

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 at patientinfo@anthohnolan.org

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The information contained in this booklet is correct at the time of going to print (Nov 2023). We plan to review this publication by Nov 2026. For updates or the latest information, visit anthohnolan.org

Anthony Nolan is a registered charity
No 803716/SC038827

3160PS/1023

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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 things 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.

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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 to treat acute myeloid leukaemia (AML)



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 an 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 meals 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, but it is an important part of the process. It 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 tube or vein feeding. This means you will either have liquid food fed directly into your stomach (nasogastric tube feeding) or directly into your vein (parenteral nutrition).

More information on tube feeding is available from Cancer Research UK (see p40).

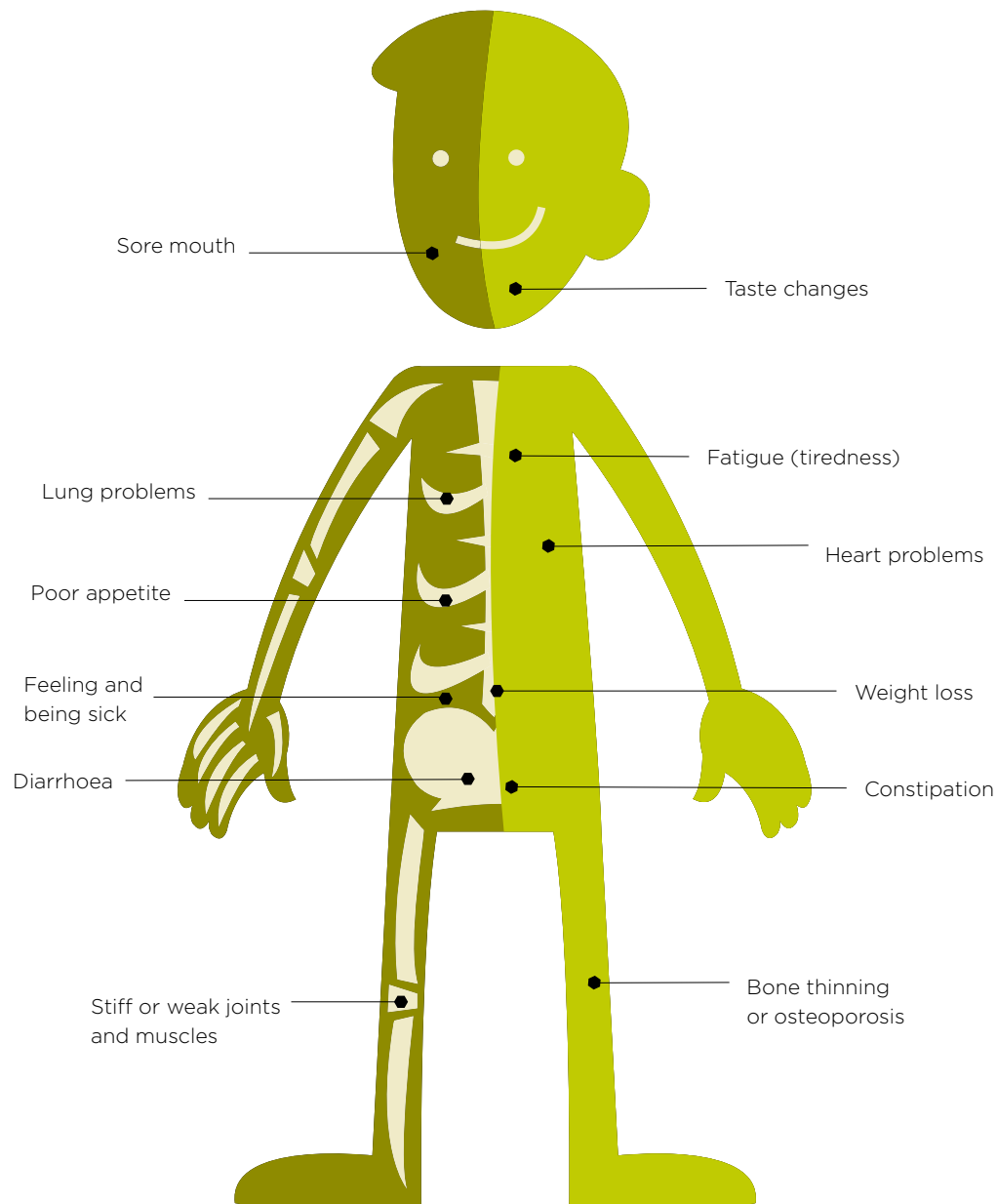
Side effects during early recovery can make it difficult to eat and drink. For example:

- Feeling and being sick
- Having a sore mouth
- Diarrhoea (runny poo)
- Lack of appetite

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.

