Cystic Fibrosis Trust

# The use of ports in cystic fibrosis

March 2022

Uniting for a life unlimited

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This information is only meant as a general guide as your own care will be individual to you.

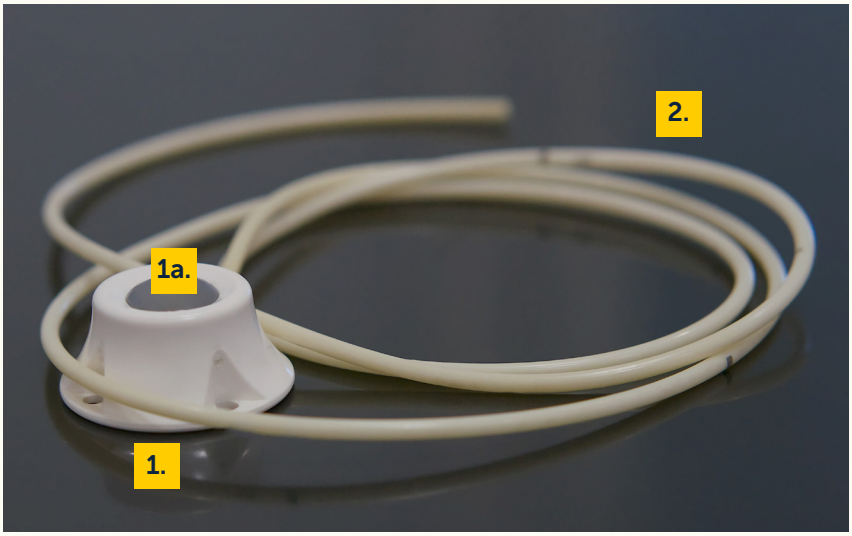
Your CF team will be able to answer any other questions you have about ports.

# Introduction to ports

## What is a port?

A portacath, more often called a port, is a small medical device that sits under the skin to easily deliver medication into the body. A port has two main parts:

- the **portal chamber (1)**, which is made out of titanium (a strong, lightweight metal) with a **silicone centre (1a)**, and
- the **catheter** (2), which is a thin tube connected to the portal chamber that is put into a vein.

