



Ustekinumab

This information is for people with Crohn's or Colitis who are on ustekinumab treatment or who are thinking about starting it. Our information can help you decide if this treatment is right for you. It looks at:

- How the medicine works
- What you can expect from the treatment
- Possible side effects
- Stopping or changing treatment

This information is about ustekinumab in general. It should not replace advice from your IBD team.

Contents

Key facts about ustekinumab	2
Other names for ustekinumab	3
How ustekinumab works	3
Why you might be offered ustekinumab.....	4
Deciding which medicine to take	5
How well does ustekinumab work in Crohn's and Colitis?	5
How long does ustekinumab take to work?	10
How to take ustekinumab	11
Dosage.....	15
How long to take ustekinumab	15
Taking ustekinumab with other Crohn's or Colitis treatments	16
Checks before starting ustekinumab	17
Ongoing checks.....	17



Special precautions	18
Side effects.....	19
Taking other medicines	22
Vaccinations	22
Pregnancy and fertility	23
Breastfeeding.....	24
Drinking alcohol	24
Who to talk to if you're worried	24
Help and support from Crohn's & Colitis UK.....	25
About Crohn's & Colitis UK	26

Key facts about ustekinumab

- Ustekinumab is used to treat Crohn's and Colitis. It can help get your symptoms under control and keep them under control. But it does not work for everyone.
- You have your first dose of ustekinumab through a drip into a vein. After this, you have it as an injection under your skin, which you can learn to do yourself at home. You take it every 8 or 12 weeks.
- Ustekinumab alters your immune system. So your body might not be able to fight off infections as well as it used to. Contact your IBD team straight away if you think you have an infection.
- You should not have live vaccines when you are taking ustekinumab. You can have non-live vaccines, like the annual flu jab and COVID-19 vaccines.
- If you have any concerns about your ustekinumab treatment, contact your IBD team.



Other names for ustekinumab

Ustekinumab is known by several brand names, including:

Otulf

Pyzchiva

- Stelara
- Steqeyma
- Uzprovo
- Wezenla

Stelara was the first brand of ustekinumab. Otulf, Pyzchiva, Steqeyma, Uzprovo and Wezenla work in the same way but are known as 'biosimilars'. This means they are very similar to Stelara and have the same treatment effects. But there are some slight differences, such as different ingredients and length of shelf life. They also vary in which of the conditions they can be used to treat. Some can only be used to treat Crohn's while others can be used to treat Crohn's or Colitis. The brand that you are given won't affect your treatment, but you may want to ask your healthcare professional which brand you take. For more about biosimilars see our information on [biologic medicines](#).

How ustekinumab works

Ustekinumab is an antibody that's made by living cells in a lab. It is a type of [biologic medicine](#).

Antibodies are proteins that recognise and stick to specific targets. Ustekinumab sticks to two different targets: chemical messengers called IL-12 and IL-23. Your immune system naturally makes these chemical messengers to help you fight infections. But they can also cause inflammation. Scientists think they are important in the inflammation that happens in your gut when you have Crohn's or Colitis.

Ustekinumab works by blocking the effects of IL-12 and IL-23. This reduces inflammation. But, like many other treatments for Crohn's and Colitis, it also alters your immune system.



Being diagnosed with Crohn's in 1995 my quality of life was very low and very restricted taking the then available medication. Since biologic treatments have been introduced my quality of life has been transformed. I still have Crohn's and need to carefully watch what I eat, but I am almost free of pain and discomfort since starting biologic medicine.

Keith

Living with Crohn's

Why you might be offered ustekinumab

Ustekinumab is used to treat adults who have moderate to severely active Crohn's or Colitis. It aims to get your Crohn's or Colitis under control and keep it under control.

Ustekinumab can only be prescribed by a specialist in a hospital. Your IBD team might suggest it for you if you have Crohn's or Colitis and:

- Standard treatments or other biologic medicines have not worked or
- Standard treatments or other biologic medicines have stopped working or
- You had to stop standard treatments or other biologic medicines because you had bad side effects or
- You cannot have standard treatments or other biologic medicines for other medical reasons

Standard treatments include [aminosalicylates](#), oral [steroids](#) or immunosuppressants like [azathioprine](#), [mercaptopurine](#) or [methotrexate](#). [Biologic medicines](#) include [infliximab](#), [adalimumab](#), [golimumab](#) and [vedolizumab](#).

