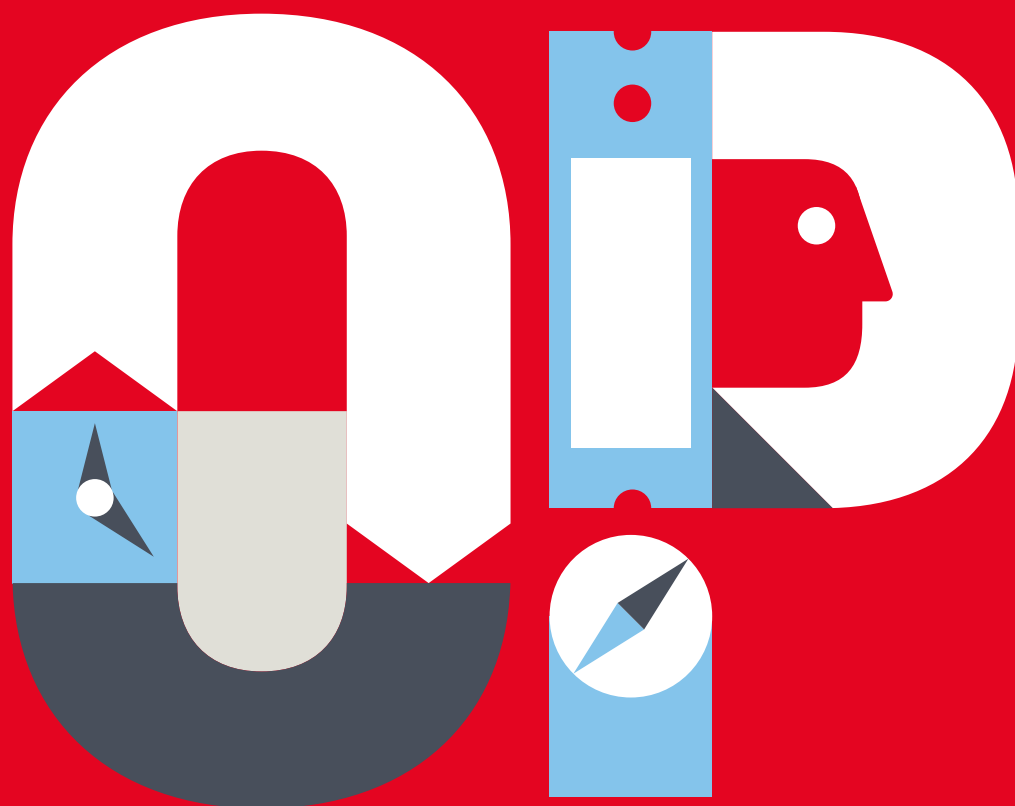




British Heart
Foundation

My heart



**FIGHT
FOR EVERY
HEARTBEAT**
bhf.org.uk

A young person's guide
to having heart surgery

The British Heart Foundation has a wide range of books, posters and leaflets for young people with a heart condition and their families. Go to bhf.org.uk/childrenandyoungpeople to find out more.

Join our fight for every heartbeat in the UK. Every pound raised, every minute of your time and every donation to our shops will help make a difference to people's lives. Visit bhf.org.uk/donate

Yheart

Yheart is the young people's section of the BHF website. You'll find information for 13 -19 year olds including videos and games on how to stay healthy and active. You can also sign up for meet@teenheart, the BHF programme for young people living with a heart condition. It's a brilliant place to make friends with people who have had similar experiences to you.

Go to bhf.org.uk/yheart

Straight from the heart

Wondering what to pack for hospital? Want to know what to expect on a ward? This booklet is the essential guide for young people preparing for their heart operation and recovery. Code G562.

Picture your journey: making the transition from child to adult care

The transition from child to adult health services can raise a lot of questions. This pack is stuffed full of helpful information and ways to keep track of your treatment. Don't make your transition without it. Code G690.

Order all these resources for free at bhf.org.uk

Hello. This book is for you. It's written for young people who need to have a heart operation.

Maybe you've been waiting for an operation for a while. You might have been feeling really unwell. Or you might be one of the people that feels fine and are quite surprised when you hear you need to have an operation. Either way, the truth is, if your medical team have said you need an operation, it's because your heart's not working properly. Even if you can't feel the effects, you need the operation to stop things getting worse.

Make sure you check out the list of resources on the opposite page. You can order them for free online.

This book is all about what happens at the hospital, who you will meet and how you might feel. So by the time you've read it, you should know exactly what to expect.

If you want to talk about anything in this book, or you have any other questions, get in touch with your specialist nurse. They know pretty much **everything** about the operation you're going to have, and it's their job to make sure you do too. You can email or phone them – whatever you prefer. If you don't know who your specialist nurse is, check with your consultant's secretary or look at the hospital website.

You can ask your specialist nurse to order a BHF ID card for you. That way, you can carry it with you and use it to explain your heart condition to other people. They need to go to bhf.org.uk/publications Order code G486.

Name:

Name of heart condition:

Name of operation:

Date of pre op:

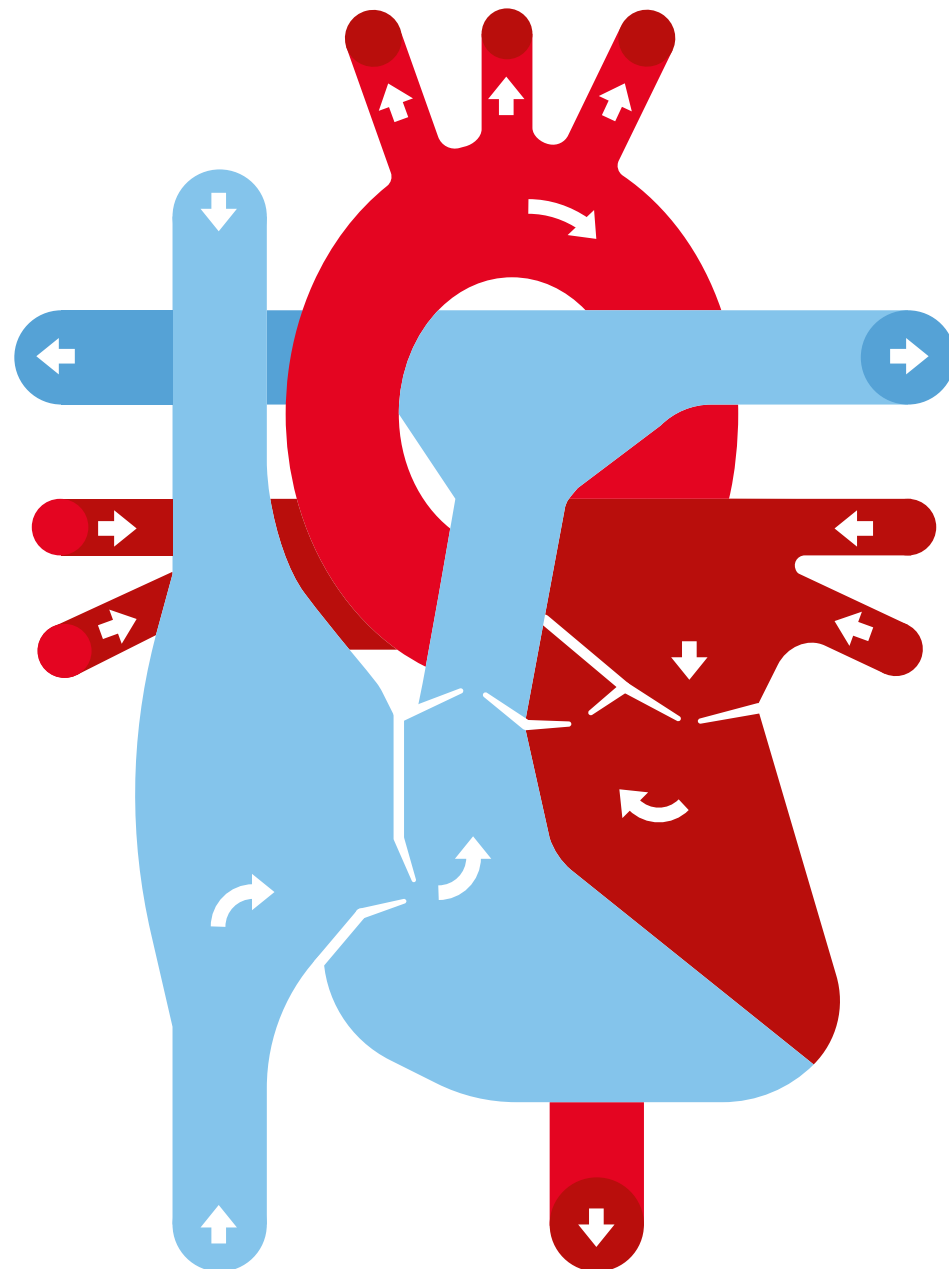
Date of operation:

Specialist nurse:

Specialist nurse's email address:

Specialist nurse's phone number:

This shows how a heart works.



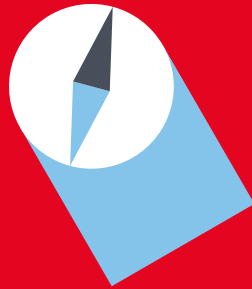
Get your specialist nurse to show you how **your heart** is working and why you need an operation.

The countdown

Meet the team
02—05



Take a tour
06—09



Pre-op tests
10—27



The big day

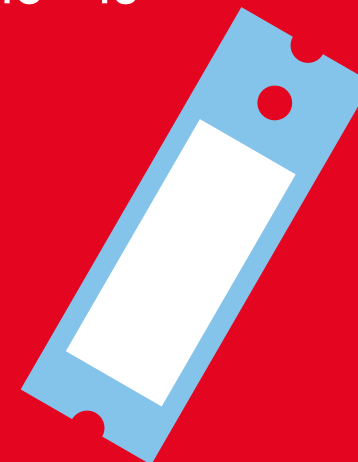
The hospital
30—35



Meeting your
anaesthetist and surgeon
36—39

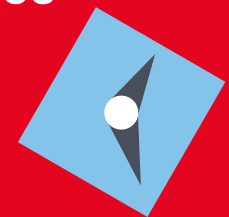


Into theatre
40—43



On the mend

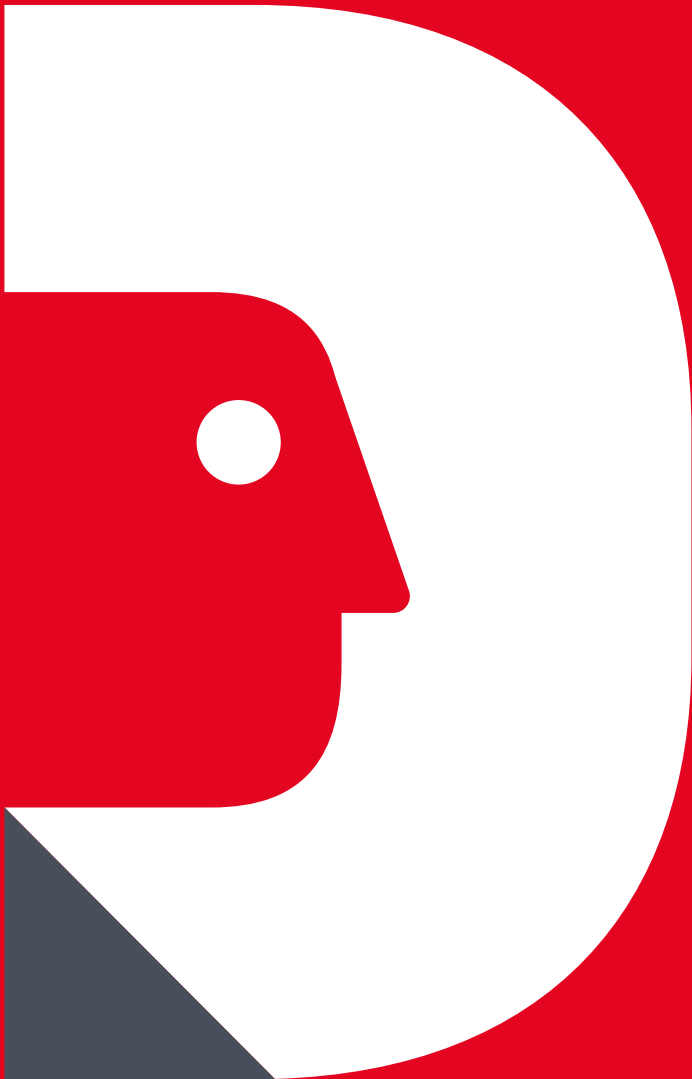
After surgery
46—68



Before the operation
there's a few checks
and tests that
you'll need to do.
This section tells
you what to expect.

