

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **DIET AND PHYSICAL ACTIVITY**



**ANTHONY
NOLAN** saving the lives
of people with
blood cancer

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At Anthony Nolan we take great care in providing 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 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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This publication was reviewed by:

Siobhan Griffin, Specialist Haematology Dietitian, University College London Hospitals NHS Foundation Trust. Carla Reid, Physiotherapist for Teenagers and Young Adults, Rehabilitation Department, The Royal Marsden NHS Foundation Trust. Anthony Nolan Patients and Family Panel.

Author: Anneliese Levy
Editors: Louise Jones, Tom Bishop
Designer: Jessica Nineham

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ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS BOOKLET?

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. But being active, eating well and looking after yourself can help with your recovery.

This guide will help you learn more about diet and physical activity after a stem cell transplant.

All the tips in this leaflet are based on ideas that other patients and health professionals have told us can be useful.

If you are preparing for a transplant, this leaflet is designed to help you learn more about what to expect and how you can help yourself after transplant.

This is a general guide, and the care people need after their transplant varies. How you feel will change before, during and after your transplant. Speak to your transplant team about what to expect and look out for in your particular situation.

CONTENTS

Eating well	6
Tips for eating and drinking	10
Do I need to follow food safety advice?	14
Eating well for long term recovery	16
Getting active	20
Exercising safely	24
Keeping active for long term recovery	26
Types of exercise	28
Getting support	30
Anthony Nolan contact details	35
Other useful contacts	36

EATING WELL



‘The nausea is overwhelming, but if I could eat something before I took my tablets, or even just have a glass of milk, it really helped.’

Joanna, who had a stem cell transplant in 2015

The advice about your diet is likely to change during the transplant process.

BEFORE YOUR TRANSPLANT

Your team will give you advice about eating and drinking before your transplant.

Try and maintain your weight and eat well if you have the appetite. If you are struggling to eat enough calories and maintain a healthy weight, it can affect your general health. Simple things, like eating little and often or boosting with protein or calorie-rich ingredients, could make a big difference.

WHAT IS A DIETITIAN?

A dietitian is a health professional who can assess, diagnose and treat dietary and nutritional problems. If you need any support with eating or drinking, your transplant team should refer you to a dietitian, or you could ask to be referred yourself.

EARLY RECOVERY

In the early days after your transplant you might not feel like doing much at all. Eating and drinking may be difficult. This will gradually get better.

