



Straight from the heart

Look inside and find out what to expect

What will happen in hospital?

What questions should I ask?

What should I bring with me?

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

STRAIGHT FROM THE HEART

Meet the inspiring young people who are here to offer their advice and support in helping you prepare for your stay in hospital.



Anna, aged 14



Dominic, aged 16



Yheart Team



Shannon, aged 19



Alex, aged 15

WHAT'S THIS BOOK FOR?

It's to help if you're going into hospital for any kind of heart procedure, including open heart surgery. It's full of answers to the questions that are probably going around in your head right now and may be worrying you.

What exactly will happen? Who will I meet? What should I bring with me? What will happen afterwards?



Sinead, aged 20

The answers to these questions and many more come straight from other young people who have been through the same kind of thing before. So there are no big medical words, just lots of straight talking friendly advice.

We start with things to think about before you go into hospital. Then there are some tips on what happens when you get there. Finally there are some ideas on coping with life afterwards and getting back to normal.

Remember, you don't have to go through this alone. There are lots of people ready and willing to help you.

CONTENTS

01

GET PREPARED

4

Whatever you're going into hospital for, it's far easier once you know what to expect.

This section contains tips on what to bring with you, questions to ask and advice on preparing yourself emotionally.

4

02

GOING IN

34

When you go into hospital, your main thought is often the procedure itself. But what's life really like on the ward?

CONTENTS

03

GOING HOME

70

A lot of people can't wait to get out of hospital and go home, but sometimes it can be difficult. Section three is packed with tips to help you get through and help your body to recover.

5

04

GLOSSARY

90

A really useful list of all the words, phrases and language that you'll hear throughout your hospital trip.

SECTION

01

GET PREPARED

Whatever you're going into hospital for, it's far easier once you know what to expect.

This section contains tips on what to bring with you, questions to ask and general advice on preparing yourself emotionally, which is equally as important.

FACT FINDING

You might already feel you know enough about your heart before you go into hospital. But you may want to find out more. If you do it's best to stick to good information from reliable sources, such as your hospital or these website that we recommend.

bhf.org.uk

British Heart Foundation

We've written a series of other leaflets for young people. You can also get a BHF card from your cardiac centre – a straight-forward way to show people which condition you have.

yheart.net

meet@teenheart

This is the BHF's programme for young people with heart conditions. It's our way of helping teenagers get together to support each other, have fun, and feel more confident. Sign up on the website to register for local events and to find out more about living with a heart condition.

Calling all young heart patients aged 13–19

BHFs meet@teenheart programme is here to help you. Whether you come along to our events, read the newsletters we send you or simply engage with us through social media meet@teenheart will help you to build your confidence, meet new people and gain new skills.

We also offer lots of printed and online information and support so you can find out more about your condition and take control of your own health. What are you waiting for? Come and join us by signing up now! **yheart.net/signup**

To order any of our resources visit **bhf.org.uk/publications**

TOP TIP

It can be tempting to look for information on websites and online forums. Remember that amongst all the useful stuff, you'll also find a lot of scare stories. Even someone with exactly the same condition as you might have a very different experience.

thesf.org.uk

The Somerville Foundation

This organisation's website has a section dedicated purely to 16–24 year olds.

chfed.org.uk

Children's Heart Federation

The teen forum Brighthearts is for 13–21 year olds with heart conditions. The CHF also publishes a range of factsheets.

Info line: 0808 808 5000

More information

Picture your journey

A resource for 13–19 year old heart patients to help them make the journey from child to adult care. This pack is a place to keep all your medical contacts, appointments and health care information together in one place. Three booklets inside offer information and support as you become an adult and start to take responsibility for your own health.

G690

Revealing the facts about your condition series

14 information leaflets in this series for 13–19 year olds provide information and support on different heart conditions.

Titles include: ICD (C9T), Pacemaker (C8T), Arrhythmias (C14T)

The BHF card

An ID card for young people who have an ongoing heart condition to be shown at times when their condition is questioned. The card is only available to order by health care professionals who will fill out the information and give to their patients.

G486

In charge of my future

A booklet packed full of useful information for 13–19 year olds who have a pacemaker or ICD.

G1015

THE GROUNDWORK

Get the most from your pre-op

This is when you'll be invited to the hospital before your procedure for a pre-admission check. A member of the team will explain your procedure to you in detail. Listen carefully, take notes, and ask questions.

You may see an anaesthetist who will explain your options for anaesthetic or sedation – the medicines that will help you sleep and be free from pain during your operation.

You may be asked to sign a consent form. If you're under 16, this will also need to be signed by your parent or carer. This checks you've understood everything and tells the hospital you're ready to go ahead.

Fighting the fear

Being afraid of a procedure is completely normal. It can help to talk about your fears with someone else. This could be a friend, family member or someone at the hospital, such as a psychologist, to develop ways of coping.

Try to stay calm and just remember
– you're in good hands.



NO1

ASK MORE QUESTIONS

TAKE CONTROL

Sometimes the more you know about what's going to happen, the less worried you'll be. Ask as many questions as possible to get the most from your pre-op.

QUESTIONS

LISTEN CAREFULLY AND ASK PLENTY OF QUESTIONS

Everyone will have different questions and certain things will be particularly important to you. It can help to have someone with you, as an extra pair of ears, in case you forget something. You could record the conversation on your mobile phone, but ask your healthcare professional for their permission first.

It's a good idea to write some questions down before you go in. Make sure you get the answers you're after, even if it means asking someone to draw a picture to show what will happen.

HOW LONG
DOES THE
PROCEDURE
LAST?

WHERE
WILL I
WAKE UP?

WHO WILL
I SEE AFTER
SURGERY?

WILL I HAVE
TO STOP
TAKING ANY
MEDICATION
BEFORE MY
PROCEDURE?

WHAT ARE THE
RISKS AND SIDE
EFFECTS INVOLVED?



WILL I NEED TO CHANGE WHAT
I EAT OR MY USUAL ROUTINE IN
THE RUN UP TO MY PROCEDURE?

QUESTIONS

TOP TIP

You can always ask to speak to your doctor alone if you're embarrassed about anything in front of your parents.

WHO WILL
CARRY
OUT MY
OPERATION?



WHAT ARE THE
OPTIONS FOR
ANAESTHETICS?

WHEN CAN
I START
EXERCISING
AGAIN?

HOW LONG
WILL I BE IN
HOSPITAL?

Don't be afraid to ask your doctor or nurse any questions or share any concerns – no question is a stupid question. Make sure you understand everything, including how it will affect you after the procedure.



SHANNON

SETTING THE DATE

Many hospital visits are organised well in advance, so if you already have something planned, you could ask if there is another date free. Remember, it's not just about the day itself but also the time it takes to get better afterwards.

