



Birdshot Uveitis Society

Immunosuppression and lifestyle advice: some Questions and Answers

Please use this Q&A factsheet as background information to help discussion with your doctors. Individual cases may vary enormously, so the best information will always come from your doctors. The information in this factsheet has been checked for accuracy by leading uveitis specialists.

CONTENTS:

- Q1. Why have I been given immunosuppressant treatment for my
- Q2. Does taking immunosuppressants mean I will have no resistance to infections?
- Q3. What can I do to reduce my chances of getting infections?
- Q4. What signs of infection mean that I need medical treatment?
- Q5. Do I continue taking my immunosuppressants if I have an infection?
- Q6. I've heard that being in contact with chickenpox and shingles can be dangerous for anyone taking immunosuppressants. Can you explain?
- Q7. What about contact with other infectious diseases?
- Q8. Any other infections to look out for?
- Q9. Now that I am immunosuppressed, which immunisations must I not have? Which are safe for me to have?
- Q10. Should I have a flu injection?
- Q11. Should I be immunised against anything else?
- Q12. Are there any foods or drinks that I should avoid because I am taking immunosuppressants?
- Q13. Can I continue with exercise and sports now I'm taking immunosuppressants?
- Q14. How does being immunosuppressed affect my chances of starting a family?
- Q15. Why do I have to have so many blood and urine tests?
- Q16. How long will it take for the immunosuppressants to work?

- Q17. What side-effects are likely with my immunosuppressants?
- Q18. How do I get repeat supplies of my immunosuppressants?
- Q19. Any other advice about my medicines?
- Q20. Should I tell my dentist that I am taking immunosuppressants?
- Q21. What about other therapists and treatments?
- Q22. What about sunbathing and sunbeds now I'm taking immunosuppressants?
- Q23. Any special advice about travelling, particularly travelling abroad?
- Q24. Anything else I should know?

Immunosuppression and lifestyle advice: questions and answers

Introduction

Learning that you have been prescribed immunosuppressant medication for your birdshot uveitis can lead to many concerns and questions. This information leaflet aims to give you some sensible advice and tips to help you take care of yourself and keep well and active while you are taking immunosuppressants.

Q1. Why have I been given immunosuppressant treatment for my birdshot uveitis?

Our body's immune system is designed to fight infections. However, cells in the immune system can sometimes fight the body's own tissues, causing inflammation and other effects. This is what happens in birdshot uveitis. Taking an immunosuppressant reduces this over activity of the immune system cells and quietens the eye inflammation.

You may be prescribed corticosteroid tablets (often referred to as steroids) as well as immunosuppressants. Prednisolone is the steroid most often used in the UK for treating uveitis. Note that corticosteroids are quite different from the anabolic steroids which are sometimes misused by body-builders.

Taking a corticosteroid controls the eye inflammation of uveitis while the immunosuppressants begin to work. When the immunosuppressants reach their full effect, the dose of steroid is then gradually reduced. This is done because taking high doses of steroids long-term can cause health problems.

Q2. Does taking immunosuppressants mean I will have no resistance to infections?

The most important thing for you to understand is that although you are taking immunosuppressants, your immune system is still working. You should be able to live your life as usual. Taking immunosuppressants reduces the effectiveness of your immune system, but your body can still fight infections. However, while you are taking immunosuppressants, you may be slightly more susceptible to infections, and you will need to seek advice from your doctor if you develop an infection (see question 4). You may find that infections develop differently or more slowly than before you were taking immunosuppressants, and infections may take longer to clear up.

Q3. What can I do to reduce my chances of getting infections?

There are some simple steps you can take to reduce your exposure to various common and preventable sources of infection. You are probably doing many of these things already, but it is more important to do them regularly now that your immune system is suppressed.

Carrying out these preventative actions may give your immune system a better chance of dealing with the many unavoidable viruses and bacteria to which we are all exposed daily as we go about our usual activities and socialising.

- Try to **avoid close contact with people suffering from coughs, colds and influenza**. If you do develop a cough or cold, use of a saline nasal spray or steam inhalations may help reduce your chances of developing a sinus infection.
- **Good hand hygiene** is very important, especially to reduce spreading infection on to your food or your face. Wash your hands thoroughly, particularly after visiting the toilet and before preparing or eating food.
- Carry **hand wipes or hand sanitising gel**, and use them when out and about, especially during and after using public transport or handling money if you are unable to wash your hands, and before eating, particularly when eating hand-held foods such as sandwiches.
- Take care over your **personal hygiene**. Avoid sharing towels, sponges and facecloths, change them regularly and launder them using a hot machine wash. Clean shower heads regularly.
- For **kitchen hygiene**, ensure that work surfaces and chopping boards are kept clean. Change kitchen towels, tea towels and dishcloths regularly, and use a hot machine wash for them.