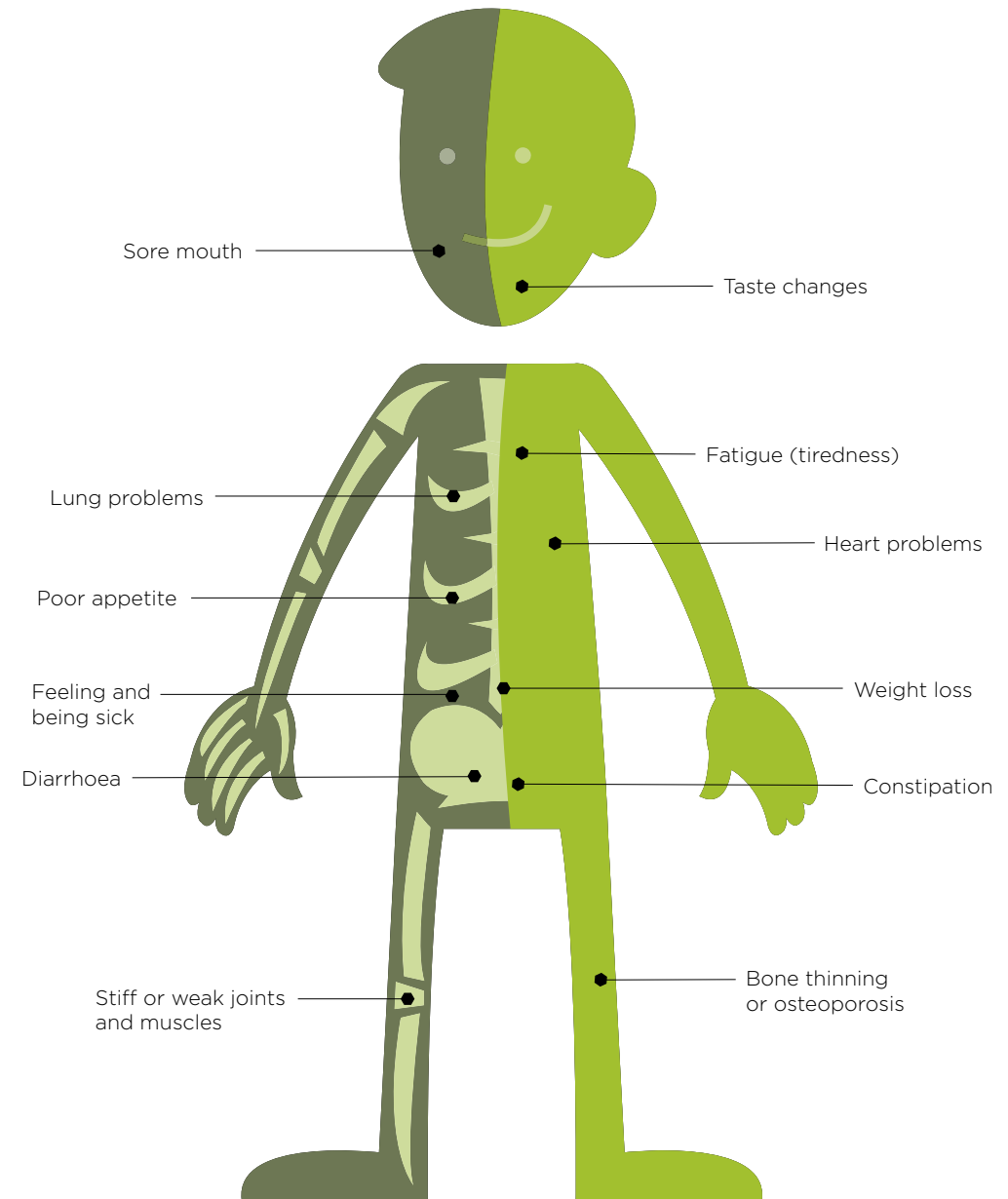
During the transplant and recovery stage, your body needs more nutrients to rebuild and repair cells and tissue, and to develop new ones. Your weight will be monitored by your medical team regularly. Your dietitian will support you with getting enough nutrients.

You might need supplement drinks or soups, or drip or tube feeding. This means you will either have liquid food fed directly into your stomach (enteral nutrition) or directly into your vein (parenteral nutrition).

More information on drip or tube feeding is available from Cancer Research UK (see p36).

Side effects during early recovery like feeling and being sick, sore mouth, diarrhoea and lack of appetite can make it difficult to eat and drink. We've suggested some basic tips that can help on the next few pages. Speak to a dietitian for more detailed advice.

You should also follow any guidelines your hospital has given you when choosing your food.



Graft versus host disease (GvHD) can also affect your whole digestive system. Find out more about GvHD by reading our *Essential Guide to Graft Versus Host Disease (GvHD)*.

TIPS FOR EATING AND DRINKING



The following pages contain tips on what can help if you experience a sore mouth, feeling sick, poor appetite and more, plus things to avoid.

Some of these tips might seem to go against standard 'healthy eating', but that can come at a later stage when you're further into your recovery, and your weight and energy levels are up.



SORE MOUTH

Brush your teeth regularly, using a soft bristled brush.

Choose food carefully:

- ✓ Ice chips, lollies, ice cream, jellies, yoghurts, custards, sips of water
- ✓ Soft creamy food, purees, stews and casseroles
- ✗ Foods that are hot, spicy or hard
- ✗ Sticky food like peanut butter

FEELING AND BEING SICK

- ✓ Eat dry foods, like toast or crackers
- ✓ Sit upright after eating
- ✓ Ginger and peppermint might help
- ✓ Cold foods smell less
- ✗ Greasy, fried, smelly, very sweet food
- ✗ Keep away from the smell of cooking

POOR APPETITE

- ✓ Eat little and often – try snacks and small meals 5-6 times a day
- ✓ Find meals that are quick to prepare, especially for when you're tired
- ✓ Go for what you really fancy and crave

