

**Pulmonary endarterectomy (PEA)  
at Papworth Hospital**  
Discharge information



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## Discharge information

You recently had pulmonary endarterectomy (PEA) surgery and are now recovering on the ward. You will normally stay in hospital for 10–14 days but this may change depending on how you recover after this major surgery.

## Planning for discharge

You will be discharged when:

- Your surgical and Papworth pulmonary hypertension (PH) team think you are well enough
- Your physiotherapist thinks you are walking safely on your own or with a frame or stick
- You walked up the stairs with a physiotherapist if you have stairs at home
- Your anticoagulation is life-long. For those on warfarin, we expect your international normalised ratio (INR) to be near or above 2
- You have someone to be with you, you have a safe place to go to or you have a care package in place

- When the PEA nurse has discussed the discharge information with you and you have received the anticoagulation letter for your GP and anticoagulation clinic.

## Going home after surgery

Most patients go straight home after surgery but you will need a family member or a friend to stay with you for the first few days.

If you live alone and do not need any additional care, you can still go home with friends and family support or you can plan to stay with your family or friends for a few weeks. If you do this it is important that you register with a local GP on a temporary basis.

You may be transferred to a hospital nearer home if you need continued medical care or rehabilitation prior to going home. Only a few patients have to do this. When you are ready to go home the nurses looking after you at your local hospital will go through the arrangements with you and your family.

Depending on your recovery and home circumstances, you may be referred to the occupational therapist if you need any additional aids at home. These are usually temporary aids and include such things as, stools for the bathroom, raised toilet seats or raised cushions to make it easier to get in and out of soft chairs.

## Travelling home

The journey home may be very tiring particularly if you are travelling a long distance. Don't be surprised if you are very tired for the next few days after travelling.

You will be unable to drive for six weeks after your surgery, so a family member or friend will need to drive you home. It may be

possible to arrange hospital transport for those who need it, e.g. if you have a medical need or you receive social benefits. If you are travelling home in a car you may need to put something soft between you and your seat belt to make it more comfortable, for example a rolled up towel, a small cushion, a bath sponge or a cuddly toy.

## What happens when I go home?

PEA is major surgery and it is normal for you to feel tired and breathless after this; it will take at least 3 months to fully recover from your surgery. Please do not compare yourself with any other patients who have had the same surgery or who had other cardiac surgery; everybody recovers at different rates.

### General information

- Some continued breathlessness is common. This should gradually improve but if you feel it is slowly getting worse call your GP. Remember to pace yourself, do not do too much work yourself and only do what you can do rather than what you want to do.
- Mood swings are common after surgery. Some people find they are more emotional or irritable than normal. Please don't worry as this will gradually get better.
- Some people have nightmares or flashbacks after surgery. It can help to talk about them or to write down what you remember. If these worry you please talk to the PEA nurse.
- Fluid retention (ankle swelling) is common for a while after surgery. If you feel this is not improving or is getting worse please contact your GP.

- Take your painkillers regularly. When you feel comfortable you can start to wean yourself off them. See page 7 for information on how to do this.
- If you are on warfarin, it is very important to keep your INR within your target range so remember to get your warfarin level checked regularly. See page 17 for more information on warfarin.

## Potential complications of surgery after discharge

### Headache

If you develop any of the following signs and symptoms please see your GP immediately or go to the nearest accident and emergency (A&E) department.

- A new headache which does not respond to ordinary pain killers
- A persistent headache which doesn't go away
- Blurred vision
- Confusion or drowsiness
- Slurred speech
- Feeling sick
- Balance problems
- Droopy eyelid.

Very occasionally in the first few weeks after PEA surgery some people have a bleed between the brain and the protective layer that covers it (subdural haematoma) or a bleed within the brain. If a bleed is suspected you will need a computed

tomography or CT scan of your head. If a bleed is found you will need to stop your anticoagulation medicine for a few weeks until the risk of bleeding has stopped. In most patients the clot will gradually reabsorb itself without the need for an operation. In rare cases, patients may need an operation to remove any clots that have formed and/or to stop the bleeding.

If you develop a bleed while you are still in hospital, your anticoagulation medicine will be stopped and the surgical team will explain to you the plans for repeating the head scan and restarting your anticoagulation therapy. The physiotherapist will assess your mobility and will plan continued support in the community if you have any mobility issues following the bleed.