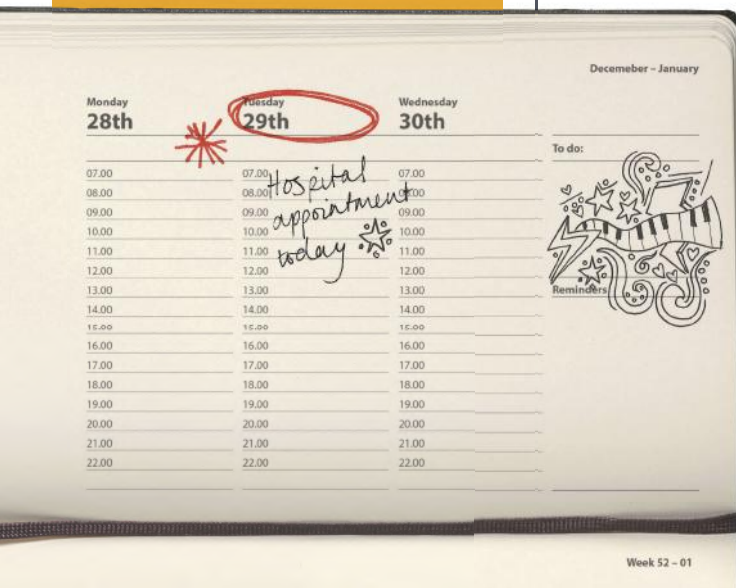
TOP TIP

It's important to let people know the dates and times of any hospital appointments you might have.

Think about:

- whether anything is happening at school/college/university or whether you have any holidays booked
- if there is someone around to care for you

Some procedures might be urgent, so that always has to come first. Sometimes surgeries are cancelled, which can be disappointing. Talk to your healthcare team for advice and support.



GETTING PREPARED

Getting your body ready for your procedure can help with everything that comes afterwards. Here are a few tips:

Eating and drinking

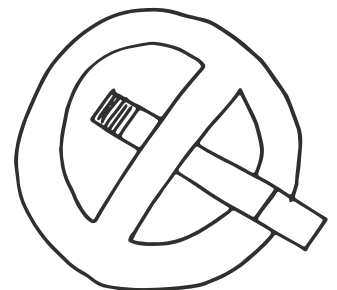
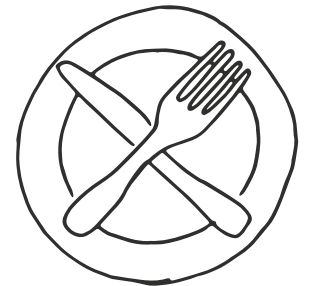
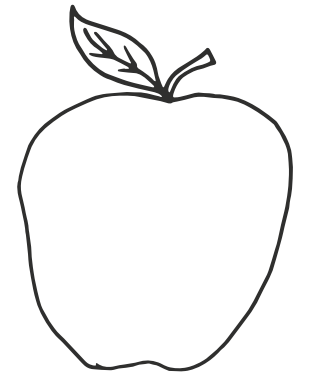
Ask your nurse or doctor if you should make any changes to what you eat and drink in the run up to your procedure. Usually, you won't be able to eat or drink for a number of hours beforehand. This is called nil by mouth. It's important to check this with the nurse or doctor and do what they say.

Nil by mouth

Nil by mouth also includes things like chewing gum – so don't have anything like that before your op as it could lead to a cancellation.

Smoking, alcohol and drugs

Discuss these with your nurse or doctor and don't feel awkward about asking.



MAKE
YOURSELF

HEARD

It's natural to feel nervous before going into hospital. Writing down the things you're worried about – or talking to a close friend or relative – can make you feel better. And if there's something you don't understand, ask someone on your healthcare team.

Try writing down your worries here, however big or small. Have a think about someone who could help and then ask them for a chat.

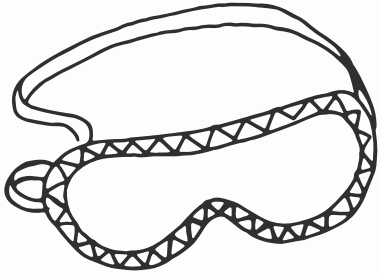
○ Can my family ^{and friends} come and visit me?

○ When will I be able to start playing sport again??

○ How long will the operation take?

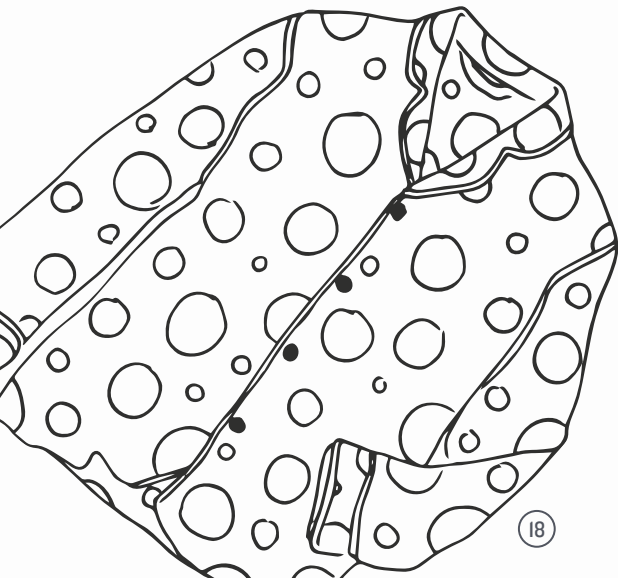
ESSENTIAL SUPPLIES

Check with your hospital about what you can and can't take in with you, as rules vary. Here are some ideas for what to pack:

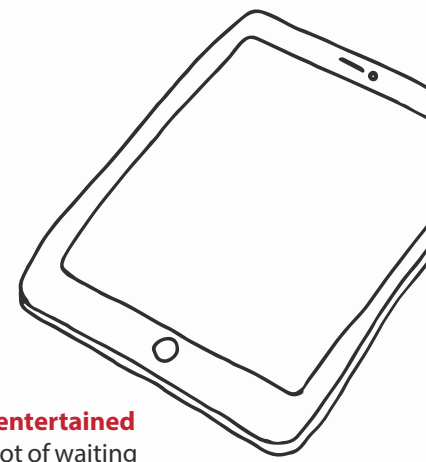


Creature comforts

Pack the things that make life more comfortable, such as slippers, pyjamas and eye masks.

