NHS
The Leeds Teaching Hospitals
NHS Trust

Advice about heart surgery for adults with congenital heart disease

Information for patients

Cardio-Respiratory Service

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This booklet has been written to provide you with information about your heart operation. We hope it answers some of your questions, but is a general guide so please do not hesitate to speak with the ward staff or nurse specialist if you have any questions.

Information about coming for surgery

You have met the surgeon and are now on a waiting list for your operation. Most people will not wait more than 18 weeks for their operation. You will receive a phone call or letter around two weeks before your surgery to ask you to attend the pre-assessment clinic. These clinics are held on Monday morning and a Wednesday afternoon and you will be seen by a Congenital nurse specialist.

Pre-assessment

Pre-assessment plays an important part in the preparation for your surgery. It includes an assessment about your general health and fitness before surgery. You will be asked questions about your health, medical history, medications and home circumstances. It also involves various tests and investigations, such as an ECG, blood tests, MRSA swabs and a chest X-ray. It would be helpful if you could bring an up to date list of your current medications with you. This is an important appointment as it gives you an opportunity to ask questions so that you fully understand the surgery, and find out more about coming into hospital. A pre-assessment appointment can take up to two hours.

Female patients (menstrual cycle)

A concern for female patients is being on a period (menstrual cycle) at the same time as your heart surgery. The surgeon will have given you an estimated length of time you will be waiting on the surgical waiting list. The nurse will also ask you when your last period was. It would help if you could keep a record of the first date of your last period. This will help the nurse work out when your next period is due and whether this will fall at the same time as your surgery. Even if your periods are irregular, it is still worth recording the date of your last period.

If your period does happen to fall at the same time as surgery then we can provide your GP with a note asking them to prescribe a tablet to delay the period.

The GP will prescribe a tablet called **Medroxyprogesterone acetate (Provera) 10mg TDS**. Medroxyprogesterone is a progesterone only preparation and therefore is safe for patients to take undergoing heart surgery. You need to take the tablet 3-4 days before your expected start date of your period. This should stop you from having a period. The tablet (Medroxyprogesterone 10mg) should be taken three times a day and should continue for the duration that you are in hospital. Once you are discharged from hospital you can stop the Medroxyprogesterone and your period will usually start 3-7 days afterwards.

If you are on the combined pill then this ideally should be stopped at least four weeks before surgery to reduce the risk of blood clots. The Progesterone only pill such as Cerelle can be continued throughout your admission.

It is very important to avoid pregnancy whilst on the waiting list for heart surgery. A safe form of contraception is advisable during this time period. If you think that you could be pregnant then you should take a pregnancy test and let us know if the result is positive. If you are unsure then a pregnancy test could be done on admission if necessary.

On discharge the Nurse Specialist will provide you with discharge advice about resuming normal daily activities and when to restart your usual contraception.

Admission

Ward L16 is the ward you will be admitted to before your heart surgery. It is on F floor in Jubilee Wing at the LGI. It is a mixed sex ward, however male and female toilets and bathroom facilities are available and the bays are single sex. The only bay that could be mixed sex is the high observation bay where you may go following intensive care. The patient age range on the ward is age 16 upwards.

The cardiac ward will telephone you on the day you are due to be admitted. You will be asked to arrive on the ward around 15.00 hrs; this may change as informed by the ward staff. When you arrive you may have to wait for a bed in the day room until one becomes available.

Medications

It is very important that you bring all your medications into hospital with you so that they can continue to be used during your admission.

Property

You will be encouraged to wear your own clothes during your hospital stay. You will need enough clothing for approximately one week. We advise that these are comfortable and loose fitting. Healthcare staff will need to review your wounds daily so please wear clothes which allow the team easy access to your chest wound.

Storage is limited on the ward; please bring only a few personal items. You will need essential toiletries for your stay although towels can be provided.

Valuables

You are advised to leave valuables at home. A safe on the ward is available for patient's valuables. However, sums of cash over £20.00 cannot be kept on the ward; they will have to be sent to the finance department for safe keeping.

Smoking

Leeds Teaching Hospitals Trust has a no smoking policy throughout all hospitals, buildings and grounds.

Visiting

Visitors are welcome between the hours of 14:00-20:00 on ward L16. Two visitors at a time are allowed at the bed area. Children under 12 are advised not to visit (as per Leeds Teaching Hospitals Trust guidelines). If children wish to visit please speak with the nurse in charge of the ward.

Restaurant and snack facilities are available on B and C Floors. We politely request that visitors do not bring food and drink onto the ward for their own consumption.

There are no toilet facilities on the ward for visitors. The nearest ones are situated on B Floor in the reception area.

Telephone numbers

Ward L16: 0113 392 7416

Your relatives are welcome to ring the nursing team on the ward for an update on your progress, but we would encourage you to nominate the same person throughout your stay and they can pass on these details to your extended family and friends where possible. Bedside telephones are available on ward L16 and are provided free by Take Heart for patients to make calls to landlines. Mobile telephones may be used on silent mode by patients only.