If you have Ulcerative Colitis, you can only have ustekinumab on the NHS if [adalimumab](#), [infliximab](#) or [golimumab](#) have not worked for you or are not suitable for you.



Ustekinumab returned me to remission from my worst flare yet. I was able to go back to work within a month, and gradually return to living a 'normal' life.

Claire

Living with Crohn's

Deciding which medicine to take

There are lots of things to think about when you start a new treatment. Your IBD team will discuss your options with you. They might give you a choice of different treatments. You should consider the potential benefits, possible risks, and the goals of your treatment together. Things to consider include:

- How you take it
- How effective it is
- How quickly it's likely to work
- Side effects you might get
- Whether you need ongoing tests or checks
- Other medicines you're on

Our [Appointment guide](#) includes a list of questions you might want to ask. It can help you focus on what matters most to you. We also have information on other [medicines](#) or [surgery](#) for Crohn's or Colitis that you might find helpful.

How well does ustekinumab work in Crohn's and Colitis?

Ustekinumab can be effective at improving symptoms and keeping your Crohn's or Colitis under control. But it does not work for everyone.

Find out more about how we talk about the [effectiveness of medicines](#).



Induction treatment and maintenance treatment

At first, the aim of ustekinumab treatment is to reduce the inflammation in your gut and **get** your Crohn's or Colitis under control. This is called induction treatment. Once your Crohn's or Colitis is under control, treatment aims to **keep** it under control. This is called maintenance treatment.

Some clinical trials look at how well a medicine works as induction treatment. Some look at how well it works as maintenance treatment. Some look at how well it works for both. We do not always have the same information for different medicines or different conditions.

Ustekinumab for Crohn's Disease







For Crohn's Disease, we have information about how well ustekinumab works for induction treatment and maintenance treatment separately.



Getting Crohn's under control with ustekinumab

The table below shows how well treatment with ustekinumab **gets** Crohn's under control after 6 weeks of treatment.

- These results are from two large clinical trials. They compared ustekinumab to dummy treatment (placebo) in people with moderately to severely active Crohn's. Some of these people had already been treated with other biologic medicines. Some had not.
- The trials looked at how well ustekinumab got Crohn's under control after 6 weeks.

	People not taking ustekinumab (placebo)	People taking ustekinumab
People with their Crohn's completely under control (in remission)	 13%	 24%
People whose Crohn's improved but was not completely under control	 12%	 19%
People whose Crohn's did not improve much or at all	 75%	 57%





More people had their Crohn's under control after taking ustekinumab compared with people who had not been taking ustekinumab (placebo). But many people did not respond to ustekinumab. Some people who did not respond after 6 weeks might have responded with more doses of ustekinumab. But they might not.



Keeping Crohn's under control with ustekinumab

Another analysis looked at how well ustekinumab treatment **kept** Crohn's under control. In this analysis, people who responded to ustekinumab induction treatment either carried on taking ustekinumab or switched to dummy treatment (placebo). Some of these people had already been treated with other biologic medicines. Some had not.

The table below shows results after 44 weeks of maintenance treatment.

	People not taking ustekinumab (placebo)	People taking ustekinumab
People whose Crohn's stayed completely under control	 36%	 51%
People whose Crohn's did not stay under control	 64%	 49%

More people had their Crohn's under control after ustekinumab than people who had not been taking ustekinumab (placebo). But not everyone responded to ustekinumab. Evidence from using ustekinumab in the real world, outside clinical trials, has shown similar results.

A long-term trial followed-up people treated with ustekinumab for 5 years. Overall, 45 to 55 in 100 people who responded to treatment with ustekinumab were still in remission after 5 years.

Perianal fistulas

Some small trials suggest ustekinumab might be effective at treating perianal fistulas in people with Crohn's. A perianal fistula is a narrow tunnel that can develop between your back passage and the skin near your bum.

Most of the trials that looked at how well ustekinumab works in people with perianal fistulas were small and did not include a placebo group. It's difficult to know for sure how effective it is, but it could be helpful for some people.

We have separate information on [Living with a fistula](#).









Ustekinumab for Ulcerative Colitis

For Ulcerative Colitis, we have information about how well ustekinumab works for induction treatment and maintenance treatment separately.