If an operation is needed to remove a blood clot, you will be transferred to another hospital under the care of a neurosurgeon.

### Increasing breathlessness

If you find that you are getting more and more breathless, please see your GP straight away, especially if you also have any of the following symptoms:

- Fast irregular heartbeat that you haven't had since surgery
- Worsening ankle swelling or swelling of the tummy
- Feeling much more faint or dizzy
- Chest pain — different from wound pain
- Feeling cold and clammy or sweaty
- Not passing much urine.

### Fluid around the heart

Occasionally, in the first few weeks after surgery some people develop a collection of fluid or blood in the sac surrounding the

heart, causing pressure on the heart; this is called a cardiac tamponade. If this is suspected an echocardiogram (Echo) of the heart will be arranged and if a cardiac tamponade is found you may need to return to Papworth Hospital to have the fluid drained. Your anticoagulation medicine may need to be stopped for a short while. Please ask the doctors who see you to call the surgical team at Papworth Hospital for advice.

## Weaning off painkillers

Remember, pain is a very individual thing and so you shouldn't compare yourself with anyone else. You can cut down the painkillers when you feel you are ready. First, try missing the lunch time dose of the stronger painkillers. If you quickly become uncomfortable or can't cough, deep breathe or walk about go back to your full dose and try again in 2 or 3 days.

If you are comfortable without the lunchtime dose after 3–4 days, try missing the teatime dose. Then drop the morning dose and finally the dose at night. After this, start cutting down the paracetamol in the same way. Keep doing this until you are off all of your painkillers. If at any point you begin to have more pain go back a step and try again 2 or 3 days later.

## Mobility, activity and exercise

Now that you have had your operation your body will gradually be able to cope with more exercise. Your muscles may be weak at first and so need exercise to increase their strength. You may not have been able to exercise for months or even years, so your increase in activity needs to be made slowly. Your physiotherapist will discuss this with you as everyone has a different rate of progress.

## Why should I exercise?

You need to keep yourself fit and healthy to make your quality of life as good as possible. Fitness is being able to do everything you need to do in everyday life without getting short of breath. If you continue with regular exercise, your fitness will improve. The golden rule is to start exercising gently, to build up gradually and to do it regularly. Regular exercise will:

- Make you feel more healthy
- Help you feel more confident and help with weight control
- Strengthen your heart, keep it healthy and improve your circulation
- Keep your blood pressure and blood cholesterol levels down
- Reduce your risk of osteoporosis (brittle bones)
- Help to reduce stress
- Give you more energy so you can do more and get back to work and hobbies
- Assist your body's natural immunity to fight infections.

## How often should I exercise?

You should aim to do some exercise every day. As before, the golden rule is to start exercising gently, to build up gradually and to do it regularly.

## How should I start exercising?

While you are in hospital you will begin exercising gently on the ward under the supervision of your physiotherapist. At first this will be based on walking and will progress to climbing stairs. Your sessions will be tailored to your individual needs. As you gain confidence you will be encouraged to increase the distance and/or the speed that you walk.

## How hard should I push myself?

You should aim to gradually increase your exercise and the best guide is the level of breathlessness you feel. You should feel comfortably breathless when you are exercising, but still able to talk — “walk & talk”.

The intensity and length of time you exercise after your surgery will depend on how you have responded to the operation, the success of the operation, your level of activity and fitness before the operation and if you have any other illnesses.

You may like to use the scale below to measure how hard you are exercising. Your physiotherapist will advise you on the right level for you to be exercising at, usually around 9–12.

Scale	Description
6	No exertion at all — at rest
7	Extremely light (7.5)
8	
9	Very light: This is a comfortable level to be walking at. You should still be able to “walk and talk”
10	
11	Light
12	
13	Somewhat hard exercise. You should not be going higher than this
14	
15	Hard (heavy)
16	
17	Very hard, is very strenuous
18	
19	Extremely hard
20	Maximal exertion

## Exercising at home

Walking is one of the best ways to exercise and increase your fitness after your operation. You can start this as soon as you get home.

