LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **EMOTIONAL WELLBEING**

#BMTsupport

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 Anthony Nolan on **patientinfo@anthonynolan.org**

The information contained in this booklet is correct at the time of going to print (March 2016)

Anthony Nolan is a registered charity No 803716/SC038827

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ANTHONY NOLAN
PATIENT EXPERIENCE TEAM

WHAT'S IN THIS LEAFLET?

Having a stem cell transplant is a life-changing event. Dealing with the treatment and its impact on your everyday life can be a challenge. So we've put together this guide to help you take care of yourself before, during and after a transplant.

All the tips in this leaflet are based on the techniques and tricks that other patients and health professionals have told us can be useful. Many patients say that that learning ways to get support and look after themselves can help them feel more in control.

If you're preparing for a transplant, this leaflet could help you learn more about what to expect and how you can help yourself.

HOW WILL I FEEL?

Everyone is different, but it's useful to know about the emotional ups and downs that people often have. Sometimes all you need is for someone to reassure you that what you're feeling is normal. We've included some of these feelings here, but not everyone will go through these feelings in the same order or for the same amount of time.

Either way, you're not alone. We've got lots of tips in the rest of this guide about what can help and where to get support.

BEFORE TRANSPLANT

What does the future hold?

Am I strong enough for the treatment?

I will miss my family.

Can I take the time off work?

'Before transplant was the most anxious time I had - worrying about whether it would happen or not. It felt like there was so much riding on it.'

Jilly, had a transplant in 2015

DURING TRANSPLANT

I'm feeling really ill – will I ever feel better?

I can't get any sleep!

Worried about whether the transplant has worked.

I've got no control over what's happening to me.

Frustrated about being in isolation.

'Emotionally I was pretty wrecked, it's very difficult to explain it – one minute you feel like you're dying and the next you're not.'

Nigel, had a transplant in 2013

GOING HOME

I still feel low – I should be feeling better.

I've still got so many hospital appointments – how will I cope?

My family expect me to be back to normal, but I don't feel normal!

'When patients first go home, this can be quite a crash point. You're tired and exhausted, this is the first time you've had a chance to stop and think about what's happened to you.'

Jean, BMT Co-ordinator

'I find that often patients are surprised at their own feelings and start to worry that they are not happy. They never expected to feel sad, angry or anxious after surviving treatment, so they try to push away the feelings and experience shame.'

Maria, Haematology Counsellor

RECOVERY

Starting to feel a bit better...

But my body is different.

I still feel really tired.

I need to get back to work.

We're stressed about money.

Oh no I've got an infection!

I don't want to go back into hospital.

I've got more tests, has my condition come back?

'I am not quite the same person I used to be, this was a bit of a problem at first, because I looked ok, everyone assumed I was back to normal.'

Julie, had a transplant in 2009

WHAT CAN I DO TO LOOK AFTER MYSELF?

Everyone has their own way of dealing with a transplant, and you will find that you have your own strengths to draw on. What has helped you with other challenges in the past? Some of these things might help:

GET SUPPORT

Share what you're thinking – find someone you can talk to. It could be a friend, or someone trained to listen; like your GP, specialist nurse, transplant team, psycho-oncology team or a counsellor.

Connecting with others who've been through transplant can improve how you feel in yourself. Join a support group through your local hospital for people who've had a transplant, blood cancer, or blood disorders.

Or visit our online transplant community and connect to other transplant recipients at **anthonynolan.org/transplantcommunity**

BE KIND TO YOURSELF

Take time out to look after yourself. When you feel up to it, learn some techniques to manage stress and to relax – like meditation, breathing exercises or massage.

Many hospitals now run mindfulness meditation courses. It can help you find ways to respond to difficulties and deal with uncertainty. Find out more at **bemindful.co.uk**

Try setting yourself goals and things look to forward to, like having one night out a week, or walking for 20 minutes each day. Take things slowly, especially when you're first recovering. Don't put too much pressure on yourself – even little achievements can give you a boost!

GET PRACTICAL SUPPORT

If you're struggling with work or money, then get support to sort through the problem and relieve some of the stress. Speak to your transplant team or GP about where to get local support, or contact Citizens Advice Bureau or Macmillan Cancer Support for information on employment, benefits and other ways to get practical help. Find out more:

macmillan.org.uk

citizensadvice.org.uk

> ***'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

RESPECT THE MIND-BODY CONNECTION

How you feel physically can have an impact on how you feel emotionally.