Meet the team	02
Take a tour	06
Pre-op tests	10
Blood tests	12
Chest X-ray	14
Echo	16
MRI	18
Pregnancy test for girls	20
Cardiac catheter	22
Weight and height	24
ECG	25
MRSA test	26
CT scan	27

Meet the team



A **surgeon** is a specially trained doctor who does operations.



A **nurse** is someone trained to care for patients.



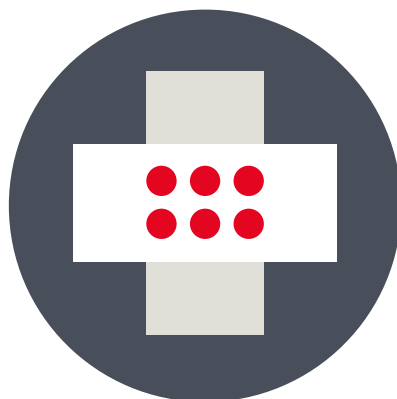
An **anaesthetist** is a type of doctor who specialises in putting people to sleep before an operation, and stays with them until their surgery is done.



A **radiographer** is a health professional who does scans like X-rays, CT scans and MRIs.



A **cardiologist** is a doctor who specialises in hearts.



An **ODP** (Operating Department Practitioner) supports the anaesthetist in caring for people before, during and after surgery.



A **cardiac physiologist** does tests that show what people's heart problems are.



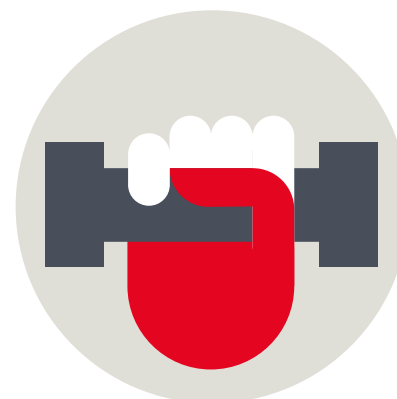
A **theatre nurse** works with a surgeon in theatre. At hospital, a theatre is the room where they do the operations.



A **psychologist** is trained to understand people's emotions and to help them to feel better. Most, but not all, hospitals have a psychologist who people can talk to.

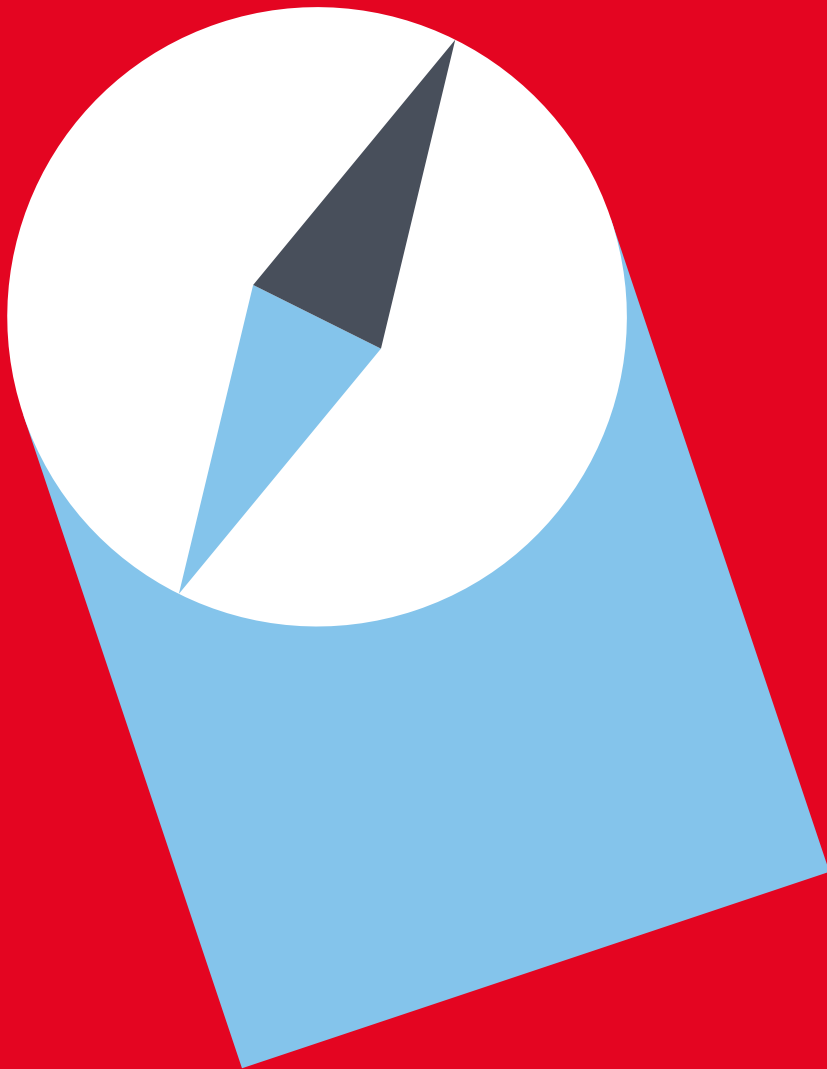


A **cardiac nurse specialist** is a nurse who looks after heart patients.



A **physiotherapist** (sometimes called a 'physio' for short) shows people exercises that are good for recovery.

Take a tour



Before your operation, you might need to go to hospital for a 'pre-op' or 'pre-admission' assessment. Not all hospitals do these on a separate day – some do them when you go in for the operation – but if you need to go in for a pre-op, you'll get a letter telling you where to go and when. It'll probably ask you to go to a part of the hospital called 'Outpatients'. Outpatients is for people who are just in for the day – not staying overnight.

You'll do quite a few tests at your pre-op – mostly to make sure that you're well enough for the operation. When you go in, tell reception you're there, then you can sit in the waiting area and wait to be called. You might want to take a book or tablet, and make sure your phone is fully charged as there can be quite a lot of waiting around.

Your pre-op can also be a good time to find out more about your stay in hospital. If you want, you can ask your specialist nurse to show you around so you know where you'll be staying. Also, you can take this chance to ask your specialist nurse any questions you have. Ask them if an adult can stay with you or whether they should just come in for visiting hours. If you are worried about anything at all, tell them. It's their job to explain things and help you get ready for your operation.

Who to take with you

If you are over 16, you can go to your pre-op appointment on your own if you want, but most people take someone with them anyway. You can take your mum, dad, grandparent or anyone who you think would be good at supporting you. They don't have to be a relation.

For information on consent, go to page 39.



*"My main issue was my GCSEs. But they said I won't actually be in that long, and I can take work to do in the hospital."
Hayleigh, age 15*

*"I've had open heart surgery 4 times. I always take my mum to appointments. You need someone there for you."
Joe, age 18*

Does the hospital have WiFi?

Will I be allowed to have an adult stay with me?

Am I allowed to use my phone in the hospital?

How many visitors can I have?

What are the visiting hours?

Can I plug in chargers and leads?

10-11 Pre-op tests

Each hospital does things slightly differently, but you'll probably have most of the tests listed below as part of your **pre-op assessment**. The person who comes with you can stay for all of these tests, although they might be asked to step outside the room for some of the scans and X-rays. If you would rather have any of these tests on your own, that's okay too – just say.

Pre-op tests:

- Blood test
- Chest X-ray
- Echo
- MRI
- Pregnancy test for girls
- Cardiac catheter
- Weight and height
- ECG
- MRSA swab
- CT scan

Blood tests are important. Doctors can find out a lot about your health from your blood, so they need to take a small amount for testing.

A nurse puts a strap around your arm, pulls it tight and then puts a tiny needle into a vein. This is usually at the crease where you bend your arm. It doesn't really hurt, but if you're bothered about it, you can ask them to use some numbing cream so you can't feel it – but you have to wait about 45 minutes for that to work.



“I’m fine with needles, you just get used to it. Look away and you hardly notice.”

Joe, age 18

A radiographer will need to take an **X-ray** of your chest. It's like a photo of the inside of your body.

You won't need to take your top off for this, but girls with underwire bras have to take them off because the metal shows up on the X-ray. This is quite an easy test, you just need to stand very still against an X-ray machine. The person you've brought with you will need to step outside while the actual X-ray is being done because X-rays should only be done on people who need them. It's really safe and you won't feel a thing.



“The X-ray is very quick. There’s no pain or anything. My dad went into a room off to the side but I could still see him from where I was.”

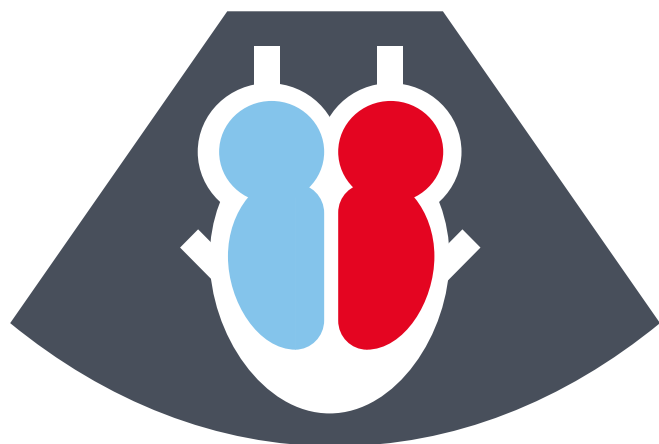
Alex, age 16

Echo is short for 'echocardiogram'. It's where they use ultrasound to make a video of your heart. You might not need one of these if you've had one recently, but if you do, a cardiac physiologist will ask you to take your top off and lie on a bed.