When you begin, take two short walks a day starting with the distance or duration you have been walking in the hospital with your physiotherapist. Gradually increase the distance and pace of your walk or the time you are walking for. As the distance or time of your walk increases, you will be able to take one longer walk instead of two short walks.

Remember, you should walk at a pace that makes you slightly short of breath. If you get excessively short of breath (unable to walk and talk) you are probably doing too much.

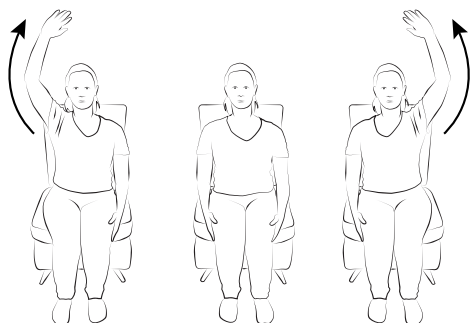
Once at home it is sometimes difficult to stick to an exercise programme. The key is to set yourself goals that mean something to you and your family. Do your best each day and adjust how much you do to how you feel. Most importantly keep a record so that way you can see your progress. Make sure to reward yourself when you achieve your goals. By involving your family and friends in exercise they can encourage you when you're not in the mood and you will be doing them a favour by getting them fitter too!

**If you feel dizzy, have excessive sweating, palpitations, chest pain or are excessively short of breath whilst exercising you should stop and seek advice before you continue.**

## Flexibility exercises

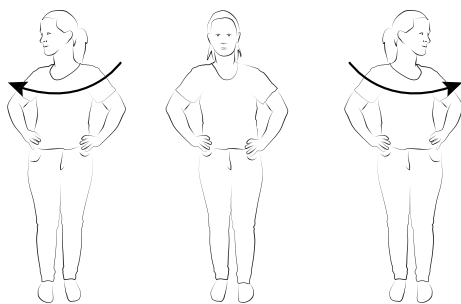
As well as improving your overall fitness, you will find that you will also benefit from doing a few simple stretches every day to increase your flexibility. These exercises target your chest and shoulder region, which can be stiff and uncomfortable after your operation.

### 1. Reaching up to the ceiling



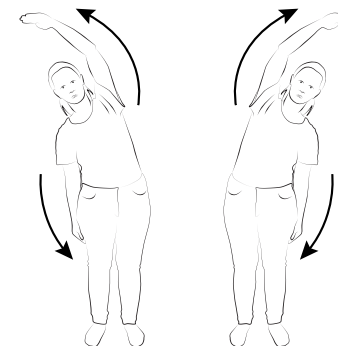
Sit down on an upright, firm chair or stand if you can, stretch one arm as far above your head as you can. Try and push gently towards the ceiling and then lower it again, repeat with the other arm. Repeat slowly five times.

### 2. Turning around to look behind you



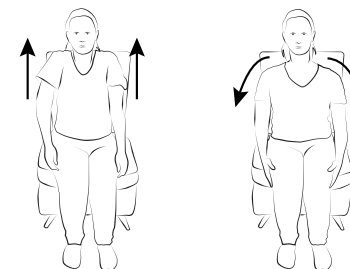
Sit down on an upright, firm chair or stand up if you can. Keep your hips and feet facing forwards then turn your head and body as far as you can comfortably go, first to the right and then to the left. Repeat slowly five times.

### 3. Bending side to side



Stand up with your feet slightly apart and your hands by your sides. Slowly slide your left hand down towards your left knee, so that you bend from the waist, (try not to twist your body as you do this). Repeat with the right hand sliding down to the right knee. You should feel a gentle and comfortable stretch down the side of the chest, no more than this. Repeat slowly five times on each side.

### 4. Shrug shoulders up and down.



These stretches should NOT be painful. Stretch to a point of comfort and hold for 30 seconds. Do not bounce or hold your breath. You can start these exercises while you are still in hospital. Continue to do these exercises three times a day for as long as you feel your chest movement is limited.

## Chest wound healing

Following surgery it is natural to have new aches, pains and stiffness in your chest, back and neck areas as bruising appears and your breastbone heals. It is important that before starting any exercise programme you remember that although your skin may have healed your breastbone will take up to 12 weeks to heal fully.