Take Heart accommodation

Rooms are available on site for relatives to stay if needed. They are limited and cannot be guaranteed. Rooms are to be used only for the first few nights and relatives may be asked to vacate the room once the patient is out of intensive care. The Take Heart charity has also very kindly supplied TV's and access to Wi-Fi. There is a deposit amount of £20 required which is refunded on return of the room access card.

Parking

There is a multi-storey carpark near Jubilee wing but it can get very full. There is another nearby carpark, Woodhouse Lane carpark, which is very convenient for visitors.

Cancellation

Unfortunately operations may sometimes be cancelled for a variety of reasons. If your operation is cancelled we will let you know the reason for this. Your operation will be rescheduled as soon as possible but you may be sent home until another date becomes available.

Day of admission

You will come in to hospital the **day before surgery**. You will meet the surgeon again who will talk through the operation and you will be asked to sign a consent form. You will also meet the ward staff and be seen by an anaesthetist who is responsible for deciding whether you are fit for a general anaesthetic. Anaesthetists are specialist doctors who support you through your operation and into the post-operative period. Most patients are nervous when they arrive in the anaesthetic room, so it helps to meet the anaesthetist the day before. If you are feeling particularly anxious the anaesthetist can prescribe you pre-medication to help you feel more relaxed.

As you are having surgery you will need to fast (nothing to eat) from midnight the night before. You are encouraged to drink plain water up until two hours before your operation as this is thought to help prevent dehydration during surgery. The ward staff will be able to tell you at what time you need to stop drinking.

On the day of surgery, your belongings will be stored away in a locked cupboard on ward L16. A nurse or member of the theatre team will escort you to the cardiac theatre.

Intensive Care Unit and High Dependency

After the operation you will be transferred to the Intensive Care Unit. Usually you will spend at least one night on the Intensive Care Unit. The doctors and nurses will monitor your recovery closely and provide the care you need during the immediate post-operative period. Whilst you are in Intensive Care there will always be one nurse at your bedside who will provide you with the nursing care that you need. When we are

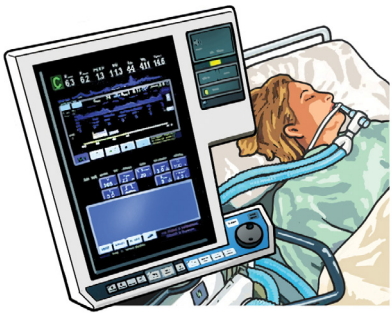
sure that your recovery has progressed well, we will transfer you back to your cardiac ward to continue your recovery. If your recovery is slower than we might have expected, you will stay a bit longer on ICU until we are sure that you are ready to go to the ward. The surgeon will update your next of kin when you are in recovery following your surgery.

Sedation

When you arrive in intensive care you will still be asleep. We will continue to keep you asleep (by using a short acting sedative into one of your drips) until your condition has stabilised and your body temperature following surgery has returned to normal. When the doctors and nursing staff feel that you are stable, your sedation will be stopped and you will start to wake up. The decision may be made to keep you asleep for a longer period depending upon your recovery.

Ventilator

While you are asleep, a ventilator is used to help with your breathing. The ventilator works by pushing a mixture of air and oxygen into your lungs via a tube placed through your mouth into your windpipe. Once you are stable and warm, we will wake you up. The nursing staff will assess when you are awake enough and it is safe to remove the breathing tube and allow you to breath for yourself and take you off the ventilator. You will still need extra oxygen and will be asked to wear an oxygen mask. You will then be able to talk and start to eat and drink.



Medical devices and pumps

Different devices and pumps are used to do a range of jobs in the intensive care and high dependency unit. Some monitor your condition; others are used for giving drugs; respiratory devices help with your breathing. The machines have alarms fitted to them and during your stay when you wake up you will hear alarms sounding around the Intensive Care Unit. The alarms are nothing to worry about. They are there to help the nurse monitor your condition.

Drips

Cardiac surgery requires a number of drips to be put in, some in your arms and some in the side of your neck. Most of these are inserted when you are asleep in the anaesthetic room. Some are used to give medications and fluids during and after surgery. Others are used to measure your blood pressure or for blood samples. Most of them will be removed around 2-4 days following surgery.

Catheter

It is important for us to measure your urine output following cardiac surgery. The amount of urine your kidneys produce is an indicator of how well your heart is working. For this reason, a catheter is inserted into your bladder in the operating theatre and connected to a measuring device. The catheter will usually be removed within a few days of insertion.

Chest drains

Your surgeon will put two or three chest drains in at the end of your surgery to drain away any fluid which can collect. The drains can be uncomfortable. We will provide pain relief to minimise the discomfort. These drains are typically removed the morning after surgery, although sometimes they need to stay in a little longer. When it is time to remove the drains the

nurse looking after you will explain what she/he is going to do and the part that you need to play in it.

Pain

While you are still asleep, the medical team will give you pain relief. When you are awake we will ask you whether you have any pain and offer you regular pain killers. Please let the nurse know if the pain relief provided is enough for your needs. It is an important part of your recovery that you feel comfortable enough to take deep breaths, cough and to be able to move yourself around the bed and sit in a chair.