- Keep your **pets** healthy, for example, regularly wormed and immunised. Wear gloves when changing litter trays. Wash your hands after handling pets. If you keep birds, especially pigeons, they may carry infections, so ask your doctor for advice on whether you should continue to keep them.
- **Cuts and scratches** may take longer to heal when you are immunosuppressed. Keep them clean, and covered with a first-aid dressing if necessary.
- When **gardening**, wear gloves.
- Travelling in **planes, trains and coaches**: see question 23.

Q4. What signs of infection mean that I need medical treatment?

You have probably self-treated many types of infections and illnesses in the past. Your immune system is still working even though you are taking immunosuppressants (see question 2). However, while you are immunosuppressed, an infection such as a cold or sore throat can become more serious. Infections may not follow their usual course when you take immunosuppressants, and the sooner you receive any necessary treatment, the sooner you will recover.

Signs of infection which require prompt medical attention include:

- raised temperature, above 38.3°C (101°F)
- sore throat
- flu-like symptoms (shivering; sweating)
- burning sensation when passing urine
- nausea and vomiting different from any which you may have had as a side-effect of your immunosuppressants
- rash on the body
- night sweats

You should seek a doctor's advice urgently if you do become ill. This may mean contacting your local out-of-hours medical service. Tell them that you take immunosuppressants.

Ask if your GP practice has a system where you can mention that you are taking immunosuppressants when you request a consultation about a possible infection. If so, this may help you to be seen more quickly.

Show the patient information leaflets from your medicines to any doctor treating you for infection, as there may be certain antibiotics that you should not receive with your immunosuppressants.

Q5. Do I continue taking my immunosuppressants if I have an infection?

You must contact your doctor if you become ill with an infection (see question 4). You should not stop taking your immunosuppressants for any reason unless your doctor has told you to do so. If you are taking steroids, your doctor may need to increase your dose of steroids during an infection.

Q6. I've heard that being in contact with chickenpox and shingles can be dangerous for anyone taking immunosuppressants. Can you explain?

If you have had chickenpox in the past, your risk of catching it again is small. However, if you are immunosuppressed, you may become ill if you are in direct contact with someone who has chickenpox or shingles.

'Direct contact' means being in the same room with someone who has chickenpox. If you have been in contact with a person who has themselves been in direct contact with a case of chickenpox, the risk to you is negligible, because this is called 'indirect contact.' You are only at risk if you come into direct contact with the disease.

Similarly, the risk of catching the chickenpox virus from someone who has shingles is very small. You are only at risk if you make direct contact with shingles through touching the skin sores.

If you have been in direct contact with someone who has either chickenpox or shingles, it is very important to consult your doctor as soon as possible, as you may need a special protective injection as well as other treatment

Q7. What about contact with other infectious diseases?

As for chickenpox and shingles (see question 6), the words 'direct contact' are important. In particular, if you have been in direct contact with someone who has measles, you may need a special protective injection from your doctor even if you have received MMR (measles, mumps and rubella) vaccine in the past.

Your occupation may mean that you are more likely to come into direct contact with outbreaks of infectious diseases, for example, in schools. It may be worth informing your employer that there may be rare occasions when your doctor might recommend avoiding contact with other people, requiring either working from home or time off.

Q8. Any other infections to look out for?

Skin infections, particularly fungal infections, can become more common if you are immunosuppressed, and may not respond to simple treatments. Ask your doctor for advice. If a fungal infection of the skin is diagnosed, use a hot machine wash for clothing which is in contact with the affected area. This is to prevent reinfection of the skin during treatment.

Q9. Now that I am immunosuppressed, which immunisations must I not have? Which are safe for me to have?

The information given here reflects current (March 2018) recommendations and availability of vaccine products in the UK. Some immunisations listed may be available only as combined vaccines. Readers in other countries should obtain local medical advice about immunisation.

You must **avoid having live vaccines** while you are immunosuppressed.

Always consult your doctor before having any immunisations.

Live vaccines include

- BCG (tuberculosis)
- Influenza nasal vaccine (a vaccine which is given into the nose)
- MMR (measles, mumps and rubella)
- Polio (oral)
- Rotavirus
- Zostavax brand of shingles (herpes zoster) vaccine*
- Typhoid (oral)
- Varicella (chickenpox)
- Yellow fever

* Shingrix brand shingles (herpes zoster) vaccine is a new type of shingles vaccine made from a protein on the herpes zoster virus. It was launched in US in October 2017 but is not yet available in UK. See <https://www.fda.gov/downloads/biologicsbloodvaccines/vaccines/approved/products/ucm581605.pdf> for more information.