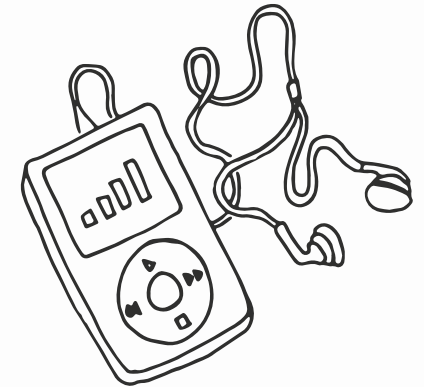


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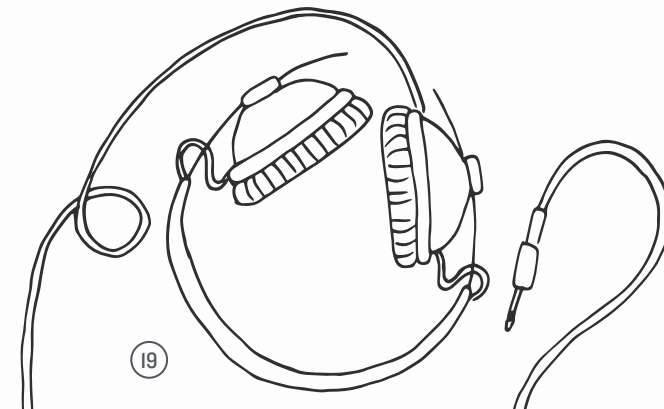
Keep yourself entertained

There can be a lot of waiting around. Make sure you've got some light relief to pass the hours.



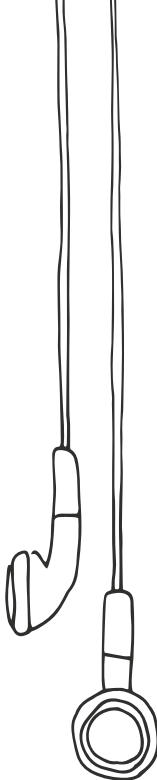
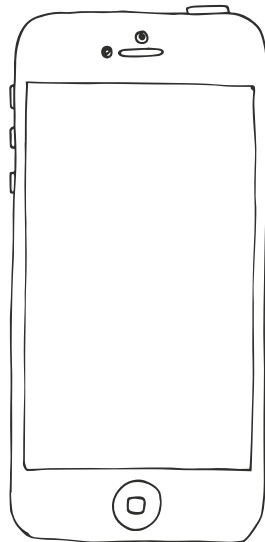
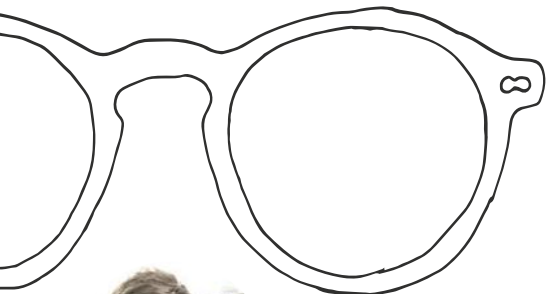
Music to your ears

Music can help calm and relax you, as well as blocking out the hustle and bustle of the hospital.



19

CHECKLIST



 **ALEX**

A great way to keep yourself entertained is by reading, writing or talking. Most nurses are happy to have a chat while they work. Reading a newspaper is also a great way to keep busy, they cost under £1, keep you educated and have puzzles that your parents can help with.



 **CHRIS, SENIOR CARDIAC NURSE**

Ask your healthcare team which would be the best kind of pyjamas, in case you need to have tubes and wires. They'll also be able to tell you the best types of clothing to bring.



 **SINEAD**

Pack your favourite home comforts such as music, films, a special blanket or pillow. It will make the stay more fun and less scary.



CHECKLIST

TOP TIP

Make sure you pack roll-on deodorant – you won't want to be spraying aerosols around sore wounds.

ESSENTIALS

- ☐ Dry shampoo
- ☐ Shampoo & conditioner
- ☐ Shower gel
- ☐ Hairbrush
- ☐ Deodorant
- ☐ Toothbrush & toothpaste
- ☐ Medication
- ☐ Tampons/towels
- ☐ Contact lenses & solution
- ☐ Glasses
- ☐ Clothes
- ☐ Underwear
- ☐ Slippers & shoes
- ☐ Money / keys

ESSENTIALS

- ☐ Notebook / diary & pen
- ☐ Books / audio books
- ☐ Magazines & Puzzle books
- ☐ Sentimental stuff: photos etc

TECH STUFF

- ☐ Laptop & charger
- ☐ Mobile phone & charger
- ☐ Portable games console
- ☐ Headphones
- ☐ MP3 player & charger
- ☐ DVDs & CDs
- ☐ Snacks / food

Occasionally things can go missing, so it's best to leave jewellery at home. Remove any nail polish and piercings.

You're healthcare team will do everything they can to look after you, but it's your body, no one else's. Below are some of the most important things to know about your rights in hospital.

Giving consent

If you're over 16, you're old enough to agree to treatment, so long as you understand what's involved. If you're younger, your parent or carer will need to give consent.

Simple procedures, such as a nurse taking blood, don't need written consent, but you may be asked if you agree to it. For the actual heart procedure, you or your parents/carers will need to sign a consent form. It's fine to ask for more information or for different options from your medical team.



**CHRIS, SENIOR
CARDIAC NURSE**

Signing the consent form is another good chance to ask questions and fully understand what's involved in the procedure.

Taking part in research

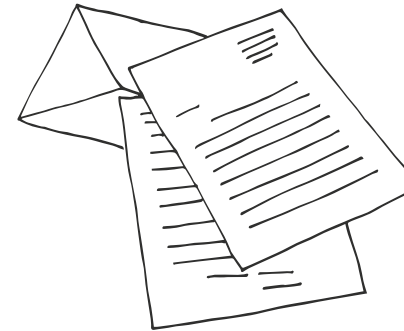
While you're in hospital, you may be asked to take part in research. You'll need to find out what will be involved in order to decide if you're happy to take part.

Your next of kin

Your "next of kin" is the person who's closest to you. When you go into hospital, you'll have to name that person. Then, if you were unconscious or unable to communicate, the hospital would ask them what they think you want.

So who should you pick? It could be anyone you trust as long as they're over 18. For many people a parent or carer is the natural choice. Just make sure you talk to them about your wishes.

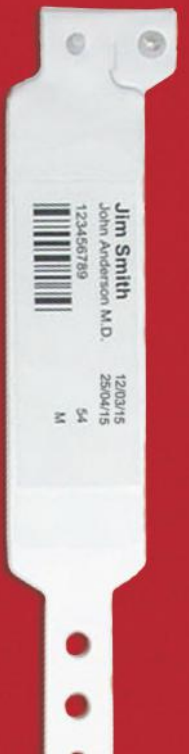
Your healthcare team keep information about you in your medical notes. Most hospitals send patients a copy of clinic letters. It is good idea to keep these because they provide a record of your medical history, plan of care and who to contact.



Under the Data Protection Act, anyone can access their hospital or GP medical notes but they will need to write a formal letter or email to request these. Notes are often written in very technical language, so a nurse or doctor may need to explain them to you. A charge up to £50 may apply to cover administration costs involved in copying medical records.