Surgical stockings

You will also need to wear support stockings to improve circulation, reduce leg swelling and help prevent blood clots. We would normally ask you to wear the stockings for a minimum of two weeks following surgery.

Visitors

The Intensive Care Unit is situated on C floor of Jubilee Wing in the Leeds General Infirmary, ward L4 and L5. We ask that only close family visit, two visitors at any one time. Visiting times are restricted to 13:00-15:00 &17:00-19:00 hours. This is so that we can give you the care that you need, and so you have time to rest.

There is an intercom at the door to get in. The ward clerk or nurse who answers will want to know who is visiting. Relatives will be asked to wait in the visitors room just inside the entrance door and wait for the nurse to come and meet them. Relatives are welcome to telephone at any time to ask how their family member is. We ask if possible that one family member makes enquiries on behalf of your family. This allows the nurse caring for you to spend as much time looking after you as possible.

The telephone numbers for ICU are:

Ward L4 - 0113 392 7404 Ward L5 - 0113 392 7405

Back to the cardiac ward

When you are ready to be discharged from intensive care you will be transferred to the high dependency bay on the cardiac ward, L16. The nurse will be looking after you and three other patients. Following on from the high observation unit you will move to another bay on the cardiac ward. You will be looked after by a nurse and the healthcare team. You will continue to have daily bloods and regular observations to monitor your progress. The nursing team will help to support your recovery and start to prepare you for your discharge home. On average patients normally spend 5-7 days in hospital.

Physical activity on the ward

On your first day following your surgery, you can expect the nursing staff to help you to get out of bed, stand up and transfer into a chair. On your second day the nursing staff will encourage you to stand up regularly during the day and walk on the spot. When you are on the ward it is important for you to get up and about as much as you can. You should aim to walk the full length of the ward by the time you go home. Some people may feel able to walk further than this, for example downstairs to the shop. Make sure you check with the ward staff before you leave the ward. Those who are unable to walk independently will receive assistance from the nursing and physiotherapy staff. The physiotherapy team are there to help you get back to normal as soon as possible. Feel free to ask members of the team any questions you may have before you go home.

How to speed up your recovery

- Sit in your chair rather than staying in bed
- Try to get washed and dressed by yourself
- Change pyjamas for your normal clothes
- Aim to walk a little bit further and more frequently each day
- Walk to the end of the ward after you have been to the bathroom instead of going straight back to bed
- When you have visitors try a longer walk with them and always see them to the door!
- Have a go at the exercises in this booklet (see page 25).

What are the benefits of exercise after surgery?

- Helps your lungs re-expand and improves oxygen levels
- Improves your ability to cough and reduces the risk of chest infections
- Tones and strengthens muscles and keeps joints flexible
- Increases blood circulation to the heart and other major organs
- Helps to reduce cholesterol and blood pressure
- Reduces the risk of blood clots and strokes
- Improves wound healing
- Increases independence when walking
- Helps with weight loss
- Improves mood and helps you to sleep better
- You will be able to do more with less effort as your fitness improves.

What sort of physical activity can I do?

Walking will have formed an important part of your hospital recovery and is the best way to progress your rehabilitation on the ward and when you go home. You can also try the exercises shown on page 25.

How much exercise is too much?

Everybody recovers differently after surgery, but the 'Walk-Talk Test' is a good indicator to ensure that you do not overdo it. This simply means that you should be able to talk and be active at the same time When you are discharged home we encourage you to remain active and go for daily walks.

I feel really tired at the end of the day, is this normal?

Yes it is normal to feel tired after surgery and some tasks that you found easy before may feel difficult now. It is important to pace yourself; you may find it helpful to break down an activity into more manageable chunks. This gives you more time to recover.

How long should it take to get back to normal?

There is no specific time frame, but it can take up to three months before you feel back to your normal self.

Can I have a bath or shower?

The nursing staff will assist you until you feel stronger and more confident with a wash and a shower. Try not to use very hot water because this can affect your circulation and make you feel dizzy. It would be better to use a shower rather than a bath as it is important not to pull yourself up and out of the bath before your breast bone is fully healed. If you don't have a shower then it is advisable to have a wash by the sink initially until you feel stronger and your wounds have healed fully.

Surgical wounds

All patients who have had cardiac surgery will have a breast bone wound. Initially this will be covered with a dressing. Many things affect the rate at which your wounds heal. These include:

- your physique
- your diet
- smoking
- your gender
- your age
- other medical conditions such as diabetes

Following the operation your breast bone is held together firmly by wires. These stay in place for the rest of your life. The bone is fully healed after about 6-12 weeks, but even after the bone edges have healed the wires will remain in place. Normally these wires do not cause any problems but you will need to seek advice from your nurse specialist or GP if:

- You can feel the wires under the skin and they are uncomfortable.
- You think infection is present because your breast bone is more painful, itchy, leaking yellow pus-like fluid or you have a temperature and feel generally unwell.
- You think your breast bone is not fixed firmly enough together and it moves about unequally.

The surgeons mostly use dissolvable stitches. This means there are only one or two stitches that need to be removed. This is done several days after your operation. Any remaining stitches will be removed by your practice nurse at the GP surgery.