CONSTIPATION

- ✓ High fibre foods
- ✓ Lots of fluids
- ✓ Hot drinks to open your bowels

FOR BOOSTING YOUR ENERGY AND WEIGHT

- ✓ High-protein, energy-rich foods such as meat, fish, pulses, tofu, dairy or vegan-friendly options
- ✓ Boost calories – add butter, cheese, beans or cream, avocado, olive oil, nuts or seeds to your dishes
- ✗ Don't fill up on low calorie food like watery soup

DIARRHOEA

- ✓ Replace lost fluids
- ✓ Eat plain, low-fibre food such as white bread, pasta, noodles, potatoes without skin, fish, eggs, tofu, cheese, fruits and vegetables without their skin or pith
- ✗ Alcohol and coffee
- ✗ Rich, high-sugar or high-fat foods
- ✗ Sorbitol, the sweetener, found in fizzy drinks for example

TASTE CHANGES

If food tastes:

Like cardboard/ cotton wool

- Try 'tart' foods like citrus fruits.
- Add a squeeze of lemon or lime to your food before serving.

Metallic

- Avoid iron-rich red meat and switch to different sources of protein, like chicken, turkey, fish or lentils.
- Use plastic or wooden cooking and eating utensils.

Bland/tasteless

- Try stronger flavours like marinades and spices to make your meals more interesting.

If water tastes horrible:

- Use cordials or fruit juices to make it easier to drink.

Your taste will change over time. If you try something and don't like it, give it week or two and try again.

For more ideas check out World Cancer Research Fund's guide *Eat Well During Cancer* (see p36).

DO I NEED TO FOLLOW FOOD SAFETY ADVICE?



As your immune system is recovering after a transplant, you'll be more vulnerable to infections.

It's important to follow general food safety advice. This means handwashing and a clean, safe approach in preparing, cooking, thawing and storing your food. Find out more from the Food Standards Agency (see p36).

If your transplant team have told you to follow a neutropenic or low bacteria diet, find out more in Blood Cancer UK's booklet *Eating well with Neutropenia* (see p36).



EATING WELL FOR LONG TERM RECOVERY

Some people find that during their recovery they struggle to eat well or have problems with diabetes, high blood pressure or becoming overweight.

After a transplant it's natural to want to reduce the risk of your condition returning. But there is no scientific evidence that any diet or supplement can cure blood cancer or blood disorders.

It's vital that your body can get the nourishment and energy it needs, so avoid cutting out foods. If you're thinking of taking any supplements, ask your transplant team first if they are safe.

It's important not to make any changes to your diet until you are well enough. If you are underweight, don't have much appetite or have any other eating or drinking issues, get support from your GP, transplant team or a dietitian.

When you're ready, eating well and looking after your body can help you manage side effects, your general health, energy levels and boosting your mood.

This means you could:

- eat more fruit, vegetables, grains and beans
- eat less fast food and processed food high in fat and sugar
- avoid processed meat and limit red meat
- limit sugary drinks
- limit alcohol.

Get more advice from World Cancer Research Fund. The NHS Eatwell Guide is a good guide to the type of foods and drinks to aim for (see p36).

'Regular exercise, and avoiding alcohol and heavy meals, really helps me to manage chronic fatigue.'

Mel, who had a stem cell transplant in 2017

5 WAYS TO MAKE EATING WELL A HABIT



1. Be kind to yourself

Eating well doesn't mean depriving yourself of your favourite foods. Treat yourself with new foods, healthier puddings or interesting recipes. For inspiration, try the World Cancer Research Fund Recipe Finder (see p36).



2. Make small changes

It might be something simple like eating more fruit with your breakfast or adding some extra vegetables to your dinner.



3. Make smart swaps

Swap your usual foods with healthier alternatives rather than cutting them out altogether. Instead of eating a sweet snack, you could go for a healthier version. Try the NHS Healthy Food Swaps (see p36).



4. Make it easy for yourself

It helps to have nutritious food on hand, so stock up your cupboards and fridge. Take healthy snacks when you're out and about. When you're cooking, make a bit extra with each meal to have the next day, or batch cook meals at the weekend for the freezer.