Your wristband

Take care of your wristband too. It'll have your personal details written on it, along with a barcode or sticker to make sure you're getting the right treatment at the right time.



SECTION

02

GOING IN

When you go into hospital, your main thought is often the procedure itself.

But you might also want to think about what it will be like to spend time on the ward.

Personal space and privacy.
One of the most common worries
for people going into hospital is
about personal space and privacy.

**WILL I HAVE
TO SHARE A
TOILET?**

WILL PEOPLE
BE ABOUT THE
SAME AGE?

WILL EVERYONE
BE THE SAME
SEX AS ME?

**WILL I HAVE MY
OWN ROOM?**

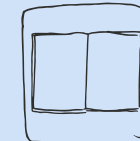
Every hospital is different. Children's wards are usually divided by age groups, whereas adult wards are split into male and female. Bathrooms and toilets are never far away and are usually either male or female.

Hospital staff are very clued up when it comes to respecting your personal space. If you're unhappy with your bed and where they put you, you can mention it to one of the nurses – they'll do everything possible to make sure you're comfortable.

Remember that respect for privacy works both ways. It's important to consider the feelings of everyone around you, especially when they're trying to rest.



GAMES



BOOKS



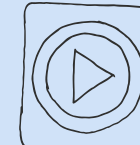
FILM



MUSIC



SCHOOL
WORK



TV

Using phones and getting online

Texting and emailing are great ways to stay connected, but check first if you can use your phone, tablet or laptop on the ward. It's best to put your devices on vibrate and your keypad and ringer on silent. Use headphones if you want to listen to music.

TOP TIP

A lot of people prefer you not to take photos. Ask permission first and make sure other people aren't in your pictures unless they've agreed to it. If you're unhappy about other people in the hospital taking pictures, you should let your healthcare team know and they'll make sure it's sorted out.

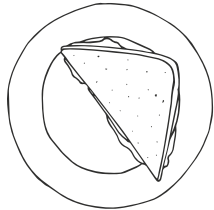
YOUR SUPPORT CREW



Anaesthetists help you relax or 'sleep' through a procedure and keep an eye on your breathing. They run Intensive Care Units (ICU).



Cardiac Nurses work on cardiac day care, ICU and cardiac wards. These are the main people you'll see because they provide your day-to-day care such as giving medications and changing dressings.



Cardiac Nurse Specialists/Cardiac Clinical Nurse Specialists/Cardiac Liaison Nurses are experts in cardiac care, providing advice and support in person and over the telephone.



Cardiac Physiologists do technical things like programming settings on a pacemaker.

Cardiac Surgeons are specialist heart doctors who do procedures such as valve replacements.

Cardiologists are specialist heart doctors who carry out procedures such as putting in a pacemaker.

Catering staff make sure you're fed!

Chaplain can offer spiritual support, whether you are religious or not.

Consultants are the head doctors in charge of your treatment.

Nursing assistants help the nurses care for you.

Nursing Students and Medical Students are training to be nurses and doctors. They may give you some care but someone will be watching closely. If they ask if they can watch you having a procedure but you wouldn't feel comfortable having them there, then feel free to say no.

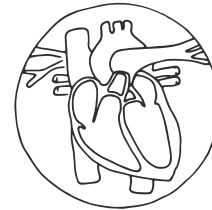
YOUR SUPPORT CREW



Occupational Therapists can help you with practical things that will make your recovery easier.



Operating Theatre Practitioners help the Cardiac Surgeon and Anaesthetist during surgery and keep you as safe as possible.



Perfusionists work the bypass machine in the operating theatre.

Pharmacists make sure that you're given the best medicines for you.

Physiotherapists help improve your movement after surgery, especially to help you breathe comfortably.

Play specialists are found in children's wards. They can help you if you are afraid about having a procedure and help take your mind off being in hospital.

Porters move you safely around the hospital in a wheelchair or bed.

Psychologists can help you understand how you feel about what's happening in your life and can give you guidance on what to do about it.

Radiographers take images of your heart using x-rays and other equipment.

Social workers help with family issues and offer practical support, such as benefits.

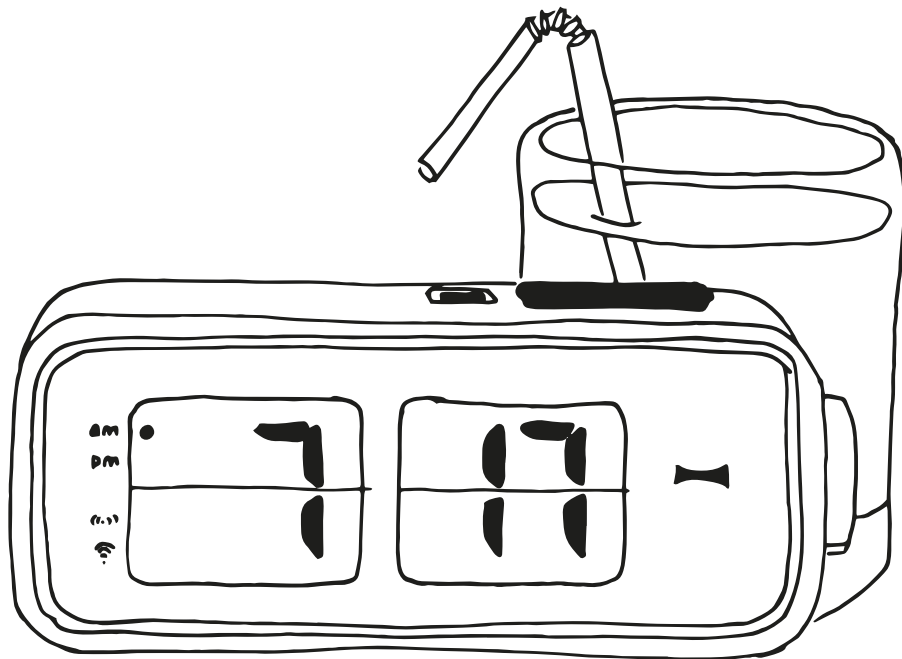
GET INTO THE RHYTHM

Hospitals have a different rhythm to normal life. If you're used to a lie-in, the day can feel like it starts pretty early!

On some wards there are set times for sleeping or resting (when the lights go down and everyone has to be quiet), as well as set times for visitors (when it suddenly gets really busy).

Just ask

It's natural not to want to cause a fuss. But there's no problem with speaking up and asking for things you need – in fact, it's a really good idea. Everyone is there to help you, so make the most of it. If you need to speak to a nurse and one isn't close by, use the call button by your bed.



CLEANLINESS AND HYGIENE

Cleanliness and hygiene

Keeping clean is very important in hospital because it stops infections spreading. You can help by:

- always washing your hands after using the toilet and before eating and drinking
- making sure your family and friends wash their hands
- double-checking with the staff that they've cleaned their hands before treating you if you're concerned.

