

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **KEEPING TRACK OF YOUR RECOVERY**



#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@anthohnolan.org

© Anthony Nolan 2016

All rights reserved. No part of this publication may be reproduced or transmitted without permission in writing from Anthony Nolan.

All trademarks and brand names referred to are acknowledged as belonging to their respective owners.

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

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **KEEPING TRACK OF YOUR RECOVERY**



saving the lives
of people with
blood cancer

ANTHONY NOLAN
PATIENT EXPERIENCE
TEAM



WHAT'S IN THIS LEAFLET?

Having a bone marrow or stem cell transplant is a starting point on the road to recovery. Once you go home from hospital, you'll still be having regular check-ups with your transplant team and they will keep an eye on your health for a number of years.

We've put together this basic guide to help you keep track of your recovery and make the most of the appointments you'll be having. It will also help you keep an eye on your own health along the way. If you're preparing for a transplant, this leaflet is designed to give you an idea about what might happen and how you can help yourself. We've included information from health professionals, and tips from patients who've been where you are now.

This is a general guide, the appointments and care people need after their transplant varies. Speak to your transplant team about what to expect in your particular situation.

LEAVING HOSPITAL

Leaving hospital for the first time after your transplant can be exciting but some people find the idea of coping on their own daunting. Your transplant team will make sure you leave the hospital well equipped to look after yourself. And you'll be checking in with them at regular appointments during the first year.

Here's a checklist of things to think about before you leave hospital:

- Contact numbers for the transplant centre
- Arrangements for your central line care (also called CVC, Hickman line or PICC line)
- Advice about your diet
- Medication and information on how to take it
- Appointments for your outpatient blood tests, the outpatient clinic and other medical checks such as bone marrow tests
- Signs and symptoms to look out for - for example, symptoms that might mean you have an infection



YOUR APPOINTMENTS

How often you have appointments depends on how long it's been since your transplant and how you're getting on. As you recover, you'll have appointments less often, and eventually a yearly check-up might be all you need. But if you have any questions or concerns in-between your appointments, contact your team at the transplant centre who will happily advise you.

THE FIRST THREE MONTHS



You'll have regular appointments as often as once or twice a week. During these appointments your team will:

- Review your progress and find out how you're feeling and getting on
- Examine you to check for signs of infection and graft versus host disease (GvHD)
- Review and adjust your medication
- Flush and clean your central line
- You'll also have regular blood tests that will measure your blood count, liver and kidney function, and to check for viruses

Your team will monitor things very carefully to pick up on early signs of problems.

'The number of appointments you have can be intensive at first - but this is all part of the transplant journey.'

Jean, BMT co-ordinator

What helps?

- Use a diary or your mobile phone to keep track of all your appointments
- Make a list of any issues you want to discuss beforehand so you don't forget to ask about something that is important to you
- If you can, bring someone with you to appointments, for moral support and to help you remember what's discussed

- Book your next appointment at each visit
- Bring a list of your medications or bring them all in with you

"I kept a check on all the appointments in an old fashioned diary. I also recorded my medication and kept a record of my weight, exercise and food. This was all helpful during consultant appointments."

Sarah, had a transplant in 2010

What else will happen?

During the first three months you might also:

- Have your central line removed. Depending on the type of line you have it can either be pulled out easily or you might need to have a simple procedure, usually as a hospital outpatient.

- Have transfusions of blood and platelets. Not everyone needs these, but if you do, they can often be arranged with your local hospital, or combined with other appointments at the transplant centre.

- Go back into hospital. It's quite common for people to need to go back into hospital after their transplant. This might be because of an infection, a side effect that needs treatment or other reasons.

Find out more, read our booklet *The Next Seven Steps*.

'I felt reassured when attending frequent appointments - that everything was going well. It was good to have regular blood tests too, as so much can be detected from them.'

Julie, had a transplant in 2009



AFTER THREE MONTHS

You may still have appointments every two weeks until about a year after your transplant. This varies from hospital to hospital and will depend on how your recovery is going:

- You may have a bone marrow test at 3, 6, 9 and 12 months after your transplant
- You might also have scans of your body, called CT or PET scans depending on what condition you originally had treatment for

You will also have chimerism tests done on your blood and bone marrow samples. This measures how well your donor's cell have engrafted – how much of your blood or bone marrow cells are being produced from your donor. 100% chimerism means that all of your bone marrow and blood cells come from

your donor, while mixed chimerism means that some of your own cells are still there.

If you have mixed chimerism your team might make changes to your medication or arrange for you to have a donor lymphocyte infusion (DLI). This is when more cells from your original donor are given to 'strengthen' the donor cells and push the chimerism levels up to 100%.



WHEN SHOULD I CONTACT MY TEAM?

