

Immunosuppressants for Crohn's or Colitis: What you can do to reduce your risk of complications

This information is for anyone who is taking an immunosuppressant for Crohn's or Colitis. It is also for people who are thinking about starting an immunosuppressant. This information will help you understand:

- Some of the risks and complications of taking immunosuppressants
- Practical things that you can do to reduce your risk

This information is about immunosuppressants in general. Different immunosuppressants weaken your immune system by different amounts, and in different ways. We also have information about the <u>individual medicines</u> used to treat Crohn's or Colitis. This explains the risks and benefits of each medicine in more detail.

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Immunosuppressants

Immunosuppressants are effective treatments for Crohn's and Colitis. They can help to get your symptoms under control and keep them under control. For many people, taking an immunosuppressant can improve their quality of life.

Immunosuppressants used to treat Crohn's and Colitis include:

- Steroids, such as prednisolone, beclometasone, and budesonide
- Azathioprine, mercaptopurine and methotrexate
- Anti-TNFs, such as adalimumab, infliximab, and golimumab
- Other biologics, such as risankizumab, ustekinumab and vedolizumab
- JAK inhibitors, such as filgotinib, tofacitinib, and upadacitinib
- Other targeted treatments, such as ozanimod

5-ASAs (aminosalicylates) are **not** immunosuppressants.



Immunosuppressants and the risk of complications

Immunosuppressants affect the way your immune system works. This means you may be at risk of complications associated with a weakened immune system. This includes infections. You can still fight off infections, but not quite as well as other people.

Not all immunosuppressive medicines affect the immune system in the same way. Some affect the immune system more than others, which may put you at greater risk from infection. Or your immunosuppressant might have a greater risk of certain types of infections. Your risk from infection increases as you get older. It is greater if you are under-nourished or obese, if you have certain other illnesses, or if you are in a flare-up. The risk is also greater if you are taking more than one immunosuppressant.

Some immunosuppressants can also slightly increase your risk of developing some types of cancer, in particular skin cancers. This risk is very small.

Even though your risk of complications may be higher it should not stop you from living life as before. Here we suggest some practical things you can consider doing to keep safe and reduce your risk.

When I first started taking biologics - more powerful immunosuppressants than what I was previously on - I was a little concerned about the risk of infection. However, I came to understand that the risk can be mitigated with some sensible precautions that just make sense. What's more, the positive improvement in my quality of life has made it well worth it!

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Living with Crohn's



General hygiene

You can reduce your general risk of infection through good hygiene.

It is a good idea to wash your hands often with soap and water, or use an alcohol-based hand gel. In particular:

- Before you prepare, cook, or eat food
- After you go to the toilet
- After touching pets or their poo or pee
- After changing nappies
- After gardening
- After using public transport

Try to avoid close contact with people who have a serious infection. If this is not possible, some experts recommend taking extra care with hand washing. You could also consider wearing a mask if the person has a respiratory infection.

Food hygiene and food choices

Some foods can make you unwell from infections such as listeria or salmonella. You can reduce your risk of this through good food hygiene and sensible food choices.

Make sure you prepare, handle, and store food safely

- Follow storage instructions and eat before the use-by date
- Wash your hands before you prepare, cook, or eat food
- Regularly clean work surfaces, chopping boards, knives, and other kitchen items
- Wash or replace dishcloths and tea towels regularly



Consider your risk of infection before eating the following foods:

- Raw or lightly cooked eggs
- Raw or undercooked meat and poultry
- Raw seafood, cold smoked or cured fish
- Unpasteurised milk, cheese, and yoghurt
- Pâté and cold meats that have not been cooked

There is little evidence about taking probiotics whilst on an immunosuppressant, but it is generally considered safe.

Vaccination

Your IBD team will make sure your vaccines are up to date before you start an immunosuppressant. Let them know if you are planning to have any vaccines, or you have had a vaccine recently. They will also check:

- If you have ever had chicken pox or been vaccinated against chickenpox. If not,
 you may be able to be vaccinated before you start treatment.
- You have HIV or hepatitis (a liver infection caused by a virus). You will usually have a blood test to check for these viruses.
- You have ever had tuberculosis (TB) or you have recently been in close contact
 with someone who has TB. You will usually have a blood test or a chest X-ray to
 check for TB.

You may also be eligible for:

- Annual flu vaccine
- COVID-19 vaccine and boosters
- Shingles (Shingrix) vaccine
- Pneumococcal vaccine



These are all 'non-live' vaccines and are safe for you to have.

You should **not** have any 'live' vaccines while you are taking an immunosuppressant

In the UK live vaccines include:

- Rotavirus vaccine.
- Measles, mumps, and rubella (MMR) vaccine.
- Nasal flu vaccine used in children: the injected flu vaccine used in adults is **not** live
- Chickenpox vaccine.
- BCG vaccine against TB.
- Yellow fever vaccine.
- Oral typhoid vaccine: but the injected typhoid vaccine is **not** live

Before you start an immunosuppressant, think about any vaccines that you might need in the future. For example, if you are planning to travel. You might be able to have these before you start treatment.