Learning the lingo

In hospital, you'll come across a lot of medical words that may seem baffling. If in doubt, just ask. You'll find explanations for some of the more common medical words at the back of this book (see page 64) and on the Yheart website. Write down words you're not sure about so that you can look them up later.

Write down any words you're not sure about here....

MIND

OVER

BODY

It's natural to feel nervous before going into hospital. Writing down the things you're worried about – or talking to a close friend or relative – can make you feel better. And if there's something you don't understand, ask someone on your healthcare team.

PUTTING PAIN IN ITS PLACE

The good news is that there are all sorts of ways to control pain and they work really well.

Some people feel more pain than others, so it's really important to tell the nurses if you are in pain so they can sort it out – they aren't mind readers!

Pain relief options include:

- **Regular painkillers**

You can take these every few hours, usually just by swallowing them with a glass of water. They might also be injected into a plastic tube already in your vein called a cannula.

- **Pain relief as required**

This can be administered by a nurse in case of pain that can't be managed by your regular pain relief.

- **Patient controlled pain relief**

This puts you in control and lets you top up your treatment whenever it hurts. A special machine is programmed to provide a safe dose of medicine (usually morphine) through a drip whenever you press a button. It can take a few minutes for the pain relief to kick in.

Trying to relax with slow, gentle breathing or by distracting yourself are both good ways to manage discomfort. The more we think about pain or the more stressed we are, the worse it gets.

- **Nurse controlled pain relief**

This is basically the same thing as the patient controlled option, except this time the nurse decides when to push the button. They use their know-how to make sure the amount of medication you have is safe.



 **SINEAD**

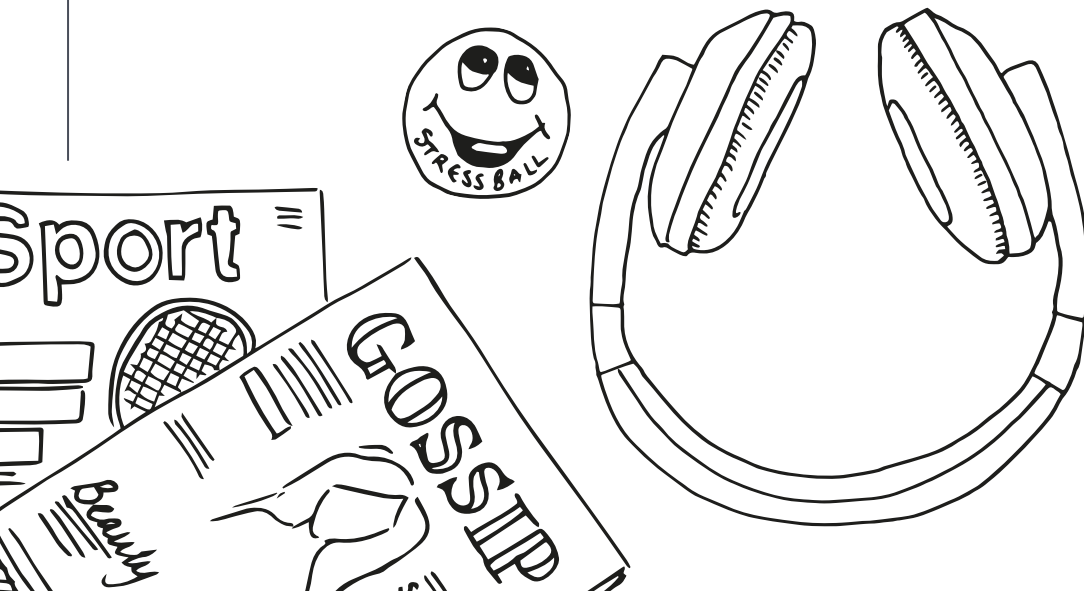
Squeezing someone's hand works well to get rid of pain. Keep thinking of what you'll be able to do once it's all over.

BEAT THE BOREDOM

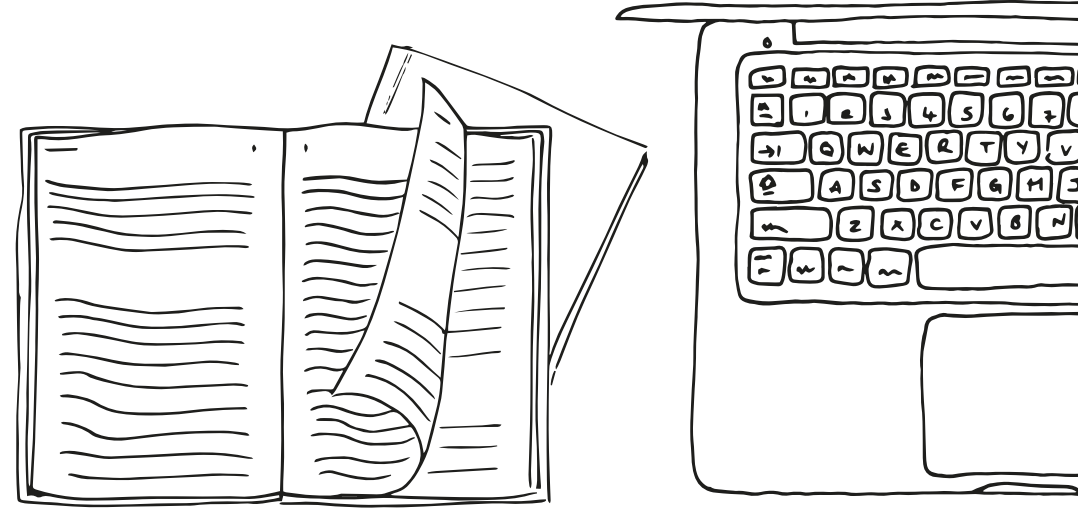
There can be a lot of lying around not doing very much, this is a good thing, because sleep and rest are very important in hospital (although if your nurse or physiotherapist have told you to move around and get exercise then you definitely should). So it's worth having a few ideas of how to pass the time.

You could try:

- listening to music
- playing on a games console
- writing a diary or blog
- testing your brain with puzzle books
- playing games like cards, chess, or solving a Rubik's cube
- reading magazines and books
- watching DVDs or online videos.