To protect your breast bone during this time AVOID heavy lifting, pushing or pulling and crossing your arms across your chest. You should avoid lifting anything heavier than 5 lbs or 2.2 kg. Things to avoid for at least the first 6 weeks after surgery include lifting children, vacuuming, mowing the lawn, digging, pushing supermarket trolleys, carrying shopping, walking dogs on leads, driving or ironing. You can gradually restart doing these things after 6–8 weeks. By 3 months after surgery you should be able to do what is expected of others in your age group.

The muscles in your chest will also take time to return to normal, so to avoid any delay in the healing process it is important not to do any heavy activity involving your arm in the first 12 weeks after surgery. At first you may find it easier to sleep lying on your back. You can lie on your side when you can do so comfortably, but remember not to use your arms to move into a side lying position.

If you need any advice on exercise and wound healing after discharge please phone 01480 364215 (Physiotherapy Department at Papworth Hospital) or ask to speak to the physiotherapist at your next Papworth Hospital clinic appointment.

## Breast bone clicking

If you notice your breast bone is clicking, take extra care not to put pressure on your chest. Support your breast bone with a

rolled towel while coughing and avoid any activity that you think has caused the breast bone to click. Please see your GP who may suggest that you need a chest X-ray.

## Advice for female patients

Women are advised to wear a bra 24 hours a day for up to 6–12 weeks after surgery to provide support and allow the sternum to heal without being pulled. A soft sports bra may be more comfortable. After open heart surgery most women find their chest size, not cup size, increases. In addition, reaching around to fasten the clasp behind the back may be painful. A front closing bra without underwire will probably be the most comfortable, you may also find it helpful to buy bra extenders rather than buying a larger size.

## Wound care

Dissolvable stitches (sutures) are used in most wounds and these will disappear as you heal. However, you will have one stitch per drain on your tummy that is usually taken out before you are discharged from hospital but it can be taken out by your GP or district nurse once you are home, if necessary.

## Going home with existing wound issues

If your wound is still a little weepy when you go home, you will be referred to your local district nurse to get the dressing changed either at your GP surgery or in your own home.

## Wound issues after been discharged

If after going home your wound begins to ooze, becomes red or angry looking, or hot and tingly, or you become feverish you need to contact your GP for advice.



A number of patients notice a hard, spiky or mobile lump above the top of their wound. This is a stitch which has been knotted a number of times. In most cases the muscle will grow over the lump over the next 3–6 months and you will no longer be able to feel it. If the stitch pokes through the skin ask your district or GP practice nurse to snip it off for you. Please don't be tempted to do this yourself.

### Ongoing wound issues

Some patients find that as the wound heals it forms red, lumpy, raised areas above the level of the surrounding skin. The scar and surrounding skin can be itchy, sensitive and irritable. This is known as hypertrophic scarring and is caused by the over production of collagen while your skin is healing. Your district nurse or nurse at your specialist centre will monitor this. They may use Mepiform dressing to soften the scar and reduce its size. The scar can be reviewed at Papworth Hospital at your visit 3–6 months after surgery.

### Oxygen in hospital and at home

Following PEA surgery it is normal for your oxygen levels to be lower than normal while your body heals and adjusts. This can make you breathless but should improve with time and as you build up your level of fitness through exercise.

During your recovery, the oxygen level in your blood will be monitored while you are resting and exercising. Most patients will be weaned off supplementary oxygen gradually. However, some people may still require some supplementary oxygen and you may still need it once you're at home.

Oxygen at home can be arranged for you if it is needed. You may only need supplementary oxygen when walking or exercising. Sometimes you may need oxygen while you sleep

and for periods of time while you are resting during the day. Your nurse and physiotherapist can give you advice about when and how to use the oxygen prescribed.

It is important to follow any advice you have been given about oxygen while in hospital and this advice will be reviewed at follow up appointments.

Your need for oxygen will be reviewed by your GP, referring PH centre, local clinic or back at Papworth Hospital because it is normally only needed for a short time. If you have any questions about oxygen we recommend that you speak to your PEA specialist nurse at Papworth Hospital.