5. Share your success

It's easier to stick to changes if you let other people know what you're doing. Tell friends and family about what delicious meals and snacks you have planned. Post on social media, or in our Patients and Families Forum (anthonymolan.org/forum).

GETTING ACTIVE

'Being in isolation immediately after the transplant was soul destroying, and opportunities for exercise were very limited. However, when I had to go outside of my room for an X-ray, I persuaded the porter I could walk to the appointment. What a difference this short journey made to my wellbeing, with both my mental and physical condition benefitting enormously.'

Dave, who had a stem cell transplant in 2014



HOW CAN IT HELP?

Stem cell transplants can cause side effects such as stiff or weak muscles, joint stiffness, bone thinning, tiredness and graft versus host disease (GvHD). This can affect your energy and fitness levels.

Find out more about long term side effects in the *Recovery: Body* section of our website (anthonymolan.org/body).

The good news is that being more active can help you cope better before, during and after your transplant.

Being more active is good for you. It can:

- boost your mood and wellbeing
- reduce extreme tiredness (fatigue)
- improve your strength and fitness
- prevent osteoporosis (bone thinning)
- reduce your risk of heart disease and some cancers.

Other people who have had a stem cell transplant say that being active also helps reduce their stress. Being active with others can also help combat loneliness.

What is a physiotherapist?

Physiotherapists are experts in finding the best ways for people going through a transplant to be active. This may involve exercise programmes or advice on everyday activities. If you need physiotherapy while you are in hospital, the physiotherapist will come and see you on the ward. Otherwise, you can ask your GP or transplant team to refer you.

BEFORE YOUR TRANSPLANT

It's normally safe to exercise before your transplant. Gentle exercise such as walking, swimming or cycling can improve your stamina and strength. Exercises like yoga can strengthen muscles, make you more flexible and help you relax, which could also be good for your mental health.

EARLY RECOVERY

It's important and normally ok to start doing some exercises while you're still in hospital or recovering at home. Check with your transplant team or physiotherapist if you're not sure.

- If your transplant team agrees, you could try exercises in your hospital bed.
- Walking and moving regularly will help. For example, getting up every day to have a shower and sitting out of bed.
- Break down activities into small chunks with some rest in-between.
- Your hospital physiotherapist can give you some suitable exercises and stretches.
- Try Blood Cancer UK's simple exercise videos that you can do lying or sitting down (see p36).

'Especially in the early stages of recovery, just walking around the block felt like a major achievement and combatted the effects of being stuck at home.'

Mel, who had a stem cell transplant in 2017

EXERCISING SAFELY

It's normally safe for most people to do some light to moderate exercise during recovery. This level of exercise means that you will increase your breathing rate, but you should still be able to talk.

If you're still going to hospital for issues related to your transplant, or you have other health problems, check with your team or a physiotherapist about what is safe for you to do. They will be able to advise on how to progress based on your own fitness levels and how you are recovering.

Speak to your doctor and avoid exercise if you have any of the following:

- Very low blood counts.
- New pain in your bones, neck or back.
- Severe, persistent headaches.
- Low platelet count (below 20) or problems with blood clotting.
- Pain in the chest, arm, or jaw.
- Irregular heart rate.
- Nausea, vomiting or diarrhoea.
- Fever (a sign of infection).
- A sudden weakness in your muscles.
- Recent pain or swelling in your joints.
- Recent dizziness or fainting.



KEEPING ACTIVE FOR LONG TERM RECOVERY

Whatever your fitness level before your transplant, exercise can be tricky if you haven't done much for a while. It's normally a good idea to start small.

If and when you are ready, try building activity into your daily routine. **NHS.uk** has more information on what to work towards (see p36). As a general guide, aim to:

- cut down the amount of time you spend sitting down if you can – if you're watching TV, resting in bed or working at a computer, get up every 10 minutes and move around if possible
- do 20-30 minutes of moderate activity daily – you can break it down to chunks of 3-5 minutes
- try activities to keep your muscles strong at least twice a week
- try activities that can improve your balance and reduce your risk of falling at least twice a week

See page 28 for activity and exercise ideas.

The websites We Are Undefeatable (**weareundefeatable.org**, **nhs.uk/oneyou**) and Move More (**macmillan.org/movemore**) have lots of other activity ideas.