- These results all come from a large clinical trial. It compared ustekinumab to dummy treatment (placebo) in people with moderate-to-severe Ulcerative Colitis. Some of these people had already been treated with other biologic medicines. Some had not.
- For induction treatment, the trial looked at how well ustekinumab got Colitis under control after 8 weeks.
- People who got their Colitis under control on induction treatment then either carried on taking ustekinumab or switched to placebo for maintenance treatment.
- For maintenance treatment, the trial looked at how well ustekinumab kept Colitis under control after another 44 weeks of treatment.

Getting Ulcerative Colitis under control with ustekinumab

The table below shows how well ustekinumab **gets** Ulcerative Colitis under control after 8 weeks of treatment.

	People not taking ustekinumab (placebo)	People taking ustekinumab
People with their Colitis completely under control (in remission)	 5%	 16%
People whose Colitis improved but was not completely under control	 26%	 41%
People whose Colitis did not improve much or at all	 69%	 43%





More people had their Colitis under control after taking ustekinumab for 8 weeks compared with people who had not been taking ustekinumab (placebo). But not



everyone responds to ustekinumab. Some people might respond after more than 8 weeks.

Keeping Ulcerative Colitis under control with ustekinumab

People who already had their Ulcerative Colitis under control after 8 weeks either carried on taking ustekinumab or switched to placebo.²⁷ The table below shows how well ustekinumab **keeps** Ulcerative Colitis under control after another 44 weeks of treatment:

	People not taking ustekinumab (placebo)	People taking ustekinumab
People whose Colitis stayed completely under control	 38%	 62%
People whose Colitis did not stay under control	 62%	 38%

More people had their Colitis under control after taking ustekinumab than people who had not been taking ustekinumab (placebo). But not everyone responded to ustekinumab.

A longer-term trial followed-up people treated with ustekinumab for 2 years. Overall, 65 to 68 in 100 people who responded to treatment with ustekinumab were still in remission after 2 years.

How long does ustekinumab take to work?

Everyone responds differently to a new medicine. You might start to feel better as early as 3 weeks after starting ustekinumab. But most people who respond to ustekinumab start feeling better within 6 to 8 weeks. In some people it could take up to 16 weeks. Some people might not respond at all.

If your Crohn's or Colitis has not improved within 16 weeks, your IBD team might suggest that you have ustekinumab every 8 weeks instead of every 12 weeks. If you still do not

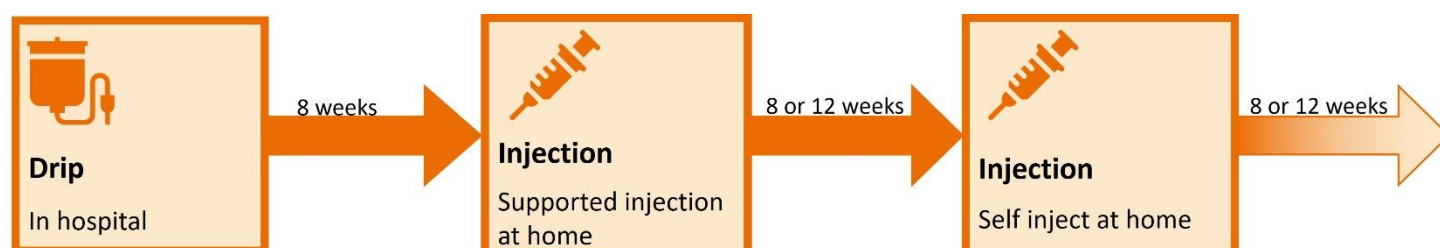


respond after another 16 weeks, they might suggest stopping ustekinumab and trying a different treatment option.

How to take ustekinumab

You cannot take ustekinumab by mouth because it is broken down by the gut, which stops it working. Instead, you have it through a drip for your first dose, and then as an injection under your skin.

