

LIFE AFTER TRANSPLANT:

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



#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@anthonymolan.org

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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 basic guide to help you learn more about diet and physical activity 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 learning ways to get support and look after themselves can help them feel more in control.

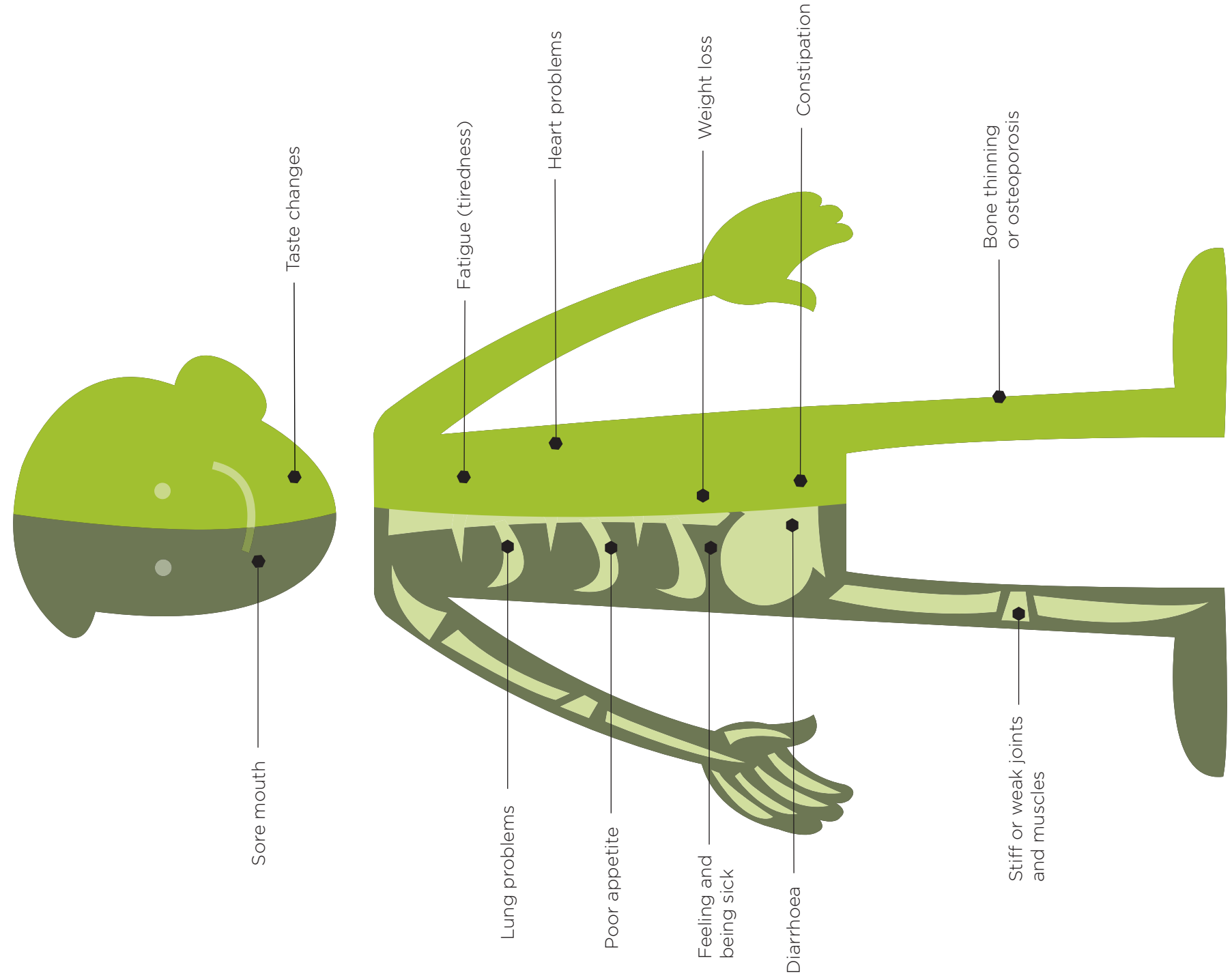
If you are preparing for a transplant, this leaflet is designed to help you learn more about what to expect and how you can help yourself after transplant.

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

HOW WILL I FEEL?

During your recovery you'll be dealing with long-term side effects that can affect your eating, drinking and physical activity levels. This can be daunting, but your team will be there for you along the way. Looking after yourself through your diet and by keeping active can be an important part of dealing with these side effects.

