

Online Appendix 13 Sample patient information leaflet: Indwelling pleural catheter

Indwelling pleural catheter insertion

Please come to _____

On Date _____

At Time _____

Medication changes _____

How to prepare for the appointment

- You may be asked to not eat or drink anything for 6 hours before your procedure. You can take any medicine you need to have with a sip of water up until 2 hours before your procedure.
- Tell your doctor about all the medication you take and any medical conditions you have, as well as any drug allergies you have.
- It is important that your doctor knows about any blood thinning or diabetes medications – these are normally stopped before your procedure. It is important that you continue to take any other medications (including those for high blood pressure).
 - Medications that ‘thin the blood’, e.g. Rivaroxaban, Dabigatran, Apixaban, Edoxaban, Dalteparin, Clexane or heparin injections, Warfarin, or Clopidogrel: these must be discussed in advance with your hospital doctor so that he/she can provide you with further advice. In general, these medications must be stopped or withheld before an indwelling pleural catheter insertion can take place.
 - There is no need to stop aspirin before the procedure.
- Arrange for someone to bring you in and take you home from the procedure. You should also not be alone overnight after your procedure.
- If you are given sedation medicine during the procedure, for 24 hours after the procedure you should not drive, return to work, operate machinery, drink alcohol, sign legal documents or be responsible for small children.
- Please make sure we have your correct telephone number. We may need to contact you by telephone before your procedure to confirm that you are still able to come or to inform you of any changes in your appointment.
- Please let us know if you may be pregnant, as this may affect the medications we use for the procedure.
- Please bring all of your medications with you when you come for the procedure. You should also bring any glasses that you need for reading. Please do not wear jewellery or nail varnish or bring in any valuables.

What is an Indwelling Pleural Catheter (IPC)?

An IPC is a specially designed small tube used to drain fluid from around your lungs (between your lungs and your rib cage, called the pleural space) whenever needed. It avoids the need for repeated uncomfortable injections and chest tubes every time the fluid comes back. The drainage can be performed either by you or a friend/relative, or by a district nurse, whichever suits you.

The IPC is a soft flexible tube, thinner than a pencil. One end is inserted in the pleural space, the middle segment of the tube is tunnelled under the skin for a few centimetres, and the other end of the tube passes out through your skin. There is a valve on the outer end of the tube to prevent fluid leaking out, and the valve can be connected to a vacuum bottle to drain the fluid when needed. The fluid is not drained continuously, so when it is not in use, the valve is covered by a cap and the external section of the tube is curled up under a dressing.

Why do I need an IPC?

There are two layers of membrane just outside your lung – one lining your lung, and the lining your chest wall. The space in between these two layers is usually almost dry, and called the pleural space. In your case, fluid has collected in this space so that your lung cannot work properly, making you breathless.

Draining away the fluid using needles and syringes helps relieve breathlessness for a short time, but the fluid will often re-collect, making you breathless again. Whilst it is possible to have repeated drainage of fluid in this way, it can be uncomfortable and means many trips to hospital for it to be done. The IPC is a way of allowing fluid to be drained repeatedly at home, without you having to come to hospital to have repeated procedures with needles to drain fluid.

What will happen on the day?

When you arrive, you will be met by a nurse, and have your blood pressure, heart rate and temperature checked. You will also be asked questions about your medical history, medications and any allergies you might have.

The nurse or doctor may insert a cannula (tiny plastic tube) into a vein in your hand or arm, in case we need to give you medication during the procedure.

The procedure will be explained to you again and you will have the opportunity to ask any questions you might have. You will be asked to sign a consent form if you have not done this prior to the appointment, to confirm that you are happy for the procedure to go ahead. You will then be asked to change into a hospital gown.

When your IPC insertion is due to start, you will be shown into the procedure room and will be asked to lie on a couch. Your blood pressure, oxygen levels and heart rate will be monitored using a cuff on your arm, a sensor on your finger and some stickers attached to your chest. You may be given some oxygen into your nose or mouth to keep the oxygen in your blood at a safe level.