Being active and thinking about what you eat and drink may have a positive impact on your mood. Find out more, read our leaflet *The Essential Guide to Diet and Activity.*

Get enough sleep or rest. Plan a relaxing night time routine, limit your alcohol and computer time before sleep and create a quiet and comfortable environment to sleep in. Find out more, read our booklet *Managing Fatigue After a Bone Marrow or Stem Cell Transplant.*

If dealing with the physical effects of your transplant is getting you down, then check-in with your transplant team. They may be able to prescribe treatments to help relieve some of the symptoms.

DO SOMETHING DIFFERENT

When the time is right, doing something different like a new activity, hobby or volunteering might help boost your mood. Doing something you're good at may make you feel more positive.

> ***'It's about finding the right balance. The other night I went to see a band at a venue that's five minutes walk from where I live. So I'm still doing things I like, but just on a smaller scale.'***
>
> **Pavlos,** had a transplant in 2010

> ***'I've achieved a fair bit since my transplant - I turned 60, I do volunteering work in tennis and was at my son's wedding nine months after my transplant.'***
>
> **Nicky,** had a transplant in 2011

WHEN TO GET MORE HELP

There are some signs that might mean you need more support to cope with how you're feeling. Let your transplant team or GP know if during the last month you've often been bothered by:

- feeling down, depressed or hopeless
- having little interest or pleasure in doing things

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

GETTING MORE PSYCHOLOGICAL SUPPORT

There are many ways to get more psychological support if you need it. Talking to your specialist nurse, GP or another member of your transplant team might help. Or you might need to speak to a specialist who is trained in assessing and treating psychological problems.

Some transplant centres have psycho-oncology services, involving clinical psychologists, psychiatrists and other professionals. They're specialists in providing support for people with cancer and their families. If this isn't available in your hospital ask your transplant team or GP to refer you to psychology or counselling.

Some counsellors specialise in working with people who have haematology problems or cancer.

You can get counselling support from Macmillan Cancer Support or Maggie's which often have centres in hospital. The British Association for Counselling and Psychotherapy has information about counsellors in your area. Find out more:

maggiescentres.org
macmillan.org.uk
itsgoodtotalk.org.uk

> ***'I did some counselling with the Maggie's Centre. I really benefited from sitting down and talking to someone who was not personally involved. I had underestimated the value of that kind of therapeutic chatting. Sometimes you just need to take a step away from yourself.'***
>
> **Crispin,** had a transplant in 2013

RELATIONSHIPS

During your transplant having a strong support system from family and friends can be very helpful. It can be a really stressful time, and even close relationships can change along the way.

'When you go home you might feel low, and have more arguments than normal, but this is normally just a temporary thing.'

Jean, BMT Co-ordinator

It's good to get support for you and your loved ones. Those close to you can speak to the transplant team or their own GP, and use tips in this booklet as well.

'I think it was harder for the family than it was for me. You're locked in your little bubble – safe. But everyone on the outside has to get on with the real world.'

Nigel, had a transplant in 2013

SOCIALISING

Keeping in touch with people and getting out and about is important, especially if you don't have a partner or close family. This can be daunting just after a transplant, but taking things step-by-step can help.

'It's common to feel anxious about social situations, lots of people deal with it by avoiding them. Instead see if you can go for just half an hour, and leave on a high, when you're not too tired and things are still going well!'

Jayne, Clinical Psychologist

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

Julie, had a transplant in 2009

WE'RE HERE TO HELP

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

NEED TO TALK?

The Patient Experience team at Anthony Nolan are here for you. Call us on **0303 303 0303** or email **patientinfo@anthonynolan.org**

GET CONNECTED

Find support from other patients and their families by joining our online transplant community at **anthonynolan.org/transplantcommunity**

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 **anthonynolan.org/patientinfo**

SHARE YOUR THOUGHTS

We work with a panel of people who've been affected by transplant to make sure we get our services and information right. And we'd love you to join them.

From sharing your experiences to coming up with new ideas and giving feedback on our resources and services: we need your ideas and insight. 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 us to find out more.

SOCIAL MEDIA

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

facebook.com/anthonynolanpatients

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The Anthony Nolan Patient and Families Panel

> ‘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 OCCASIONAL, EXHILARATING BURSTS OF OPTIMISM.’

Daffydd, (front cover) had a transplant in 2012

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903PA/0216

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