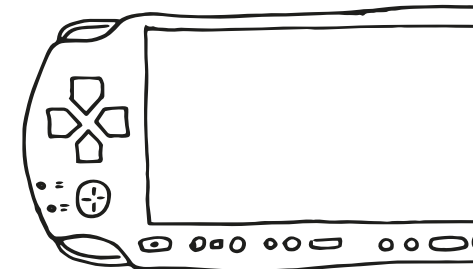
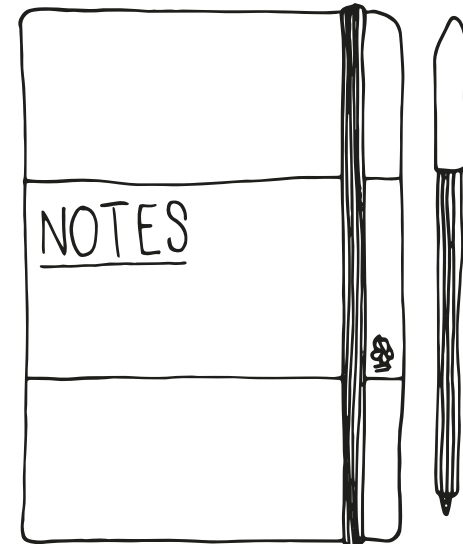


BEAT THE BOREDOM



 ANNA

There will already be a few things to do at the hospital, but it can be nice to have a few of your own things to entertain yourself with.



BE MY GUEST

- Check visiting hours before you go in and let your friends and family know.
- Plan it so there are only a couple of people visiting you at once. Having visitors is a great way to pass the time and stay upbeat, but remember that you need to rest.
- The nurses might sometimes tell you that you can't have visitors if you are too unwell or need to rest. It's really important to take their advice so you can recover sooner.
- Tell people not to visit if they have a cough, cold or other infection.
- Pets aren't normally allowed.
- There is usually a restriction in the number of people who can be at the bedside. This is in case there is an emergency and they need to limit the numbers of people on the ward.
- Always think about other patients who are trying to rest.



DOMINIC

As well as my parents, I had visits from my brothers, grandparents, and other family. It's always nice to see them.



Nº4

**PLEASE
DO
~~NOT~~
DISTURB**

Having visitors is a great way to pass the time and stay upbeat, but remember that you need to rest, so don't be afraid to say no. Plan the timings so there are only a couple of people at once.

SECTION

03

GOING HOME

A lot of people can't wait to get out of hospital and go home, but sometimes it can be difficult. Not only will your body take time to recover but it is quite normal to feel tearful, worried or a bit down after a procedure. You may not feel as well as you hoped you would. Here are some tips to help you get through.

THE CHECK-OUT CHECKLIST

Make plans for getting home – get someone to collect you.

Gather loose, comfortable clothes to wear home – you may have large dressings over your wound. If you can't lift your arms up, it's best to wear a zip-up top or one with buttons down it, so you don't have to pull it over your head.

Check you know what medicines you need to take and when. Get a discharge letter to take to your GP and keep a copy for yourself too.

Find out where and when you'll be seen for a follow up appointment.

Note down the numbers to call if you have any questions after you leave hospital.

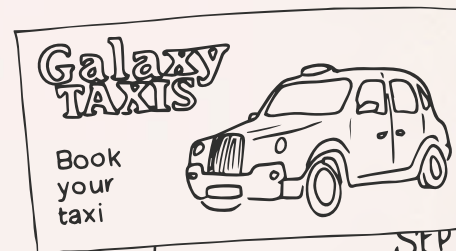
If your healthcare team have given you exercises to do, make sure you know what they are and how often you need to do them.

Collect any personal belongings you brought with you.



TOP TIP

Bring a towel for the journey home to place between your chest and seatbelt, it'll make your journey much more comfortable.



SEPTEMBER

M	T	W	T	F	S	S
					2PM - APPOINTMENT DR. S.	AM - WALK
		PM - MEDS PICK UP	AM - WALK			
				CINEMA - JOE + PAUL	AM - WALK	11AM - HOSPITAL - DR. S.
	10AM - APPOINTMENT DR. S.		SOPIE'S BIRTHDAY!	PM - WALK - MARK		
	EVE - WALK			AM - MEDICATION COLLECTION		

CHECK-OUT CHECKLIST

- How to get home
- Loose, comfortable clothes
- Medication
- Discharge letter
- Follow up appointment
- Important phone numbers
- Exercise timetable
- Personal belongings

GETTING ACTIVE

After any procedure, be patient and remember to take advice. Listen to your own body and the advice from your healthcare team.

Some physical activity is good to start with. Go for a short walk every day and you can get more active as the days and weeks go by. But it's best to avoid heavy lifting and anything that will wear you out – a good excuse to get out of the hoovering.

You may find your energy comes and goes. One day you might feel fine, the next you could be completely washed out. This is just your body's way of saying it needs more time to recover.



ALEX

Walking is a great, simple and easy way to stay active!

TOP TIP

Keep taking your painkillers even if you're not feeling pain – you'll be performing more unusual movements and exercises outside of hospital which may be uncomfortable at first.



THINGS TO DO:

- ☐ Walking
- ☐ Going to the cinema
- ☐ Seeing friends

THINGS TO AVOID

- ☐ Vacuuming
- ☐ Dog walking
- ☐ Heavy lifting
- ☐ Sports



Nº5

STRONGER

EACH

DAY

Go for a short walk every day and you can get more active as the days and weeks go by.

LOOKING AFTER YOURSELF



Relationships

Hugging can suddenly seem a bit tricky if you've been told to be careful about lifting your arms up, or if your wound is still healing. Just be honest with people so they understand. Luckily, kissing is more straightforward – that's fine any time after a procedure.

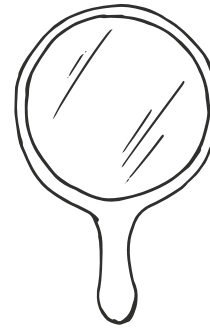
If you want to and are old enough to have sex, you'll need to ask your nurse or doctor when you can do this again. Don't be embarrassed to ask because healthcare teams are used to talking to young people about sex.



Alcohol, smoking and energy drinks

It's in your best interests to completely cut out smoking and drinking alcohol. Also, you should avoid drinks with caffeine in them, such as cola, coffee or caffeine-based energy drinks.

SCARS



Any procedure where skin is cut will lead to a scar. With some procedures, such as those through a catheter, the scar will be small and not very deep, so it should fade quickly, usually disappearing within a few weeks. If you have a deeper cut, for example when you have a pacemaker inserted, or bigger still for open heart surgery, then the scar will remain for longer – but it will gradually fade in colour.

It takes time to get used to a new scar. Some people feel proud of their scars and don't want to cover them, but others feel embarrassed and don't like others seeing them. Skin camouflage creams can be a good way to help cover your scars once you have been told your wound has healed enough.

Raised scar tissue is harder to hide with camouflage creams, but there are some treatments made from silicone gel that really help. Just ask your specialist nurse for more details.