They put cold, clear jelly on your chest, and then use something shaped like a big marker-pen but with a smooth end to take pictures inside your chest. You need to stay still for this test, but it's pretty easy. The only thing is that they sometimes need to press between your ribs which can hurt a bit. If it's really uncomfortable, tell the cardiac physiologist and they'll try another position.

Taking your top off

Some people feel shy about taking their top off in front of a doctor or nurse. But remember, medical staff are totally used to it. Girls might be asked to take their bra off. If you're bothered about it, don't wear an underwire bra on the day – they definitely have to be taken off. Wear a vest top that can be pulled up, and you can ask to cover up with a sheet while they are doing the test.



“You probably won’t be able to have some of these tests with a bra on. But ask them if they can do the scans and stuff through a gown or vest top. They let me.”

Rebecca, age 19

MRI stands for ‘magnetic resonance imaging’. It means using magnets to see inside your body. It’s different from an X-ray because it shows a much more detailed picture.

It’s probably the longest test you do – it can take up to 90 minutes. You lie on a flat surface and then they slide your whole body into the machine. It’s completely safe and it doesn’t hurt, but it can feel a bit weird to be in such a small space. The machine is quite noisy. You can take someone into the room with you, but they’re not allowed to chat with you while you’re in the machine.

They might put a small tube called a cannula in the back of your hand. That allows them to put dye into your blood so that the doctors can see how blood is flowing around your body.

The most important thing about being in an MRI scanner is staying still. It can get a bit uncomfortable, but you just have to try not to move. They’ll ask you to hold your breath at some points too – that’s so they can get a picture of your body when it’s not moving.

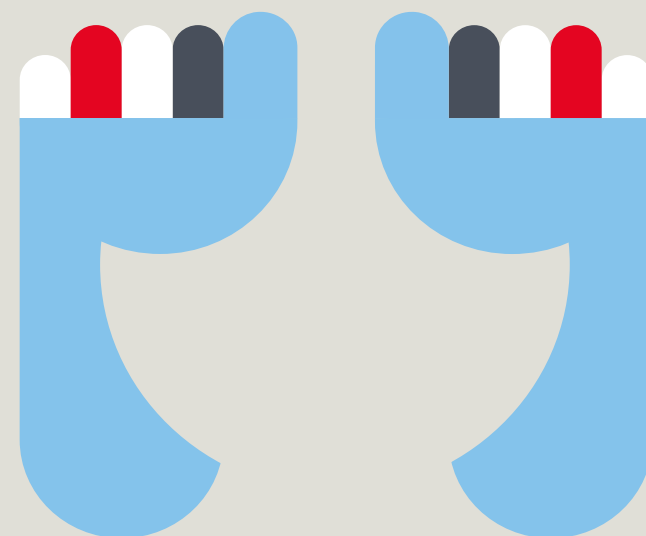
If you can try to stay relaxed and focus on doing what the technicians are asking you, the MRI is fairly straightforward. Some hospitals can play a film or music while you are in the scanner so you have something to think about.

No metal

Because an MRI scanner uses very powerful magnets, you’ll need to take all jewellery, watches and piercings off, before the MRI. You can wear a hospital gown or you can wear your own clothes, but only if they don’t have any metal buttons or zips. Girls can’t wear a bra with metal wires or clasps either.

“My advice would be, close your eyes before you go in and keep them closed so you don’t think about how small the space is.”

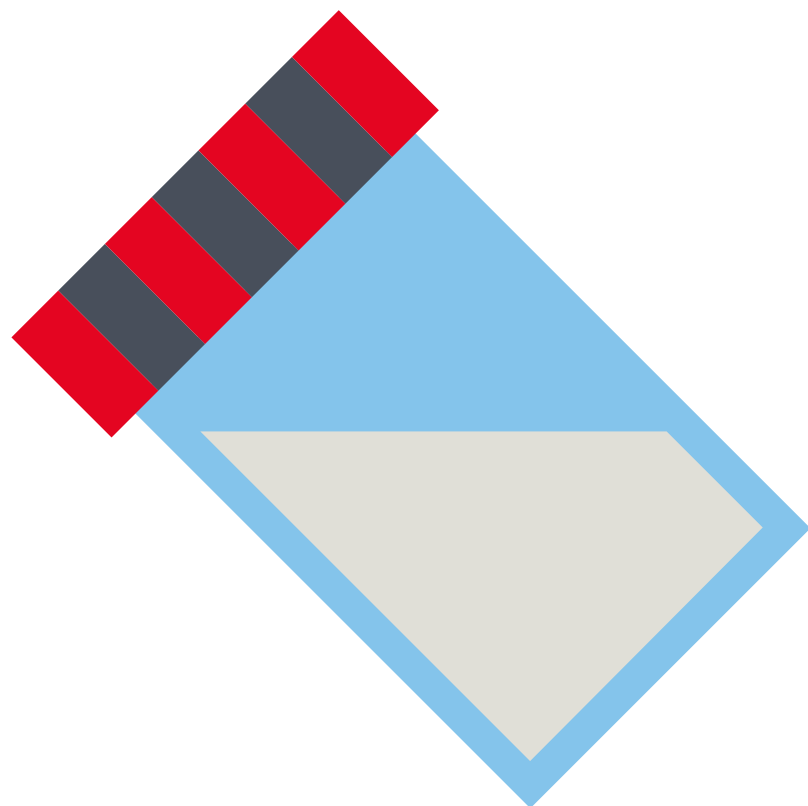
Rebecca, age 19



The nurses need to make sure that no-one is pregnant for some of the tests, and also for when they have their operation, so girls need to have a **pregnancy test** as part of their pre-op.

A nurse will ask you to take a little pot into the toilet and wee into it. They'll test your urine to make sure you're not pregnant. If a patient is pregnant, the doctor will explain what needs to happen next. They may need to delay the operation date.

If you have any worries about being asked about your sexual activity in front of a parent, talk to your specialist nurse. You can email them before you go in if you like.



“They’ll ask you if you think you could be pregnant and get you to do a test. It’s to make sure it’s safe for you to have the operation.”

Kaytie, age 16

A **cardiac catheter** is a test that looks inside the arteries and chambers of your heart. They put a little tube into the top of your thigh, wrist or neck all the way to your heart. Then they can put dye in to see how the blood flows.

You will either have a general anaesthetic for this (that's the one that puts you to sleep) or you will take medication to make you sleepy and relaxed. You won't feel any pain because you will also have pain killers.

Probably the most unusual bit of having a cardiac catheter is the shaving. A nurse will either do it for you or give you a razor and ask you to shave some of your pubic hair off. This is because they sometimes need to put the catheter in where your leg meets your body.

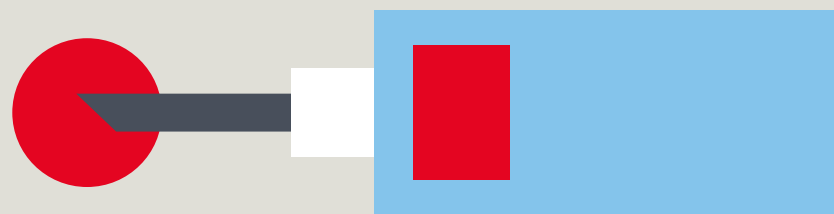
You'll also need to go behind a screen and take all your clothes off. You can wear a hospital gown until the catheter is put in, so no-one will see you naked. If you don't like the gown being open at the back, ask for an extra one and put it on like a dressing gown.

There will be quite a few people in the room for this test – a cardiac physiologist, a radiographer, an anaesthetist, some nurses and a couple of cardiologists. How long the procedure takes can really vary. Your cardiologist will tell you what to expect, but the medication usually makes you feel as though time has passed really quickly.

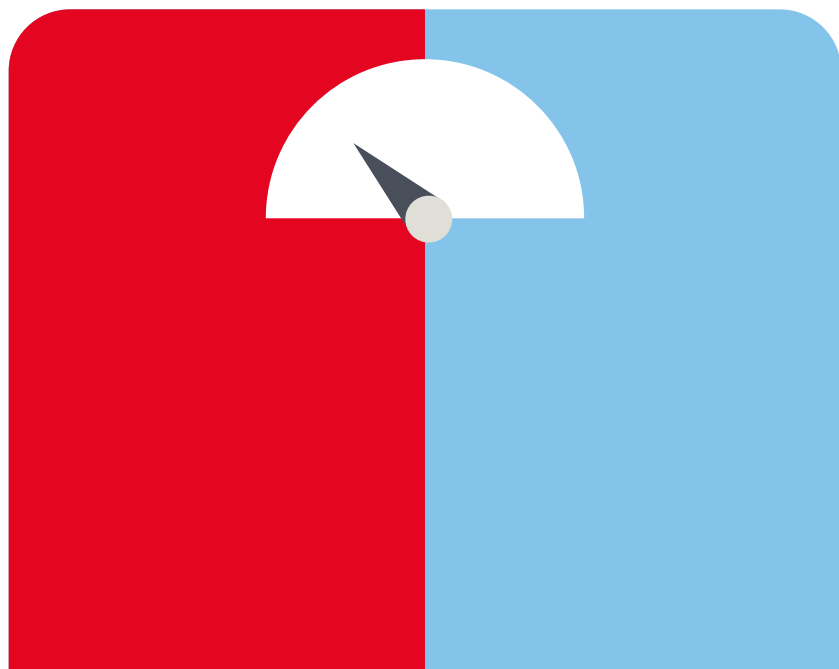
Unless you have something called an angioseal to seal your artery, you will need to lie flat for an hour or two after the catheter. A nurse will keep checking on you to make sure that there's no bleeding and that your blood is flowing properly.

“Just relax and do what they tell you with the cardiac catheter. It's actually alright. They wouldn't do any of this if it was not helping you.”

Alex, age 16



Having your **weight and height** measured is really straightforward. You just need to stand on some scales and against a chart on the wall.



ECG stands for ‘electrocardiogram’. An electrocardiogram shows activity in your heart.

For this, a cardiac physiologist will ask you to lie down and take your top off. They’ll put a load of little stickers with wires coming out of them on your chest. You won’t feel a thing – it’s really quick and easy. The wires go to the ECG machine which makes a graph of the electrical activity inside your heart.