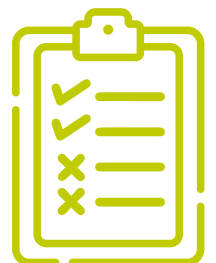
Tips for eating and drinking



Graft versus host disease (GvHD) can also affect your whole digestive system. Find out more about GvHD by reading our booklet: *An essential guide to graft versus host disease (GvHD)* or webpage: anthohnolan.org/GvHD

The following pages contain tips on what can help if you experience side effects that affect you eating and drinking, plus things to avoid.

Some of these tips might seem to go against standard 'healthy eating'. That can come at a later stage when you're further into your recovery, and your weight is stable and energy levels have improved.



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
- ✓ Choose foods which are high in calories and protein
- ✓ Go for what you really fancy and crave
- ✗ Avoid low fat and 'healthy' versions of foods

Boosting your energy and weight

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

Sore mouth

Brush your teeth regularly, using a soft bristled brush.

Choose food carefully:

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

Feeling and being sick

- ✓ Eat dry foods, like toast or crackers
- ✓ Sit upright before and after eating
- ✓ Ginger and peppermint might help
- ✓ Cold foods smell less
- ✓ Try and distract yourself while eating, e.g. talk to someone, watch TV, or listen to the radio or a podcast
- ✗ Greasy, fried, smelly, very sweet food
- ✗ Keep away from the smell of cooking

Constipation

- ✓ High-fibre foods
- ✓ Lots of fluids
- ✓ Gentle walking or exercise can stimulate your bowels

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

- Use sauces, spices or marinades to adjust the flavour of iron-rich red meat. Or 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.

Make a list of foods you like, or are able to eat. Make the most of those and experiment with new foods. Try 1-2 new foods per day and make a note of which foods you are able to eat.

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 webpage and booklet: *Eat well during cancer* (see p40).

Do I need to follow food safety advice?



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

It's important to follow general food safety and hygiene advice. This means washing your hands and a clean, safe approach in preparing, cooking, thawing and storing your food. Find out more from the Food Standards Agency (see p40).

If your transplant team have told you to avoid foods which are considered to have a high risk of bacteria, find out more about a neutropenic diet on Blood Cancer UK's webpage:

[bloodcancer.org.uk/infection](https://www.bloodcancer.org.uk/infection)



Eating well for long term recovery

Some people find that during their recovery they:

- struggle to eat well
- have problems with diabetes
- have high blood pressure
- become overweight.

It's natural to want to reduce the risk of your condition returning after transplant. 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 individual foods or food groups. 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 your appetite has returned to how it was before treatment, making nutritious food choices and looking after your body can help you manage side effects, your general health, energy levels and can improve your mood.

This means you could:

- eat more fruit and vegetables – fresh, frozen and tinned all count
- choose foods high in fibre to support your gut health – oats, wholegrain cereal, wholewheat pasta and bread, nuts
- eat less fast food and processed food high in fat and sugar
- avoid processed meat and limit red meat
- limit sugary drinks
- limit alcohol to less than 14 units per week.

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:

[NHS.uk/eatwellguide](https://www.nhs.uk/eatwellguide)



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

Mel, who had a stem cell transplant to treat chronic myelomonocytic leukaemia (CMML)

Five ways to make eating well a habit



1. Be kind to yourself

Eating well doesn't mean completely depriving yourself of your favourite foods. Healthy eating should be sustainable but can include treats. You can also try new foods or interesting recipes – eating should still be enjoyable. For inspiration, try the World Cancer Research Fund Recipe Finder: wcrf-uk.org/food



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 Healthier Food Swaps: nhs.uk/healthier-families/food-facts/healthier-food-swaps



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 can be 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, or share on 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 after being diagnosed with myelodysplastic syndromes (MDS) and then acute myeloid leukaemia (AML)



How can it help?

Stem cell transplants and the associated medication can cause side effects such as:

- stiff joints
- achy and weak muscles
- reduced bone density
- fatigue and tiredness.

This can affect your energy and fitness levels, as well as your ability to complete everyday tasks.

Find out more about long term side effects in the *Recovery* section of our website:

[anthonynolan.org/recovery](https://www.anthonynolan.org/recovery)

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, but be sure to check with your transplant team to make sure it's safe for you to be around others after transplant.