### Nutrition

Loss of appetite is common after an operation. Some patients find their appetite improves within a few days, but for others it takes a little longer. It is important to try to eat a healthy diet because poor eating can lead to:

- Increased risk of infection
- Delayed wound healing
- Increased risk of pressure sores
- Loss of muscle tissue and weakness
- Increased risk of postoperative complications
- Depression
- General weakness and illness, which can further reduce your appetite and your physical ability to eat, making poor nutrition even worse.

Eat healthy balanced meals that provide vitamins, proteins and carbohydrates which will promote wound healing. Avoid using too much salt if your ankles are swollen and you are on

a restricted fluid intake. It is also important to watch for weight gain after your surgery, because unwanted weight gain may reduce or limit the amount of exercise that you can do.

## Anticoagulation

You had the PEA surgery to clear blockages in your pulmonary arteries caused by clots. Anticoagulants are medicines that stop your body forming new blood clots and stop existing blood clots getting bigger. You will need to take anticoagulants for the rest of your life to prevent further clots that may block your pulmonary arteries again.

## Warfarin

Warfarin is the most common anticoagulant and the INR blood test is a measure of how well it is working. The results of these INR tests will help your doctor or warfarin clinic decide the correct dose of warfarin to be taken each day. After surgery we recommend that you have an INR in the same range that was set by your anticoagulation clinic or GP before your surgery. Because warfarin takes several days to build up in the bloodstream, an injection of an anticoagulant called subcutaneous heparin, which has an immediate effect, is used until the blood is thinned fully by warfarin. After initial treatment with both drugs, warfarin is usually continued alone.

It is very important to prevent further clots forming by taking warfarin at the correct dose, keeping the INR level above 2 and taking subcutaneous heparin injections (e.g. Clexane) when the INR falls below 2 in addition to increasing the warfarin dose. You may have to have frequent blood tests for 4–6 weeks when you first leave hospital until your INR becomes stable and after this you may be advised to test less frequently.

The PEA nurse will give you a letter for your GP that explains how to manage warfarin after your surgery. You will also be given copies of this letter to give to your anticoagulation clinic and for your own future use. It is crucial, and your responsibility, to make sure you give this letter to your GP and to the relevant team who look after your INR and go for regular INR blood tests. It is important to realise that no two people are the same and you may need a higher or lower dose of warfarin to achieve the correct INR range.

## What should I avoid whilst on warfarin?

Some food and drink can affect your warfarin level as they contain vitamin K. Vitamin K is used by the body to produce factors that control blood clotting. Eating foods high in vitamin K will reduce the effect of the warfarin making your blood clot more rapidly. A diet low in vitamin K will enhance the effect of the warfarin making your blood clot more slowly and increasing the risk of bruising or bleeding.

Vitamin K is particularly found in leafy green vegetables and root vegetables. The key is to try to eat a similar amount of vitamin K each day as a sudden change in the intake of vitamin K can affect the action of warfarin.

Foods high in vitamin K include: asparagus, avocado, blue cheeses, broccoli, Brussels sprouts, cabbage, cauliflower, chickpeas, chives, cranberries, green beans, green tea, kale, lettuce, liver, mayonnaise, parsley, rapeseed oil, soybean oil, spinach, spring onions and watercress.

Remember, it is only when you eat these foods in excess or only occasionally that they cause problems. The trick is to eat small amounts from this list regularly. Big changes in diet, such as 'crash' dieting or suddenly becoming vegetarian, can also affect your warfarin control.

There are also a number of medicines, herbal remedies and food supplements (e.g. garlic capsules, vitamin E capsules and cod liver oil capsules) that can affect your warfarin level. In some cases the medicine or supplement should not be taken with warfarin, in other cases it may be fine to take the two at the same time, as long as your warfarin level is checked more frequently (at least to begin with) and adjusted accordingly. It is important to check with your pharmacist before starting any new medicine, herbal remedy or food supplement to make sure that it is safe.

A moderate amount (up to three units per day) of alcohol is allowed. However, binge drinking will cause problems with your warfarin level and must be avoided.

### What else do I need to know?

You may notice that minor injuries take longer to stop bleeding. If any unusual bruising occurs or you have nosebleeds or you notice blood in your urine or stools you must tell your doctor.

As with all medicines, you must keep warfarin away from children and store it in a clean dry dark place.