- You have your first dose of ustekinumab through a drip into a vein. This is called an intravenous infusion. You go to hospital to have it. It takes about 1 hour to have the dose. You will be monitored for a while afterwards to make sure you do not have a reaction to the medicine.
- You have your second dose 8 weeks later. You have this dose as an injection under your skin. This is called a subcutaneous injection. A doctor or nurse will give you the injection. They usually come to your home to do it.
- After this, you have an injection under your skin every 8 or 12 weeks, depending on how well you respond to treatment. Your IBD team will tell you how often you need it. Once you are used to having ustekinumab, your doctor or nurse will teach you how to inject it yourself at home. If you're not comfortable injecting yourself, tell them. They could teach a friend or family member to do it for you. Or they might be able to arrange for a nurse to give you your injection at home.



Taking ustekinumab at home

Ustekinumab injections are available as a pre-filled syringe or a pre-filled injection pen.



You have your ustekinumab injections delivered directly to your home. They come in a box containing either one pre-filled syringe or one pre-filled injection pen. Each syringe or pen contains one dose of medicine. Ustekinumab is free for people who are entitled to NHS care.

Ustekinumab pre-filled syringe



You must keep ustekinumab in the fridge at a temperature of 2°C to 8°C. Do not freeze it. If you need to, you can keep it out of the fridge at room temperature (up to 30°C) for up to 30 days. If you do this, keep it in its box to protect it from light. Write the date you took it out of the fridge on the box.

Once ustekinumab has been out of the fridge at room temperature, do not put it back in the fridge.

Ustekinumab pre-filled pen

You must keep ustekinumab in the fridge at a temperature of 2°C to 8°C. Do not freeze it. If you need to, you can keep it out of the fridge at room temperature (up to 30°C) for up to 30 days. If you do this, keep it in its box to protect it from light. Write the date you took it out of the fridge on the box.



Once ustekinumab has been out of the fridge at room temperature, do not put it back in the fridge.

Do not shake the pre-filled pen as this may damage the medicine.

Get rid of any doses that are past their expiry date or have been out of the fridge for more than 30 days. Your pharmacist can tell you how to dispose of them.

Tips on injecting

Your doctor or nurse will teach you how to inject yourself with ustekinumab. The Patient Information Leaflet also contains detailed instructions on what to do. This is in the box. It is sometimes called a Package Leaflet. You can also get it online: [Patient Information Leaflet for ustekinumab pre-filled syringe](#) or [Patient Information Leaflet for ustekinumab pre-filled pen](#).

One of the most common side effects of ustekinumab is pain and redness at the injection site. These tips can help:

- **Allow your medicine to come up to room temperature**

It can be uncomfortable if you inject yourself with ustekinumab straight from the fridge. Take it out of the fridge around 30 minutes before you inject it so it can warm to room temperature naturally. You should not warm it in any other way, such as in hot water or a microwave.

- **Apply an ice pack before you inject**

If you're worried about pain, you could try applying an ice pack to the injection site for 2 to 3 minutes before you inject. If you do this, put a thin towel under it or wrap it in a cloth so it does not damage your skin.

- **Choose your injection site**

The upper thigh or tummy (away from the belly button) are good places for the injection. Avoid any areas where your skin is red, scarred, bruised or hard. Do not use the same place every time.



- **Wash your injection site**

Make sure the skin is clean before you inject yourself.

- **Use a good injection technique**

Gently pinch the skin at the injection site between your thumb and finger. Use a quick, dart-like motion to insert the needle into the skin. Push the plunger slowly and evenly to inject all of the medicine, keeping the skin pinched.

- **Apply an ice pack after you inject**

If the injection site hurts afterwards, it might help to apply an ice pack or cold damp towel for 10 to 15 minutes. If you use an ice pack, put a thin towel under it or wrap it in a cloth so it does not damage your skin.



Dosage

Your first dose of ustekinumab depends on how much you weigh.

- If you weigh 55kg (8 stone 9) or less, you have 260mg.
- If you weigh between 55kg and 85kg (8 stone 9 to 13 stone 5), you have 390mg.
- If you weigh more than 85kg (13 stone 5), you have 520mg.

This is the dose that you have through a drip in hospital.

After the first dose, all the rest of your doses are 90mg. The dose is the same however much you weigh. You have these as an injection under your skin.

How long to take ustekinumab

If you respond to ustekinumab and have no serious side effects, you usually carry on taking it for at least a year. Every year, your IBD team should assess you to check whether continuing ustekinumab is the best option. If you, or your IBD team, feel that it is no longer right for you, you should discuss other treatment options together.