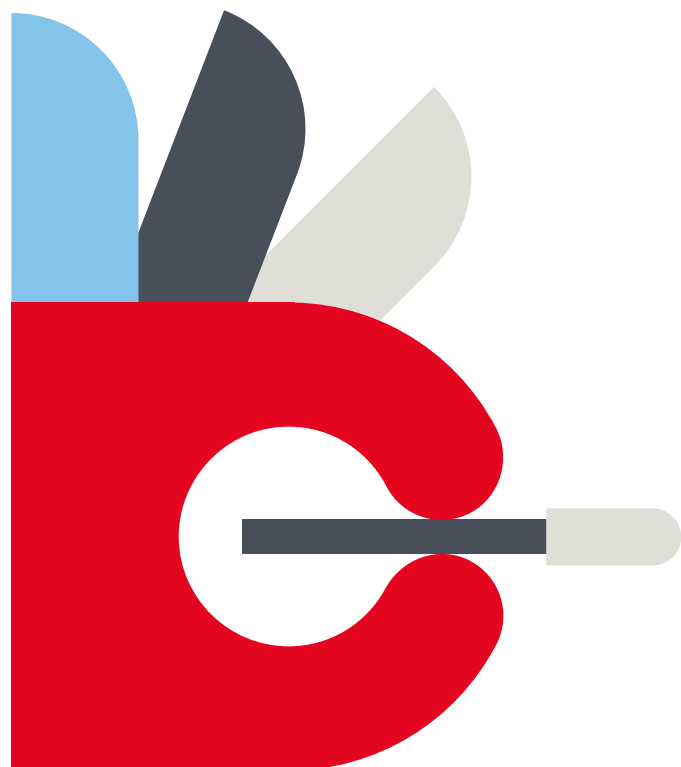
“ECG is a breeze, they’re just having a look.”
Alex, age 16



You might have heard of **MRSA**. It's an infection that's very easy to catch. It's important no one in a hospital has MRSA because it can make patients more ill.

The nurse will test you to make sure you don't have it. They use long cotton buds to take a sample. You might be asked to put one up your nose, under your arm, in your mouth or just where your underwear meets your leg. They send the cotton buds you've used to a lab for testing.

If the tests show you are carrying MRSA, they'll give you special liquid to wash your hair and body with, and a cream for up your nose, so that you don't bring MRSA into the hospital.



CT stands for 'computed tomography' which means it's a test that takes lots of X-rays and then uses computers to make 3D pictures of the inside of your body.

They will put a cannula into the back of your hand – that's a little tube that dye can go through so that it's in your bloodstream. You might have had this before for an MRI. The dye will flow around in your blood and show the doctors how your circulation is working.

You need to lie down and stay still for about half an hour for this test. Staying still is important because that's how they make sure the pictures don't get blurred.



On the day of your actual operation, there's a lot to think about. This section goes through it all, bit by bit.

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Children's or adult services?	32
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Bring someone with you	34
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Getting changed	35
Meeting your anaesthetist and surgeon	36
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Your surgeon	38
Consent	39
Risks	39
Into theatre	40

The hospital



Your operation can be anything from the day after your pre-op to a couple of months after. Your surgeon's secretary should know when it will be – and you should be sent a letter in the post too.



“If you don’t understand anything about your operation or what you need to do, just ask. There’s an explanation for everything.”

Alex, age 16

Children's or adult services?

The letter about your operation should tell you if you are going into an adult ward or a paediatric ward – a paediatric ward is a children's ward. If it doesn't say, you can email or phone your specialist nurse and ask. If you are going to a children's ward, you can expect to see other young people around and staff that are trained to work with young people. If you are going to an adult ward, you will be with adult patients and staff that are used to working with adults. Adult wards separate male and female patients, but on children's wards boys and girls are together. Each hospital moves young people to adult care at a different age – it's not about how mature you are.



In some hospitals, they will have talked to you about this and helped you prepare for the move from children's to adult services – it's called transitioning. You will find the BHF 'Picture Your Journey' pack helpful too – see how to order it on the red page inside the front cover of this book.



"There are things I like and things I don't like about children's and adult wards. On children's wards you have to listen to a lot of babies crying, but on adult wards the grown-ups do a fair bit of moaning!"

Joe, age 18

"Being on an adult ward can actually be quite nice for young people. You find that older patients are very kind to younger patients. We get a lot of friendships across the ages."

Lynda, Specialist Nurse

Nil by mouth

The letter will have instructions about when you have to stop eating and drinking before the operation. This is really important. If they say nothing except water – or even nothing including water – you have to stick to it. That means no toothpaste, no chewing gum, no smoking, nothing. They might have to cancel your operation if you haven't followed the instructions exactly.

But I'm starving!

Food and drink can stay in your stomach for quite a while. If you have anything in your stomach while you are having your operation, it could make you throw up. Throwing up while you are asleep under general anaesthetic is not safe.

→ “Not eating and drinking is quite annoying, especially if your operation is delayed by a few hours – you get really thirsty. But it's okay – you can survive it!”

Shannon, age 19

Bring someone with you

You can bring someone over 18 with you on the day you come in, but make sure they are a calm and supportive person.

You might need to do some of the tests you did in pre-op again – the nurse will tell you which ones.



→ In some hospitals they ask you to come in the day before your operation, in others you get there on the morning of the actual operation. Have a look in the 'Straight from the heart' booklet to see what you need to pack. Go to the red page inside the cover of this book to see how to order.

Medication

The letter will also tell you if you should keep taking the medications you normally take or not. Some people worry about whether they should come off Warfarin and similar drugs, so if you are unsure of anything at all, email or phone your specialist nurse.

Girls that take the combined oral contraceptive (the pill) normally need to stop taking it 4 weeks before the operation, but hospitals quite often forget to mention this. If you are on the pill, ask your specialist nurse about it. If you do stop taking the pill, remember that it is really important not to get pregnant before the operation – if you are having sex, make sure you use a condom.



→ “Usually you will need to stop Warfarin around 5 days before surgery, because it stays in your system for a long time. If your risk of having a blood clot is high, you might have to go into hospital a few days before your surgery for a drip that will give you a similar drug that doesn't stay in your body for as long.”
Chris, Senior Cardiac Nurse

How long will I be in hospital?

The amount of time you will be in hospital is usually between 7 and 10 days. You can ask your specialist nurse how long they think you will be in for.

Wrist band

As soon as you arrive, one of the nurses will give you a wrist band with your details on. That's so everyone knows who you are – even when you're asleep. People with allergies have red wrist bands to make sure no-one gives them anything they are allergic to.

Getting changed

You'll probably be told to get changed into a hospital gown and your own dressing gown and then wait on the ward. You can watch films, read or just relax. You might also need to wear special compression socks to reduce the risk of blood clots in your legs.



→ “Remember, the only reason they're asking you to put something on or whatever is because they're trying to help you.”
Alex, age 16

Meeting your anaesthetist and surgeon

On the day of your operation, an **anaesthetist** and a **surgeon** will come to see you. They will talk you through what is going to happen and explain the risks of the operation. They will also answer any questions you have. If you are worried about anything it is important to tell them, they should be able to make you feel better.



“I understand there are risks, but there’s no point thinking about that. You just have to accept that they know what they’re doing and trust them.”
Joe, age 19

Your anaesthetist

At some point the anaesthetist will come to talk to you. The anaesthetist is the doctor who puts you to sleep for the operation and then makes sure you stay asleep until the operation is over.

The anaesthetist will want to know how you are feeling, if you are allergic to anything and to check that you understand what will happen in the operation. They will explain that they can put you to sleep in 2 ways – either by getting you to breathe a special gas through a mask, or by injecting the anaesthetic into a cannula in your hand or arm.

A cannula is a little tube they put into a vein in your hand or arm so that they can put the anaesthetic in. It shouldn't hurt much. If you are worried about any of this tell the anaesthetist – they should be able to help you feel better. If you are very anxious before your surgery, ask for a sedative to help you relax. A sedative is medication that can keep you calm.

Your surgeon

When you have your operation, a team of surgeons will work on your heart. One of them will come and meet you before the operation. You can ask them any questions you have.



"I am confident I will be okay. I know they need to do the operation to make me stay well."
Hayleigh, age 15

Consent

The surgeon will ask you to sign a consent form. The form is to say that you understand what is going to happen and that you agree to the surgery. If you are under 16, the adult with you will also need to sign to say they give their permission for the operation.

The person who signs for you has to have something called 'parental responsibility'. This means that they have legal responsibility to make decisions on your behalf. Your biological mum or adoptive parents have this. Your dad has this if he was married to your mum when you were born or if his name is on your birth certificate. If you don't live with either of your parents, it's best to talk to your specialist nurse before you go into hospital.



The 'Straight from the Heart' booklet has some great tips on what to ask surgeons and on giving consent. Go to the red page inside the front cover of this book to find out more.

Risks

The other thing the surgeon will talk about is risks. Heart operations usually go very well, but the surgeons have to tell you what problems could come up and how likely they are. If you want to have a better understanding of what the surgeon is saying, feel free to ask them what they mean.

Putting it out there

When it comes to surgery, there are a lot of feelings flying around. Parents, and sometimes doctors, might try and protect you by avoiding anything negative. But the truth is, if you are worried about something, talking about it and getting your questions answered will help you feel stronger.

If you don't feel you can talk to the adults in your life, ask the doctor, surgeon or specialist nurse if you can have a few minutes alone with them. Or, if you prefer, write down what you want to ask and pass it to them. You're allowed to know what is going on – it's your body after all.



"I haven't wanted to worry my mum. Sometimes I will ring my nurse about a symptom I am having or whatever. You have to take responsibility for talking about whatever's on your mind – it's your health."
Joe, age 19

Into theatre



When the surgical team is ready, you'll be taken to the anaesthetic room. The adult with you can go as well. The anaesthetist will be there to give you either the gas or the injection through your cannula to make you go to sleep. You will fall into a deep **sleep** almost immediately. The anaesthetist will stay with you the whole time you are in surgery.

Once you're asleep, you will be taken into theatre and the adult who came with you will wait outside. Then the surgical team will start the operation. The first thing they do is put a catheter into your bladder to take away your urine during the operation and make sure there is the right amount of water in your body all the time.

A catheter is a tiny tube that goes into the hole you wee out of, right up into your bladder. You won't feel anything because you'll be asleep. It will still be in when you wake up as you won't be able to walk to the toilet for a while. It also helps to measure how much urine your body is making, which is important straight after surgery.

Don't worry about being seen without your underwear on – anaesthetists and ODPs put catheters into patients all the time and are very used to it. They will also cover you with a sheet during the operation.

It can take anything between 4 and 8 hours to do a heart operation. When it is finished, you will be taken to the intensive care unit (ICU). That's where you will wake up.