If anyone in your household has to have a live vaccine, check with your doctor to see if you need to take any extra precautions to protect yourself from infection. This may depend on the method by which the vaccine is given to your household contact.

For example, oral polio vaccine (not now routinely used in the UK) is not advised for your household contacts because contact with live vaccine passed out in their bowel motions may pose a risk to you.

If a child in your household receives the live influenza nasal spray vaccine, you are not likely to be at risk of infection. The viruses in the vaccine have been treated so that they are unlikely to cause influenza. There have been no reported cases of illness or infection in immunosuppressed patients inadvertently exposed to the nasal vaccine virus in the US, where this vaccine has been widely used for several years.

Your household contacts can receive injected live vaccines without causing you problems.

You **may receive inactivated vaccines** while you are immunosuppressed.

Inactivated vaccines include

- Anthrax
- Cholera (oral)
- Diphtheria
- Haemophilus influenza (Hib)
- Hepatitis A
- Hepatitis B
- Human papillomavirus (HPV)
- Influenza (injection)
- Japanese encephalitis vaccine
- Mantoux test for tuberculosis
- Meningococcal vaccines
- Pertussis (whooping cough)
- Pneumococcal vaccines
- Polio (injection)
- Rabies
- Tetanus
- Tick-borne encephalitis vaccine
- Typhoid (injection)

Although you can receive these inactivated products, they may be less effective because you are immunosuppressed.

Q10. Should I have a flu injection?

Anyone taking immunosuppressants is recommended to have an annual influenza injection immunisation. Check with your GP practice if you will automatically be notified about this. If not, find out when the influenza vaccine becomes available (usually from September onwards in UK) at your GP practice and make an appointment for your immunisation. See also question 9: the nasal influenza vaccine is a live vaccine, and it is not suitable for people taking immunosuppressants.

Q11. Should I be immunised against anything else?

Yes. If you are to receive immunosuppressant treatment, or if you are likely to have systemic (oral) corticosteroids for more than one month at a dose equivalent to 20mg or more of prednisolone per day, you are at an increased risk of getting pneumococcal disease.

The best response to pneumococcal vaccine is obtained if it is given before you start treatment with immunosuppressants and/or oral corticosteroids, but it will still give you protection if you have the vaccine during your birdshot treatment.

Different pneumococcal immunisation recommendations apply in UK and in US.

The UK recommendation is for you to have a single dose of pneumococcal polysaccharide vaccine, also called PPV23 vaccine, to protect you against pneumococcal disease. This vaccine is also offered as a single dose to anybody in the UK aged 65 or over unless you have already received it.

Routine pneumococcal re-vaccination is not currently recommended in UK unless you have no spleen or if you have chronic kidney disease.

For US recommendations, see National Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, www.immunize.org/catg.d/p2015.pdf

Q12. Are there any foods or drinks that I should avoid because I am taking immunosuppressants?

It is important to eat a balanced and nutritious diet and take plenty of fluids to maintain your good general health while you are taking immunosuppressants. Some foods do carry a risk of infection, so they are probably best avoided if you take immunosuppressants. This applies particularly when you are eating away from home or in another country. These are:

- foods containing raw eggs, including mayonnaise
- raw or undercooked meats
- raw fish, eg, sushi
- undercooked poultry
- pâtés
- unpasteurised milk and cheeses
- shellfish

Also, check the patient information leaflet enclosed with your medicines for any special advice on foods or drinks to be avoided.

For example, if you are taking ciclosporin or tacrolimus, eating grapefruit or drinking grapefruit juice affects the blood levels of these medicines in an unpredictable and prolonged way. To avoid these problems, it is best not to consume either grapefruit or grapefruit juice at all if you are taking ciclosporin or tacrolimus.

Q13. Can I continue with exercise and sports now I'm taking immunosuppressants?

Yes. Coping with your birdshot uveitis and its treatment can be stressful. The exercise and relaxation tips here may be things you are already doing. If so, you should aim to continue them, but if not, they are worth considering doing, as they may help you to regain and retain a sense of balance in your life as well as contributing to your good health.

- Make time for regular exercise. This could be anything from a walk, simple stretching exercises, or joining a movement and exercise class.
- Sporting activities can generally be enjoyed without problems. Avoid extreme exercise, such as weightlifting with very heavy weights, bungee jumping and similar high acceleration activities, as these may put your eyes at risk of damage.

- Make time to include some relaxation in each day. As well as the more obvious relaxations of favourite hobbies or pastimes, this might be the time to try yoga or meditation exercises which may benefit your immune system as well as helping you relax.