Stopping or changing treatment

There are a few reasons why you or your IBD team might think about stopping or changing your treatment:

- **Your Crohn's or Colitis is under control**
If your Crohn's or Colitis stays under control for a year or more, you might be able to stop taking ustekinumab. If this is the case, your IBD team will discuss it with you and make the decision together. If you stop ustekinumab and you become unwell again, you should have the option to start ustekinumab treatment again.
- **Ustekinumab has not worked**
If your Crohn's or Colitis has not improved within 16 weeks, your IBD team might suggest that you have ustekinumab every 8 weeks instead of every 12 weeks. If you still do not respond after another 16 weeks, they might suggest stopping ustekinumab and trying a different treatment option.



- **Ustekinumab stops working well**

Some people make antibodies that stick to ustekinumab and stop it working. This happens to around 5 in 100 people over 2 to 5 years of treatment.

- **You have side effects**

If you have side effects that are serious or hard to manage, stopping ustekinumab might be the best option for you.

- **Difficulty injecting yourself**

If you are struggling with the injections, you might prefer to try a treatment you can take by mouth or have through a drip in hospital. Or you could ask your IBD team if they can arrange for a nurse to give you your injections at home

Do not stop taking ustekinumab without discussing it with your IBD team.

If ustekinumab is no longer the best treatment for you, your IBD team should discuss other treatment options with you. You should consider the potential benefits, possible risks, and the goals of your treatment together.

Taking ustekinumab with other Crohn's or Colitis treatments

It is safe to take ustekinumab alongside [steroids](#) or immunosuppressants like [azathioprine](#), [mercaptopurine](#) or [methotrexate](#). Your IBD team will talk to you about whether you need to take other medicines for your Crohn's or Colitis.

If you are on steroids when you start ustekinumab, you might be able to gradually stop them if you respond well to treatment. Your IBD team will advise you about this.

Do not stop steroid treatment without talking to your IBD team.



Checks before starting ustekinumab

Having treatment that alters your immune system makes you more likely to get infections. And it can sometimes cause any inactive viruses you have in your body to become active again. Before you start ustekinumab, your IBD team will do thorough checks to make sure it's suitable for you. They are likely to:

- Check if you've ever had chicken pox, shingles, TB, coldsores or genital herpes
- Ask if you've ever travelled or lived in a place where TB is very common or if you live with anybody who's had TB
- Find out if all your vaccinations are up-to-date
- Take blood tests to check for hepatitis viruses, the chicken pox or shingles virus, and HIV
- Do a chest X-ray and blood test to check for TB

If you have an infection, you might need to delay starting ustekinumab until it's been treated.

You should not take ustekinumab if you have active TB. If you have underlying, inactive TB, it needs to be treated before you start ustekinumab.

Tell your IBD team if:

- You are allergic to latex. The needle cover of the ustekinumab pre-filled syringe contains latex. The needle cover inside the bottom cap of the pre-filled pen contains latex.
- You are having, or have ever had, injections to treat allergies. We do not know yet if ustekinumab affects these.

Ongoing checks

After you start ustekinumab, you should have regular checks to see how well it is working. Your IBD team will ask about your symptoms, any side effects you're getting,



and how you're managing with the injections. They will also check for any signs of infection. They may check whether you have any factors that put you at higher risk of having a heart attack or stroke. You might have blood tests and faecal calprotectin testing. Your IBD team will tell you what checks you need and how often.

Once you've got used to ustekinumab, you should have a check-up every year. This is to check if you are still responding to ustekinumab or whether you need to change the dose or stop treatment.

Special precautions

In theory, there is a risk that ustekinumab might slightly increase your risk of developing some cancers. This is because of the way ustekinumab affects your immune system.

Clinical trials of ustekinumab found that people taking ustekinumab had a similar rate of cancer to the general population. But some cases of cancer have been seen in people taking ustekinumab for psoriasis. This is being checked in larger, long-term studies.

If you have cancer, or you've had cancer in the past, ustekinumab might not be the right choice for you. Your doctor should carry out regular skin examinations to check for any signs of skin cancer.