HOW TO BUILD UP YOUR ACTIVITY LEVELS



'Having a goal to help you get going is paramount. Even if that goal is: by three days' time I will be able to hang out all the washing or walk to the end gate.'

Joanna, who had a stem cell transplant in 2016

TYPES OF EXERCISE

It's good to do a bit of each of these four different types of exercise. Speak to your transplant team about any types of exercise you should avoid.



AEROBIC

Good for: increasing your breathing and heart rate, keeping your heart, lungs, and circulatory system healthy.

Try: walking, cycling, running, dancing, an aerobics class, or team sports like football.



FLEXIBILITY

Good for: lengthening your muscles and improving movements in your joints.

Try: yoga, tai chi or pilates.



RESISTANCE

Good for: making your muscles stronger.

Try: lifting weights, using a resistance band, and everyday activities like carrying shopping.



BALANCE

Good for: improving the muscles that help you balance and can help prevent falls.

Try: yoga and tai chi, or simple exercises like standing on one leg.



GETTING SUPPORT



Speak to your transplant team or GP about accessing exercise classes for free, or at a reduced cost.

Your GP may be able to give you an exercise referral for reduced-cost sessions with a specialist instructor.

Some gyms have programmes for people who have had cancer or other illnesses.

Your local hospital and support centres, such as Maggie's Centres or Macmillan Cancer Support, will also have more information (see p36).

Your council will have a list of leisure centres, community centres and activities near you.

5 WAYS TO MAKE PHYSICAL ACTIVITY A HABIT



1. Do what you love

It's easier to stick to something you enjoy that doesn't take much effort or planning. You don't have to join a gym or an exercise class. What about going for a walk, dancing at home to music, or gardening?



2. Make activity a routine

See if you can build more activity into your daily life. You could try:

- walking instead of taking the bus or driving
- using the stairs instead of the lift
- carrying your shopping home
- doing some cleaning or DIY.



3. Set clear goals

It helps to write down some specific goals and a plan for what might get in the way. For example: 'I will go for a walk every day after breakfast. If it's raining, I will do an exercise video indoors instead.'

Use our My Transplant Tracker App to track your progress (anthonymolan.org/mytransplantracker).



4. Build in rest and relaxation

Getting a good night's sleep, and making time to rest and unwind, can help with your recovery and reduce tiredness. You could try relaxation exercises, massage or meditation.

Mind has some useful relaxation tips (see p36).



5. Set yourself a challenge

Having something to work towards can be good motivation. When you're feeling up to it, you could try the NHS Couch to 5k programme to get into running, or train for the British Transplant Games (anthonymolan.org/btg).

'It's curious that you can feel completely exhausted, but a short 15-20 minute walk can actually make a huge difference. It also gives me the energy and motivation to tackle things I've been avoiding doing!'

Mel, who had a stem cell transplant in 2017



ANTHONY NOLAN CONTACT DETAILS

If you or a loved one is affected by a stem cell 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@anthonymolan.org**

GET CONNECTED

Find support from other patients and their families by joining our **Patient and Families Forum** at: **anthonymolan.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: **anthonymolan.org/patients-and-families**

OTHER USEFUL CONTACTS

BLOOD CANCER UK

bloodcancer.org.uk
0808 169 5155

Funds research and supports anyone affected by blood cancer, including extensive patient information.

CANCER RESEARCH UK

cancerresearchuk.org

Research and awareness charity with information on cancer types and treatment plus advice on living with cancer.

FOOD STANDARDS AGENCY

food.gov.uk

Independent Government department which gives food safety advice across England, Wales and Northern Ireland.

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

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
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

nhs.uk
111

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

WORLD CANCER RESEARCH FUND

wcrf.org

Carries out and publishes cancer prevention research related to diet, weight and physical activity.

NOTES

‘THE BIGGEST IMPACT
ON MY RECOVERY
WAS ACCEPTING THAT
IT WAS DOWN TO ME
LEARNING ABOUT
THE IMPORTANCE
OF NUTRITION AND
PRIORITISING MY
SLEEP, REST AND
DAILY EXERCISE.’

Simon, who had a stem cell transplant in 2012



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patientinfo@anthonymolan.org
0303 303 0303

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