For more information on warfarin visit [www.anticoagulationeurope.org](http://www.anticoagulationeurope.org)

## Diuretics

### What are they?

Diuretics are medicines that get rid of excess fluid (ankle swelling) and you may have been taking these before your surgery to help stop further damage to your heart. They are also known as 'water tablets' and work by increasing the amount of urine that your body produces which reduces the volume and work load of the right side of your heart.

You may have to continue using diuretics after your surgery to help the right side of your heart while it is recovering its size and function. Diuretics can remove salts from your body in addition to removing water. You may need to contact your GP to check your blood for kidney function while you are taking diuretics. The dose of diuretic and the fluid restriction can be reviewed or stopped by your GP or your specialist centre based on your kidney function and improvement in swelling in your feet.

Commonly used diuretics are Furosemide, Bumetanide, Amiloride, Spironolactone and Metolazone.

### What side effects do I need to be aware of?

Usually diuretics are very well tolerated (although some people find that frequent trips to the toilet can be annoying!); however, rarely side effects can occur. Side effects include:

- Nausea, vomiting, diarrhoea, indigestion, headache, rash
- Dehydration, dryness of the mouth
- Low blood pressure
- Changes to levels of potassium and/or sodium in your blood
- Gout
- Painful breasts or breast enlargement in men on Spironolactone (this is reversible)
- Raised blood sugar levels.

This is not a full list of side effects. For more information see the patient information leaflet that came with your medicine. If you notice any side effects (whether in the list above or not) please contact your GP.

## What else do I need to know?

You may find that you have the urge to go to the toilet soon after taking your medicine. For this reason it is recommended that you take your diuretics early in the morning so that you pass extra fluid early in the day leaving you free to go about your usual daily routine. If your GP asks you to take two doses per day, the second dose is usually at midday or early afternoon. You can delay your dose(s) until later in the day, but the later you take your dose, the more likely it is that your sleep may be disturbed by trips to the toilet.

You will require blood tests from time to time, to check the levels of potassium and sodium in your blood and kidney function.

Some patients are advised to stick to a low salt diet and to a 1.5 litre fluid restriction following surgery. Check with your medical team if this applies to you.

## Omeprazole

### What is it?

Omeprazole belongs to a group of medicines called proton pump inhibitors, which reduce stomach acid production. Omeprazole is usually prescribed for patients after surgery to protect against stomach ulcers. Your need for this medicine will be regularly assessed. Omeprazole is usually stopped 4 weeks after surgery, when the initial risk period is over.

### What side effects do I need to be aware of?

Omeprazole is usually very well tolerated. The most common side effects are:

- Skin rash, with or without itchiness
- Diarrhoea or constipation
- Headache
- Nausea and/or vomiting
- Wind or bloating
- Dizziness or feeling faint.

This is not a full list of side effects. For more information see the patient information leaflet that came with your box of omeprazole. These effects usually go away as treatment continues. If you notice any side effects (whether in the list above or not) please contact your GP.

### What else do I need to know?

Omeprazole can interact with a few medicines. If you buy any medicines over the counter at a pharmacy, please let the pharmacist know that you are taking omeprazole so that they can choose the most appropriate medicine for you.

## Amiodarone

### What is it?

Amiodarone is an anti-arrhythmic medicine that helps to steady your heart rhythm. It is common for patients to have irregular heart rhythms for a few weeks after surgery. Amiodarone is prescribed only for a few weeks while your heart is recovering from the irregular heart rhythm and for most patients who are started on amiodarone it will be stopped 6–12 weeks after surgery. Amiodarone can affect your thyroid gland so it is important that you contact your GP to get thyroid function tests done. The need for treatment with amiodarone will be decided

by your PH doctor at the time of your follow up visit. You can also ask advice from your local cardiologist or PH specialist centre.

### What side effects do I need to be aware of?

The most common side effects of amiodarone are:

- A slow pulse
- Sensitivity to sunlight (including sunburn and/or skin discolouration). This may continue to affect you for some time after stopping amiodarone
- Problems with your thyroid
- Difficulties with your vision
- Nausea, vomiting and taste disturbance
- Shakiness
- Nightmares and disturbed sleep
- Breathing problems, including persistent cough or shortness of breath or fever
- Liver disorders (including yellowing of eyes or skin).