It is quite normal to see small lengths of stitch come away from your wound. Remember that the deep stitches in your heart and chest wall are firm and secure and not affected by the changes you see around the skin.

Check your wound regularly and if you experience any pain, swelling or redness then this may be a sign of infection. If you are worried or have any of these symptoms then please contact the nurse specialists or GP for advice.

Scar

Most scars fade to a fine line over a period of time but this may take several months. Once the wound has healed and if you wish to make it less noticeable then a skin camouflage service is available. This is run by the British Red Cross who provide a service using skin-coloured make-up to cover the scar. You can self-refer or ask your practice nurse to make a referral on your behalf ***www.redcross.org.uk***

Discomfort and pain relief

You may suffer mild discomfort whilst moving around for a few days. Pain killers can be taken for this. You may find that your sleep patterns change for a while after you leave hospital. This is normal and can be due to changes in your usual routine and the effects of sedating medications. The key to sleeping better is to get back into your normal bedtime routine once at home. Try not to worry because the more you worry the harder it will be to sleep. Listening to relaxing music or reading a chapter of a book can help prepare you for a good night's sleep. Most of all, be patient with yourself and allow your body to adjust and recover from the operation.

After your operation it is normal to experience aches and pains. Everyone is different; the aches and pains you experience may be different from those experienced by someone else. It is common to feel discomfort or numbness around the neck, shoulders, back and breastbone. These will fade as your breastbone heals. It is important to do the exercises that are described later on in this booklet.

You will be prescribed regular pain relief tablets and we strongly recommend that you take these as instructed. If this is not adequate, please see your GP.

Do not wait until the discomfort is unbearable, as they will take longer to work.

Pain relief is very important for your general recovery; it enables you to perform deep breathing exercises and allows you to get moving about quicker.

When will my stitches be removed?

Most surgeons use dissolvable sutures to close the skin. The only stitches that will need to be removed will be drain sutures. You will be advised during your hospital stay when these will be removed.

Common questions asked about wound healing

Some fluid is leaking from the wound. Is this normal?

If any clear or blood stained fluid starts to leak from your wound, please tell the nurse specialist teamwho will advise you on how to deal with it. If the discharge becomes yellow or pus-like, you should see your GP or speak with your Specialist nurse as it may be a sign of infection.

I have noticed pieces of skin coming off my wound. Is this normal?

Yes, you may notice that small lengths of skin appear to come away. This is part of the wound healing process and is entirely normal. Remember that the deep stitches in your heart and chest wall are firm and secure and are not affected by the changes you see around the skin.

Can my wound get infected and how would I know?

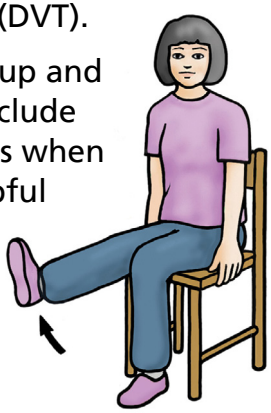
If your wound or the surrounding skin becomes red, painful, swollen or warm, you should contact the nurse specialist or GP as soon as possible. If your wound starts to leak yellow or pus-like fluid, you should also contact your GP straight away. There may not be a need for any treatment or you may just need a course of antibiotics to help fight the infection.

People with diabetes

Having diabetes can affect how long it takes for wounds to heal. It is therefore very important that you monitor your diabetes carefully when you leave hospital. You should contact your GP if your blood sugars are persistently higher than 10mmols/litre or urine testing continues to show glucose in the urine. If you notice any signs of wound infection (as described on the previous page) you should contact your nurse specialist or GP as soon as possible.

Why do my legs swell?

It is not uncommon if you've had a valve replacement that your ankles swell. This is quite normal and may occur for up to several months following surgery. The doctors might prescribe you 'water tablets' to help with this. You will also need to wear elastic stockings for several weeks following your operation. This is to encourage blood flow and to reduce your risk of developing a venous thromboembolism which is the development of a blood clot in the veins of the legs. These are often referred to as 'Deep vein thrombosis' (DVT).



The nursing staff will encourage you to get up and move about as early as possible. This may include asking you to regularly perform leg exercises when you are in bed or sat in a chair. It is also helpful to keep your legs elevated when sitting, to help fluid return and reduce swelling. However, if the swelling gets more noticeable, please seek advice from the nurse specialists, Cardiologist or GP.

Whilst you are in hospital you will be given a daily injection of a low dose heparin. This medicine thins the blood and reduces the risk of blood clots forming whilst you are less mobile.

Do all my stitches dissolve?

Sometimes stitches that would normally dissolve under the skin may not. This is very common at the top and bottom of the wound. If left in place they may delay healing or increase the risk of infection. See your GP or practice nurse to have them removed.