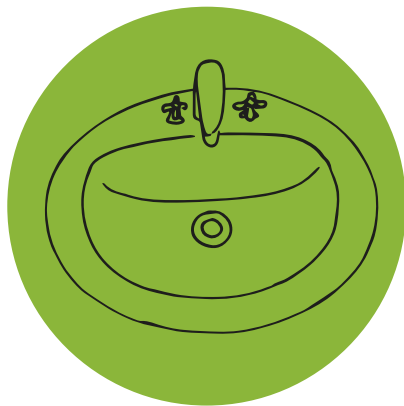
Visit yheart.net/meet@teenheart and go to the straight from the heart section for more information

PRACTICAL TIPS



DRESSINGS AND STITCHES

If you have wound dressings, a nurse should tell you how to look after it. If the wound gets a bit leaky, smelly or painful, you'll need to contact your GP as soon as you can. You might also need an appointment to have your stitches removed.



WASHING

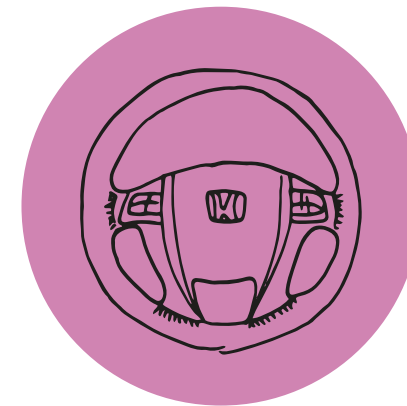
The nurses will tell you to keep your wound or catheter site out of water, which might mean not having a bath or shower for a few days. You can keep yourself clean in the meantime with a quick wash. If you're not sure, ask the nurses about the easiest way to do this.

PRACTICAL TIPS



TRAVELLING

If you're going on holiday, your travel insurance company will need to know about your treatment. After open heart surgery, it's usually best not to fly for a few weeks, but for other procedures you may be able to fly much sooner. Just ask your healthcare team if you're not sure.



DRIVING AND SEATBELTS

If you've passed your test or are learning to drive, you'll need to ask the nurses and doctors when you can get behind the wheel again. If you've had an ICD fitted there are special rules – the DVLA website and your healthcare team can give you all the info.

You still need to wear a seatbelt, but you can add a bit of padding (such as a towel) under the seat belt if your wound is sore.

IT'S GOOD TO TALK

With help from all the places
and people mentioned in this
leaflet, you can fight back
from your procedure.

HOW ARE YOU FEELING?

Sometimes it's only when you get home that everything catches up with you. Emotions can run high. Some people may be in floods of tears, others feel very numb or down. You might feel annoyed that people are wrapping you up in cotton wool. Or you may feel frustrated at yourself because you're not getting better as fast as you would like.

Everyone's recovery is different

The main thing is not to bottle things up. It helps to let the people closest to you know how you're feeling. You can also talk to specialist nurses and psychologists.

When you go back to school or college, people might ask you questions about what happened. Generally, people are just concerned and want to support you, but you only have to say as much as you feel like saying.

Visit yheart.net for information and support

You're not alone

If you'd like to watch video clips of other young people sharing their experiences of having a procedure then go to **yheart.net**. You can also see doctors and nurses talking honestly and openly about procedures.

With help from all the places and people mentioned in this leaflet, you can get back on your feet quickly and feel much fitter or healthier than you did before.



ANNA

I have managed to meet many people with heart conditions thought the BHF who have felt just the same. Heart surgery is a difficult thing to go through, but you just have to keep thinking of all the great things you'll be able to do when it's over.

SECTION

04

GLOSSARY

Medical words and terms that you might come across, along with an explanation of what they mean.

In hospital, you'll come across a lot of medical words that may seem baffling. Some common terms are listed over the following pages but if in doubt, just ask.

A Ablation

Catheter procedure to destroy an extra electrical pathway, or electrical cells, that are causing an arrhythmia.

Anaesthetic

Medicine for an operation or procedure. Makes you sleep (general anaesthetic) or stops you feeling pain while awake (local anaesthetic).

Analgesia

Painkillers – medicines given to control pain.

Aneurysm

An artery or part of the heart bulges becoming stretched and weak.

Anticoagulant

A medicine (such as warfarin and heparin) that makes blood take longer to clot.

Aorta

The biggest artery in your body.

Aortic valve

Valve between the left ventricle and the aorta.

Arrhythmia

Abnormal heart rhythm. Your heart is beating too fast, too slowly, or irregularly.

Arteries

Blood vessels that carry blood from your heart to your brain, lungs and the rest of your body.

Atresia

This means “blocked” or missing, like a missing or blocked heart valve.

Atria

The two top chambers of the heart, where blood collects before draining into the ventricles.

Atrial fibrillation (AF)

Arrhythmia from the atria that causes an irregular pulse. Can sometimes be too fast or slow.

Atrio ventricular (AV) node

Part of your heart's electrical pathway that allows messages to get from the top of your heart through to the bottom.

B Balloon dilatation

A procedure that makes a narrow part of the heart wider by inflating a balloon on a catheter.

Balloon septostomy

A procedure that makes or enlarges a hole in the wall of the heart by inflating a balloon on a catheter.

Bicuspid

Heart valve that has two cusps, or little flaps. This is normal for the mitral valve but the other three heart valves should have three cusps.

Biopsy

Removing a small piece of body tissue for examination.

Biventricular pacemaker

Or cardiac resynchronisation therapy (CRT). A special pacemaker used in heart failure if the heart is pumping out of sync.

Blood pressure

The pressure as your blood pumps through your blood vessels.

Bradycardia

Slow heart rate.

C Cannula

Plastic tube put under your skin into a vein for intravenous drugs and fluids.

Cardiac arrest

When someone stops breathing normally and their heart stops pumping blood around the body.

Cardiac catheterisation

A catheter is put into the heart through an artery or vein to find out pressures, see the heart in detail or to give treatment. Dye is injected to show up the heart in x-rays.

Cardiomyopathy

disease of the heart muscle.

Cardiovascular

To do with the heart (cardio) and blood vessels (vascular).

Cardioversion

Using drugs or electrical shocks to stop an arrhythmia and allow a normal heart rhythm to start again.

LEARNING THE LINGO

Catheter

A narrow tube used in cardiac catheterisation and treatment.

Chest drains

Tubes left in after heart surgery to drain away excess fluid from around the lungs or heart.

Congenital heart disease

Any heart condition you are born with. For some people, the condition isn't detected until they are older.

Coronary arteries

Small arteries that supply all of your heart muscle with blood.

Corrective procedure/surgery

Treatment to make blood circulation more normal.

CT scan

Takes a series of x rays in very fast slices of a part of your body and puts them together as a picture.

Cyanosed

Lack of oxygen in the blood, which can be because of a heart condition, and can make lips look blue.

D Defibrillator (AED)

life saving machine used for cardiac arrest. It gives an electrical shock through the chest wall to the heart, to try to restore a normal heart rhythm.

Dyspnoea

Breathing that isn't normal.

E Echo or echocardiogram

Ultrasound scan to show how well the heart muscle is pumping blood and if blood goes through the valves normally.

EMCO

Advanced bypass machine that can be used to rest the heart and lungs when someone is very unwell.

