

PREPARING FOR HOSPITAL ISOLATION



**ANTHONY
NOLAN**

saving the lives of
people with
blood cancer



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

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

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

Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on patientinfo@anthohnolan.org

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patientinfo@anthohnolan.org

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Cover image: Alex, who had a stem cell transplant in 2016.

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ANTHONY NOLAN
PATIENT SERVICES

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 your hospital or transplant centre's protective isolation units – so you have a better idea of what to expect.

It's been written with guidance and advice from our remarkable patients who have been where you are now, as well as specialist healthcare professionals, to help you come to terms with your current situation.

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

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KEY QUESTIONS

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 will be at risk of getting 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 depending on your situation and how long it takes for your blood cell counts to increase. Your consultant or registrar will check your cell 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 – but they may have to wear protective equipment, such as a gown and gloves, and take certain precautions to reduce the risk of infection spreading. If you have children, they will be able to visit your ward but probably won't be allowed into your room.

WHAT AM I ALLOWED TO DO?

Initially you will have to stay in your room at all times so it's a good idea to take lots of activities with you to keep you busy – we have made some suggestions on **p10**. 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 isn't too demanding.

WHEN CAN I START TO LEAVE MY ROOM?

Once your blood cell counts start to increase you will be allowed to venture out of your room and possibly outside for a short period of time. The decision will be made by your medical team, so check your progress with them regularly.

REMEMBER:

Every isolation unit has its own set of rules and procedures, so check with your medical team about what you can and cannot do.

WHAT IS PROTECTIVE ISOLATION?



Rupert, having a school lesson in isolation after his bone marrow transplant in 2016.

You will 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 protective isolation after you had chemotherapy. Although the set-up and rules can vary between hospitals, the overall purpose is to keep you in a germ-free environment while your blood cell counts are low.

You will be in your own room, where you will spend most of your time. It will 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 the door and windows will be kept closed at all times. A typical protective isolation room is pictured opposite.

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.

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

Jo, had a stem cell transplant in 2012



DURING ISOLATION

ROUTINE

Many of our patients recommend getting into a daily routine during your stay. It doesn't have to be anything complex, but giving structure and meaning to your day can make the situation feel more normal. Making the effort to get out of bed, showered and into fresh clothes can make a huge difference to how you feel. However, on days when this is difficult, you should still try to get out of bed at mealtimes at least.

'At nine in the morning, most people in the isolation ward were still in their pyjamas. Whereas I was up and dressed and ready to take on whatever they threw at me that day.'

David, who had a transplant in 2014

ENTERTAINMENT

Anything that you can bring into the hospital to keep you entertained will really help pass the time. You could lose yourself in your favourite film or set up membership to a media streaming service. Listening to music, podcasts or audiobooks is another option, especially if you don't feel up to reading just yet.

'I became a TV addict when I was in hospital and isolated. I never really watched television before and I had insisted I'd never see Game of Thrones. My work bought me it and I think I saw it in five days!'

Rachel, who had a transplant in 2016

INTERNET

Your smartphone or other similar device is the simplest way to keep in contact with the outside world, whether it's catching up with friends and family on social media or reading about world events. Find out if your hospital offers free Wi-Fi and check on the 4G coverage/data usage of your phone contract.

GET CREATIVE

Although it might be difficult, focusing on your creative side can be a very enjoyable experience during isolation. It can allow you to express your emotions in ways that might otherwise be difficult to put into words. Often, you might not have the energy to concentrate but if you bring in what you need for your favourite hobby you can give it a try if you feel up to it.

EXPECTATIONS

There will 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 on a bad day – but you should also take advantage of the good days 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 a transplant in 2016

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 so 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.

'Focus on something that you want to improve on, or you just want to learn about, whatever it may be. Have some goal, some objective, while you're in isolation.'

David, who had a transplant in 2014

DAY/NIGHT CYCLE

It can be difficult to sleep in unfamiliar surroundings, and your sleep will be disrupted by your medical team checking on your progress every four 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 anthonyolan.org/fatigue

KEEPING IN TOUCH WITH LOVED ONES



Rupert, during his stay in protective isolation, with his brother, Hector

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 – they may or may not be allowed into your room but can talk to you through an intercom or your mobile phones.

'I had friends and family who came and visited most days and that was really helpful, a bit of the outside world coming in. You do get a bit stir crazy.'