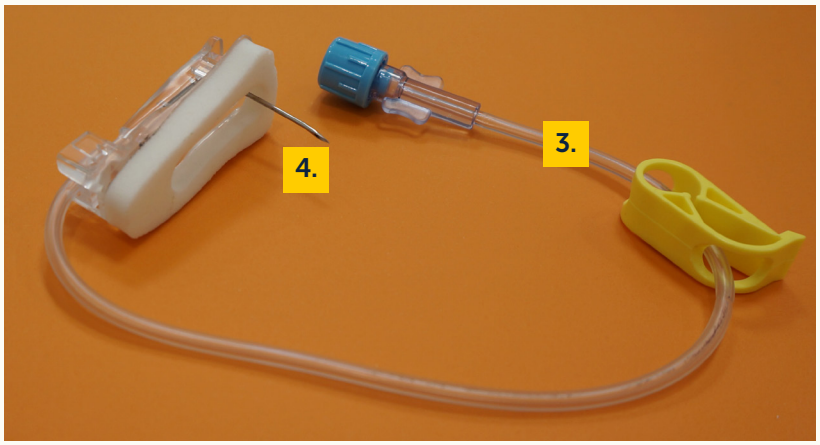



**1.** Portal chamber

**1a.** Silicone centre

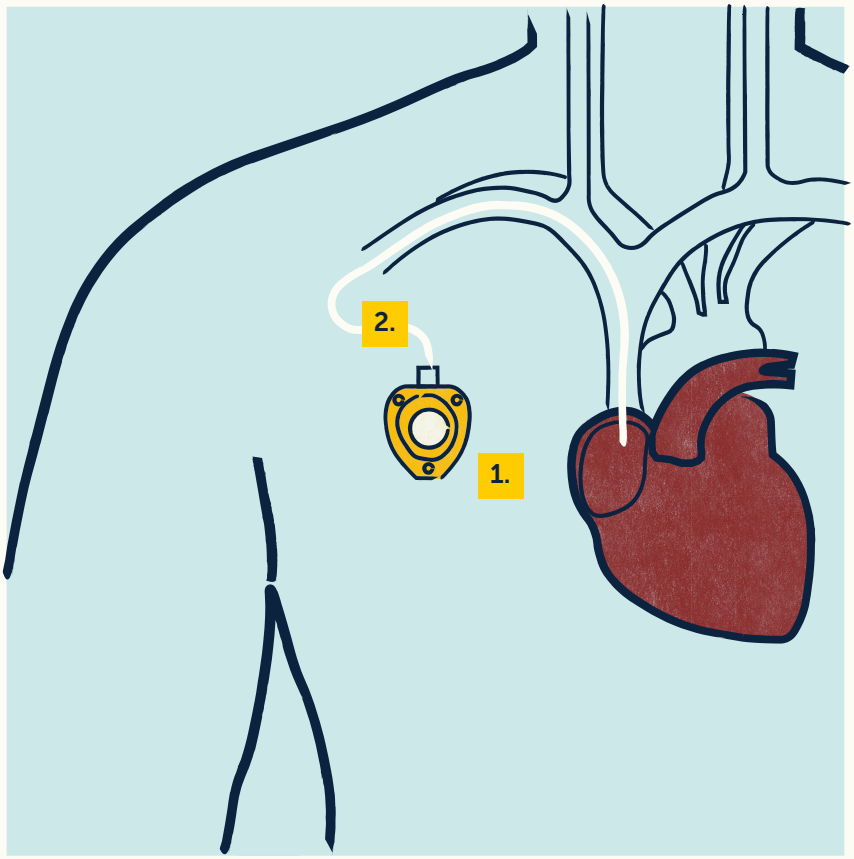
**2.** Catheter

When a person with CF needs intravenous (IV) treatment with antibiotics, the port is connected to **tubing outside the body (3)**. A special **needle (4)** is inserted through the skin and silicone centre and into the portal chamber. The back of the portal chamber is hard, so the needle never goes any further. Medication can then travel from the tubing outside the body straight into a large vein.

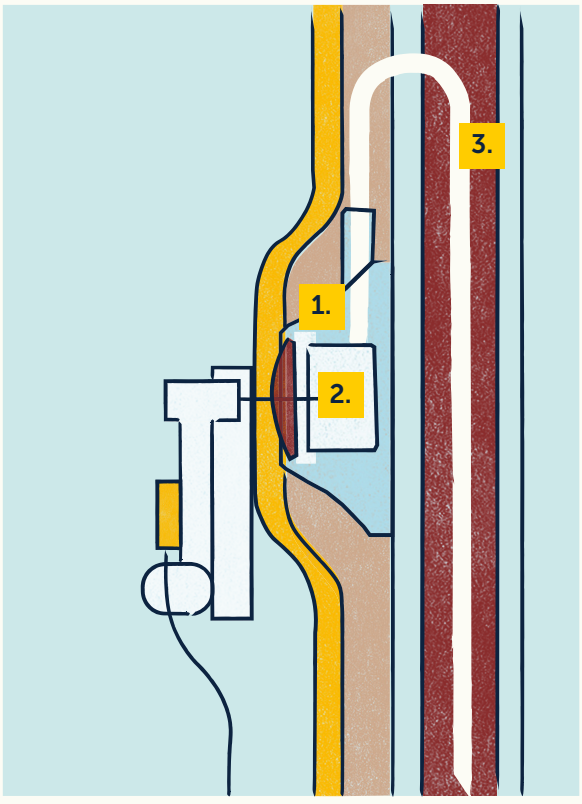



**3.** Tubing

**4.** Needle




1. Portal chamber
2. Catheter




1. Portal chamber
2. Needle
3. Catheter

## Why might I need a port?

You might need a port if you will be having intravenous (IV) antibiotic treatments (where antibiotics are put straight into your veins) very often or over a long time. Ports are also helpful if it has been difficult to use a cannula or long line in the past. This may be because your veins are small or hard to see on the surface of your skin.

You probably won't need a port if your treatment is short-term or if you don't have IV antibiotics very often. Your CF team will let you know if they think a port is a good option for you.

## Getting and using a port

### How are ports put in?

A port is put in with an operation. This is either done while you are under a general anaesthetic (where you are asleep) or using a local anaesthetic (where you are awake but the operation area is numb – you won't feel it). Children will almost always be given a general anaesthetic.

A small opening is made for the catheter to be put into a large vein leading to the heart. The other end of the catheter is then attached to the portal chamber. Another small opening may be made to create a small pocket under the skin for the portal chamber to sit in.

Some people feel well enough to go home the same day, but some stay in hospital. There is likely to be some bruising or swelling over the area and some discomfort after the operation, but this generally disappears within a week. The stitches are usually under the skin and will dissolve on their own.

Some people with CF say that it takes some time to get used to having a port. Your CF team or surgeon can tell you what you can do to take care of the port site while it heals. You can let them know if you are worried about how the port is healing.

**"It took me quite a long time to feel 'normal' with a port. Even though it wasn't in use, I could feel it and was worried about lying on it or straining the area for a year. And I definitely had a little chest pain for a while. Even now I don't lie on my side as much as I can feel it under the skin."**

Rachel, who has CF and a port

## What will the port look like – will I have a scar?

The port and catheter are put in under the skin, so no tubes can be seen from the outside when you are not having IV treatment. Depending on your build and the position of the port, it may be visible as a small bump under the skin or it may not be visible at all.

You will have a small scar up to 5cm long where the portal chamber has been placed and possibly another where the catheter has been put into the vein. Everyone heals differently but most people find the scars are small and fade well. Take a look at page 38 of our **Body image and cystic fibrosis booklet** if you would like tips on how to improve the appearance of scars.

Ports can be placed in different parts of the body but are usually put in the upper part of the chest. Sometimes they can be put in the side of the chest or arm. You can talk to your CF team and the surgeon about where you want the port put in.