Everyone is different, but these are some of the side effects you might experience after a transplant:



Graft versus host disease (GvHD) can also affect your whole digestive system. Find out more about GvHD and other side effects by reading our booklet, *The Seven Steps: The Next Steps*.

‘AFTER TRANSPLANT FOOD CERTAINLY DIDN’T TASTE THE SAME AND I WENT OFF A FEW FOODS THAT I LOVED BEFORE TREATMENT, PARTICULARLY CHOCOLATE! THANKFULLY MY TASTE RETURNED TO NORMAL SOME TIME AGO.’

Steve, had a transplant in 2013

TIPS FOR EATING AND DRINKING

During the transplant and recovery stage, your body needs more nutrients to rebuild and repair cells and tissue, and to develop new ones. You might also need to make some changes to your diet during your recovery depending on whether you have any of the symptoms described on page 7 and 8.

We’ve suggested some basic tips that can help on the next pages, but speak to a dietitian for more detailed advice.

You should also follow any guidelines your hospital has given you when choosing your food. See page 12 for more information.

In general, advice about diet will change at different points during the transplant process.

Some of these tips might seem to go against ‘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

Follow good mouth care

Choose food carefully:

- ✓ Ice chips, lollies, 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
- ✓ 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
- ✓ Quick to prepare meals are good 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

BOOSTING YOUR ENERGY AND WEIGHT

- ✓ High protein, energy rich foods
- ✓ Boost calories - add butter, cheese, beans or cream to your dishes
- ✗ Don’t fill up on low calorie food like watery soup

DIARRHOEA

- ✓ Replace lost fluids
- ✓ Eat plain, low fibre food
- ✗ Alcohol and coffee
- ✗ Rich food and foods with the sweetener sorbitol in them e.g. fizzy drinks

TASTE CHANGES

Food tastes like:

Cardboard/cotton wool

Try ‘tart’ foods like citrus fruits.

Metallic

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

Bland/tasteless

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

DO I NEED TO FOLLOW FOOD SAFETY ADVICE?

Many foods contain small amounts of bacteria and fungi – this is not normally a problem. But as your immune system is recovering after a transplant, you'll be more vulnerable to infections, so your transplant team may advise you to continue following food safety advice in the early stages of recovery.

Your hospital should give you more specific information about this diet. In general make sure that your food is well cooked, stored properly and that you're following food hygiene practices. For more information read Bloodwise's booklet, 'Dietary Advice for Patients with Neutropenia'.

bloodwise.org

'I actually really enjoyed the hospital food, two cooked meals a day, including puddings! But after about five days of the conditioning therapy you don't really feel like it, the weight just dropped off me. I've gradually built myself back up.'

Peter, had a transplant in 2012

HEALTHY DIET AND LIFESTYLE

As you make progress and recover, try and maintain or work towards a healthier diet or lifestyle. If you're thinking about making lifestyle changes, ask your GP, transplant team, dietitian or physiotherapist for help. Make sure you're eating or exercising in a way that will help your recovery.

After a transplant it is natural to want to make changes that will help reduce the risk of your condition returning. But further scientific research is needed before we can fully understand the role of diet and lifestyle on cancer risk for people recovering from cancer. Based on the available evidence, the World Cancer Research Fund advise people who've had cancer in the past to follow their cancer prevention recommendations:

1. Maintain a healthy weight

Be as lean as possible without becoming underweight.

2. Move more

Be active for at least 30 minutes a day.

3. Eat well

Avoid sugary drinks. Limit consumption of high-calorie foods (particularly processed foods high in added sugar, or low in fibre or high in fat).

4. Enjoy a plant based diet

Eat more vegetables, fruits, wholegrains and pulses such as beans.

5. Reduce red meat

Like beef, pork and lamb, and avoid processed meat.

6. Cut down on alcohol

Limit alcoholic drinks to two for men and one for women a day.

7. Eat less salt

Limit consumption of salty food and food processed with salt.

8. For cancer prevention don't use supplements

Supplements contain vitamins, minerals and other components of food. Aim to get all your nutrients by eating a healthy, balanced diet. But if you're not absorbing enough nutrients from your diet, or you can't eat a normal diet you may need to take some supplements. Ask your dietitian or doctor for advice.

For more information read World Cancer Research Fund's leaflet 'Healthy Living after Cancer' **wcrf.org**



KEEPING ACTIVE

HOW CAN IT HELP?