It can be hard to know when you should contact your transplant team, for example if you're feeling slightly unwell. Some patients worry about 'bothering' their team or don't want to seem pushy. Generally speaking if you have any concerns, it is always good to ask questions. If you're feeling unwell, or have any new symptoms, then your team will want to know about them.

Your transplant team may have specific instructions, but as a general rule you should contact them immediately if:

- You have a temperature of 37.5 °C or above
- Feel shivery, flu-like or generally unwell
- Have any signs of infection

Seeking advice quickly, and being reviewed in person by your transplant team or GP if necessary, is often the best way to avoid bigger problems later on.

Your team will advise you about signs and symptoms of graft versus host disease (GvHD) and infection, which are generally the most common complications to be aware of after a transplant.

For more information you can also read our leaflets:

Life After Transplant: The Essential Guide to Dealing With Infections

Life After Transplant: The Essential Guide to GvHD

‘YOU SHOULD NOT WORRY ABOUT BOTHERING US UNNECESSARILY- IT’S IMPORTANT WE CAN ASSESS YOU SO WE KNOW THE SIGNIFICANCE OF YOUR SYMPTOMS.’

Nijole, Associate BMT Clinical Nurse Specialist

AFTER A YEAR

Some people start to feel like they're gradually getting back to normal life. Perhaps you're returning to work or education?

This varies for different people, but it's still important for your transplant team to continue to review you in clinic.

WHAT WILL HAPPEN?

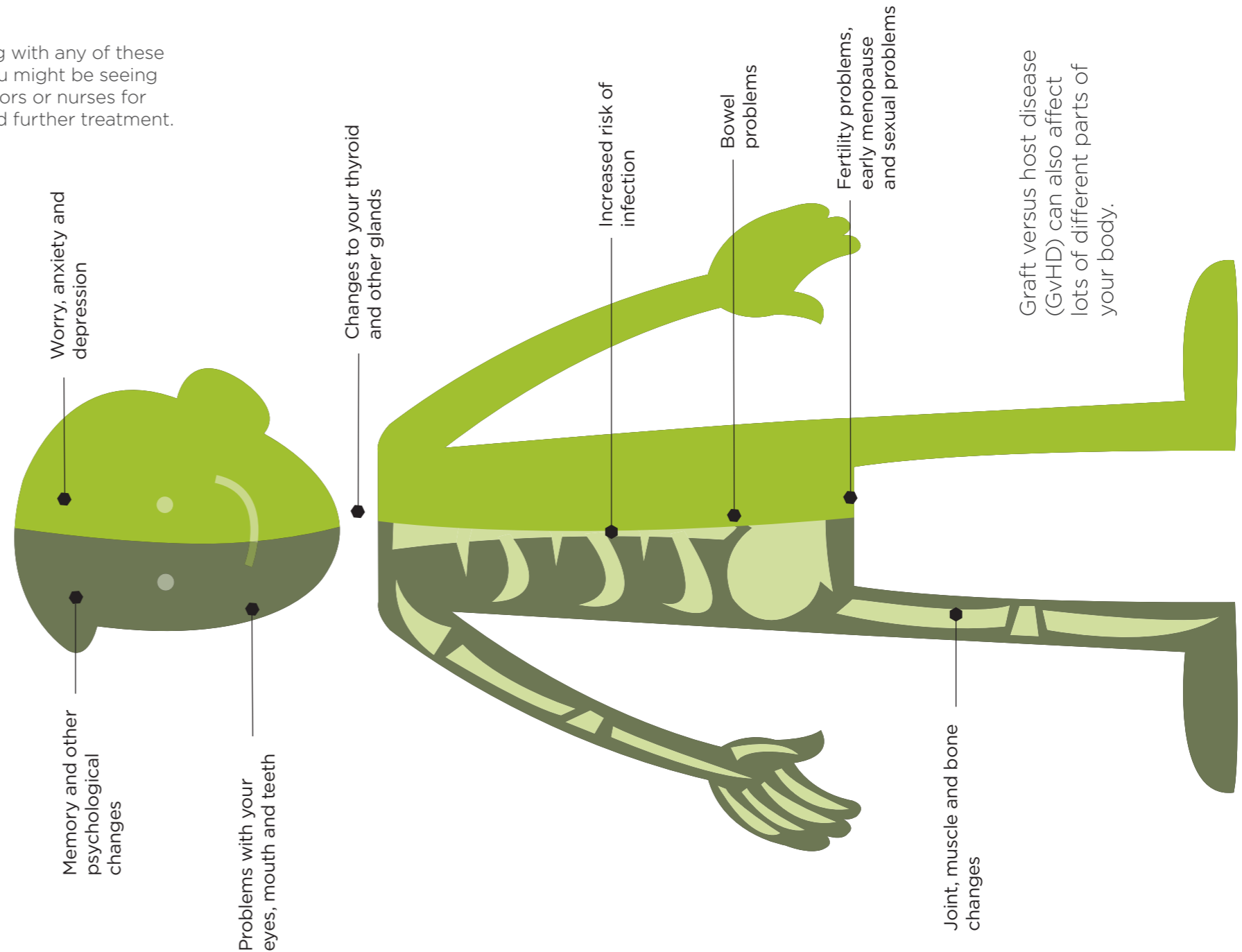
You will probably be monitored less often now, perhaps only every three months. But you'll always have a point of contact, normally the bone marrow transplant co-ordinator or your clinical nurse specialist (CNS).

