DEALING WITH **ISOLATION**

Information to help you during
your time in hospital isolation

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WHAT'S IN THIS LEAFLET?

We've put together this leaflet to help you through your time in hospital isolation during your bone marrow or stem cell transplant.

We've enlisted the help of patients who have been where you are now, as well as specialist healthcare professionals. All the tips in this leaflet are based on the techniques and tricks they've found useful while in isolation.

We hope you find it useful. And if you ever want to ask us any questions or need more support, please don't hesitate to get in touch with the Patient Experience team at **patientinfo@anthonynolan.org** or **0303 303 0303**.

PROTECTIVE ISOLATION

During the early stages after your transplant you'll be at increased risk of developing an infection because you'll have a low number of white blood cells.

When your white blood cell count drops below 1.0, you'll need to be in a germ-free environment – called protective isolation.

Protective isolation is done differently in different hospitals, but where possible you'll be in a single room with the door closed. There is normally a special air conditioning system, making the air in your room very clean and reducing the risk of infections.

You won't go outside your room much and, although you can have visitors, it's important that you don't have too many and that no one with a suspected infection comes in.

PREPARING FOR ISOLATION

The length of time that people spend in hospital isolation after a transplant varies from days to weeks.

Talk to your doctor about how long you might be in isolation. They might not be able to give you an exact time frame, but even having a rough idea can help you feel more prepared.

You could turn your room into a temporary home by adding personal touches such as bringing in your own photos, decorations, blankets or other things to make you comfortable. These things must be wipe-clean or washable at high temperatures to reduce the risk of infection. It can also help to have nice things to look at in your room – such as pictures or posters that you like. Inspiring images could help lift your mood, make the days go faster and remind you of the outside world.

Many people worry about who will look after everyone else when they are in hospital. Ask friends and family for support with your children, pets or house – people are often more than happy to help and want to feel useful. Speak to your transplant team to find out what other help might be available.

At times it might be noisy or light on the ward, or the medical team may need to wake you to check your pulse and temperature. Taking ear plugs and an eye mask to hospital can help with this.

If you already have a lot on your plate, you might feel that the transplant is adding to these burdens and potentially stretching your resources to their limit. If you can, talk to us or your medical team about these concerns. They can support you or put things in place to allow you to focus on the most important thing: your recovery.

ACTIVITIES DURING ISOLATION

Here are some tips from other patients on how you could spend your time during isolation:

Don’t get carried away – some patients find that they don’t have the energy or concentration needed to do all the things they planned to do. So don’t be too hard on yourself and don’t worry if you are having a bad day. Just do what is best for you and take one day at a time.

> ‘Every morning and every evening, I thought of at least three things that I was lucky to have and was grateful for.’
>
> **Jayne**, transplant recipient

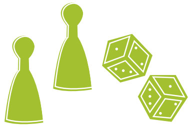
Some people who’ve been through isolation have found that sticking to a daily routine can help. Having a structure and purpose to your day can help things feel more normal despite the unusual environment that you find yourself in. You could come up with set times when you will get up, shower, change from your pyjamas into comfy clothes, and sit in an armchair for a bit rather than your bed. Others try and avoid doing too much planning and take a more relaxed approach. Have a think about whether you’re the type of person who likes being in control with planned activities or not.

Move around as much as you can to stop yourself from stiffening up but don’t be too ambitious as you will need lots of rest. Ask to speak with a physiotherapist for ideas of exercises you can do and ways to stay active.

The internet can be a great way to stay connected to the outside world and to do practical things such as internet banking. Find out if your hospital has Wi-Fi or 3G/4G and talk to your mobile phone provider about internet access during your stay.

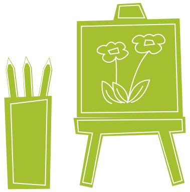
Even though you may be tired, your medical team might recommend that you have the curtains open during the day to help your body keep track of day and night. This will help to regulate your sleep patterns and make you feel more awake during the day and ready to sleep at night.

Find out if you have access to a TV or DVD player, and bring in DVDs or box sets. You could also play board games and puzzles when people come to visit.



Take music or an audio book and something to play it on with you for when you’re tired. Listening to music can improve your mood after transplant. Create different playlists for relaxation, exercising, and cheering yourself up. Why not look into getting a music or film subscription?

If you’re creative, bring in some art materials such as pencils and a sketch book. Drawing and painting can help you feel more positive and relaxed during isolation. They’re also another way of expressing feelings or ideas that are difficult to put into words. Learning relaxation techniques such as progressive relaxation or meditation might help. There are also CDs and online podcasts that you could try.



In some transplant centres, you may be able to get access to complementary therapies in your room – for instance, massage – which can make you feel relaxed and more comfortable.

KEEPING IN TOUCH WITH LOVED ONES

While you’re in isolation, you may have conflicting feelings about seeing your friends and family.

Some people find they want to protect their friends and family from seeing them while they’re unwell; others get worried about people bringing in infections.

As long as they’re following the hygiene and isolation procedures, then visits from friends and family can be a great way to cheer you up and make you feel supported. See how you feel each day and let your family know if you’re not up for visitors.

> ‘We limited our visitors to a few close friends and family who offered positivity and support.’
>
> **Una**, wife of transplant recipient

Ask a few people close to you to update your wider friends or family for you. That way you won’t lose touch with anyone, but aren’t under pressure to be in contact with everyone if you’re not feeling up to it.

If you feel comfortable with computers, you could update a blog or Facebook page to keep your friends and family in the loop. Comments and ‘likes’ can be a great source of support.

GETTING THE SUPPORT THAT YOU NEED

During isolation it's common to feel worried. It's natural to feel this way, especially if you're feeling physically unwell.

Some people feel down about being isolated in the room or ward. You might also feel cut off from your family and friends or anxious about whether the transplant is working. Sometimes all you need is for someone to reassure you that what you're feeling is normal. Often these emotions will change over time, and some of the things we've suggested in this leaflet might help you to cope.

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

They'll make sure you get the help and support that's right for you.

If you already have a tendency to feel anxious or depressed, it's a good idea to let your transplant team know when you're preparing for transplant. That way they can make sure you get psychological support during this time.

CONNECTING WITH OTHER PATIENTS

Sometimes you might feel that although people are incredibly supportive, they don't really understand what you're going through.

Connecting with others who've been through a transplant can help you feel less alone. Visit our online community to talk to other transplant recipients at **anthonynolan.org/transplantcommunity**

GETTING OUT AND ABOUT AGAIN

When your white blood cell count comes back up to around 1.0 (this can vary), you'll be able to leave your room again, for trips down the hall and even outside.

When you leave 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. Our handbook 'The Seven Steps: The Next Steps' can help you adjust to leaving the hospital and support you in your long-term recovery. Order it on our website or by contacting the Patient Experience team.

WE'RE HERE TO HELP YOU DO THIS

Our website has lots of helpful information for you about going through a transplant, and links to other places where you can get more help and support. Visit **anthonynolan.org/patientinfo**

Questions? Just need to chat?
Get in touch with our Patient Experience team at **patientinfo@anthonynolan.org** or call **0303 303 0303**.

‘CARDS, MESSAGES AND PICTURES FROM THE GRANDCHILDREN KEPT ME SMILING AND GAVE ME SOMETHING TO AIM FOR.’

Bill, transplant recipient

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