Exercise or being physically active can help:

- Improve your quality of life and how you feel emotionally before, during and after your transplant
- Keep your joints mobile
- Build up muscle strength and stability
- Prevent osteoporosis
- Reduce your risk of heart disease and some cancers
- Reduce treatment-related fatigue and improve your physical strength

WHERE SHOULD I START?

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

Everyone will have had different levels of fitness before the transplant. But it's normally a good idea to start small – it can be tricky if you haven't done much for a while. Break it down into chunks, aim for 10-20 minutes a day, but spread it out into bursts of 3-5 minutes. Try our one minute exercises on the next page for a gentle way to keep active.

'As part of my recovery I was receiving some physiotherapy, and those daily exercises helped get some movement back into my routine.'

Ashling, had a transplant in 2012

ONE MINUTE EXERCISES

Pick an exercise and repeat it at a steady pace for one minute, a few times a day. For more exercises read our booklet, *Managing Fatigue After a Bone Marrow or Stem Cell Transplant*.

START BY LYING ON YOUR BACK

Ankle bends - point your toes up to the ceiling, then straighten your ankles and point your toes away from you. Keep your knees straight to stretch your calf muscles.

Leg raises - lift up one knee so your foot is flat on the bed. Keep the other leg straight, toes pointing towards the ceiling, and lift it up about six inches, hold for five seconds, and lower it down. Repeat on both sides.

START BY SITTING IN A CHAIR OR BED

Leg strengthening - starting with both feet flat on the floor, straighten one knee slowly and smoothly to lift your foot up, then lower it back down. Repeat on both sides.

Tricep lifts - hold a bottle above your head with your arm straight. Bend your elbow and slowly lower the bottle towards your shoulder, behind your head, keeping your elbow high. Then straighten your arm again. Repeat on both sides. (You can also do this from standing.)

'See who's around for support to keep you motivated - find cheerleaders! Often family and friends want to help out but don't know how, exercising together could be a good way.'

Lucy, Physiotherapist

HEALTHY DIET AND LIFESTYLE



Keep track of your activities for one week.

Pick one activity you can do now. Do this every day. Start small - walk to the end of the garden, march on the spot, or try a one minute exercise.

Increase how often you do it over weeks or months. Try it twice a day.

Increase how long you do it over weeks or months. Try it for 10 minutes instead of 5.

Increase how hard you work when you're doing it. Walk at a faster pace.

A good long term goal is 30 minutes of moderate intensity exercise, 5 days a week.

WHAT TYPE OF ACTIVITIES SHOULD I DO?

It's up to you. It's often easier to stick to something you enjoy, that doesn't need much effort or planning. You don't have to join a gym or an exercise class, try and build things in your everyday routine.

- Walk instead of taking the bus or driving
- Use the stairs instead of the lift
- Carry your shopping home
- Do some cleaning or DIY
- Dance around at home to music

'Walking was a godsend because you can be outside enjoying the fresh air, you can pace yourself, and you can avoid crowds. At first I didn't go out alone so that I had someone to lean on if I got tired. This enabled me to walk a bit further because I felt safe and supported.'

Sarah, had her transplant in 2010

TYPES OF EXERCISE

It's good to do some of each of the four different types of exercise, but 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, aerobics class or team sports like football.



RESISTANCE

Good for: Making your muscles stronger.

Try: Lifting weights, using a resistance band, 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 also help with balance. You could also try simple exercises like standing on one leg.



FLEXIBILITY

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

Try: Yoga, Tai Chi, or Pilates.

WHEN ISN'T IT SAFE TO EXERCISE?

If you're recovering well, it's generally safe to do light or moderate exercise. If you're feeling unwell or still need to go to hospital for problems related to your transplant, or you have other health problems, ask to speak to a physiotherapist about what's safe for you to do.

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

- Very low blood counts
- Severe skin reactions to radiotherapy
- New pain in your bones, neck or back
- Severe, persistent headaches
- Low platelet count 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

WHERE CAN I GET 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 prescription for free sessions with a physiotherapist, or with a personal trainer at your local gym. 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 also have more information:

maggiescentres.org
macmillancancersupport.org

'I like getting plenty of fresh air and treating myself to good healthy food so I know I'm giving my body the very best chance. Life couldn't be better.'

Simon, had a transplant in 2012

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

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The Anthony Nolan Patient and Families Panel



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Johnny, had a transplant in 2012

‘I LIKE GETTING PLENTY
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SO I KNOW I’M GIVING MY
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BE BETTER.’

Simon, had a transplant in 2012

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