This is not a full list of side effects. For more information see the patient information leaflet that came with your box of amiodarone tablets. If you notice any side effects (whether in the list above or not) please contact your GP.

It is important to know that amiodarone can stay in the blood for many weeks after you stop taking it. This means that side effects and interactions that occurred while you were taking amiodarone may continue even after you've stopped the drug.

It is also recommended that you cover up when out in the sun and apply a high (15+) SPF factor sun cream to avoid sunburn and skin discolouration while taking amiodarone. You may need to continue to do this for a few weeks after stopping amiodarone.

### What else do I need to know?

Amiodarone can interact with a number of medicines including warfarin. If you buy any medicines over the counter at a pharmacy, please let the pharmacist know you are taking amiodarone (or have taken amiodarone in the last few weeks) so that they can choose the most appropriate medicine for you.

You may find that the amount of warfarin you need to take changes while you are also taking amiodarone.

### Resuming daily activities

Most people find that it takes around 3 months after surgery for them to make a full recovery but this will depend on the severity of your breathlessness and any other medical conditions you may have. Age is also relevant, since older patients usually need a longer recovery period than younger patients. As a general rule, do what you can without becoming short of breath and then increase the number and demands of daily activities gradually. The physiotherapist will explain this fully to you before you leave hospital. We do not recommend any form of class-based rehabilitation until you have had your first follow up visit at Papworth Hospital.

### Showering

As your breastbone heals, you should shower daily with your back facing the showerhead. This prevents water from spraying directly on your wound. Do not take long, hot showers. Do not bathe in a tub, hot tub or sauna for at least 30 days or until your wounds are fully healed. Use fragrance-free soap and pat your incision dry when done.

## Housework

Light housework (e.g. dusting or drying up) can be introduced into your daily activities when you feel fit and able to do it, usually within the first 1–2 weeks you are at home. You should avoid heavier housework (e.g. vacuuming) for 6 weeks after surgery.

## Gardening

Light gardening such as weeding may be done 6 weeks after discharge. Things like mowing the lawn and heavy digging should not be done for 12 weeks. This will allow the breast bone to become stronger after healing.

## Driving

You may drive 6–8 weeks after your operation. Your GP will need to agree that you are ready before you start driving again. When you do start driving expect to feel some heaviness or discomfort around your shoulders or arms as you move the steering wheel. It is illegal to drive if you are not wearing your seat belt, but you might find placing a cushion or padding under the seat belt is more comfortable. You must inform your insurance company about your surgery.

## Exercise

Your physiotherapist will give you information about how to build some form of exercise into your lifestyle. Activity makes the heart grow stronger. After 12 weeks, if the wounds have healed, the following may be restarted:

- Bowling
- Fishing
- Walking your dog on a lead
- Golf, but wait 12 weeks before starting the full swing

- Racquet sports and road cycling should not be attempted before 12 weeks. If you have an exercise bike this can be used as soon as you feel able
- Gentle swimming: can be resumed after 12 weeks if the wounds have healed.

## Sleep

It is not unusual to experience a disrupted sleep pattern for around 6 weeks after your surgery.

## Sexual activity

Most doctors suggest waiting for around 4–6 weeks after surgery before starting sexual intercourse again. You may be worried about your wound. If you remain relaxed and possibly adopt a more passive role then you will return more easily to your normal routine.

The assessments you will be having over the first 3 months after surgery will give an idea of the recovery of your heart and lungs, and your doctor will tell you when it is safe to return to more strenuous levels of activity. If you are concerned or worried, do not hesitate to talk to your GP or the staff at Papworth Hospital.

## Contraception

For women, it is very important that contraception is thought about seriously. Almost all patients will be taking warfarin, which can be dangerous to unborn children and can result in birth defects. In addition, becoming pregnant can be hazardous to your own health and so should only be considered after you have fully recovered from your surgery and after considerable discussion with the medical team caring for you. Unfortunately for some women it may never be safe to consider getting pregnant.

The combined oral contraception pill should be avoided as it may increase the risk of new blood clots. The progestogen only pill (“the mini-pill”) may not be sufficient, as some medications may affect its effectiveness but your GP or pharmacist will be able to advise you on this. Other options include condoms, an implant, a coil or diaphragms. You should discuss these options with your GP.

