in advance. Get familiar with the surroundings and hospital staff if you can. It might be a good idea to take your child along too, if you think it could help them feel calmer. Check how often you can visit, and the arrangements for staying overnight.

During their stay in hospital, your child is entitled to continue their education. When they are fit and well enough, your child's school or local council will provide the support needed to do this. However, if you have any concerns, talk to someone at the school so that plans can be put in place.

Talk to your child's teacher or head teacher on a regular basis to keep them updated on your child's condition. They'll need to know:

- how much time off your child is likely to have
- the support the school needs to provide when they return.

Take care of yourself

Your child will understandably be nervous and even frightened about what they are going through. They will look to you for the support and reassurance that nobody else can give them. So, you need to make sure you are looking after yourself, both physically and mentally, during this time. After all, this is probably one of the hardest things you've ever had to go through too.

Alongside eating healthily and sleeping well, try to get a support network in place to help you when you need it. Do you know someone who can take your mind off things for a bit? There's no need to feel guilty about forgetting your stresses for a little while. It's ok for you to have a laugh, or a good chat about something else.

Get support

If you feel like things are getting on top of you, it might be time to get some extra support from a professional counsellor. For more information see page 25.

Protective isolation and your emotions

During your stay in protective isolation, you will have lots of spare time on your hands. Many of our patients talk about how much of an emotionally sapping and lonely experience it can be.

It's easy to have negative thoughts about your situation and become anxious about an uncertain future. Although it's perfectly normal to have these thoughts, they could turn into something more serious, especially if you're not able to see the people you love as often as you need.

“Being in isolation is a scary experience. The best thing about it is that you have your own room and yet the worse is that at times, you feel so lonely.”

SIMON WHO HAD STEM CELL TRANSPLANTS TO TREAT APLASTIC ANAEMIA

Coping mechanisms

In simple terms, a 'coping mechanism' is anything you do to feel less stressed. They can help relieve stress, help you relax or control your emotions. Different things will work for different people in different situations, so we can't say what will work for you, but here are a few suggestions.

Take a deep breath – it sounds simple, but it can really calm your nerves.

Mindfulness

This meditation-based approach can help you stay calm and focused on the present, rather than worrying about the future. To introduce yourself to mindfulness, mobile apps such as Headspace can be downloaded to your phone or tablet and require a subscription. There are also very similar free apps, such as Smiling Mind and Healthy Minds Program. They can provide you with daily meditation programs that take around ten minutes to complete and focus on a wide range of different topics.

Discovery

Give your mind a different topic to focus on, other than your health. You might want to learn about something new that interests you, such as a period in history or a famous person.

Laughter

Everybody has something that always makes them laugh. Try taking your favourite comedies with you or ask your friends for their recommendations.

Find out more

If you are unsure about anything to do with your transplant or recovery, talk to your medical team, they will be able to put your mind at ease.

“I had help keeping my mind positive; initially it was very difficult to stop my mind jumping to negative thoughts so I looked at various self-help processes.”

SUE WHO HAD A STEM CELL TRANSPLANT TO TREAT AML

Signs of something more serious

A time may come when you feel you need extra support to help you cope. It's not always easy to identify when you might need this, especially if you are feeling low.

You might start to experience some of the following signs. You should talk to your medical team if:

- you've been feeling very low for two weeks or more
- you can't find the motivation to do anything, even important tasks
- you feel unable to control your thoughts
- you're feeling much more anxious than usual.



Getting some extra help

If you would like to talk to a counsellor or try a talking therapy, your transplant team will be able to refer you. If you have never used this kind of therapy before, it can seem a little strange at first – but hopefully it will make you feel more positive.

“For me it was the most challenging time of my life, with all the highs and lows (and there were many). It truly is ‘one day at a time’ and at your lowest moment, remember there is always hope.”

CAROLE WHO HAD A STEM CELL TRANSPLANT TO TREAT AML

The Patients and Families section of our website has information about our free Telephone Emotional Support service. It also contains handy suggestions to help you cope with the challenges of having a stem cell transplant. Visit anthoynolan.org/patients-and-families

Anthony Nolan contact details

Where can I get more information and support?

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

Talk to us

The Patient Services team at Anthony Nolan is here for you. Call us on 0303 303 0303 or email patientinfo@anthohnolan.org

Get connected

Find support from other patients and their families by joining our Patients and Families Forum at anthohnolan.org/forum

Find information

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

Other useful contacts

Anxiety UK

anxietyuk.org.uk

Information on anxiety plus support including affordable access to therapy, live chat and support groups.

British Association for Counselling and Psychotherapy

bacp.co.uk
01455 88 33 00

Information about counselling and therapists in your area.

Citizens Advice

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

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

GOV.UK

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

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

Macmillan Cancer Support

[macmillan.org.uk](https://www.macmillan.org.uk)
0808 808 00 00

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

Maggie's

[maggies.org](https://www.maggies.org)
0300 123 1801

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

Mind

[mind.org.uk](https://www.mind.org.uk)
0300 123 3393

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

NHS

[nhs.uk](https://www.nhs.uk)
Helpline: 111

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

Rethink mental illness

[rethink.org](https://www.rethink.org)
0808 801 0525

Supporting people with mental health concerns through expert information, campaigning and a network of local groups and services.

Samaritans

[samaritans.org](https://www.samaritans.org)
Helpline: 116 123

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

Teenage Cancer Trust

[teenagecancertrust.org](https://www.teenagecancertrust.org)
020 7612 0370

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

Young Lives vs Cancer

[younglivesvscancer.org.uk](https://www.younglivesvscancer.org.uk)
0300 330 0803 (Monday to Friday, 9am to 5pm)

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



“You have to keep telling yourself this is not permanent, this is only temporary. You will be home in your own bed at one point and when you do finally get there, it’s a really nice feeling.”

JIMMY

WHO HAD A STEM CELL TRANSPLANT TO TREAT LYMPHOMA



For further patient information:

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anthohnolan.org