Q14. How does being immunosuppressed affect my chances of starting a family?

Some immunosuppressants should not be taken by men or women who are trying to conceive, nor by women during pregnancy or breastfeeding. Ask your doctor for advice.

Q15. Why do I have to have so many blood and urine tests?

These are done to check that the immunosuppressant is reducing the activity of your immune system satisfactorily, but that it is not causing unwanted effects on your liver, kidneys and blood cells. Testing is particularly important at the start of your treatment, when the tests may be very frequent to check how you are beginning to respond to the medication. However, it is still essential for your continuing good health that you attend regularly for all tests requested by your doctor.

If, for whatever reason, you find you cannot keep a test appointment, contact your test centre as soon as possible to discuss this and to arrange another appointment.

Q16. How long will it take for the immunosuppressants to work?

Most immunosuppressants take several weeks to reach their full effect in the body, and the effects take several weeks or months to wear off when the medication is stopped. This is why it is important not only to tell anyone treating you that you are taking an immunosuppressant, but also to tell them after you stop taking it, as your body may still be recovering its immune response to infections. See also questions 20 and 21.

Q17. What side-effects are likely with my immunosuppressants?

Side-effects are a possibility with any medicine, and you may be concerned about the list of potential side-effects in the patient information leaflet supplied with your medicine. The list may be long because any side-effect that has been reported has to be mentioned in the leaflet. Many reported side-effects are very rare.

Though the expected benefits of your immunosuppressant treatment have to be balanced against any adverse effects, people react in different ways to the same medicine.

If you think that your immunosuppressant is causing you a problem, particularly if you notice any unexplained bruising or bleeding, contact your doctor for advice.

Q18. How do I get repeat supplies of my immunosuppressants?

You may receive hospital prescriptions for your medicines. However, if your GP is prescribing your medicines, your community pharmacist is likely to have to order them specially for you, and there can be delays in medicine supply chains. This is why it is important to obtain and present your repeat prescriptions for dispensing in plenty of time so that you do not run out of medicines.

Immunosuppressants are used for treating a variety of conditions. It is worth letting your pharmacist know that you are taking immunosuppressants because of your birdshot uveitis.

Q19. Any other advice about my medicines?

Read the patient information leaflet supplied with your medicines, and keep a copy in your purse or wallet. You can then refer to it if you are buying over-the-counter medicines, including herbal or complementary medicines and food supplements, as some purchased products may not be suitable for you to take with your immunosuppressants. Ask your pharmacist for advice.

You should always mention your immunosuppressants to your doctor whenever a new medicine is being prescribed or a current medicine is discontinued. Show your patient information leaflets to your doctor so that they can check for any possible interactions with your treatment. Some medicines must not be taken with immunosuppressants, and this varies according to which immunosuppressants you are taking.

In the UK, letters from hospital doctors to your GP detailing your treatment and medication are now usually scanned into your GP's patient record system. However, your GP repeat medication record may not include the medicines prescribed or recommended by the hospital doctor unless your GP is actually issuing your repeat prescriptions for those medicines.

Because of this, you will find it useful to keep your own simple record of all the medicines you take or use, whether prescribed by a hospital doctor or your GP, or purchased by you. This record should include the medicines' strengths and doses. Keep this record in your purse or wallet with the patient information leaflets from your medicines, and keep the record up to date. You can then show your record to anybody who needs to know exactly what medicines you are currently taking or using.

Q20. Should I tell my dentist that I am taking immunosuppressants?

Yes. Because immunosuppressants alter the activity of your immune system against infection, it is important to take good care of your mouth and teeth. Visit your dentist regularly every six months, tell them that you are taking immunosuppressants, and let them know which one(s).

Your dentist will then know to keep a special watch for any signs of infection in your gums, mouth and teeth.

Some immunosuppressants, for example, ciclosporin, methotrexate and mycophenolate, can cause swollen gums as a side-effect, so if you are taking these medicines, your gums will need special care.

You do not need to receive preventative antibiotic treatment for routine dental work while you are taking immunosuppressants. However, if you need to receive antibiotics for treating a dental problem, remember to show your dentist the patient information leaflets from your medicines in case there are antibiotics that you should not receive.

Let your dentist know if you change, taper or stop your immunosuppressants. You will still need special dental observations for several months after stopping immunosuppressants.

Q21. What about other therapists and treatments?

Treatments which involve needles or skin removal are a potential source of infection for anybody, but these treatments pose a higher risk to you when you are immunosuppressed. Always tell your therapist that you take immunosuppressants, or if you are tapering or have recently stopped them.