Ectopic beat

Extra heartbeat that can make you feel like your heart has skipped or missed a beat.

Electrocardiogram (ECG)

Printed out pattern that shows the electrical rhythm of the heart.

LEARNING THE LINGO

Electrophysiological studies (EPS)

Catheter procedure to see exactly where in the heart extra electrical pathways are and where abnormal heart rhythms are coming from.

Endocarditis

Rare but serious condition where the inner lining of the heart – which can be one of the heart valves becomes infected.

Exercise ECG

Sometimes called an "exercise stress test" or "exercise tolerance test" it involves having an ECG (a test to record the electrical activity of your heart) when you walk on a treadmill.

F Familial hypercholesterolaemia (FH)

Genetically inherited condition where someone has very high cholesterol levels.

Fontan

Surgical procedure that makes blood go straight from the body to the lungs, the right ventricle is bypassed but blood still flows through the right atrium to the lungs.

H Heart block

Delay in the electrical pathway from the top to the bottom of the heart, which can sometimes make the heart rate too slow.

Heart failure

When the heart is not pumping blood as well as it should.

Heart-lung bypass machine

Machine that is often used during open heart surgery. It pumps blood around the body while the heart is stopped and operated on.

Heart murmur

Unusual heart sound heard through a stethoscope. It can have several causes, including a narrowed or leaking heart valve or a hole in the heart.

Heart valve

Like a door between chambers in your heart, opening and closing so that blood flows one way only. There are normally four heart valves in the heart.

High dependency unit/intensive care unit (HDU/ICU)

Where people who need especially intensive levels of nursing are cared for after surgery.

LEARNING THE LINGO

Homograft

Using donated human tissue, like a heart valve.

Hyper

Too much, as in hyperactive, or hypertension (high blood pressure).

Hypo

Too little, as in hypotensive (low blood pressure).

I Implantable cardioverter defibrillator (ICD)

Small device that monitors the heart rhythm and, if needed, gives a small electrical shock if the heart has a dangerous arrhythmia.

Implantable loop recorder (ILR)

Small temporary device just under the skin on the chest, which records arrhythmias that only happen once in a while.

Intravenous drugs (IVs)

Drugs that go into a vein through a cannula which can be in your arm or hand, or through a bigger vein called a central line in the neck or chest.

L Left ventricle

Main pumping chamber of the heart. Pumps blood to our brain and body.

M Magnetic resonance imaging (MRI)

Scan giving detailed pictures of the structure of your heart.

Mechanical/metal valve

Artificial valve for replacements.

Minimally invasive heart surgery

Heart surgery without fully opening the chest. Done through small cuts to the chest to reach the heart.

Mitral valve

Valve between the left atrium and the left ventricle.

P Pacemaker

Small device that can improve the pace (speed) of the heart if it's beating very slowly or very fast.

Pacing wire

To pace temporarily. After heart surgery, the heart may develop an arrhythmia. A pacing wire is sometimes left in place just in case it's needed.

Palpitations

Feeling your heart beating. Can be when your heart is beating at a normal rate, or when it is beating abnormally fast or irregularly.

LEARNING THE LINGO

Paroxysmal

Something that only happens from time to time, such as "paroxysmal atrial fibrillation".

Pulmonary arteries

The blood vessels that take blue blood from the right side of the heart to the lungs to collect oxygen.

Pulmonary artery banding

Making the pulmonary artery narrower with a band to reduce blood flow to the lungs.

Pulmonary valve

Heart valve between the right ventricle and the pulmonary arteries.

R Red blood

Blood with a high level of oxygen that is pumped out of the left ventricle.

Regurgitation of valve

Heart valve is leaking, so blood flows back the wrong way through the valve.

Respiration rate

Number of times you breathe in a minute.

S Sats

Short for "oxygen saturation levels" – how much oxygen you have in your blood.

Shunt

Surgically made hole or way between two areas of the heart.

Sick sinus syndrome

Problem with the heart's natural pacemaker, the sino-atrial node. This causes slow and fast heart rates.

Stenosis

Narrowing, could be of a heart valve or an artery.

Stent

Short, metal mesh tube. Using a catheter, this is expanded to hold open a narrow artery.

Sternum

Breast bone.

Stress echo

Echocardiogram scan to see how your heart copes when it has been made to work harder – either after exercise or taking a special medicine.

Supraventricular tachycardia (SVT)

– Fast arrhythmia from above the ventricles. Most SVTs are due to one or more extra electrical pathways (routes) between the atria and the ventricles.

LEARNING THE LINGO

T Tachycardia
Fast heartbeat.

Tissue valve replacement

Heart valve made from animal tissue, usually from a pig (porcine) or a cow (bovine), or from preserved human valves.

Transoesophageal echo (TOE)

Echocardiogram of the heart that is done from inside the body through the oesophagus (food pipe) to get clearer images.

Tricuspid valve

Valve between the right atrium and the right ventricle.

V Valvotomy
Cutting the valves sometimes removing it altogether.

Valvuloplasty

Procedure where a stiff or narrowed heart valve is stretched open.

Vein

Blood vessel that carried blood back to the heart from the rest of the body after it has delivered oxygen.

Ventilator

Artificial breathing machine that is often used to help patients breathe after heart surgery.

Ventricles

Lower two pumping chambers of the heart.

Ventricular arrhythmias

Dangerous arrhythmias that start in the ventricles. Can cause cardiac arrest.

We've written a series of other leaflets for young people.

Order line: 0870 600 6566

The British Heart foundation (BHF) is the nation's heart charity. Saving lives through pioneering research, patient care, campaigning for change and by providing vital information. In the UK around 1 in 180 babies are born with congenital heart disease.

The BHF currently funds over £14 million into congenital heart disease research. The incidence of congenital heart disease has decreased over the last 30 years and there have been dramatic improvements in treatment, many made possible by BHF-funded research – Professor Peter Weissberg, Medical Director, BHF

Join our fight for every heartbeat in the UK. Every pound raised, every minute of your time and donations to our shops will help make a difference to people's lives.

Visit: bhf.org.uk/donate

**FIGHT
FOR EVERY
HEARTBEAT**

Heart helpline

Call us on 0300 330 3311 (9am – 5pm Mon to Fri)

Our cardiac nurses and heart health advisors are on hand to help with any questions or concerns you have about heart health and heart conditions.



**British Heart
Foundation**

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

But cardiovascular disease still kills around one in four people in the UK, stealing them away from their families and loved ones.

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.

Text FIGHT to 70080 to donate £3

**FIGHT
FOR EVERY
HEARTBEAT**

bhf.org.uk

This is a charity donation service for the BHF. Texts cost £3 + 1 standard rate msg. The BHF will receive 100% of your donation to fund our life-saving research.

To opt out of calls and SMS text NOCOMMS BHF to 70060, or if you have any questions about your gift call 02032827862.

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