Tips for effective wound healing

- Keep your wound clean by taking regular showers. This will prevent a build-up of bacteria. Do not use soap or perfumed products directly on the wounds.
- Pat your wounds dry with a clean towel after bathing/ showering.
- Ensure you eat a well-balanced diet. Protein which is found in low fat dairy products or lean meat will help wound healing.
- Wound healing takes place during rest and sleep, so do try to ensure that you get enough rest.
- Protect your wound from damage i.e. knocking the wound.
- Try not to poke at the wound as this may cause infection.
- Do not use any dressings, creams, talc's etc. on the wound unless advised to do so by your doctor or nurse.
- Try not to expose your wound to sunlight without protection. The wound is prone to sun burn, so keep it covered or apply a total sun block (make sure the skin is not broken before applying sun block).

Common questions asked about aches and pains

Why am I getting pain in my shoulders?

It is common to feel discomfort or numbness and other sensations around your neck, shoulders, back and breast area. This is due to your chest being held open during the operation. These aches will fade as your breast bone heals. It is important that you keep moving your arms and do the exercises shown on page 25.

Part of my chest feels tingly and numb, why is this?

There may be some areas of lost sensation in the skin around the wound. This is normal and causes no harm. Usually normal sensation will return after a few weeks or sometimes months. You may experience discomfort similar to 'chest pain', tingling or numbness. Women may find it more comfortable to wear a supportive bra without under wires (i.e. a sports bra) even at night. Do not worry if any of these sensations happen, they will fade in time. Your GP may be able to prescribe anti-inflammatory painkillers if this really becomes a problem.

How long should I take my painkillers for?

When your aches and pains start to become less uncomfortable you can start to take less painkilling tablets. You may find that you experience more pain and discomfort at night so stop those last. You should notice that your aches and pains get less and less as each week passes and you may find that some days are better than others. The main thing is to try to keep yourself moving. Your pain will gradually reduce as time goes on. If you feel you need different pain killing tablets, you should discuss this with your GP. Remember, everyone recovers at different speeds and some aches and pains can go on for up to a year. Some people find that they get more discomfort when they first get home compared to when they were in hospital. This is because the tendency is to do more for yourself than you did in hospital, so do not worry. This is perfectly normal.

Other effects of the operation

Emotions

It is quite usual to feel low, fed up or emotional after your surgery and this is thought to be part of the normal recovery process. This may take the form of tears, anger, frustration and irritability. Some people complain of feeling vague and vacant. These feelings are often short lived but some people may experience them several times.

Visual disturbances

You may find that you can't concentrate as well as normal and your vision is slightly blurred. This is thought to be due to having been on the heart bypass machine during your operation. The visual disturbances should resolve within a few weeks.

Appetite

You may find that things don't taste the same. This may contribute to the loss of appetite that some people experience. Again this is thought to be due to the heart bypass machine. Over time your appetite will return to normal.

Sleep

It is not unusual to experience restless sleep and vivid dreams following your operation. In time your sleep pattern will return back to normal and the vivid dreams will fade. Discomfort can prevent a good night's sleep so make sure you take your painkillers. Also taking a rest during the afternoon helps to make sure you don't become over-tired.

Medication

If you are taking medication they will be provided for you to take home. You will be given up to 28 days supply and it is important that they do not run out! A discharge letter will be provided for your GP which gives information about any prescriptions that need renewing. Keep taking the medication until you are seen in the Outpatients Department around six weeks after you leave hospital.

Before you go home you should know these facts about each medication you are taking:

- What the medication is called and what it is for
- How often you need to take the medication
- How to take the medicine (with, before or after food)
- How long to take the medicine for
- What are the side effects
- What to do if side effects occur
- If there is anything special about diet or alcohol

Warfarin - You may need to take Warfarin (this is also called an anticoagulant), a tablet that can prevent clots forming around the heart. This is often prescribed after valve surgery. If you take warfarin because you have a mechanical heart valve it is particularly important that you take it as prescribed and that your international normalised ratio (INR) is measured at the recommended time.

If your INR is too low (i.e. your blood is not thin enough) it may be necessary for you to have a daily injection of an alternative blood thinner to ensure that a clot does not develop on the valve. Whoever monitors your INR (an anticoagulation clinic or your GP) will advise if this is necessary. You will usually require the injections until your INR is back to within range. You will be discharged home with a supply of Tinzaparin (heparin) along with a sharps bin. The pharmacist will discuss this with you in more detail and you will be given a "yellow" book, to record your blood results and daily dosage.

N.B. Unless you are entitled to free prescriptions, you will have to pay for Warfarin.

Rehabilitation after discharge from hospital

Following your heart operation it is extremely important to maintain and increase your exercise tolerance.

Exercise should become part of your daily routine starting the day of discharge. It is important to keep active in the first few weeks after your operation. However you must realise that you will be starting from a lower level of fitness at first so it is important to build up gradually.

Some people can feel a bit unsure and scared about returning home and doing "normal" activities. The key to overcoming these worries is by pacing your activity to build up your strength and confidence step by step. Rushing into activity may tire you quickly and then make you think you can't do things. Equally, avoiding activity will only decrease your fitness levels. Try to strike a balance between the two.

Exercise at your pace and avoid sudden bursts of activity

The following exercise regime should be carried out in hospital and then at home until your clinic appointment. It is also useful to continue to use these exercises as a 'warm up' before you're walking or other activities.