In the UK, treatments such as:

- acupuncture
- body piercing
- podiatry (chiroprody)
- electrolysis
- tattooing

should all be performed by registered therapists using sterile, single-use equipment. If you have any doubts about a therapist or their equipment, do not proceed with treatment.

Q22. What about sunbathing and sunbeds now I'm taking immunosuppressants?

When you are taking any immunosuppressant, it is even more important than usual to take sensible precautions to protect yourself from the effects of the sun on your skin, whether you are in the UK or in sunnier countries. This is because your skin will be more sensitive to sun damage. The risk of sun damage, including the development of skin malignancies, is related to the intensity and duration of your immunosuppression rather than to any specific immunosuppressant.

Follow the Australian 'slip, slop, slap' sun protection advice, even if you have skin which tans easily:

- slip on a blouse or shirt - to cover your skin as much as possible against the sun
- slop on a sunscreen - use a high factor sunscreen (SPF 30 or higher) and re-apply it regularly
- slap on a sunhat
- You should avoid using sunbeds.

Contact your doctor if you notice any changes to your skin, such as the development of moles or warts.

Q23. Any special advice about travelling, particularly travelling abroad?

Many of the precautions suggested here for the immunosuppressed traveller are things which you would normally consider doing when travelling. However, some of them may be new to you. Following these tips should help you to stay as well as possible and enjoy your travelling.

Before travel

- Contact your doctor to discuss what immunisations, antimalarial protection or other medicines may be needed for the areas you intend to visit.
- See question 9 for which immunisations you may or may not receive when you are taking immunosuppressants.
- Some immunisations have to be given several weeks or months before travel, so allow enough time for this to be done.
- If you are travelling to an area where yellow fever is a risk, your doctor may give you a medical exemption letter because you cannot have yellow fever vaccine. However, some countries may not admit you without proof of actual immunisation, and when you travel from a yellow fever risk area to another country, immigration officials are

legally entitled to quarantine you. Seek advice before booking your travel.

- Check with your doctor that any malarial preventative medications recommended for the area you intend to visit are suitable for you to take with your immunosuppressants.
- Useful information can be found on the websites:

i) www.fitfortravel.nhs.uk

ii) www.travelhealthpro.org.uk

Medicines tips

- Pack them in your hand luggage in case your checked-in luggage goes astray.
- Take extra medication with you in case there are any delays to your travel.
- Take a list of all your medications, strengths and doses with you, and the patient information leaflets, in case you require medical treatment or need to buy medicines while you are away (see question 19).
- If you are travelling across different time zones, you will need to work out how best to adjust your medication times to the country you travel to, and then move the times back when you return.

Planes, trains and coaches

- If you are sitting under an air vent, either turn it off or direct it away from your face so that you reduce your exposure to recirculated air and airborne infections.
- On flights, keeping well hydrated with regular non-alcoholic drinks helps counteract the drying effect of low-humidity cabin air on your nose and throat, which are your first line of defence against airborne infections.
- For long-haul flights, you could consider wearing a face mask for protection.

Food and drink. Use all the tips in question 12, plus:

- Follow the traditional rule of 'boil it, peel it, cook it, wash it or forget it'.
- Bottled carbonated (fizzy) mineral water is likely to be safer than still mineral water because the presence of bubbles shows that the bottle has not been previously emptied and refilled with local tap water.
- Use bottled water when cleaning your teeth.
- Avoid street food likely to have been exposed to flies.

- Avoid salads, as they may have been washed in unsafe water.
- Avoid food that has been kept warm.
- Avoid ice in drinks.
- Avoid swallowing water while swimming.

Q24. Anything else I should know?

Only to emphasise what was said at the beginning - the most important thing for you to remember is that although you are taking immunosuppressants, your immune system is still working. Your body can still fight infections.

You now know some simple precautions you can take to reduce your exposure to various common sources of infection. You now also know when you should seek advice if you do develop an infection, and you have some useful lifestyle tips. By putting this information into practice, you should feel more confident about managing your treatment, your health and your lifestyle.

Useful Birdshot Uveitis Society links	
Email address:	mailto:info@birdshot.org.uk
Website:	https://birdshot.org.uk
Address:	Birdshot Uveitis Society, PO Box 64996, London SW20 8PT
Facebook support group:	https://facebook.com/groups/Birdshot/
Twitter:	https://twitter.com/birdshotcharity
YouTube channel:	https://www.youtube.com/user/Birdshot100/videos

Prepared for Birdshot Uveitis Society (BUS), August 2013 and checked by members of the BUS standing advisory committee. Revised September 2016, March 2017 and March 2018.