You'll normally have a full assessment after every year. Your transplant team will keep an eye on whether you're experiencing any late effects of a transplant. We've listed some examples of these late effects on the next page, but this doesn't mean you will get all of them.

What helps?

- Keep track of your clinic letters, appointments, treatment summaries and other important paperwork in a file
- It's OK to ask questions and give feedback. Let your team know if you're having any side effects from medication, what's working well and what isn't

If you are living with any of these late effects you might be seeing specialist doctors or nurses for monitoring and further treatment.



‘IT’S IMPORTANT TO BE PROACTIVE – I’VE MADE MYSELF AN EXPERT IN MY OWN HEALTH AND I’M NOW GOOD AT GIVING QUICK SUMMARIES TO MY DOCTORS.’

Pavlos, had a transplant in 2010

AFTER FOUR TO FIVE YEARS

Depending on your health and your transplant centre, you may now be discharged as a patient or seen once a year in clinic. If you’re living with the long-term effects of the transplant you might be seeing different specialist doctors, nurses or other health professionals. You can always ask your GP to refer you back to your transplant centre if you’re worried about your transplant related health.

WHAT HELPS?

Even though you’re being monitored less often, there are steps you can take to feel in control of your own health:

Cancer screening – Your risk of some cancers is slightly higher after a transplant, so it’s important that you go for any usual routine screening tests that are offered to you. This includes bowel cancer screening, breast and cervical screening for women, and checks for prostate problems for men.

Thyroid tests – You will also have blood tests and sometimes a check-up once a year in clinic to check for signs of thyroid problems.

You’ll also need to see:

- Your dentist at least once a year. If you have GvHD you will need to see them every 6 months

- An ophthalmologist or optician once a year to check your eyes
- A gynaecologist, if you’re a woman, for advice on hormone replacement therapy (HRT) or other treatment for menopausal symptoms

LOOKING AFTER YOURSELF

This can be a good time to start making choices to help you stay healthy and feel as well as you can. Work towards eating a healthier diet, getting more active, reducing your alcohol intake, or stopping smoking. Ask your GP or transplant team for help and for more ideas read our booklet *Life After Transplant: The Essential Guide to Diet and Activity*.

YOUR EMOTIONS

There can be lots of ups and downs during recovery from a transplant. At times you’ll be having many appointments which can feel overwhelming. Some people find that being monitored for signs of their disease also makes them feel anxious. As time goes by you won’t have so many appointments, and this can feel strange. These different emotions are normal, but if you feel like things are getting too much, there is support there if you need it, as well as ways you can look after yourself.

Find out more, read our leaflet *Life After Transplant: The Essential Guide to Emotional Wellbeing*.



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@anthohnolan.org**

GET CONNECTED

Find support from other patients and their families by joining our online transplant community at **anthohnolan.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 **anthohnolan.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/anthohnolanpatients

This publication was reviewed by

Dr Robert Danby, Consultant Haematologist, Oxford University Hospitals NHS Foundation Trust

Nijole Gimberiene, Associate BMT Clinical Nurse Specialist, Central Manchester Foundation Trust

Aileen Nield, Bone Marrow Transplant Co-ordinator, Sheffield Teaching Hospitals Foundation Trust

Susan Paskar, Anthony Nolan Post-Transplant Clinical Nurse Specialist, Northern Centre for Cancer Care, Newcastle Upon Tyne Hospitals NHS Trust
The Anthony Nolan Patient and Families Panel

‘AS YOU PROGRESS AND
YOU BECOME BETTER,
THERE ARE FEWER
APPOINTMENTS TO
ATTEND AND YOUR
LIFE STARTS TO RETURN
TO NORMAL. THAT IS
A GREAT FEELING!’

Julie, had a transplant in 2009

anthohnolan.org/patientinfo
facebook.com/anthohnolanpatients

patientinfo@anthohnolan.org
0303 303 0303

Reg Charity no 803716/SC038827
903PA/0216



saving the lives
of people with
blood cancer