Rachel, who had a transplant in 2016

However, it's perfectly normal if there are times when you don't feel like seeing visitors. Try to not feel guilty about letting someone else down. Your wellbeing is the most important thing to you and they will understand that you have 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 they are honest about how they are feeling and follow the rules the unit has for infection control. However, if you have concerns, you shouldn't be afraid of being cautious and challenge them if you feel you have to.

'It doesn't matter how many times you tell your visitors that they need to be healthy to see you, they will still come with coughs, colds and flu-like symptoms because they just don't get it and they want to help you by coming to cheer you up. My sister said, "It's only a little cough, I'll be fine in a couple of days."'

David, who had a transplant in 2015

STAYING CONNECTED

By writing an online blog or using social media, you can connect with your wider circle of friends and family and update everyone on your progress easily 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 anthohnolan.org/forum

Alternatively, 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.'

Sue, who had a transplant in 2011

CHILDREN VISITING

Unfortunately, most 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.

However, they might have the chance to see you and talk to you through an intercom. Video calling can also be a good alternative, enabling you to see your children face-to-face every day.

YOUNG PATIENTS AND PROTECTIVE ISOLATION



Rupert, during his stay in protective isolation, in 2016

HELP YOUR CHILD UNDERSTAND

Protective isolation can be very difficult and stressful for children of all ages, as well as their parents.

They will be anxious of the unknown, the future and staying in an unfamiliar hospital.

Take the time to explain to them what's going to happen. (Hopefully this booklet has helped you to understand the process better.) Try to not overload them with too much information at once and encourage them to ask questions so that you can fill in the gaps.

For whatever reason, your child may not want to follow the rules surrounding infection control or understand how important they are. If this becomes a problem, try to engage with them about it – try making this a child-friendly experience that's silly or fun. At the end of the day, you know your child better than anyone else, what makes them happy and how they are likely to respond.

Our storybook *Lucy and the Good Soldiers* is a useful way of helping young children understand what is happening during a stem cell transplant.

PLAN AHEAD

Many parents find that being prepared for the approaching transplant helps them to cope with the situation. If possible, try to visit the hospital ward beforehand to familiarise yourself with the surroundings and hospital staff. It might be a good idea to take your child along too, if you think it could settle their nerves. You should also 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.

You should also update the school regularly on your child's progress. They need to be made aware of the time off your child is likely to have and the support they will need 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 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 the hardest thing 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. Make sure there are people you can talk to about your situation and how you are coping, or who can take your mind off things for a bit. Don't feel guilty about laughing and forgetting about your stresses for a short time.

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 p27.

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 a transplant in 2012

'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 transplant in 2015

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 to stay calm and focus on the present, rather than worry about the future. Mobile apps such as Headspace can be downloaded to your phone or tablet and act as a good introduction. They can provide you with daily meditation programs that take around 10 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.

HAVE A LAUGH

Everybody has something that always makes them laugh, so take 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 transplant in 2011

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. If you start to experience some of the following, you should talk to your medical team about it:

- 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 about your situation.

'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 transplant in 2014

The Patients and Families section of our website **anthohnolan.org** also contains handy suggestions to help you cope with the challenges of having a stem cell transplant.

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:

NEED TO TALK?

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

GET CONNECTED

Find support from other patients and their families by joining our Patient 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

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

itsgoodtotalk.org.uk
01455 88 33 00

Information about counselling and therapists in your area

CITIZEN'S ADVICE

citizensadvice.org.uk
03454 04 05 06

Advice on a wide range of issues, including financial and legal matters. Online advice is available at: **adviceguide.org.uk**

CLIC SARGENT

clicsargent.org.uk
0300 3300 0803

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

GOV.UK

gov.uk

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



Hayley, Anthony Nolan's Lead Nurse

IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES (IAPT)

england.nhs.uk/mental-health/adults/iapt/
Enables patients to self-refer to NHS-funded counselling and therapy services available in their local area.

MACMILLAN CANCER SUPPORT

macmillan.org.uk

0808 808 00 00

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

MAGGIE'S CENTRES

maggiescentres.org

0300 123 1801

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

MIND

mind.org.uk

020 8519 2122

Mental health charity which offers information, advice and support to anyone going through stressful situations or experiencing a mental health problem.

NHS CHOICES

nhs.uk

helpline: 111

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

'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 transplant in 2015



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