*"As nurses, we put in and take out catheters all the time and we try to maintain your privacy as much as possible with only a doctor or nurse and you in the room."
Suzanne, Ward Charge Nurse*

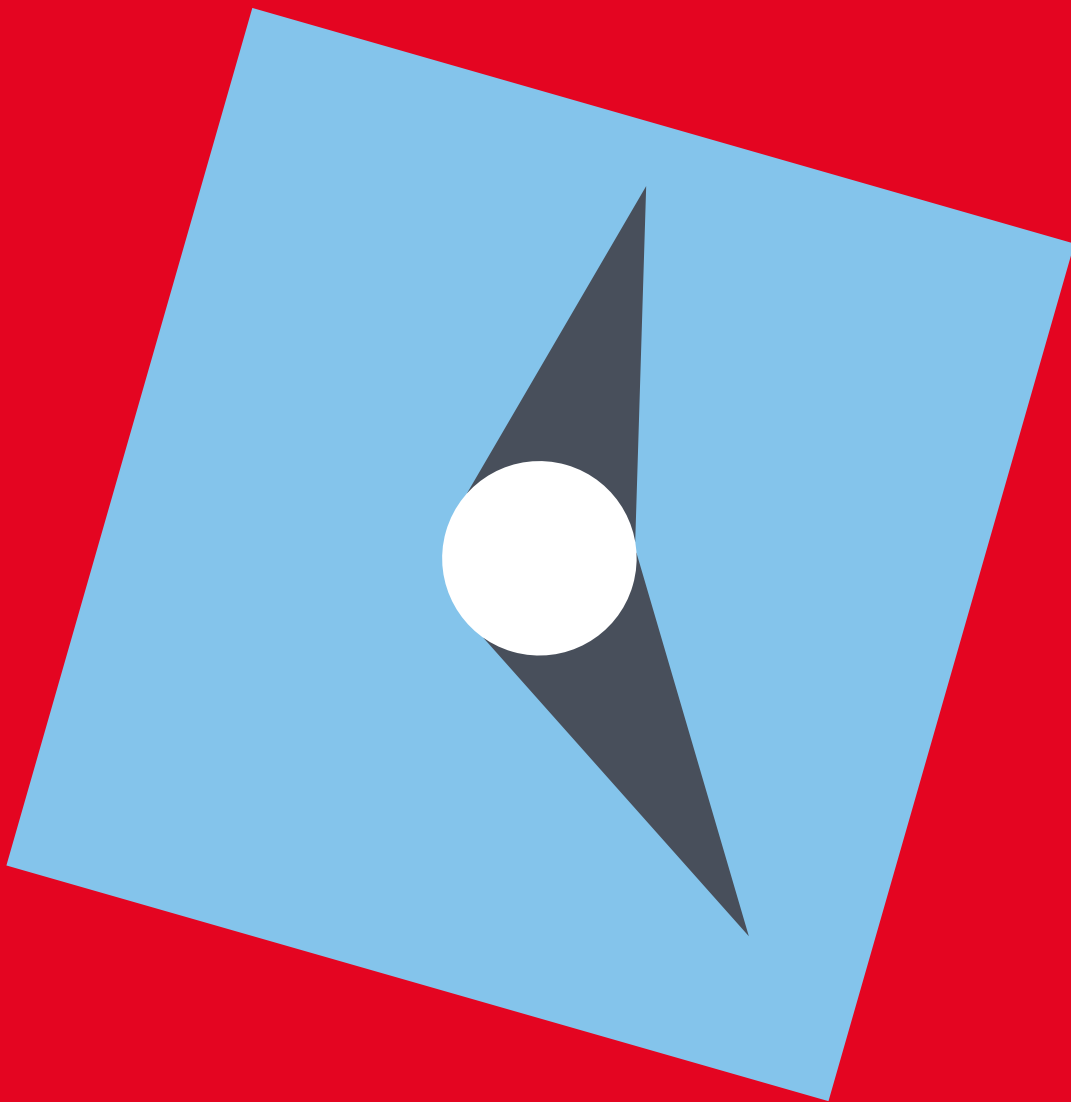
"I don't like to think about being put under. Take something to concentrate on – a book or something like that. Then you won't think about what's happening and it's over before you know it."

Joe, age 19

After the operation, you go through a couple of stages at hospital and eventually go home. This section covers all that and gives you tips for a good recovery.

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After surgery: on the units and wards

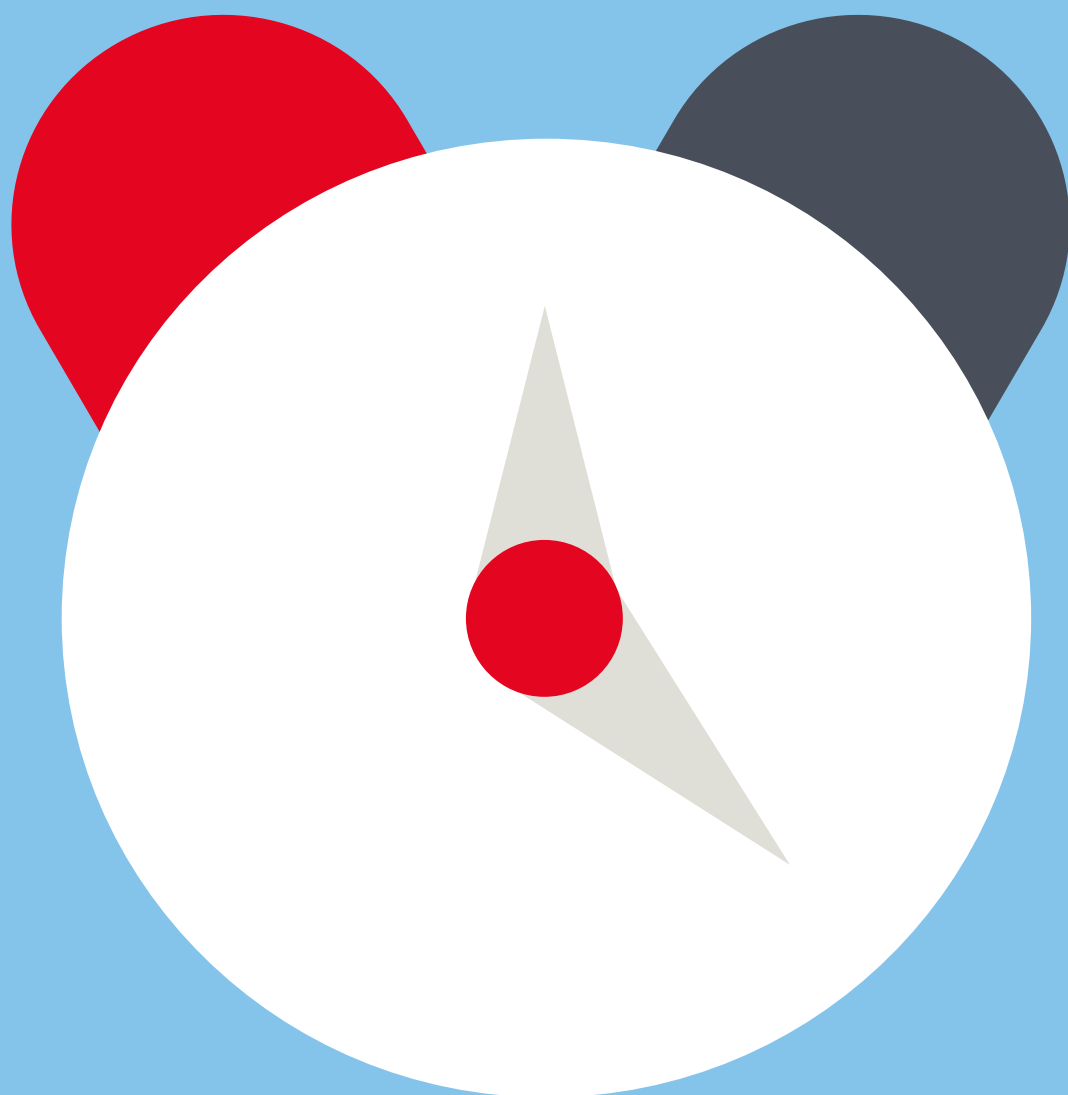


You'll still be quite drowsy after your operation – which is good because sleep helps you to **recover**. You'll start off in ICU, and then when you're well enough you'll get moved to HDU. By the time you move back to the ward, you'll be feeling quite a bit better.



"I just wanted to get out of bed, but you have to take it easy. You're quite weak and dizzy to start off."

Kaytie, age 16



ICU stands for **Intensive Care Unit**. Sometimes it's called ITU or Intensive Therapy Unit. Everyone wakes up in ICU, but the funny thing is, not many people remember it. You will be on a lot of different drugs and they can make you feel sleepy and spaced-out. On ICU there is usually 1 nurse for every patient.

How you doing?

After the operation, everyone from home will want to know how you are. It is important that the nurses can focus on their job and not have to answer the phone too many times, so it's best if you've asked one person to phone and ask how you're doing. They can tell everyone else.

You'll be in ICU for at least a day, maybe more. You should be allowed visitors, but perhaps not too many to start with. As you start to recover, staff will reduce the amount of drugs you are on. When you don't need a ventilator anymore, you'll be moved to the High Dependency Unit (HDU).



"I remember bits of ICU. Nothing bothers you. You just wake up and fall asleep. You can't feel the neckline or tubes. It sounds weird but they're actually no bother. You're on a lot of painkillers at that stage."

Joe, age 18

What about number 2?

Because you didn't eat or drink before your operation, you're not likely to need a poo in ICU or HDU. The drugs you are on slow your digestion down too. You should be able to use a bedpan or walk to the toilet by the time you need to go.

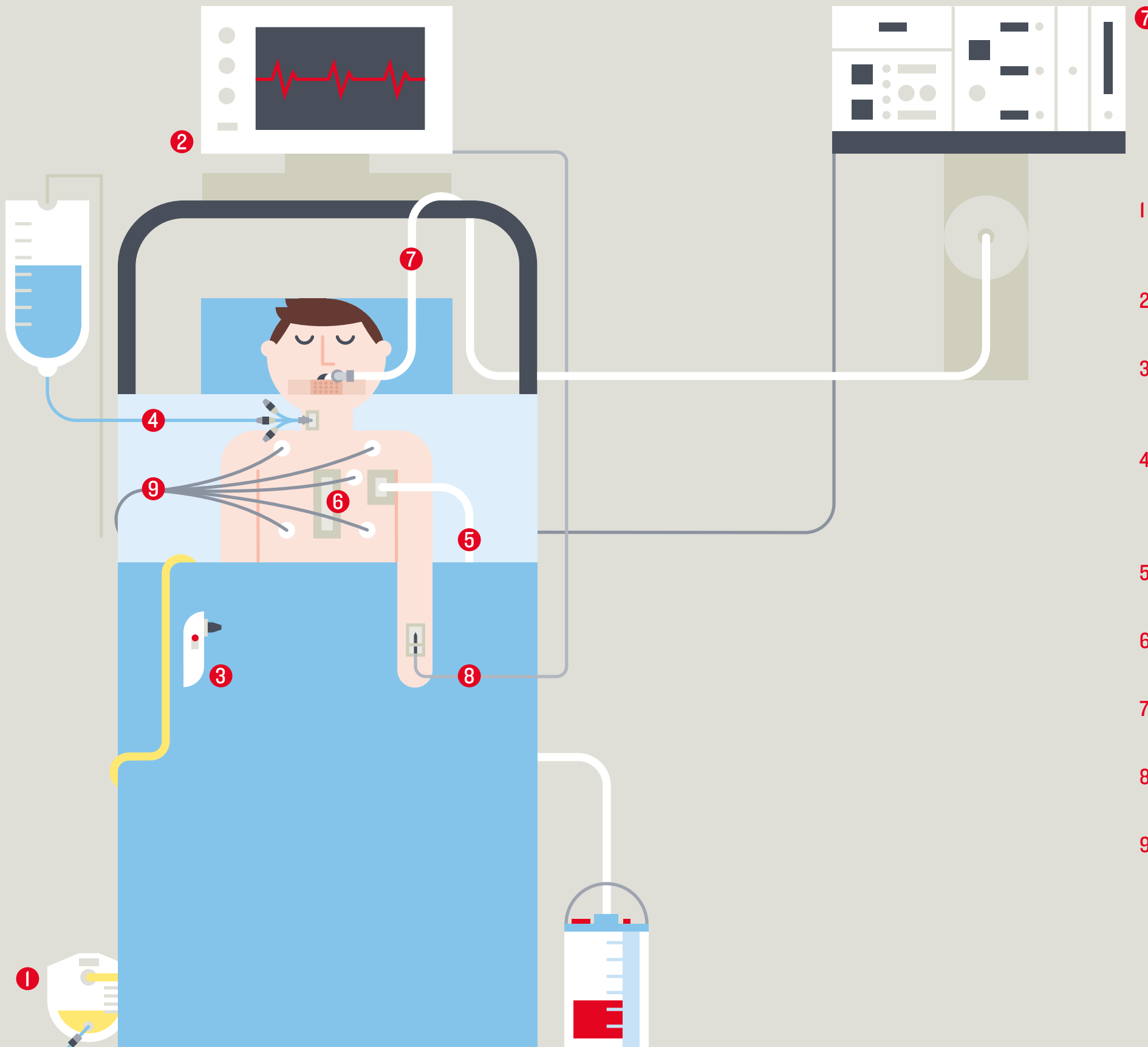
If you have your period

If you are having your period when you go in for the operation, tell your nurse. Use sanitary towels rather than tampons so that the nurses can make sure you are fresh and clean while you are asleep. You can use tampons once you are walking around again, but make sure you bring your own supplies.