Close contacts of people who are immunosuppressed should also be up to date with their vaccines. This reduces the risk of spreading infection. If someone you live with has had a live vaccine, they could pass on the infection for up to 2 weeks after. But this risk is very low. If your child is due to receive the live nasal flu vaccine, you can ask for them to have the non-live vaccine instead.



Travelling abroad

Plan your trip in advance. If you can, try to plan your trip at least 6 to 8 weeks before you go. If you are travelling for more than 3 months, allow a bit longer if you can. This gives you time to get travel advice, order medicines and arrange any vaccines you might need.

To reduce your risk while travelling:

- Get advice about any vaccines that you might need
- Be aware of food and water risks
- Wash your hands often
- Take care to avoid insect bites
- Take anti-malaria tablets if recommended. Some anti-malaria tablets make your skin more sensitive to the sun.
- Stay safe in the sun
- Make sure you have valid travel insurance

IBD passport has useful advice and information on travelling with Crohn's or Colitis.

See <u>Travelling with Crohn's or Colitis</u> for more information on planning your trip.



Take care in the sun

If you are taking an immunosuppressant, you may be slightly more at risk of skin reactions, and in rare cases skin cancer.

To reduce your risk:

- Stay in the shade when the sun is strongest (between 11am and 3pm)
- Use sunblock or high factor sunscreen (at least factor 30)
- Cover your skin and wear a hat when you are out in the sun
- Do not use tanning equipment (such as a sunbed or tanning booth)

Some immunosuppressants make your skin more sensitive to the sun. Exposure to the sun can cause a severe reaction that looks and feels like sunburn. Exposed skin may develop a rash, redness, swelling, blisters, red bumps, or oozing wounds. If the reaction is severe the skin can become infected. Immunosuppressants that can make your skin more sensitive include azathioprine and methotrexate.

Check your skin regularly and contact your GP if:

- You have a new or unusual mark on your skin that stays for more than 4 weeks.
- You have a mole that has changed size, shape or colour, or is swollen, painful, itchy, or bleeding.

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Cosmetic procedures

People with a weakened immune system are at increased risk of skin infections.

There is likely to be a small risk of skin infection with procedures such as tattooing, body piercing and cosmetic surgery.

To reduce your risk, consider the following:

- Wait until your Crohn's or Colitis is stable
- Choose a licensed, experienced professional in a reputable location
- Make sure they use sterile equipment
- Follow the instructions for aftercare
- Try not to scratch the area

In general, laser hair removal is considered safe.

- If you're on a medicine that increases your sensitivity to sunlight, test laser treatment on a small area of skin first. Immunosuppressants that increase your sensitivity to sunlight include azathioprine and methotrexate.
- Laser treatment around the mouth can re-activate cold sores
- Stay out of the sun for at least 24 hours after treatment

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Animals

Animals can carry diseases that could make you unwell. Some animals may be more high risk. This includes:

- Reptiles, poultry, rodents, and exotic pets
- Young or sick animals
- Farm animals or wild animals

If you have a weakened immune system, you can still enjoy interacting with animals.

Follow the tips below to stay safe and healthy:

- Wash your hands after handling any animal, its poo and pee or its food.
- If you have a cat, try to get someone else to clean out its litter tray every day.
- Keep your pet's routine vaccinations up to date.

The kennel cough vaccine for dogs is a modified live vaccine. It contains a weakened form of the bacteria that causes kennel cough. If your dog needs a kennel cough vaccine, it can be a good idea to:

- Stay out of the room when the vaccine is given
- Ask someone else to wipe your dog's face after it has been vaccinated
- Try not to touch or be close to your dog's face after it has been vaccinated

There is no agreement as to how long you should avoid your dog after it has had a kennel cough vaccine. The product information for the vaccine says that people who have a weakened immune system should avoid contact with vaccinated dogs for up to 6 weeks after vaccination. But the company that makes the vaccine also says that the vaccine is not likely to represent a major risk. And that the risk would be greater if your dog got kennel cough. You may want to discuss precautions or other options with your vet. You could also discuss concerns with your GP or IBD team.



Open water swimming

Swimming in open water, such as lakes, rivers, natural pools, and the sea can help your physical and mental health. But it can increase the risk of infections such as tummy bugs and lung, skin, ear, or eye infections.

To reduce your risk of infection:

- Check the water quality
- Cover cuts, scratches, or sores with a waterproof plaster
- Wear suitable protective clothing such as a wetsuit, gloves, and protective footwear
- Try to avoid swallowing water
- Wash your hands after swimming, and shower if possible
- Look for any signs or symptoms of infection afterwards. These include diarrhoea,
 vomiting, coughing, or skin rashes



If you get an infection

If you think you might have an infection, contact your GP, IBD team or NHS 111.

Signs of an infection include:

- Flu-like symptoms
- A cough that will not go away
- Sore, red skin or a painful skin rash with blisters
- Feeling tired or short of breath
- Peeing more than usual or a burning feeling when you pee
- A severe headache with a stiff neck

Who you contact will depend on your local service. But if your symptoms are severe and you need urgent help then contact NHS 111.

Search our Find an IBD nurse specialist page to find your local specialist service.

Find out more about the <u>medicines</u> used to manage Crohn's and Colitis (<u>www.crohnsandcolitis/treatments</u>).

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.

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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**.

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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.

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