Aches, pains and stiffness around the chest, back and neck are very common after heart surgery. These exercises are designed to help prevent your neck, rib cage and back from becoming stiff and painful. They also help to make you more aware of your overall posture.

Breathing exercises

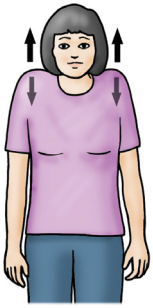
It is important to do deep breathing exercises for the first two weeks or so after you are discharged home. This will help prevent chest infections; improve your lung function and improve your rib cage mobility. These exercises should be continued as long as you feel they are helping.

The exercises are to help ease some of the stiffness/aching you may develop after your heart operation.

- They should always be done in a slow, controlled movement.
- Always avoid jerky or vigorous movement with your arms.
- Aim to do these twice a day.
- Start with five of each and gradually build up until you can do 10 of each.

Shoulder exercises

1. Shrug your shoulders slowly towards your ears and then push them down.



2. Sit on a chair with your feet flat on the floor. Put your hands on your shoulders with elbows out to the side. Using your shoulders gently circle both arms forwards and then backwards. Always do this in a slow, controlled manner.

3. With alternate arms slowly reach high towards the ceiling. Do not lift both arms at once.

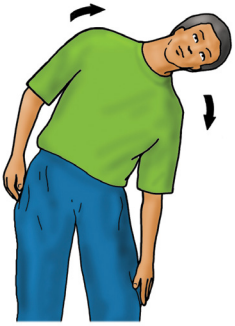
Trunk exercises

Alternate side bending while standing

(a) Bend sideways to the right without leaning forwards or backwards. Slide your fingers towards your knee

(b) Count to five and slowly return to standing.

(c) Repeat to the left side.



Thoracic rotation

(a) Sitting with your hands across your chest, slowly turn to the right keeping your hips and knees still.

(b) Hold for a count of five.

(c) Repeat to the left.

Leg exercises

These exercises will help improve your circulation and ease any stiffness.

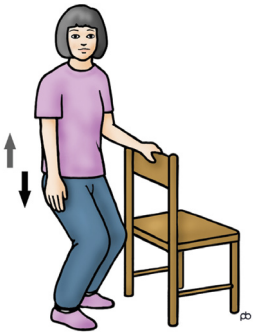
These should be done at the same time and in the same amount as the shoulder exercises. You should continue these exercises for six weeks.

Alternate knee bends

(a) Sitting with your legs straight out in front of you bend one knee towards your chest.

(b) Straighten and repeat with the opposite leg.

Half squats holding onto sturdy furniture for support



(a) Stand with feet slightly apart and back straight.

(b) Bend your knees to 45° slowly and straighten.

(c) Keep heels on the floor throughout.

Step-ups

(a) Lift your right foot onto the first step of your staircase.

(b) Bring your left foot up to join it.

(c) Step down.

(d) Repeat leading with your left foot.

Walking

As well as these exercises it is most important that you continue to take regular walks, twice a day to start with.

Before your discharge from hospital you will have taken regular walks. It is essential that you continue to walk when you go home. You should gradually increase the length of time walking as you feel able. Aim for a 10 minute walk to start with and then gradually increase the time and speed of your walk depending on how you feel.

- It is natural to become slightly short of breath on exercise. To guide you as to the best pace, we advise using the 'Walk and Talk Test'; this means you should feel a bit 'puffed' during exercise but still able to talk in sentences. If you are too breathless to speak, you are working too hard.
- Try to aim for a 30 minute walk by the time of your clinic appointment at around six weeks after your operation.
- Although we encourage walking, if you own a dog we would advise you do not hold their lead for the first six weeks to avoid any damage to the healing sternum.

A useful tool to stay fit and control your weight is through the use of a pedometer. Pedometers are a way of recording your daily steps. A 30 minute moderate walk is equivalent to 3,000-4,000 steps a day. The recommendation to staying fit and healthy is to walk around 10,000 steps a day.

Remember regular exercise helps you feel better, improves your heart and lung function and benefits long-term health.

Some general exercise advice

- During the first 6-8 weeks following surgery, it is important to protect your breastbone by avoiding lifting, carrying, pushing or pulling anything heavy. For example, do not lift anything heavier than a full kettle; avoid vacuuming and carrying heavy shopping/bags.
- Physical sports such as football, golf, etc can usually be started again once the breastbone has healed which usually takes 8-12 weeks. Before attempting any contact sports, such as Rugby, please check with our physiotherapist in your 6 week follow up appointment.
- Swimming can be started again at 6-12 weeks if the skin wound is completely healed.
- Very few people need to limit the amount of activity they do, the physiotherapist or consultant will tell you of any necessary restrictions.

It is essential that you continue with some form of regular exercise for life. Choose something you enjoy, but activities such as brisk walking, cycling or swimming are good aerobic exercises.

Continue to increase the distance of your brisk walks as you feel comfortable.

Exercise is for life!

- The minimum to aim for is 30 minutes a day of moderate intensity activity.
- Always warm up and cool down.
- Gradually build up to your 30 minutes.
- Any extra activities above your 30 minutes will be beneficial to your health.