To be safe, it's a good idea to:

- Go to any routine cancer screening you're invited to
- Contact your GP if you have any skin growths, new moles or moles that have changed
- Protect your skin from the sun – cover up, use sunscreen and stay in the shade if you can

Very rarely, people taking ustekinumab may develop a condition similar to [lupus](#). Contact your GP, IBD team or NHS 111 straightaway if you get a skin rash, especially if it's on a part of your skin that's exposed to the sun or you also have joint pains. If you develop a



condition related to lupus, your IBD team might advise you to stop taking ustekinumab. Tell your IBD team if you have had lupus in the past before starting ustekinumab.

Side effects

All medicines can have side effects, but not everyone gets them. Some side effects can happen right away, others might happen later.

Some side effects are mild and may go away on their own or after you stop taking ustekinumab. Others may be more serious and could need treatment. Some side effects might mean that the ustekinumab is not right for you.

In clinical trials, the risk of getting side effects was similar in people taking ustekinumab to people not taking ustekinumab (the placebo group).

Speak to your IBD team if you get any side effects.

We also encourage you to report any side effects to the Medicines and Healthcare Products Regulatory Agency (MHRA). You can do this through the [Yellow Card scheme online](#) or by downloading the MHRA Yellow Card app. This helps collect important safety information about medicines.

Possible serious side effects

Some people might get serious side effects that need urgent treatment. These do not happen often, but it is important to know what to look out for.

Allergic reactions

Up to 1 in every 100 people taking ustekinumab might have an allergic reaction. But serious allergic reactions are rare. Less than 1 in every 1000 people taking ustekinumab get them.

Contact NHS 111 straight away if you think you are having an allergic reaction



Signs to look out for include:

- Difficulty breathing or swallowing
- Feeling dizzy or light-headed
- Swelling of your face, lips, mouth or throat
- A rash or raised, itchy patches on your skin (hives)

After the allergic reaction has been treated, contact your IBD team to let them know what has happened.

Infections

Ustekinumab alters your immune system. This means your body might not fight off infections as well as other people. You might get more infections than you used to. Or they might last longer or be more serious than usual.

Up to 1 in every 10 people taking ustekinumab might get a cold, a cough or a throat or sinus infection. Up to 1 in every 100 people taking ustekinumab might get more serious infections, like chest infections, skin infections or shingles.

Contact your GP or NHS 111 straight away if you think you have an infection

Signs to look out for include:

- Flu-like symptoms – a high temperature, feeling hot and cold, shivering or sweating
- A sore throat, blocked or runny nose or earache
- A cough that will not go away
- Feeling tired or short of breath
- Warm, red and painful skin, or a painful skin rash with blisters
- A burning or stinging feeling when you wee
- Diarrhoea



If you have an infection, you may need urgent treatment. Your IBD team might advise you to stop taking ustekinumab until you are better.

To reduce your risk of getting an infection, try to avoid close contact with people who have infections. It's sensible to wash your hands often, especially before meals and after using the toilet. And take care to [store and prepare food safely](#).

Most common side effects

Here, we list the most common side effects of ustekinumab. These might affect up to 1 in every 10 people taking ustekinumab.

- Common cold, sore throat or sinus infection
- Feeling dizzy
- Headache
- Diarrhoea
- Feeling sick or being sick
- Itching
- Back pain, muscle pain or joint pain
- Fatigue
- Pain or redness where the injection went in

This is not a full list of side effects. There is information about less common side effects of ustekinumab in the Patient Information Leaflet. This is also called a Package Leaflet. It should be in the box with your medicine. You can also get it online: [Patient Information Leaflet for ustekinumab pre-filled syringe](#) or [Patient Information Leaflet for ustekinumab pre-filled pen](#).

Having ustekinumab on a much more spread out basis (8 to 12 weeks) means I don't have the experience of side effects every week after the injection like I did with my previous biologic.

Ally, Living with Crohn's



Taking other medicines

There is no evidence that ustekinumab interacts with other medicines. But it's always best to check first.

Speak to your doctor or pharmacist if you're taking, or plan to take, any other medicines. This includes medicines you buy from a pharmacy or supermarket, as well as herbal, complementary, or alternative medicines.

Vaccinations

- You should not have live vaccines until at least **15 weeks** after your last dose of ustekinumab.
- If you have had a live vaccine, you should wait **2 to 4 weeks** before starting ustekinumab.