If you are uncomfortable during the procedure, we can give you sedation medication into the cannula to make you feel sleepy, although we do not normally need to do this.

The doctor will do an ultrasound scan to find where best to place the IPC. This involves putting gel onto your chest and using a hand-held device to roll over your skin. The ultrasound uses sound waves to create an image on a screen. It is not painful.

The IPC is usually put into the side of your chest, below your armpit, as this will be more comfortable for you and means you will be able to sleep on your back afterwards.

Once you are resting comfortably, the skin over the area where the IPC will be placed will be cleaned with an alcohol based liquid to kill any bacteria. This fluid often feels cold. A local anaesthetic will then be injected into your skin to numb the place where the IPC will go. This may sting to begin with, but the pain will disappear quickly.

Your doctor will then make two small cuts (incisions) in the numb area of skin and gently open a path for the IPC. This should not be painful, although you may feel some pressure or tugging. One cut is for the IPC to

pass through your skin, and the second is for it to be passed into your pleural space. The IPC will then be inserted gently.

What happens after the procedure?

The IPC insertion procedure usually lasts between 30 and 60 minutes. Afterwards, you will be monitored and have a chest X-ray to confirm the IPC is in the correct place.

After a short stay on the day ward, provided your X-ray is satisfactory and you feel well, you will be free to go home. If you have a cannula in your hand/arm, this will be removed by a nurse before you leave.

It is essential that someone accompanies you home, either driving you home or traveling with you in a taxi. You should not go home on public transport after this procedure. You will need to be taken home by car. This will be more comfortable for you and also quicker for you to return to the hospital if there are any complications on the journey home. You should also not be alone overnight after your procedure, even if you haven't had sedation, in case you feel unwell.

If you were given any sedative medication during the procedure, you should not drive, work, operate machinery, drink alcohol, sign any legal documents or be responsible for small children for 24 hours after the procedure. This is because the sedation can affect your judgement and behaviour slightly (even if you think you are feeling fine).

What are the risks?

In most cases, the insertion of the IPC and its use is a routine and safe procedure. However, like all medical procedures, IPCs can cause some problems. All of these can be treated by your doctors and nurses.

- Most people get some discomfort from their IPC in the first week. You can take simple painkilling medication to control this.
- Sometimes IPCs can become infected and need treatment, but this is uncommon (affecting about 1 in 50 people). Your doctor will thoroughly clean the area before putting in the IPC, to try to prevent this. You will also be taught how to keep your IPC clean. Tell your doctor if you have any problems such as fever, increasing pain or redness around the IPC.
- Very rarely, during its insertion, the IPC may accidentally damage a blood vessel and cause serious bleeding. This only affects less than 1 in 500 people. Unfortunately, if this does happen it can be a serious problem which will require an operation to stop the bleeding. Very, very rarely such bleeding can be fatal. During the procedure everything possible will be done to avoid this.

What should I look out for when I am at home after the procedure?

- After the procedure your chest may feel bruised or sore for about a week. Simple painkilling tablets, such as paracetamol and ibuprofen, are usually enough to relieve this discomfort.
- Contact your doctor if you have increasing chest pain, fever or any redness around the IPC, or if you are concerned the IPC has become dislodged.

Are there risks associated with long-term IPC use?

Generally IPCs are very well tolerated in the long-term.

- The main risk is infection entering the chest through the IPC. This risk is reduced by carrying out good IPC care and hygiene. We will teach you how to look after your IPC, to help prevent an infection.
- Sometimes, IPCs are used to manage pleural fluid collections caused by cancer. If this is the case, very rarely cancer tissue can grow in the area around the IPC. Please let your doctors know if you develop a lump or any pain around your IPC in the weeks and months after it is inserted. If this problem does develop, your doctor will advise you on appropriate treatment.

How does the IPC stay in place?