"Being on so much morphine means nothing really bothers you, but painkillers can make you feel a bit sick. Tell a nurse if you feel sick, they can give you stuff for that."

Shannon, age 19



- 1 This is the **catheter**. It takes urine away so you don't have to get up and go to the toilet.
- 2 This is a **heart monitor**. It helps staff see your heart beat and rhythm.
- 3 This is a **temperature probe**. It's to make sure that you're not too hot or too cold.
- 4 This is a **neckline**. Your drugs will go through here into your body. Staff can take measurements and blood samples from here.
- 5 This is a **chest drain**. It gets rid of fluid and air in your chest.
- 6 This **dressing** covers the place where you had the operation.
- 7 This is a **ventilator**. It makes it easier to breathe.
- 8 This is an **arterial line**. It shows your blood pressure.
- 9 These are **ECG leads**. They carry information about your heart to the monitor.

There will be a nurse with you to make sure you are okay. They will stay with you all the time in ICU, even when you are asleep.

HDU



HDU stands for **High Dependency Unit** – it's where patients go after ICU and before they are ready to go onto a normal ward. There's usually 1 nurse for every 2 patients. You'll be there for about 1 or 2 days and you can usually have a few visitors, but probably not small children.

The nurses will encourage you to be more active. They'll get you to sit in a chair and walk around a bit because that actually helps you get better quicker. A physiotherapist will come and explain exactly what you need to do.

You will have your catheter taken out while you're in HDU. It's a bit uncomfortable, but it is over very quickly.

If you haven't had them out before, you will probably have your neckline and chest drain out in HDU too. The chest drain can hurt a bit when they take it out, especially when they tie the stitch, but don't worry, the nurses will give you pain killers first.

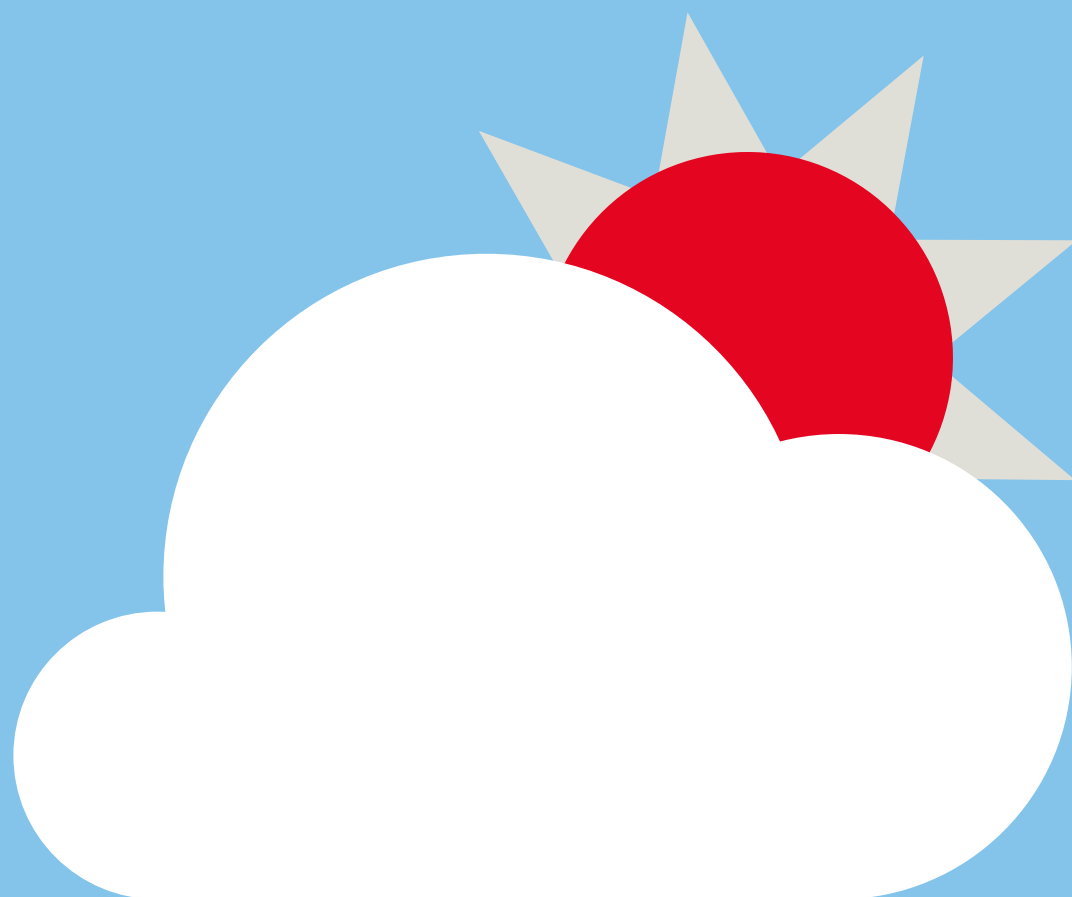
The nurses will tell you how to breathe while the chest drain is taken out and it's important you do what they tell you, so make sure you focus on what they say.



"Having the chest drain out isn't brilliant, but think of it as the last hurdle. By the time you've had that taken out, the operation is well and truly over. You're practically on your way home."

Alex, age 16

The ward



By the time you get back on a **ward**, you should be feeling quite a bit better. You'll probably have had your neckline or chest drain taken out already, and you'll start eating normally again. You'll be on the ward until you're ready to go home – possibly about 3 days.

You can have friends and family to see you in visiting hours and you might even feel up to doing a bit of work or studying. It is important that you're active and don't stay in bed all day. Lots of sitting upright in a chair and walking around will really help your recovery and reduce your risk of complications.

If you have any pain, tell a nurse straight away. There's no need to be in pain because there are lots of different painkillers. A nurse should be able to help you deal with it pretty quickly.

Some people feel nervous about getting out of bed to start with, or worried about doing their physio exercises. Don't worry on your own. Ask to speak to your physio or specialist nurse and they will help you think everything through and feel more confident.

Paediatrics or adult ward

Paediatrics is the name for a children's ward. If you are on a children's ward, you'll find there are young people mixed in together – boys and girls. Adult wards are separated into male and female, but you'll find a real range of ages from 16 year olds to elderly people.



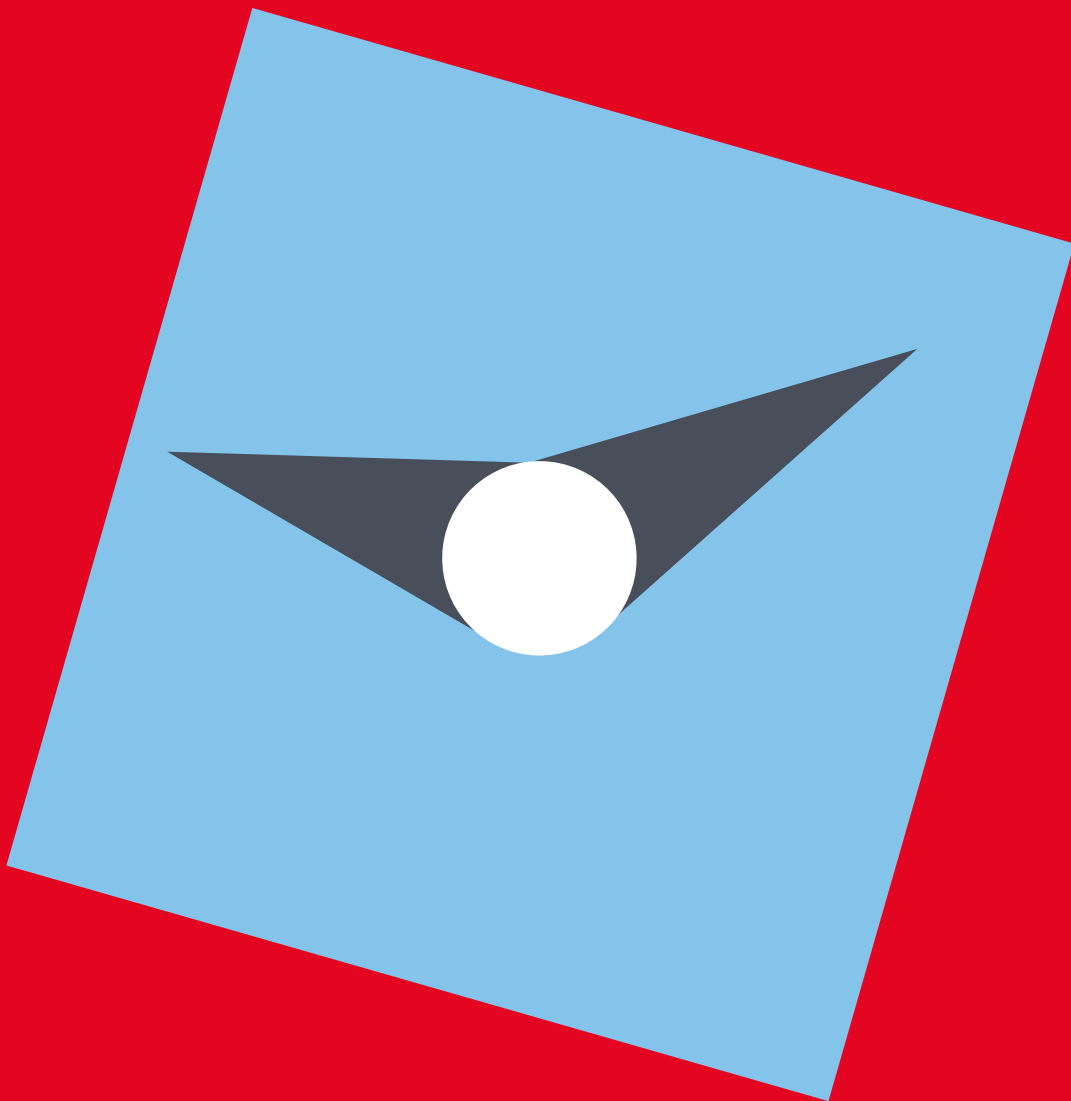
Find out more about adult wards in 'Picture Your Journey' – the transition pack for teenagers with a heart condition.