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.

What is an occupational therapist?

Occupational therapists provide practical support to help you do the activities that matter to you. It is normal to feel fatigued during and following treatment. You should slowly start to resume your daily routine, but recognise you may need help with some activities of daily living. Occupational therapists can help to manage this by giving you tips on how to save your energy and pace yourself, or by providing aids and adaptations.

Top tip: We have lots more information and support on fatigue and stem cell transplant in our booklet *Managing fatigue after a stem cell transplant* and on our website: [anthonynolan.org/fatigue](https://www.anthonynolan.org/fatigue)

Before your transplant

It's normally safe to exercise before your transplant. Building up your fitness is often recommended as it can help with your recovery after transplant. This is part of prehabilitation (prehab). Your hospital might have a prehab programme for you. If not, ask your medical team about it. They should still be able to offer advice.

Gentle exercise such as walking, using an exercise bike, or dancing can improve your stamina and strength. Exercises like yoga, Pilates and tai chi 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 continue doing some exercises while you're still in hospital or recovering at home. Not being active will cause muscle weakness, leading to increased fatigue. Check with your transplant team or physiotherapist if you're not sure what you're able to do.

Top tips:

- If your transplant team agrees, you could try exercises in your hospital room – even in your bed or chair.
- Walking and moving regularly will help. For example, getting up every day to have a shower and sitting out of bed.

- Even doing very gentle exercises or stretches can help with your circulation. This is important, especially when you don't feel like getting up and moving around the room.
- Exercise can help break the day up and give you a sense of routine while you are in hospital.
- Break down activities into small chunks with some rest in between.
- A hospital physiotherapist may be able to give you some suitable exercises and stretches.
- Try Blood Cancer UK's simple exercise videos that you can do lying or sitting down: [bloodcancer.org.uk/support-for-you/living-well/keeping-active](https://www.bloodcancer.org.uk/support-for-you/living-well/keeping-active)



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 to treat chronic myelomonocytic leukaemia (CMML)

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.

More strenuous exercise should wait until your immune system has recovered and your energy levels have improved.

If you're still going to hospital for issues related to your transplant, or you have other health problems, check with your medical 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
- Feeling or being sick, or diarrhoea (runny poo)
- 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.

Remember: Recovery is different for everyone and you may encounter setbacks along the way. Don't let this dishearten you.

If and when you are ready, try building activity into your daily routine. 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 30 minutes and move around if possible.
- Do 20-30 minutes of moderate activity daily, like short walks, housework or using a static bike – you can break it down to chunks of 3-5 minutes if you need to.
- 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.

We Are Undefeatable: weareundefeatable.co.uk and Macmillan: macmillan.org/movemore have lots of other activity ideas.



How to build up your activity levels



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

Keep track of your activities for one week, either in a diary, on your phone or using an app.

Create some short term and long term goals. Make them realistic and achievable, like Joanna's quote below.



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 to treat acute myeloid leukaemia (AML).



Increase how hard you work when you're doing it.

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

Increase how often you do this activity over weeks or months. Try it twice a day instead of once.

Stay motivated. Doing something is always better than doing nothing. On the days that you aren't feeling motivated to go for your walk or complete an exercise programme, something as little as doing 30 seconds of marching on the spot can make a big difference.

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.



Resistance

Good for: making your muscles stronger.

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



Flexibility

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

Try: yoga, tai chi or Pilates.



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 if you have any concerns about exercise, or are interested in getting a referral for physiotherapy. They could also help with 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 or Macmillan Cancer Support, will also have more information (see p41).

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



Five 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
- practise your balance while waiting for the kettle to boil or brushing your teeth.



3. Set clear goals

It helps to write down some specific goals and 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: mind.org.uk/relaxation



5. Set yourself a challenge

Having something to work towards can be good motivation. You could try the NHS Couch to 5k programme or parkrun 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 to treat chronic myelomonocytic leukaemia



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@anthohnolan.org**

Get connected

Find support from other patients and their families by joining our **Patient and Families Forum** at **anthohnolan.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 **anthohnolan.org/patientinfo**

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

maggies.org

enquiries@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.

parkrun

parkrun.org.uk

Free, weekly, timed 5ks across the UK and the world. Find your local and join them for a run, jog, or walk.

World Cancer Research Fund

wcrf.org

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



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 to treat aplastic anaemia



anthonymolan.org/patientinfo

facebook.com/anthonymolanpatients

patientinfo@anthonymolan.org

0303 303 0303



Patient Information Forum



saving the lives of people with blood cancer