USTEKINUMAB

This information is for people with Crohn's or Ulcerative 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 treatment
- Possible side effects
- Stopping or changing treatment

In this information, where we use 'Colitis', we refer to Ulcerative Colitis only.

This information might use words you have not heard before. Our page on **medical words** can help provide an explanation.

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

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KEY FACTS ABOUT USTEKINUMAB

- Ustekinumab is used to treat Crohn's and Colitis.
- Ustekinumab can be given to adults. It can also be used to treat Crohn's in children aged 2 or older.
- 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. You may be able to learn to do this yourself at home. You usually take it every 8 or 12 weeks.
- You may be more likely to get an infection while you are taking ustekinumab. Contact your IBD team straight away if you think you have an infection.

Your IBD team can help if you have any concerns about your ustekinumab treatment.

OTHER NAMES FOR USTEKINUMAB

Ustekinumab is known by several brand names, including:

- Imuldosa
- Otulfi
- Pyzchiva
- Stelara
- Steqeyma
- Usymro
- Uzpruvo
- Wezenla
- Yesintek

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Stelara was the first brand of ustekinumab. Imuldosa, Otulfi, Pyzchiva, Steqeyma, Usymro, Uzpruvo, Wezenla and Yesintek work in the same way but are known as 'biosimilars'. This means they are very similar to Stelara and have the same treatment effects. There are some slight differences between different brands. These include other different ingredients and the length of shelf life. The brand that you are given will not affect your treatment. But you may want to ask your healthcare professional which brand you take. Your medicine will be prescribed by brand name.

For more about biosimilars, see our information on **biologic medicines**.

HOW USTEKINUMAB WORKS

Ustekinumab is an advanced medicine known as an interleukin inhibitor. Interleukins are proteins that have an important role in controlling your **immune system**. Your immune system is your body's natural defence system. Ustekinumab blocks interleukin 12 and 23 (IL-12 and IL-23). These have a key role in long-term inflammation in the gut. By blocking IL-12 and 23, ustekinumab eases some of the inflammation that causes the symptoms of Crohn's and Colitis. But, like many other treatments for Crohn's and Colitis, this medicine can affect your immune system.

WHY YOU MIGHT BE OFFERED USTEKINUMAB

Ustekinumab is used to treat adults with moderate to severely active Crohn's or Colitis. It can also be used to treat children with moderately to severely active Crohn's aged 2 or older.

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 ustekinumab if standard treatments or another biologic medicine:

- Have not worked

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- Have stopped working
- Have caused side effects that are severe or difficult to manage
- Are not suitable for you

Standard treatments include:

- **Aminosalicylates, known as 5-ASAs**
- **Steroids**
- Immunosuppressants, including
    - **Azathioprine**
    - **Mercaptopurine**
    - **Methotrexate**
- **Biologics**, including
    - **Adalimumab**
    - **Golimumab**
    - **Guselkumab**
    - **Infliximab**
    - **Mirikizumab**
    - **Risankizumab**
    - **Ustekinumab**
    - **Vedolizumab**

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 think about the possible benefits and risks, and the goals of your treatment together. Things to consider include:

- How you take it
- How well it works
- How quickly it's likely to work

- Side effects you might get
- Whether you need ongoing tests or checks
- Other medicines you're taking

Our **appointment guide** includes a list of questions you might want to ask a healthcare professional about this medicine. 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.

> **"Taking this medication has been life-changing for me – I have been on it for over three years and it stabilised my Crohn's and helped me get my life back in so many ways. I am now in remission and can do so many more things and to places which I couldn't have previously."**
>
> **ALLY**
> **LIVING WITH CROHN'S**

HOW WELL DOES USTEKINUMAB WORK IN CROHN'S?

Ustekinumab can be effective at improving symptoms and keeping your Crohn's under control. But it does not work for everyone. Different medicines work for different people, and it may take time to find the medicine that is right for you.

Understanding clinical trial results

The information below shows the results of clinical trials. These looked at how effective ustekinumab is. To find out, scientists compared people who took ustekinumab with people who took a placebo. A placebo is something that looks the same as the treatment but does not have any medicine in it.

You can find out more about clinical trials in our information on talking about the effectiveness of medicines.

Getting Crohn's under control

Two large clinical trials have looked at how effective ustekinumab is at getting Crohn's under control. These trials compared ustekinumab to a 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.

After six weeks of treatment with ustekinumab, around 5 in every 20 people, or 24%, had their Crohn's in remission. And around 4 in every 20 people, or 19%, improved but did not have their Crohn's completely under control.