"I remember that as soon as my parents went out of the room, I felt very lonely. But you've just got to chat to someone – a nurse or whoever is in the room. It makes you feel better."

Alex, age 16

After surgery: going home



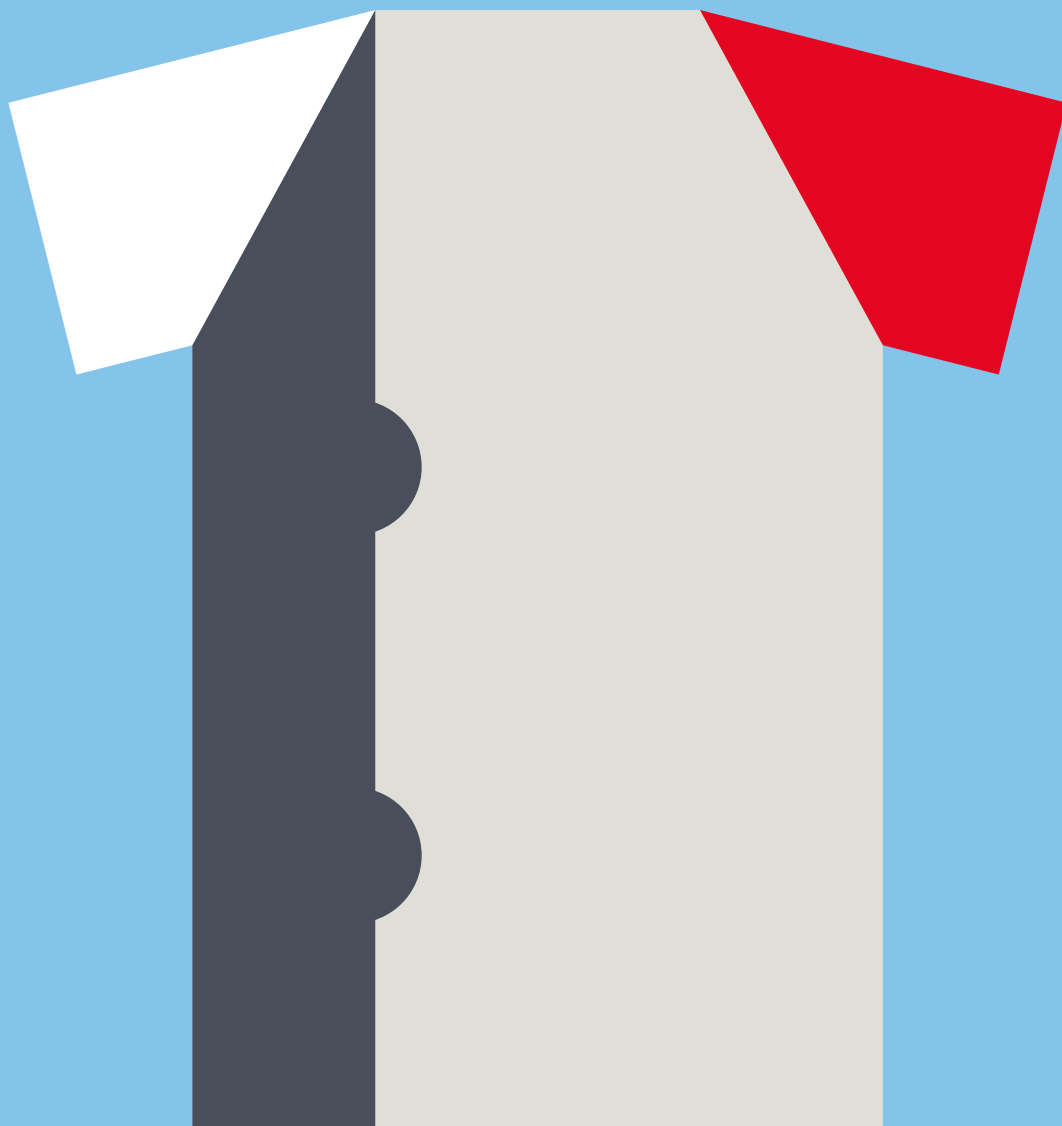
Your surgical team will come and visit you most days on the ward to see how you're doing and to start planning for you to **leave hospital**. At some point they'll tell you that you are well enough to go home. Most people are glad to hear that they're going home, though you might feel a bit nervous too.



"Carry a pillow or rolled-up towel around in case you need to sneeze or cough. It really helps if you hug it. Also, you can put it under your seatbelt on the ride home."

Joe, age 18

Later!



Your nurses will help you organise your medication before you go **home**. They can also tell you if you'll need any more operations. Have a chat about how active you can expect to be too.

The nurses will make sure you have all your medications before you go and that you know how to look after your wound. Girls that came off the pill before the operation should ask when they can start taking it again – you usually can't re-start it until at least two weeks after the operation, so remember you are not protected against pregnancy. The nurses will also tell you who to contact if you have any problems or worries. If there is anything else you are not sure about, ask to speak to your specialist nurse.

Future operations

It's also worth asking your doctors if they think you will need another operation in the future. Some heart operations will need doing again when you are older, and people don't always remember to talk to patients about this.

Getting things moving

When you're home, you need to be active – it will help you recover and get stronger. Try and walk a little further every day. You need to eat well to help your body repair itself too. Fast food and sweets don't have the nutrients your body needs, so try to mainly eat healthy meals that include a lot of fruit and veg.

Your friends can go out with you or visit you at home if you feel well enough, but they shouldn't visit if they've had any illnesses themselves lately.

Your specialist nurse will tell you how long you should wait before you can go back to school or work. Most people go back after about 6 to 8 weeks.

You can make a car or train journey as soon as you feel well, although avoid carrying any heavy bags and don't travel during rush hour. You may be on medicine after your operation which makes you need a wee more often, so make sure you think about this when you plan journeys. You should also take regular breaks to stretch your legs, and remember to drink plenty of water. If you want to fly, ask your specialist nurse or cardiologist when this would be safe for you. You will need to wait about 6 weeks for the bone in your chest to heal before you can drive – double check with your specialist nurse though.

One of the last things they'll tell you is when your next outpatients appointment is. It should be about 6 to 8 weeks after the operation. You'll be given a time to come back to the hospital so they can see how you are doing and if they need to change any of the medications you're on.



"I was just so happy. Relieved because I could go home and get back to normality."
Joe, age 18

Being good to yourself

Your nurses will give you lots of advice about your recovery. Remember:

- Don't lift, twist or push anything heavy for about 6-8 weeks.
- Don't take any long car or train journeys until your specialist nurse says you can.
- Follow your nurse's instructions on how to look after your wound. They will show you how to wash it and what to look out for.
- Don't do any physical sports until you have fully recovered.
- Take your medications at the right times, in the right amounts.
- Never smoke.
- Avoid energy drinks and drinks with caffeine in like coffee and cola.
- Get plenty of rest and sleep.
- Go to your follow-up appointments.
- Stay active and take regular walks.
- Eat healthily and drink plenty of water.

Looking after your wound

Always follow your nurse's instructions on how to look after your wound. They will probably tell you no baths for about 4 weeks – showers only – and to use mild soap – no lotions or potions. You can pat the area dry, but don't rub. Keep an eye out for signs of infection like increased redness, swelling, tenderness, pain, heat or discharge. If you have any worries, contact your specialist nurse straight away.

Don't be a stranger...

It's really important that you go to all your follow-up appointments. You'll probably have a few after surgery and then one every year or so for the rest of your life. Sometimes people feel really well and they think they don't need to go, but you must. At follow-up appointments you have tests to make sure your heart is still working properly – sometimes there can be a problem even if you haven't noticed anything – so it's always important to go.

Remember, if you move house or change your phone number, you need to tell your hospital.



'Picture Your Journey' is a great resource for young people with a heart condition. It covers everything from what kind of contraception you can use to if it's safe to have piercings or tattoos. Find out how to order your pack on the red page inside the front of this book.

Ummm... what if?

You won't feel much like partying for a while, but if you think you are going to be in a very smoky environment, or may want to drink alcohol, talk it through with your specialist nurse. Alcohol and recreational drugs may interact with your medications and harm your heart. Your specialist nurse should be able to honestly tell you if there is any risk.

Smoking is never a good idea, especially for someone with a heart condition because smoking raises your heart rate, reduces the oxygen in your blood and increases your chances of a heart attack. If you're struggling to quit smoking, talk it through with your specialist nurse.

If you are sexually active, it's safe to go back to having sex as soon as you feel like it – having an orgasm will not damage your heart. Remember to make sure you use contraception, and don't rush into it if you don't feel ready. If you're anxious about anything, talk to your partner about it. They might have worries they want to share with you too.



Have a look at 'My Life' – it's a booklet in the 'Picture Your Journey' transition pack. There's loads of information on everything from travelling and career choices to sex, contraception and pregnancy. See the red page inside the front of this book for how to order.

Where's your head at?



A lot of people feel quite up and down after an operation – sometimes really high and pleased the operation is over, at other times a bit low and teary. Give yourself a break. It's okay to have **mixed emotions** – having a heart operation is a big deal.

You're going to feel really tired to start with – so don't do too much. Walking will help your recovery, so try to walk a little more every day, but for most of the time, line up the box-sets and get plenty of sleep.

After about 6 or 8 weeks, you're hopefully going start to feel more like your old self again. You should be back at school or work, and you can start doing sports and other normal activities. But remember, it can take a long time to completely get over a heart operation, so be patient with yourself.

A lot of people struggle with their feelings after a heart operation. If you're feeling low or very anxious, you should speak to someone about it. Tell your nurse specialist – there should be a therapist at the hospital who knows how to help you through this. Your GP should be able to help you too.

Page 68 has a list of helpful contacts in case you need someone to talk to.

Putting a brave face on it

If you're finding things tough, tell someone – they can't help you if they don't know.

Kicking low mood into touch

Try to:

- Go outside for a walk
- Chat with family and friends – invite them over or get in touch
- Do something you're good at – playing a musical instrument, art, languages – whatever's your thing.