Remember it is normal during physical activity to:

- Feel yourself breathing harder than normal.
- Feel warmer during and after exercise.
- Feel your heart beating faster than normal.
- Use the ***'Walk and Talk'*** test as a guide to the right intensity for exercise.

Questions about sex

Following discharge from hospital you are advised to gradually increase your daily exercise as you gain strength and confidence, pacing yourself as you feel most comfortable. This applies to all your daily activities including sexual intercourse. You can have sex as soon as you feel ready.

Many people have concerns about having sex after heart surgery.

Some commonly asked questions are:

I don't feel like sex as I still feel tired and not very energetic, is this common?

Sex is a physical activity and like any activity following your surgery you have to increase the intensity and duration gradually until you become fitter. Generally if you can walk up and downstairs without undue breathlessness, you can resume sexual activity and gradually build up your stamina.

My breast bone is still healing and sore and I can't do anything strenuous for at least six weeks. How can I have sex without causing pain or damage?

Until your breast bone is healed and your chest is comfortable you must avoid putting pressure on it. Avoid positions which involve you leaning on your elbows, arms or chest or your partner leaning on your chest. For example, if you have had surgery, you could try lying on your back with your partner taking the more active role on top. Some people find lying side by side more comfortable exploring new positions and sensations that do not put pressure on the chest. Remember these are only suggestions; you must do what feels comfortable for you.

I don't feel like having sex. Is this normal?

It is very common for people who have had surgery to experience a temporary loss of their sex drive. This is normal and will, given time, return. Many people and their partners also feel anxious and frightened about having sex after heart surgery.

I have difficulty maintaining an erection and sometimes experience pain in my penis. Why?

This may be due to short term effects of surgery or catheterisation (the tube that drained your urine). It should resolve in time. If it persists, consult your GP. Also some drugs, i.e. beta-blockers, can result in lack of desire or impotence. Again if you think this is a problem consult your GP.

On a positive note, resuming sexual activity along with your other usual activities, once home, can make you feel like things are getting back to normal again and may help to improve relationships which could have become strained due to your illness, anxiety and awaiting surgery.

Returning to work

Returning to work very much depends on what you do. You may have to be off longer if you have a physical job and thus may be up to 12 weeks. Please get advice from the surgeon at your first outpatients' appointment. A fit note will be provided by the ward Doctor, whilst you are in hospital, which can be sent to your employer whilst you are off work. If required, a further fit note can be provided during your six week follow up appointment after surgery.

Driving

The general advice given by the DVLA (Driving Vehicle License Authority) is not to drive for four weeks following surgery. The surgeons here at the LGI strongly advise that you wait six weeks. This is to ensure that the breastbone is protected and you feel comfortable wearing a seat belt.

You do not need to advise the DVLA of your operation unless you have had a pacemaker fitted. However, you do need to let your car insurance company know.

If you do not inform them then your car insurance policy may not be valid.

Pacemaker operation - when you inform the DVLA about your pacemaker operation, they may need further details from the medical staff about your medical condition. This usually means a short period license will replace your existing license. This is to ensure that regular checks can be made to ensure that your health does not affect your ability to drive.

Remember these are only guidelines - some people feel that they are not up to the stresses and concentration necessary for driving in today's traffic until much later than this six week period whilst other people do not have any problems. It is up to you to make sure that you are safe to drive again, in whatever conditions you might meet.

For further information or specific advice contact the DVLA

Telephone. **0870 174 7001** Website: **www.gov.uk**

Returning to the outpatient department

Following discharge you will be followed up in the Outpatients Department. The surgical registrar, specialist nurse, physiotherapist and psychologist will see you at the Leeds general infirmary approximately six weeks after your surgery. Once discharged from the surgeon, your care is then transferred back to the Cardiologist, who will generally see you about 6 to 12 months after your operation. If you do not receive a follow up appointment, please get in touch with us.

Travel

The surgeons' advice is that you wait for at least 6-12 weeks before flying on an aeroplane. wait until your six week follow up appointment before planning any trips on abroad. During the flight make sure you take regular walks around the cabin. The flight on the aeroplane is often the least physical part of your journey; remember the hassle of finding a parking place, queuing at the check-in queue and waiting around can be very tiring, so it is worth bearing these things in mind before you book your holiday.

Most travel insurance policies ask you to declare any medical condition and some airline companies may ask for a letter from your Doctor to say that you are medically fit to fly.

General health advice

Preventing infective endocarditis

Endocarditis is a serious infection of the heart. You can greatly reduce the risk of getting infective endocarditis by following a few simple rules:

- Visit your dentist regularly (every 6-12 months).
- Tell your dentist about your heart problem.
- Brush your teeth with fluoride toothpaste at least twice daily and ask your dentist about other ways of preventing dental disease.
- Avoid other potential causes of infective endocarditis e.g. body piercing and tattoos.

Smoking

It is of the utmost importance not to smoke for the following reasons:

- The main action of a cigarette is to give a smoker a burst of nicotine. Nicotine is the addictive drug in cigarettes that keeps people coming back for more. It also makes the heart pump faster, increasing blood pressure (hypertension). Cigarette smoking also narrows the arteries that supply blood to the heart muscle. This puts you at risk of a heart attack. Smoking also increases your risk of lung cancer and chronic bronchitis.