Before insertion of needle



With needle in place for treatment

**"When we were considering ports I was obsessed with how it would look and where it would be!"**

A parent of a child with CF

## How will my port be used?

When you need to have treatment, a special needle will be put into your port. This needle is connected to tubing that will be used to deliver medication through your port.

The needle will be covered with a dressing while you are having treatment. and will usually stay in for the whole treatment without needing to be changed, though the dressing may need changing. The needle will be removed when the treatment is finished.

Though treatments are often done in CF clinic appointments, some people and their families choose to be taught how to do their treatments at home. You can find out more about this in our leaflet called **Home intravenous (IV) therapy**. Ports can also be used for blood tests, instead of using veins in your arms.

## Does it hurt to use the port?

You can ask for local anaesthetic (numbing) cream or spray to stop you from feeling pain from the needle. You should check with your CF team whether they can give you this or whether you need to get it prescribed from your GP.

You may still feel a small 'push' or slight sting as it goes in. After a while, your skin may lose feeling over the port area and you may no longer need to use any local anaesthetic.

It shouldn't hurt when the medication is going in, either.

Once the dressing is over your port, you should not feel any discomfort. You can let your team know if you experience any pain.

**"In that first hour or so after the needle goes in, that is the time when there may be a noticeable sensation, but otherwise the actual delivery is painless. It might feel cold but not sore, similar to feeling the cold liquid when using a cannula"**

Rachel, who has CF and a port

## How long will the port last?

A port can last many years. The silicone centre can take between 1,500 to 2,000 needle punctures before it needs replacing, but this can vary between different port sizes and the size of the needles used.

Occasionally ports can stop working properly – this can happen when the catheter is blocked, twisted, or leaking, or it has become infected. This is unusual but can happen after the port has been in for a long time. If this happens the port is removed and replaced if still needed.

## Living with and looking after your port

The whole port is under the skin so you can have baths, showers and go swimming once it has healed and you are not having treatment. You can also continue with most sporting activities. Ports are designed to be long-lasting but you may be asked to avoid contact sports such as boxing, judo and rugby.

While you are having treatment there will be a needle in your port, covered by a dressing. You should avoid getting the dressing wet to help lower the risk of infection. You should also avoid doing any vigorous activity that may dislodge the needle.

Many children and adults continue with education or work while they are having treatment through their port. A member of your CF team will be happy to speak to your school or employers if needed.

## X-rays and MRIs

It is safe to have X-rays or scans when you have a port. You will need to let the radiologist know that you have a port as it will be visible on your chest X-rays.

Some types of port can affect MRI scan images. The radiologist should ask you whether you have any 'implanted devices', and you should tell them you have a port. Your CF team will be able to tell you what kind of port you have.

## What if I no longer need the port?

The port can stay in the body for a long time if it is flushed every four to six weeks. It can also be removed in another operation. You and your CF team can talk about the best options for you.

## Summary

### Who can I talk to about ports?

Many people with CF feel uncomfortable about getting a port – it's ok to feel that way. You can talk to someone from your CF team about any questions and concerns you have.

### What are the overall benefits of having a port?

- Your CF team will be able to start treatment quickly when you need it.
- You will be able to have IV medication painlessly while leaving your hands and arms free from cannulas or long lines.
- The port and cannula are under the skin with no visible tubes outside the body when you are not having treatment.
- As the port is under the skin, there is a low risk of infection or damage to the port.
- You can have baths, showers and go swimming when the port is not in use.
- You or a family member can choose to be taught how to do treatments through your port at home, meaning you will not need to be in hospital.

### Are there any downsides or other things I should think about?

- You will need to have a small operation and may need a general anesthetic to have a port put in.
- The port may be visible as a small bump under the skin. It might take a while to get used to having a port.
- Ports are less suitable for people with CF having short-term treatment or those who do not have IV antibiotics very often.
- You will need to have another operation to take the port out if it needs replacing or you no longer need it.

## Finally

If you have long-term or frequent IV antibiotic treatments, or if having IVs through your veins has been difficult in the past, a port may be a good option for you. You can talk about anything you have read in this factsheet with your CF team. They will be able to answer your questions and you can decide together if a port is right for you.

> **"I really like my port as it took a lot of the stress out of IVs"**
>
> Rachel, who has CF and a port

## Further information

Find more information resources about living with cystic fibrosis at **cysticfibrosis.org.uk/information**.

**Our Helpline** is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

You can contact our friendly team by:

- phoning **0300 373 1000** or **020 3795 2184**

**If you are worried about the cost of the call please let us know and we'll call you back.**

- emailing **helpline@cysticfibrosis.org.uk**
- reaching out on all our social media channels

Visit **cysticfibrosis.org.uk/helpline** for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file. Email **infoteam@cysticfibrosis.org.uk.**

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The information in this resource does not replace any advice from your doctor or CF team. It is important that you seek your team's advice whenever you want to change your treatment.

Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis (CF). We fund vital research, improve care, speak out and race towards effective treatments for all. Cystic Fibrosis Trust is here to make sure everyone with cystic fibrosis can live without limits.

Since 1964, we've supported people with cystic fibrosis to live longer, healthier lives – and we won't stop until everyone can live without limits imposed by CF.

**cysticfibrosis.org.uk**

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