Live vaccines are made using weakened versions of living viruses or bacteria. If you have a lowered immune system, there is a possibility they might cause infections. Live vaccines used in the UK include:

- TB vaccine
- Shingles vaccine – but a non-live version is also available
- Chickenpox vaccine
- Measles, mumps and rubella vaccines
- Nasal flu vaccine used in children – but the injected flu vaccine used in adults is **not** live
- Rotavirus vaccine
- Yellow fever vaccine
- Oral typhoid vaccine – but the injected typhoid vaccine is **not** live

If someone you live with is due to have a live vaccine, ask your IBD team if you need to take any precautions.



It is safe to have non-live vaccines when you are on ustekinumab.

Everyone with Crohn's or Colitis taking a biologic medicine should be invited to have the flu jab every year. You may be advised to have the pneumococcal vaccine. You are also eligible for all doses of [COVID-19 vaccination](#). These are **not** live vaccines and they are safe to have when you are taking ustekinumab.

We have not found any clinical trials that looked at the best time to have vaccinations in relation to your ustekinumab dose. But in general, people taking ustekinumab for Crohn's or Colitis respond well to vaccination.

Pregnancy and fertility

Ustekinumab did not have harmful effects on pregnancy during studies on animals. Studies in humans have not found any sign that ustekinumab causes problems during pregnancy or to babies exposed during pregnancy. But the number of people who have taken ustekinumab while they were pregnant is fairly small.

Drug manufacturers advise you to use effective contraception while taking ustekinumab and for at least 15 weeks after you stop treatment. This is to prevent pregnancy.

Experts agree that taking ustekinumab while you're pregnant is probably a low risk. You and your IBD team should discuss whether the benefits of taking it outweigh any potential risks to you and your baby.

- If you're taking ustekinumab and you're pregnant or planning to get pregnant, talk to your IBD team. They can discuss your treatment options with you.
- Having a flare-up during pregnancy can lead to problems. So it is a balance between keeping your condition under control and keeping any risk to your baby as low as possible.
- If you take ustekinumab during pregnancy, healthcare professionals may recommend delaying your baby's live vaccines until they are 6 to 12 months old. It's



important to tell your baby's healthcare team that you were taking ustekinumab when you were pregnant. Decisions on whether and when your baby should have live vaccines should be made on an individual basis. See our information on [Pregnancy and breastfeeding](#) for more on your baby's live vaccines.

In studies on animals, ustekinumab had no effect on male fertility. Ustekinumab does not pass into semen, or affect semen quality, in humans.

We have separate information about [Reproductive health and fertility](#) and [Pregnancy and breastfeeding](#).

Breastfeeding

Ustekinumab passes into breast milk in very low levels. You can't take biologic medicines like ustekinumab by mouth because they are broken down and destroyed by your gut. Ustekinumab in breastmilk is likely to be broken down in your baby's gut. So very little will be absorbed by your baby.

There is very little information on taking ustekinumab during breastfeeding. But experts agree that it is unlikely to be harmful to your baby.

Tell your IBD team if you are thinking about breastfeeding while taking ustekinumab. They can help you weigh up the benefits of breastfeeding against any possible risks.

We have more information about [Pregnancy and breastfeeding](#).

Drinking alcohol

There is no evidence that drinking alcohol affects the way your body deals with ustekinumab. But to keep the health risks from alcohol low, it is best to keep to [recommended limits](#).

Who to talk to if you're worried



[Taking medicines](#) and managing side effects can be difficult – we understand and we're here to help. Our [Helpline](#) can answer general questions about treatment options and can help you find support from others with the conditions.

Your IBD team are also there to help. You can talk to them about your dosage, how they'll be monitoring you and what other options there might be. You should also get in touch with your IBD team if you have any new symptoms or side effects.

It can take time to find the medicine that's right for you. Don't be afraid to ask questions and seek out extra support when you need it.

This information is general and does not replace specific advice from your health professional. Talk to your GP or IBD team for information that's specific to you.

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to



- Help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis.

You can share your experiences and receive support from others at:

facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See

crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis:

call 01727 734465 or visit crohnsandcolitis.org.uk.





About our information

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE** or contact us through the **Helpline: 0300 222 5700**.

© Crohn's & Colitis UK, 2022, 2024

Ustekinumab, edition 2i

Last review: August, 2022

Updated: October, 2024

Next review: August, 2025