  For help to stop smoking see your GP or visit:
  NHS Choices website - **www.nhs.uk**

Recreational Drugs

Drugs are powerful chemicals that can change how you think, feel and behave.

Recreational drugs are particularly dangerous for a person with a heart condition, especially stimulant drugs such as ecstasy and speed, as these can cause heart rhythm irregularities. Intravenous drug usage puts you at risk of endocarditis.

For free and confidential advice contact:

NHS Choices website - **www.nhs.uk** or **www.talktofrank.com**

Diet

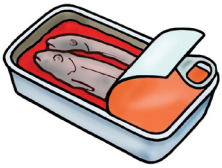
After your operation it is important to eat a varied diet. This will aid wound healing and help you get your strength and energy back. Eating a healthy diet helps reduce the risk of developing many conditions such as cancers, heart disease, high blood pressure, high cholesterol, diabetes, obesity, painful joints and tooth decay.

Eating a good variety and balance of foods, taking regular exercise and not drinking too much alcohol gives you the best chance of being fitter and healthier.

Healthy eating includes:

- Eating at least five portions of fruit and vegetables a day - fruit and vegetables are a good source of vitamins and minerals as well as fibre. Fibre helps to maintain a healthy gut and prevent digestive problems. Eating '5 a Day' can help reduce the risk of heart disease, stroke and some cancers.

- Eating starchy foods such as potato, rice, pasta and wholemeal bread - starchy foods are an important part of a healthy diet. They are a good source of energy and supply fuel for the body.
- Eating two portions of fish per week, one of which is oily - eating one portion of oily fish is a good source of Omega 3 which will help to reduce your cholesterol. Fish is also a good source of protein essential for growth and repair.



- Eating lower fat meats and dairy products - fat contains a lot of calories and eating too much of it increases your weight. Over time eating too much saturated fat can raise cholesterol and increases your risk of heart disease.
- Reducing your salt intake to 6g a day - too much salt can raise your blood pressure. If you have high blood pressure you are more likely to develop heart disease or have a stroke. One easy way to eat less salt is to stop adding salt to your food.
- Reducing foods high in sugar, such as fizzy drinks - too much sugar means excess energy, which can lead to stored fat in the body and can cause heart disease, type 2 diabetes, obesity and tooth decay.
- Drinking less alcohol - sticking to the recommended guidelines of 14 units for men and women, spread over three or more days will help reduce the risk of alcohol-related health problems. Over a number of years excess drinking can cause liver problems, reduced fertility, high blood pressure, increase your risk of cancers and heart disease. Remember you don't have to be an alcoholic to have alcohol-related health problems.

Alcohol units

- Half pint of beer/ single spirit shot **- 1 unit**
- Small glass of wine/Alcopops **- 1.5 units**
- Large bottle of beer/ medium glass of wine **- 2 units**
- Large glass of wine (250mls) **- 3 units**
- Bottle of wine **- 9 units**
- Bottle of spirits 40% **- 30 units**

You may suffer with constipation following your operation. This is often due to the painkillers that you are taking. Drinking plenty of fluid and eating fruit and fibre will help relieve constipation. If required the doctor can prescribe a laxative for you until your bowel habits have returned back to normal.

Sometimes, blood loss during the operation will result in anaemia (loss of iron). Eating a varied and balanced diet should provide adequate iron intake. The following foods are good sources of iron to help you restore your iron levels during your recovery - lean red meat, turkey and chicken, liver, oily fish, eggs, cereals, pulses/ beans, and leafy green vegetables.

Notes

Useful contact numbers

Ward L16:

Telephone. ***0113 392 7416***

Adult Congenital Heart Disease Nurse Specialists:

Jo Birkett, Hannah Swift, Angela Leeper & Daniel Robinson

Telephone. ***0113 392 8154*** Email: ***leedsth-tr.achdnurse@nhs.net***

Congenital Cardiac Specialist Physiotherapist:

Sarah Hibbert

Telephone. ***0113 392 0609*** Email: ***sarah.hibbert3@nhs.net***

Congenital Cardiology Psychology and Counseling service:

Dr Sara Matley, Dr Kat Bilbrough & team.

Telephone. ***0113 392 5143*** Email: ***leedsth-tr.ccpt@nhs.net***

The Somerville Foundation:

A support group which offers peer support to people with congenital heart defects

Telephone. ***0800 854759*** Website: ***www.thesf.org.uk***

LEEDS CONGENITAL HEARTS

Visit our website:

www.leedsth.nhs.uk/patients/resources/heart-surgery-for-adults-with-congenital-heart-disease/

What did you think of your care?

Visit: www.leedsth.nhs.uk/patients/support/feedback-complaints/friends-family-test/

Scan or click the QR code - Your views matter

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Developed by: Emma Pick and the Adult Congenital Heart Team July 2019

Produced by: Medical Illustration Services • MID code:20241029_003/BP

LN003947
Publication date
Ver 2 05/2026
Review date
11/2027