## Going back to work

One of the aims of surgery is to return people to as normal a life as possible. For many, but not all patients returning to work is an important part of recovering from their illness and there may be pressure for you to do so financially. Depending on the type of job you had before, this may not be possible for everyone. You should not under-estimate how tiring and stressful work can be and returning too early may compromise your physical health and self-confidence.

You should not expect to go back to work before 3 months after your surgery. You can check with your GP or referring PH centre or seek advice from your occupational health adviser in your work place before going back. Generally, we recommend that you speak with your employer as early as possible and plan to restart with part-time work at first.

You will have a full assessment of your PH condition and the benefit of your surgery at the time of your first review at Papworth Hospital (around 3–6 months after surgery). You can talk to the medical team at this time if you have any worries about returning to work.

Jobs that require heavy lifting or strenuous activity should be avoided for at least 6 months after your surgery. Jobs in which there is a higher risk of injury that may result in bleeding should

also be avoided. Jobs that require prolonged standing, resulting in leg swelling, should also be avoided or modified.

If you are unable to go back to work, we will try to advise you as to how to get any benefits you are entitled to. The medical team involved in your care may need to write to Disability Support advising them of your condition.

## Flying

Following surgery most people are able to travel by air but some may need a ‘flight assessment’ to check if oxygen will be needed during the flight. This can be arranged locally in agreement with your referring PH centre.

## Travel costs and benefits

### Travel costs

For your follow up visits you will have to make your own way to Papworth Hospital. If you need assistance with transport please contact your GP to arrange this. If you are receiving certain low-income allowances, e.g. Income Support or Family Credit, you may be entitled to help with your travel costs. If you need someone to travel with you for medical reasons, you may also get help with their travel costs. Travel costs payable are those “necessarily incurred”. This means travel by the cheapest means of transport available at the time you need to travel.

For example:

- Public transport fares
- Mileage allowance if travel is by private car

- Contribution made towards transport provided by a local voluntary car scheme or similar arrangements.

Taxi fares will be reimbursed only if there is no other way for you to travel for all or part of your journey. If you have any queries about the help you can get with your travel costs, please contact the Finance Officer at Papworth Hospital on **01480 830541 ext 4276** before you travel.

To claim your travel costs you or your next of kin should see the Finance Officer (situated close to the Main Reception) each time you come for treatment at Papworth Hospital. You will need to bring with you the correct information (e.g. benefit book or letter of notification of your entitlement to Income Support or Family Credit). If you do not bring evidence of entitlement you will have to claim a refund using form HC5. The form will tell you what to do and you can get a copy from the Finance Officer. The Finance Office is open from Monday to Friday, 8.30 am to 12 noon and 12.30 pm to 4.30 pm.

### On state pension or benefit

If you receive any state benefit, e.g. Income Support, Incapacity Benefit, Disability Living Allowance, Attendance Allowance or Retirement Allowance, please follow the instructions given in your benefit book under “Admission to hospital”. You will need to have your benefit books with you when you go on hospital visits.

## Follow up visits

After surgery you will have follow up appointments to assess how well you are recovering. Most of these will be at your referring PH centre, but the 3–6 month and 1-year appointments will be at Papworth Hospital. If the PH team at Papworth referred you for surgery then all your follow up appointments will be at Papworth Hospital.

The following is a rough guide to what will happen at your follow up visits at Papworth Hospital. Tests may vary according to your condition and your doctor’s discretion. Your local PH centre will also arrange for your follow up review.

Time after surgery	Where is the visit?	What will happen?
1–2 weeks	Phone call from PEA nurse	Assessment of your recovery and advice on any issues you may have
3–6 months	Papworth Hospital	Blood tests, ECG, chest X-ray, echocardiogram, lung function test, 6 minute walk test, right heart catheterisation, CT scan and/or MRI
12 months	Papworth Hospital	Either as day case or inpatient for a couple of days depending on tests needed



## Useful contact numbers

PEA nurse	01480 830541 (for emergencies Bleep 785)
	01480 364952 (voicemail)
PVDU co-ordinator	01480 364708
Pharmacy helpline	01480 363739
Physiotherapy	01480 830541 - extension 4215
Social worker	01480 830541 - extension 4279

## Notes:

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