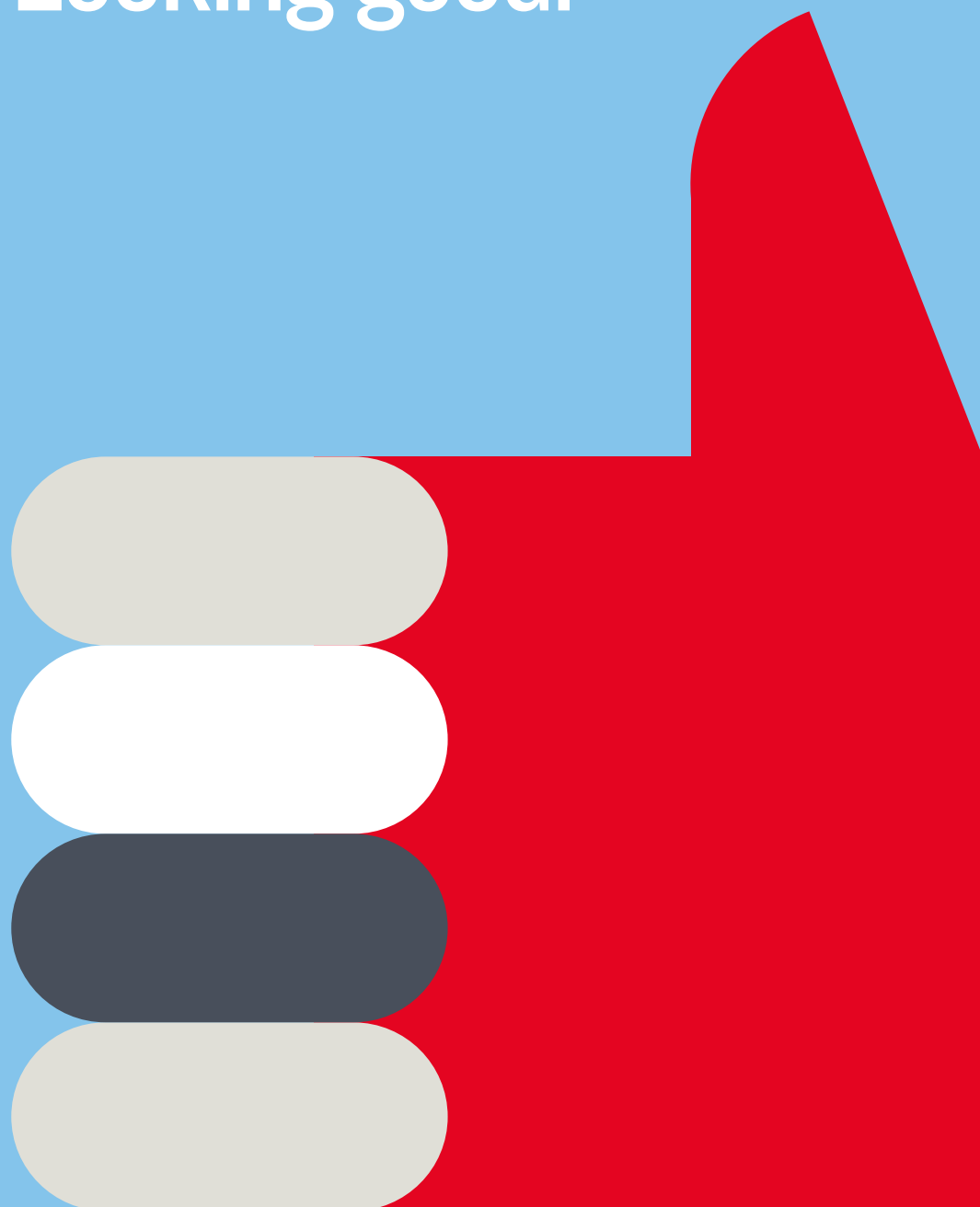
Remember, you won't always feel like this. Recovery can be tough, but you'll get through it.



"The first few weeks are quite difficult. You can't really stand up straight and you get achy. Staying in all the time makes me crazy, so I got someone to push me around the shops in a wheelchair."

Joe, age 18

Looking good!



Everyone who has had a heart operation will end up with a **scar** of some kind. Scars can take over a year to settle down. They start off very red and visible, but they fade over time.

Some people love their scars – it tells the world what they've been through and how strong they are. But other people feel self-conscious and don't want others to see. There's no right or wrong way to feel, so if you want to cover up your scar, that's up to you.

Counselling can be really helpful if you're feeling self-conscious and want to learn to feel better about your scar and feel more comfortable in your own skin.



*"A scar is a scar. It'll get more faint, but it'll always be part of you. There's no point in being self-conscious – you are who you are."
Shannon, age 16*

Camouflage creams

Camouflage creams are a good way to cover scars – for boys and girls. Just make sure your doctor or nurse has said that your scar has healed enough first. Your GP can prescribe special camouflage cream, but you'll probably need to ask them to.

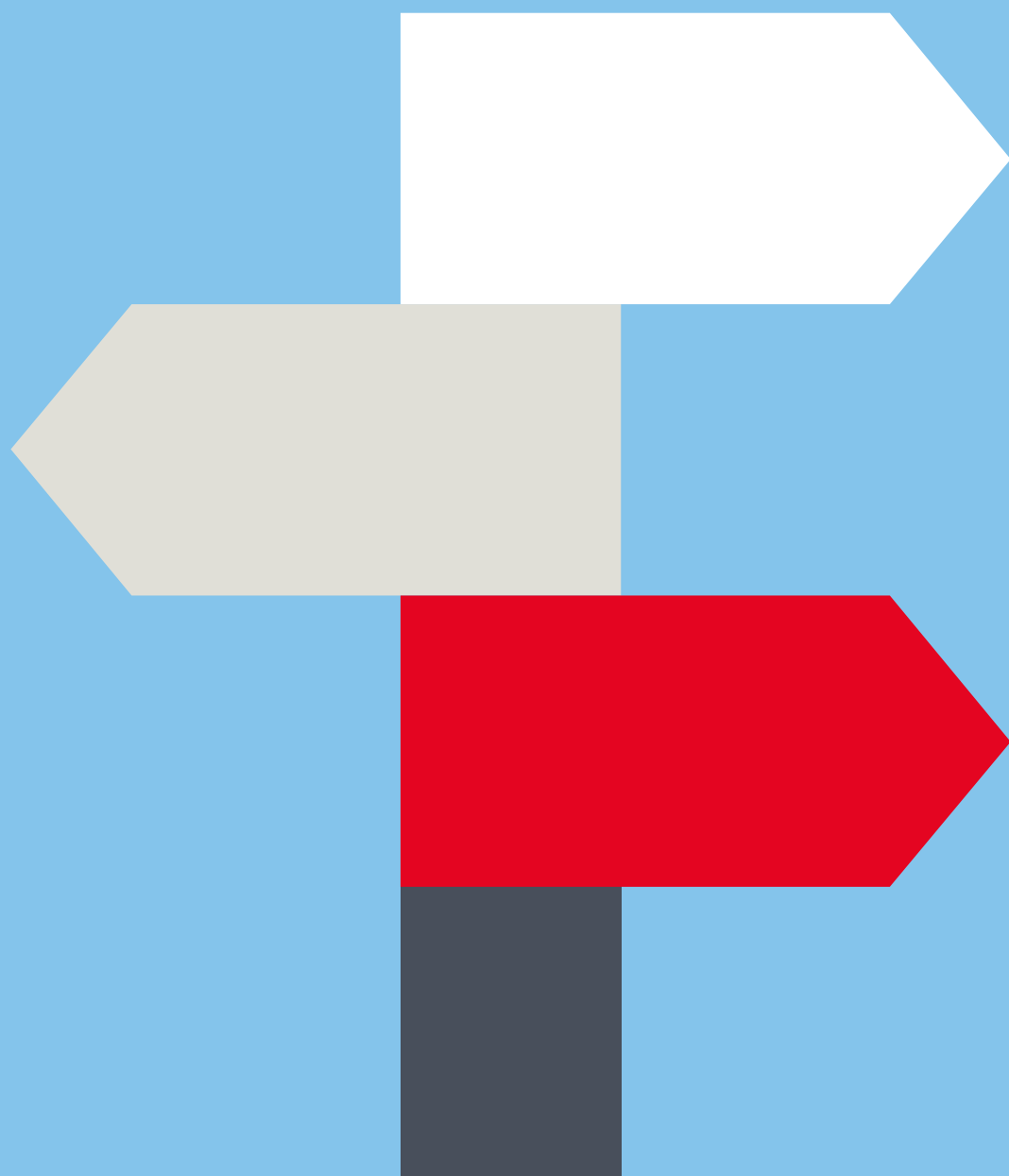
Treatments

There are some oils, creams and dressings that might help your scar fade after your wound has healed – but don't believe everything you see written on a packet. Ask your specialist nurse or cardiologist to help you decide on what is right for you.

Keloid scars

Keloid scars are scars that are raised up a bit – they're not so easy to cover. There are treatments for this, including silicone injections, so if this is an issue for you, talk to your doctor or specialist nurse.

What now?



When it's all over and you've made a full recovery from your surgery, it's time to press play on your life again. You might find it helpful to get to know some other young people who have heart conditions. If you haven't already joined a group, there are a some **great organisations** that can help you.

Meet@teenheart

Meet@teenheart is the BHF programme for young people with heart conditions. If you're aged 13-19 you can sign up and receive newsletters, invitations to events and access an online community of people your age who have had similar experiences.

Go to bhf.org.uk/yheart

The Somerville Foundation

The Somerville Foundation supports young people and adults that were born with a heart condition – they give emotional and practical support as well as having a get-together for 16-24 year olds every year.

Find out more at thesf.org.uk



Order 'Picture your journey' – the free pack for young people with heart conditions, packed full of young people's stories and opinions on living with a heart condition. See the red page inside the front cover of this book for details.

Over to you...

Just like anyone who cares about their heart, make sure you:

- Have a healthy balanced diet – eat at least 5 portions of fruit and veg a day.
- Be active – walk instead of catching the bus, take the stairs instead of the lift.
- Try and get 8 hours of sleep every night.
- Drink plenty of water.
- Don't smoke.
- Have fun!

If you feel you would like some extra support, here are some places to try:

SupportLine

01708 765200

supportline.org.uk

Emotional support and information on other helplines for young people in the UK. Can signpost to phone and face-to-face counselling support groups.

Childline

0800 1111

childline.org.uk

Call, email or live chat emotional support for children and young people up to the age of 19.

Samaritans

0845 790 9090

(Republic of Ireland – 1850 60 90 90)

samaritans.org

24 hour phone service offering emotional support.

Worth Talking About

0300 123 2930

nhs.uk/worhtalkingabout

Helpline for young people aged 12-18 on sexuality and sexual health. Issues dealt with include contraception, pregnancy, family planning clinics, sexually transmitted diseases, peer pressure and relationships.

Children's Heart Federation (CHF)

chfed.org.uk/brighthearts

The CHF is dedicated to helping children with congenital heart conditions and their families in the UK.

Huge thanks to all the young people and healthcare professionals who helped to develop this book, and an extra special thank you to all at the Royal Brompton Hospital and Great Ormond Street Hospital.



**British Heart
Foundation**

Coronary heart disease is the UK's single biggest killer.

For over 50 years we've pioneered research that's transformed the lives of people living with heart and circulatory conditions. Our work has been central to the discoveries of vital treatments that are changing the fight against heart disease.

But so many people still need our help. From babies born with life-threatening heart problems to the many mums, dads and grandparents who survive a heart attack and endure the daily battles of heart failure. Join our fight for every heartbeat in the UK. Every pound raised, minute of your time and donation to our shops will help make a difference to people's lives.

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk