

# Home intravenous (IV) therapy

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## Introduction

People with cystic fibrosis (CF) may sometimes need to have treatment with IV antibiotics. Some people have IVs in hospital, while some do them at home. This factsheet explains how home IV therapy works, and lists the advantages, disadvantages and other considerations for having IV antibiotics at home.

## Should I have IVs at home or in hospital?

Most of the time there are two options for having IV antibiotics:

- 1) Starting your IV therapy in hospital and then continuing at home, or
- 2) Staying in hospital for all of your IV antibiotic treatment.

Your CF team will be able to tell you which of the two options is best for you, considering your own needs and wishes. This might have to change for different IV treatments. Sometimes your team might be happy for you to start your IV antibiotics at home – talk to them to see if this is an option for you.

You and your CF team could talk about:

- your level of health and how stable you feel
- if your family can support you
- whether you need any extra support from your CF team to get the most out of your IV antibiotic treatment, for instance physios
- how far you live from the hospital
- your lifestyle and personal needs
- whether you have a portacath (port) or a PICC (peripherally inserted central catheter) or other type of IV line
- which antibiotics you'll be having, how they will come (pre-mixed or needing preparation) and how they can be given (for instance through an IV ball, drip infusion or IV push)

**If you want to have the option to do home IVs, ask your CF team if you can learn how to do this.**

## How can I start having my IV therapy at home?

If you decide that you would like to have IV treatments at home if possible, your CF team will help you or trusted person such as a family member or a partner learn how to do this. Your team will arrange this. You can ask your team at any point if you'd like another person to learn how to help you with your IVs. They don't have to learn at the same time that you do.

You and your trusted person can learn entirely at your own pace – you may have had IV treatments before and know a lot already, or you may not have had IV treatments before and need more support. The most important thing is that you, your family and your CF team are all confident that you can safely do IV treatments at home.

You'll learn:

- how to set up IV equipment
- how to maintain good hygiene
- how to prepare and give the antibiotics through your port, PICC or other type of IV line
- how to safely bin equipment when you are finished with it
- what to do if you have any problems have problems or side effects from the IV antibiotics

To learn more about ports you can read our factsheet called '**The use of ports in cystic fibrosis**'. If you have any other questions about ports, PICCs, or other types of IV lines that are used for IVs, you can talk to your CF team.

You will also learn basic life support (a type of first aid care) and what to do if you have a severe allergic reaction (anaphylaxis). This is very rare, but your CF team may give you an EpiPen to give yourself an injection of adrenaline in case you do have a severe allergic reaction.

## Can I be taught again or have a refresher?

Yes – if you don't have IV treatments very often or you are starting a new IV antibiotic treatment you or your trusted person might need to have a refresher on how to do home IV therapy.

Your CF team can organise this for you, and you can always ask if you think it's needed.

## Can someone else learn to help me with home IVs?

Yes, if you would like a trusted person such as a family member or a partner learn how to do this, you can ask your CF team. Your trusted person can learn at the same time as you, or at another time that suits everyone. Your team may be happy for more than one trusted person to learn to help you with your home IVs.

Some people find it comforting and useful to have another person to help with home IVs when they are feeling tired and unwell from an infection or from side effects of the IV antibiotic treatment itself. Others may have a port that is in a position that is not easy to access by themselves. Even if this is not the case for you, you can still ask for a trusted person to learn how to help you do IVs at home.

## What will I need at home to do IV treatments?

Your CF team will tell you what you will need to have at home, and will give you all the equipment you need, special bins for sharp waste and instructions for doing home IVs. Sometimes the antibiotics and equipment will be given to you by a home provider, but your CF team will organise this for you.

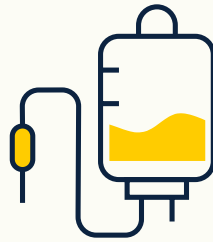
Some antibiotics will need to be stored in a fridge – your pharmacist or another person on your CF team will tell you if this applies to your antibiotics. You might be given a fridge if needed, for example if you are a university student with a shared kitchen area.

The checklist below gives an idea of the things you will need:

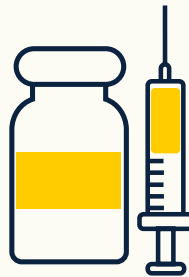
**A cool, clean and dry shelf or cupboard (and sometimes a fridge)** – for storage and preparation of antibiotics and equipment, out of reach of pets or children. Ask your team if your antibiotics need to be kept in the fridge. Your team can also give you wipes to keep your chosen surface clean.



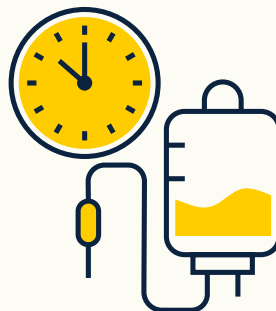
**Antibiotics** – your CF team will make sure you have these, either through them or a home IV provider. You may be given enough for a week or two at a time, but this can vary. IV antibiotics can come in different forms, such as pre-mixed bags, mini bags, IV balls and others. Your team will tell you which form your IV antibiotics will come in and how to use them.



**IV equipment** – including needles, syringes, syringe bungs, and others. Your CF team will give you this.



**Additional equipment** – some antibiotics are 'infused', meaning they are taken slowly over a stretch of time. IV infusions are done with a drip or a pump. There are a few different kinds of pumps which your team or home IV provider can give you.



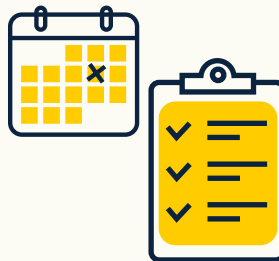
A special bin called a sharps box – for used needles, syringes and other sharp items. Your team will tell you how to bin each part of the IV equipment and what to do with the sharps box when you finish your IV treatment.



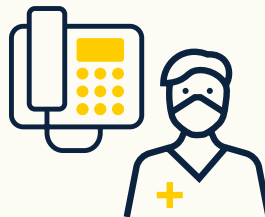
Instructions to remind you how to set up and give yourself your IV antibiotic treatments – including advice on how to deal with any problems.



Instructions on what to do when your treatment is finished



Contact numbers for your CF team – make sure you have the main number as well as out of normal hours numbers so you know who to contact at any time of day, including weekends.



**Ask your CF team whether they have any other checklists or instructions they can give you before you start doing IVs at home.**

## Will my CF team still be available for support if I do my IV therapy at home?

You can contact your CF team at any point while you are having home IV therapy if you have any questions or concerns. They should also give you instructions for what to do if you have any problems out of normal hours.

Your CF team will check on how you're doing with your home IV therapy by visiting your home or with a phone call, or you may be asked to go for a clinic appointment. You may need to have blood tests to check that the dose of your antibiotics is correct and that your body can handle the treatment – your CF team will let you know if this is the case for you.

After your home IV course is finished your team may also want to check that the treatment has worked. You will likely need to go to a clinic appointment to check this, sometimes a few weeks after your IV antibiotic course has finished. You may be able to ask for an appointment sooner if you don't feel any better.

## What if I have a reaction to the IV antibiotics while at home?

Reactions and side effects while taking antibiotics can occur, which is why you will have the first dose of any new IV antibiotics in hospital where your team can check on you closely. You may also be asked to stay for an hour or so to check you do not have a delayed reaction.

If you have any of the following reactions, you should stop your treatment immediately and contact your CF team:

- rashes or itching
- nausea
- severe diarrhoea
- a temperature
- vomiting



Severe allergic reactions (anaphylaxis) are very rare but must be treated as an emergency by stopping treatment immediately, calling 999 and asking for an ambulance. If your CF team has given you an EpiPen you should use this as instructed.

You could be having a severe reaction if:

- you suddenly collapse
- you have severe difficulty breathing
- your neck, lips or tongue start swelling
- you have a severe rash
- your lips, fingers or toes are turning blue

## Can I continue with my normal life while having home IV therapy?

Some people continue with their jobs or education whilst having home IVs, while others find it better to just focus on their treatment.

You can change the daily timing of your IVs to fit your own schedule. You might find that different antibiotics are easier than others to fit into your normal life – for example, some infusion pumps are less portable than others. If you are taking antibiotics that need to be infused with a pump, talk to your CF team about the kind of pump that might be right for you.

It is best to tell your employer, school or university that you are having IV treatment for health and safety reasons. It may even be possible to do your IV antibiotic treatment while at work or school.

The rest of your CF treatments will stay the same while you are having home IV therapy. Some nebulised antibiotics may have to stop – your CF team will tell you if this is the case. It's important that you can keep up with physiotherapy, good nutrition and have enough rest to get the most from an IV antibiotic course. Work with your employer, school or university to make sure of this.

## What if I decide that I don't want to do my IVs at home any more?

Tell your CF team if you decide you would like to have IVs in hospital instead of at home. If you are not currently having an IV treatment course, your team should be able to make sure that you have a bed on the CF ward the next time you need IV antibiotics. If you are currently doing home IVs, talk to your CF team before changing or stopping anything. They can work with you to form a plan.

You can choose to start doing home IV therapy again, even after not doing them at home for a long time. You may need to do a refresher course so that everyone is happy that you are still confident with what to do.

## What are the main advantages of home IV therapy?

- You can have treatments in the comfort of your own home
- You can spend more time with family and loved ones and have their support
- You can avoid frequent visits to the hospital which could save you time, money and energy
- You can choose to continue with your normal life and be more independent with your care

## What are the disadvantages and considerations of home IV therapy?

- You or a trusted person need to learn to do home IVs, and may need to have refreshers if you don't have IV therapy very often
- You will need a space in your home that you can keep cool, clean and dry for storage of antibiotics and equipment, out of reach of pets or children
- There is a bigger responsibility for your own care, which can be time consuming or make some people anxious
- You will have to deal with any waste (your CF team will tell you how to do this)

## Further information

Find more information resources about living with cystic fibrosis at [cysticfibrosis.org.uk/information](https://www.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](mailto:helpline@cysticfibrosis.org.uk)
- reaching out on all our social media channels

Visit [cysticfibrosis.org.uk/helpline](https://www.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](mailto: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. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all. We won't stop until everyone can live without the limits of cystic fibrosis.

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](https://cysticfibrosis.org.uk)

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