Of those who took a placebo, around 3 in 20 people, or 13% were in remission. And 2 in every 20 people, or 12% improved but did not have their Crohn's completely under control.

The clinical trials showed that around twice as many people got their Crohn's under control, compared with people taking a placebo. But ustekinumab did not work well for everyone. Some people who did not respond after six weeks may have responded with more doses of ustekinumab.

The table below shows the data from these clinical trials.

	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%

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Keeping Crohn's under control

Another clinical trial looked at how effective ustekinumab was at keeping Crohn's under control. This trial used people who had responded to ustekinumab treatment and were in remission. In the trial, some of them carried on taking ustekinumab, while others were switched to a placebo. Some of these people had already been treated with other biologic medicines. Some had not.

After 44 weeks of treatment with ustekinumab, around 10 in every 20 people, or 51%, were still in remission.

Of those who took a placebo, around 7 in every 20 people, or 36% were still in remission.

The clinical trials showed that more people kept their Crohn's under control with ustekinumab compared to a placebo. But ustekinumab did not carry on working for everyone.

The table below shows the data from these clinical trials.

	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%

Evidence from using ustekinumab in the real world, outside clinical trials, has shown similar results to this trial.

A long-term trial followed up people treated with ustekinumab for 5 years. Overall, around 10 in 20 people, or 45 to 55%, who responded to treatment with ustekinumab were still in remission after five years.

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Perianal fistulas

Some small trials suggest ustekinumab might be effective at treating perianal fistulas in people with Crohn's. A perianal fistula connects the very end of the bowel to the skin near the bottom, where poo leaves the body.

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 may be helpful for some people.

We have separate information on **fistulas**.

HOW WELL DOES USTEKINUMAB WORK IN COLITIS?

Ustekinumab can be effective at improving symptoms and keeping your Colitis under control. But it does not work for everyone. Different medicines work for different people, and it may take time to find the medicine that is right for you.

Understanding clinical trial results

The information below shows the results of clinical trials. These looked at how effective ustekinumab is. To find this out, scientists compared people who took ustekinumab with people who took a placebo. A placebo is a substance that looks the same as the treatment but does not have any medicine in it.

You can find out more about clinical trials in our information on talking about the effectiveness of medicines.

Getting Colitis under control

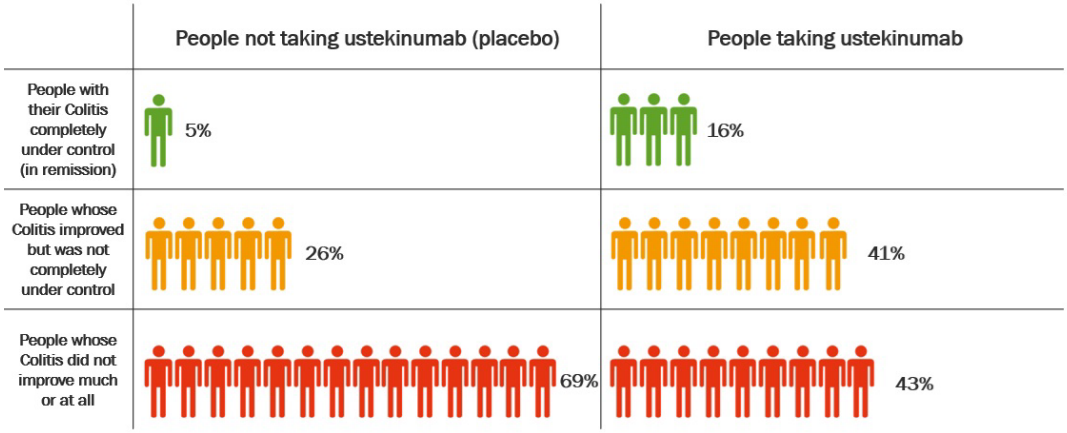
One large clinical trial looked at how effective ustekinumab was at getting Colitis under control. This trial compared ustekinumab to a placebo in people with moderately to severely active Colitis. Some of these people had already been treated with other biologic medicines. Some had not.

After eight weeks of treatment with ustekinumab, around 3 in every 20 people, or 16%, had their Colitis in remission. And around 8 in every 20 people, or 41%, improved but did not have their Colitis completely under control.

Of those who took a placebo, around 1 in every 20 people, or 5% were in remission. And around 5 in every 20 people, or 26%, improved but did not have their Colitis completely under control.

The clinical trial showed that around three times as many people had their Colitis under control with ustekinumab, compared to a placebo. But ustekinumab did not work well for everyone. Some people who did not respond after eight weeks may have responded with more doses of ustekinumab.

The table below shows the data from these clinical trials.



Keeping Colitis under control with ustekinumab

In the same clinical trial as above, researchers asked those people who were in remission after eight weeks of taking ustekinumab to carry on the trial. This next stage of the trial looked at how effective ustekinumab was at keeping Colitis under control. In the trial, some people carried on taking ustekinumab, while others were switched to a placebo. Some of these people had already been treated with other biologic medicines. Some had not.

After 44 weeks of treatment with ustekinumab, around 12 in every 20 people, or 62%, were still in remission.

Of those who took a placebo, around 8 in 20 people, or 38% were still in remission.

The clinical trial showed that more people kept their Colitis under control with ustekinumab, compared to a placebo. But the ustekinumab did not carry on working for everyone.

The table below shows the data from these clinical trials.

	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%

A longer-term trial followed up on people treated with ustekinumab for two years. Overall, around 14 in 20 people, or 65 to 68%, who responded to treatment with ustekinumab were still in remission after two years.

HOW LONG DOES USTEKINUMAB TAKE TO WORK?

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

Your IBD team may suggest that you stop taking ustekinumab if it has not worked by:

- 16 weeks after your first infusion, or
- 16 weeks after switching to eight-weekly injections.

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HOW TO TAKE USTEKINUMAB

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

Your first dose

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 this infusion. It takes about one hour to have the dose.

The doctor or nurse should flush your drip through with a solution of saline. Saline is a mix of salt and water. This is to make sure that all the ustekinumab goes into your vein, and none is left in the drip. The flush should not be painful, but it may feel a bit cold.

You will be monitored for a while after your infusion to make sure you do not have a reaction to the medicine.

Your second dose

You have your second dose eight weeks later. This is called a subcutaneous injection. A doctor or nurse will give you the injection. They usually come to your home to do it.

Ongoing treatment

After your second dose, you will usually have an injection under your skin every eight or twelve weeks, depending on how well you respond to treatment. Your IBD team will tell you how often you need it.

Depending on your symptoms, your IBD team may suggest another infusion of ustekinumab or a shorter time between your doses. This may be shortened to every six or four weeks.

Once you are used to having ustekinumab, your doctor or nurse will agree for you to be trained on how to inject it yourself at home. This training may be given by your homecare medicines service. This is the company that will deliver your medicine. 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.

> "The self-injection and large gaps between taking the medication work around my job and personal life. I no longer get any side effects too, which is a bonus and the more you self-inject, the more your confidence will improve. 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 ustekinumab at home

Ustekinumab injections are available as a syringe, pre-filled syringe or a pre-filled injection pen. Currently, the pre-filled pens are not available for children.

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

Storing your medicine

- You must keep ustekinumab in the fridge at a temperature of 2°C to 8°C.
- Do not freeze it.
- If you need to, some vials, syringes and pens may be kept out of the fridge at room temperature, up to 30°C, for a short time. Whether you can do this, and the number of days that you can keep it out of the fridge will depend on the brand of ustekinumab you use. Check the package insert that comes with your medicine.
    - If you store your ustekinumab out of the fridge, 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 medicine as this may damage it.

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

Tips on injecting

You will be given training on how to inject yourself with ustekinumab. The patient information leaflet also contains detailed instructions on what to do. This can be found in the box your medicine comes in. It is sometimes called a package leaflet. You can also get it online at the **Electronic Medicines Compendium** website.

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 your injection out of the fridge about 30 minutes before you

inject. This means it can warm to room temperature. Do not warm the injection in any other way, such as in hot water or a microwave.

- **Apply an ice pack before you inject**
  You might find it helpful to apply an ice pack to the injection area for two to three minutes before you inject. If you do this, put a thin towel under the ice pack 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 the skin is red, scarred, bruised or hard. Do not use the same place every time.
- **Wash your hands and clean the skin at the injection site**
  Wash your hands with soap and water. Make sure the skin at the injection site is also clean before you inject. You can use an alcohol wipe to do this. This helps to lower the risk of infection.
- **If using a syringe or a pre-filled syringe, use a good injection technique**
  Gently pinch the skin at the injection site between your thumb and finger. For a syringe, push the needle into the pinched skin. For a pre-filled syringe, 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**
  Some people recommend applying an ice pack or cold, damp towel to the area for 10 to 15 minutes after you have injected. This can help with pain at the injection site. Remember to put a thin towel under the ice pack or wrap it in a cloth.
- Wear loose clothing.
  Wear loose clothing to avoid rubbing or pressure on the injection site.

If you have problems injecting your ustekinumab, ask your IBD team for help

> "I found ustekinumab easy and painless to use. It was very convenient to be able to administer it at home after the initial induction treatment at the hospital."
>
> **SARAH**
> **LIVING WITH CROHN'S**

DOSAGE

Your first dose of ustekinumab depends on how much you weigh. For adults and children who weigh 40kg or more:

- You'll have 260mg if you weigh 55kg or less. This is 8 stone 9 or less.
- You'll have 390mg if you weigh between 55kg and 85kg. This is 8 stone 9 to 13 stone 5.
- You'll have 520mg if you weigh more than 85kg. This is 13 stone 5 or more.

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

After the first dose, all the rest of your doses are 90mg. These doses are the same, for adults and children who weigh 40kg or more. You have these as an injection under your skin.

For children who weigh less than 40kg, the dose will be changed depending on their size.

HOW LONG TO TAKE USTEKINUMAB

Your IBD team will review your treatment regularly to check whether it is still the best option for you.

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> "Ustekinumab has been a game-changer for me, after infliximab, adalimumab and vedolizumab lost effectiveness. I found it to be as effective as infliximab but the benefits last longer, and it comes with the convenience of being able to inject at home. I know biological drugs aren't usually effective long-term, so I'm hoping that if I have to move to another, it's as effective as ustekinumab."
>
> **ALUN**
> **LIVING WITH CROHN'S**

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, you and your IBD team will 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**
  Your IBD team may suggest that you stop taking ustekinumab if it has not worked by:
  - 16 weeks after your first infusion, or
  - 16 weeks after switching to eight-weekly injections.
- 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 two to five 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 there is an option for you to be given 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 possible benefits and 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.

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CHECKS BEFORE STARTING USTEKINUMAB

Infection risk

Having treatment that affects your immune system can mean that your body may not be able to fight off infections as well as it used to. Before you start ustekinumab, your IBD team may ask you some questions and do some tests. This is to make sure your risk of infection is as low as possible.

Tell your IBD team if:

- You have an infection, or you are feeling unwell or feverish. You may need to delay your treatment if you have an infection. Also let your IBD team know if you have often had infections in the past.
- You have recently been in close contact with someone who has tuberculosis (TB) or been in a place where TB is common. If you may have or have had tuberculosis, it will need to be treated before you start ustekinumab. You will usually have a blood test and a chest X-ray to check for TB.
- You have HIV or hepatitis. Hepatitis is inflammation of the liver. This can be caused by certain viruses. You will usually have a blood test to check for these viruses.
- You have ever had chickenpox, shingles, cold sores or genital herpes. If necessary, you may be able to be vaccinated against chickenpox or shingles before you start treatment. At the moment, there is no vaccine for cold sores or genital herpes.
- You have a condition or take any other medicine that weakens your immune system.
- Your vaccinations are not up to date. If they are not, your IBD team may suggest you have the ones you need. This is to help protect you from infections. Let them know if you plan to have any vaccinations or if you had a vaccination recently. If you had a live vaccine recently, you may need to wait a while before starting treatment.

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You can find out more information on how to prevent infections in our **immunosuppressant precautions** information.

Tell your IBD team if:

- You are allergic to latex. For some brands, the needle covers contain latex or material derived from 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
- 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 tests on your poo, known as faecal calprotectin testing. Your IBD team will tell you what checks you need and how often. You can find out more about blood tests and tests on your poo in our **tests and investigations** information.

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

Get urgent medical care if you have any signs of a heart attack or stroke.

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These can include:

- Chest pain or tightness. This may spread to your arms, jaw, neck or back.
- Shortness of breath.
- Cold sweat.
- Light headedness or sudden dizziness.
- Weakness or numbness in the face, arms or legs.
- Slurred speech.
- Blurred vision.
- Confusion.
- Severe headache.

SPECIAL PRECAUTIONS

In theory, some immunosuppressants, such as ustekinumab, may slightly increase your risk of getting cancer. This risk is very small.

Clinical trials of ustekinumab found that people taking ustekinumab had a similar rate of cancer to the general population.

Another study looked at the effect of ustekinumab on the risk of cancer among people who had a history of cancer. The study found that the risk of cancer was the same for people taking ustekinumab, compared to people who had not. However, if you have cancer or have had cancer in the past, ustekinumab might not be the right choice for you.

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To lower your risk of skin cancer, your doctor may carry out regular checks of your skin.

To lower your own risk of cancer, it is a good idea to:

- Go to any routine cancer screening you're invited to.
- Contact your GP if you notice any changes to your body that you are worried about. The NHS website has information on symptoms to watch out for.
- Practice good sun safety. This includes:
    - Wearing a hat
    - Using high-factor sunscreen
    - Staying in the shade
    - Avoiding sunbeds

The NHS website has more tips for staying safe in the sun.

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, and
- 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

When you start taking ustekinumab, you may be given a Patient Alert Card. This is sometimes also known as a patient reminder card. You can carry this card with you. This is so that anyone treating you will know that you are taking ustekinumab. You can also add it as emergency medical information on your phone.

All medicines can have side effects, but not everyone experiences them. Having certain side effects might mean that ustekinumab is not right for you.

- Some side effects can happen right away. Others may happen after you have been taking ustekinumab for a while.
- Some side effects are mild. Others may be more serious and could need treatment.
- Some side effects may go away on their own. Others may go away after you stop taking ustekinumab. Some may be long-lasting.

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

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 1,000 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. This is known as 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
- A throat infection
- A sinus infection

Up to 1 in every 100 people taking ustekinumab might get more serious infections, like:

- A chest infection
- A skin infection

- 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, such as 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
- Problems with how you see, being sensitive to light or losing your vision
- Headache, or a stiff neck
- Feeling sick
- Feeling confused

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 lower your risk of getting an infection, try to:

- Avoid close contact with people who have infections
- Wash your hands often, especially before meals and after using the toilet

- Take care to store and prepare food safely

Find out more about **immunosuppressant precautions**.

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
- Feeling tired
- 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 on the **Electronic Medicines Compendium** website.

> **"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 are taking, or plan to take, any other medicines. This includes:

- Prescribed medicines
- Over-the-counter medicines that you buy from a pharmacy or supermarket
- Multi-vitamins or supplements
- Herbal, complementary or alternative medicines

VACCINATIONS

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

Live vaccines used in the UK include:

- Rotavirus vaccine. This is given to babies only.
- Measles, mumps and rubella. This may be given as the triple MMR vaccine.
- Nasal flu vaccine. The injected flu vaccine is not live.
- Chicken pox vaccine. This is also known as varicella.
- BCG vaccine against tuberculosis, or TB.
- Yellow fever vaccine.
- Oral typhoid vaccine. The injected typhoid vaccine is not live.

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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 two weeks before starting ustekinumab.

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 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

Fertility

The effect of ustekinumab on human fertility is not known. But in studies on animals, ustekinumab had no effect on male or female fertility.

Ustekinumab does not pass into semen or affect semen quality in humans.

Contraception

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.

Pregnancy

Ustekinumab did not have harmful effects on pregnancy during studies in 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. For this reason, manufacturers suggest not to take it during pregnancy. However, experts agree that taking ustekinumab while you're pregnant is probably a low risk.

Speak to your IBD team if you are offered or are taking ustekinumab and want to start a family. They can help you make an informed decision about your care and your baby's safety.

Do not stop taking your medicine without talking to your doctor first.

Stopping your medicine may increase your risk of a flare-up. Having active Crohn's or Colitis can increase the risk of pregnancy complications, such as:

- Premature birth
- Low birth weight
- Miscarriage

This is why it is important to keep your condition under control during pregnancy. You and your IBD team should discuss whether the benefits of taking it outweigh any potential risks to you and your baby.

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If you take ustekinumab during pregnancy, always make sure you go to any scheduled prenatal scans.

Unplanned pregnancy

Contact your IBD team straight away if you take ustekinumab and find out you are pregnant. If you cannot contact your IBD team, speak to your GP. Your GP may be able to help you contact your IBD team.

Do not stop taking your medicine until you have spoken to your healthcare professional.

If you have taken ustekinumab during the early part of your pregnancy, always make sure you go to any scheduled prenatal scans.

Find out more about pregnancy and birth with Crohn's or Colitis.

Your baby and live vaccines

Tell your baby's healthcare team if you took ustekinumab during your pregnancy. If you did, you may be told that your baby should not have live vaccines until they are a bit older. This includes the rotavirus vaccine and the BCG vaccine for tuberculosis.

The BCG vaccine is not routinely given as part of the NHS vaccination schedule but is sometimes recommended. For these vaccinations, you may need to wait until your baby is between six and 12 months old or until ustekinumab cannot be found in your baby's blood. But sometimes the benefit of giving a live vaccine earlier may be greater than the potential risk.

Taking ustekinumab during pregnancy should not affect the rest of your baby's **vaccination schedule**. You might want to discuss this with your IBD team and your baby's healthcare team. Decisions on what vaccines your baby should have, and when, will be made on an individual basis. Your IBD team and midwife or baby's healthcare team should be able to help you make a decision.

If you take ustekinumab, you should take extra care if your baby has the rotavirus vaccine. Live virus can be found in the baby's poo for a few weeks. Make sure you wash your hands or wear gloves when changing their nappy.

We have separate information about reproductive health and fertility and pregnancy and birth.

BREASTFEEDING

Experts agree that ustekinumab is likely to be of low risk to your baby. Many children have been safely breastfed while their mothers were on ustekinumab.

Ustekinumab passes into breast milk in very small amounts. You cannot 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.

Babies breastfed while their mothers took ustekinumab have similar risks of infection and similar life milestones compared to other breastfed babies.

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 postnatal care and breastfeeding.

DRINKING ALCOHOL

There is no evidence that drinking alcohol affects the way your body deals with ustekinumab. But, just like everyone else, you should follow **NHS guidelines** on counting your weekly alcohol units to reduce general health risks.

WHO TO TALK TO IF YOU'RE WORRIED

We understand that taking medicines and managing side effects can be difficult. We're here to help.

Our Helpline can answer general questions about treatment options and can help you find support from others with Crohn's or Colitis. Your IBD team are also there to help. You can talk to them about:

- Your dosage
- How they'll be monitoring you
- What other medicines 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.

CROHN'S & COLITIS UK MEDICINE TOOL

Our **Medicine Tool** is a simple way to compare different medicines for Crohn's or Colitis.

The Medicine Tool can help you:

- Understand the differences between types of medicines
- Know how each medicine is taken
- Explore different treatment options
- learn how well each medicine works
- see what ongoing checks you may need
- Feel empowered to discuss medicine options with your IBD team

You can find out more on our **Medicine Tool webpage**.

Always talk to your IBD team before stopping or changing medicines.

IMMUNOSUPPRESSANT PRECAUTIONS

Immunosuppressant medicines affect the way your immune system works. This means you may be at risk of complications linked with a weakened immune system.

Our information covers some of these risks and offers practical ways to lower your risk. It includes:

- General hygiene
- Food hygiene
- Travelling abroad
- Taking care in the sun
- Cosmetic procedures
- Animals

Read more about **precautions if you are taking an immunosuppressant**.

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our **website.**

Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our **helpline web page.** Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can provide support by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. Or visit our **LiveChat service**. You can read our information on **when the Helpline** is open for more details..

You can email **helpline@crohnsandcolitis.org.uk** at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Virtual Social Events

We offer people affected by Crohn's or Colitis the chance to join a virtual social event with others across the UK. The events will be a chance to chat, share experiences and potentially learn from others. Each event may have a specific topic but the overall discussion will be driven by what those attending wish to talk about.

Family, friends and colleagues are more than welcome to attend.

Visit our **Virtual Social Events** page to find out what is available.

Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the **Crohn's & Colitis UK Forum.**

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card.

This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See **our membership webpage** for more information. Or you can call the Membership Team on **01727 734465**.

ABOUT CROHN'S & COLITIS UK

We're Crohn's & Colitis UK and we're changing what it means to live with these lifelong gut conditions. 1 in 123 people in the UK have Crohn's Disease or Ulcerative Colitis. These are unpredictable conditions that could flare up at any time.

No one should face that alone. That's where we can help.

We provide trusted information and support cutting-edge research. We also lead bold campaigns to get more people talking about Crohn's and Colitis. We help people understand these conditions, give them the attention they deserve and bring people together to create change.

This year, 25,000 people will be told they have Crohn's or Colitis. Once diagnosed, the obstacles continue. Today, there is no cure. People simply don't understand these conditions. So, we have listened. It's time for change & we're leading the way.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465.** Or you can visit **our website**.

ABOUT OUR INFORMATION

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on **our website**.

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We hope that you've found this information helpful. Please email us at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- 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 you can contact us through the **Helpline** on **0300 222 5700**.

We do not endorse any products mentioned in our information.

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