

Patient information

Ustekinumab

Digestive Diseases Care Group

Ustekinumab is a medication used to treat Crohn's Disease and Ulcerative Colitis. It may be an option if your disease is moderately or severely active. It is offered if other drugs have not worked or if they have caused major side effects, and when surgery is not considered the right treatment option for you at this time.

What is Ustekinumab?

Ustekinumab is a drug that has been specially designed to mimic normal human molecules. For this reason, it is classed as a "biological drug". It works by blocking two chemicals produced by the body during inflammation, called IL (interleukin)-12 and IL-23. These chemicals contribute to the development of the inflammation and symptoms of Crohn's Disease and Ulcerative colitis.

How often do I have to have this drug?

Your first treatment will be given in hospital in the infusion unit. This first dose is given as an infusion (drip) into a vein. This means that we will need to place a drip into your arm or the back of your hand. The dose of the drug given to you will depend on your weight.

Eight weeks later you will have your next dose. This will be administered through an injection under your skin (subcutaneous).

You will have further subcutaneous injections every eight or twelve weeks.

Your doctor will decide how often you will need to receive this drug.

How long will it take to work?

The speed of response to the treatment varies. Most people find that they start to feel better within 16 weeks of treatment. This may take longer in some situations.

Do I need any investigations before starting my treatment?

Yes. Ustekinumab can affect the way the body fights certain infections. You will need a chest X-ray and a blood test to ensure that you do not have current or past infection with tuberculosis. Blood tests will also look for previous exposure to chicken pox, Hepatitis B, Hepatitis C and HIV viruses, as the drug may re-activate a previous infection with these viruses.

Additional or alternative treatments may be required should you have these infections present in your body.

What are the benefits of Ustekinumab?

Clinical trials and local experience have shown that the use of Ustekinumab provides a rapid improvement in symptoms amongst patients with Crohn's Disease and Ulcerative colitis.

What are the side effects?

Common side effects (may effect up to 1 in 10 people)

- Diarrhoea.
- Nausea.
- Vomiting.
- Feeling tired.
- Feeling dizzy.
- Headaches.
- Itching.
- Back, muscle or joint pain.
- Sore throat.
- Redness and pain where injection is given.
- Infections (sometimes severe).

Other rarer side effects may occur.

If you experience any of these side effects you must alert your doctor or IBD nurses.

Allergic reactions- these may need urgent treatment. Tell your doctor or seek urgent medical help if you notice any of the following:

- Swelling of the face, lips, mouth or throat.
- Difficulty breathing.
- Difficulty swallowing.
- Low blood pressure, which causes dizziness or light headedness.
- Rash or hives.

Ustekinumab can make you less able to fight infections and some infections could become serious.

Look out for signs of:

- Fever, flu-like symptoms and night sweats.
- Feeling tired or short of breath or experiencing a cough which will not go away.

- Warm, red and painful skin, or a painful skin rash with blisters.
- Burning when passing urine.
- Severe diarrhoea.

If you develop these symptoms you must tell your doctor or IBD nurses immediately.

If you are unwell on the day of treatment, such as suffering from a cold or have a high temperature, you must tell the nurse or doctor. This is important as it may be necessary to delay treatment until you are feeling better.

Are there alternative treatments available?

If you develop side effects with Ustekinumab, or your Inflammatory Bowel Disease is not well-controlled your doctor will discuss other possible treatment options with you.

What will happen if I decide not to have treatment with Ustekinumab?

Your symptoms will continue or worsen unless you have an alternative treatment.

Do I continue my other medications for inflammatory bowel disease?

Yes.

Can I take other medicines alongside Ustekinumab?

Most medicines are safe to take with Ustekinumab. It is important that your GP and other doctors are aware that you are taking Ustekinumab if any new medicine is prescribed.

Can I have vaccinations whilst on Ustekinumab?

Pneumovax and the annual influenza vaccinations are safe and are recommended. You should avoid any live vaccines such as some polio vaccines, BCG (Tuberculosis) and MMR (measles, mumps and rubella). If unsure speak to your doctor or IBD nurses.

Can I drink alcohol while I am taking Ustekinumab?

There is no interaction between alcohol and Ustekinumab.

Does Ustekinumab affect fertility, pregnancy or breastfeeding?

There is little information from research studies about using Ustekinumab when trying to become pregnant, during pregnancy or when breastfeeding. Talk to your doctor if you are pregnant, think you may be pregnant or are planning to become pregnant or if you are breastfeeding.

Where can I obtain further information about Ustekinumab?

If you have any questions about Ustekinumab ask your doctor, IBD nurse or your pharmacist.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

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