IPCs are designed to be a permanent solution to the problem of pleural fluid (although they can be removed if they are no longer needed). There is a soft cuff around the tube which is positioned under your skin, and the body makes scar tissue around this. This keeps the IPC in position and prevents it from falling out.

Two stitches will be put in when your IPC is inserted. The stitch which has been used to close one of the incisions used to insert the IPC will need to be removed after seven days, whilst the other stitch (the stitch which holds the IPC securely in place) should be removed after three weeks. These stitches should be taken out by your GP's nurse.

Drainage of the fluid is a straightforward procedure. There are a number of ways that this can be done. Usually we arrange for a district nurse to come to your home to perform the drainages. We will make these arrangements so you will not need to organise any of this for yourself. If you would like, the district nurses will be able to teach you or a relative/friend how to drain the fluid.

We will discuss these arrangements with you further before you are discharged after the procedure.

How often should I drain IPC?

When your IPC is inserted, most of the fluid from your chest will be removed at the same time. The rate at which the fluid comes back varies; some people need daily drainage whilst others require only weekly drainage or less.

You can drain fluid as often as is needed. We will discuss with you how often this may need to be done.

How will drainage bottles be supplied to me?

Your local district nurses will order catheter drainage bottles to be delivered directly to your home address. These will usually arrive within 2-3 days of your clinic appointment and in plenty of time for your catheter placement appointment. You will also receive a booklet to record how much fluid is drained. It also contains useful advice about how to care for your drain and what to do if there's a problem with it. It is sensible to take 2-4 bottles with you if you are ever admitted to hospital in the future to ensure that there are no delays in your pleural drainages while you are an inpatient.

Can I wash and shower normally?

Initially, after the insertion of the IPC, you will have a dressing covering the area where the IPC comes out of your side. We advise you to keep this dry for 1-2 weeks after the IPC is inserted, and during this time your ability to shower normally may be slightly restricted. Providing the site is then clean and dry, you will then be able to have a bath and shower as you would normally. After a month it is even possible to go swimming, as long as you are healing well and as long as the dressings and area around the IPC are kept clean (the dressing may need to be replaced afterwards). It is advisable to time swimming/bathing with drainage of fluid, so that after wetting the dressing, the wet dressing can be removed, IPC drained, and a clean dry dressing applied, minimising the duration of the wet dressing remaining in contact with the skin and IPC.

When will the IPC be taken out?

IPCs are designed to remain in position for as long as they are needed. However, sometimes the fluid drainage from the chest dries up and the IPC is no longer needed. In this situation the catheter can be removed. You or your district / community nurses would let us know when the IPC has stopped draining, and we will organise a date for you to come back to hospital to have the IPC removed as a day case procedure (that is, you go home the same day of the procedure).

The removal of the IPC is usually quite straightforward. You will be asked to lie on your side (just like you did when it was inserted) and the skin will be cleaned thoroughly. Local anaesthetic will be injected around the cuff and exit site of the catheter, which may sting to start with but the stinging wears off quickly. After that, it should not be painful although you may feel some pulling or tugging. The doctor may make a small incision where the indwelling pleural catheter goes under the skin and will use instruments to release the scar tissue

around the cuff. After the IPC has been removed, the hole will be stitched up and covered with a dressing. In rare cases the doctor may need to make an additional hole to help release the drain.

You may need a chest x-ray afterwards and after a short stay on the ward you will be free to go home. The stitch needs to be removed after 7 to 10 days.

The area on the chest where the IPC was may feel sore and bruised for around a week after the IPC has been removed, but this should be controlled with simple painkillers. There is a small risk of infection and bleeding, although this is rarely serious. Very occasionally it is not possible to remove the IPC completely and the tip may be left inside, although every effort will be made to get it all out. If this happens, it only very rarely causes long-term problems such as pain or infection.

What should I do if something happens to the IPC?

If you have any problems with the IPC, or if you have any questions, please contact:
