



Managing my uveitis

For anyone living with axial spondyloarthritis (AS)
including ankylosing spondylitis (AS)



Contents

Who is this guide for?	3
What is axial spondyloarthritis?	3
What is uveitis?	4
Symptoms of acute anterior uveitis	5
What you should do if you have symptoms of acute anterior uveitis	5
Early treatment	6
Getting your diagnosis	8
Treatment	9
Top tips for dealing with acute anterior uveitis	11
Become a NASS member today!	13

Who is this guide for?

This guide is for anyone with axial spondyloarthritis (axial SpA) including people with ankylosing spondylitis (AS).

What is axial spondyloarthritis?

Axial Spondyloarthritis (axial SpA) is a painful form of inflammatory arthritis.

The main symptom is back pain but it can also affect other joints, tendons and ligaments. Other areas such as the eyes, bowel and skin can also sometimes be involved.

Axial spondyloarthritis is an umbrella term. It includes:

Non-radiographic axial spondyloarthritis

Where x-ray changes are not present but inflammation is visible on MRI or your blood tests and clinical picture fit the diagnosis.

To keep things simple in this guide we have tried to just refer to axial SpA (AS) throughout unless we need to highlight a difference between non-radiographic axial spondyloarthritis and ankylosing spondylitis.

Ankylosing Spondylitis (AS) (sometimes also called radiographic axial SpA)

Where there are changes to the sacroiliac joints or the spine that can be seen on x-ray.

What is uveitis?

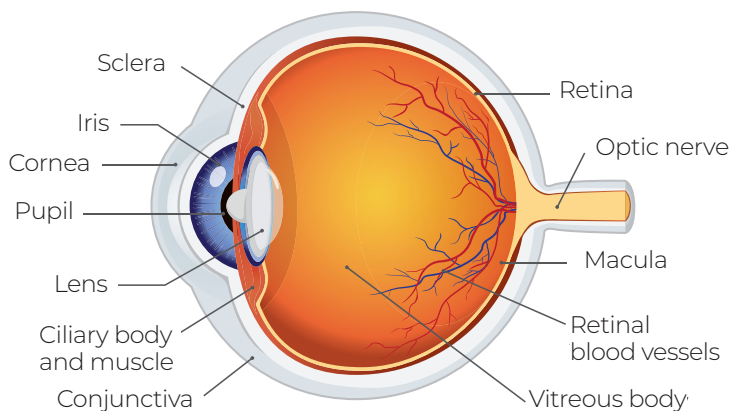
The terms anterior uveitis and iritis are both medical terms for inflammation in the front part of the eye, between the cornea (the clear window at the front of the eye) and the lens.

Iritis is an older term for anterior uveitis but is still in frequent use. In this guide we will only refer to anterior uveitis.

Anterior uveitis can be acute or chronic. Acute means short term whereas chronic means a condition which lasts 3 months or more.

Most people who develop this condition will have acute anterior uveitis. Acute anterior uveitis is the most common type of uveitis.

About a quarter of people with axial SpA (AS) will have an attack of acute anterior uveitis at some time in their life.



Symptoms of acute anterior uveitis

- Pain in the eye.
- Sensitivity to light. The brighter the light the more pain in the eye as the pupil gets smaller causing pain.
- Redness and soreness of the eye.
- Blurred vision.

Symptoms of acute anterior uveitis usually develop quickly over a few hours. Sometimes it can be more gradual, worsening over a number of days.

Each single attack usually lasts a few weeks and should last no more than 3 months. The inflammation can range from mild to severe and each attack may be different, even in the same person.

Repeated attacks can occur over a period of several years and can be in the same eye, the other eye or even in both eyes.

What you should do if you have symptoms of acute anterior uveitis

If you think you have symptoms you should see an eye doctor (ophthalmologist) as soon as possible, ideally within 24 hours, to confirm this and start you on treatment.

Some people experiencing recurrent episodes of uveitis know the symptoms of an episode and can self-medicate before seeing a doctor. However, it is still recommended that

you consult an ophthalmologist as soon as possible.

Some of the treatments cause complications and should be supervised by an ophthalmologist.

Early treatment

Early treatment reduces the risk of long-term damage to the eye which can affect your vision.

Untreated inflammation can damage the lens by causing the iris to stick to it. Inflammation in the eye which is left untreated can also cause:

Cataract

Inside the eye, behind the iris (the coloured part of the eye) is a lens. In the normal eye, the lens is clear and transparent, and helps to focus light rays on to the retina, the tissue at the back of the eye.

When a cataract develops, the lens becomes cloudy and prevents the light rays passing into the retina. The picture that the retina receives becomes dull and fuzzy. Cataracts usually form slowly and people experience a gradual blurring of vision.

Raised pressure in the eye

This can lead to glaucoma. Glaucoma is an eye condition in which there is progressive loss of the field of vision as a result of damage to the optic nerve which carries sight images from the eye to the brain. Usually, the damage occurs because the pressure within the eye is too high.

Ophthalmologists monitor your eye pressure to ensure it stays within an acceptable range and also examine the nerve at the back of the eye for signs of damage.

They may also ask you to do a visual field test (which plots how sensitive the different areas in your vision are) to see whether your vision is being affected by high pressure.

People in whom the eye pressure is not well controlled with drops may require surgery to help bring down the eye pressure.

Waterlogging

Anyone with acute anterior uveitis can get 'waterlogging' of the retina at the back of the eye. This is known as macular oedema.

The macula is the central part of the retina and is required for crisp vision. The retina is like the film in a camera, and waterlogging with fluid distorts the image that you see. Ophthalmologists can detect macular oedema with special equipment called OCT (optical coherence tomography) which doesn't cause any discomfort to the eye.

The image from the OCT works rather like taking a slice out of a cake and looking through the different layers in the cake - the cake is thicker in areas where there is fluid.

Sometimes macular oedema resolves as the uveitis attack is treated but it may require additional treatment with steroid injections or tablets.

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*Early treatment
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long-term damage
to the eye.*

Getting your diagnosis

Only an ophthalmologist should make the diagnosis. This can usually be done by asking your GP to make an urgent referral to the local ophthalmology team or you can go to your local hospital A&E department who will contact the ophthalmologist to arrange an urgent review.

Do check the local process in your area.

The diagnosis is made by looking at your eyes with a slitlamp microscope. The doctor will be looking for cells in the front chamber of the eye and deposits

of cells on the back of the cornea (the glass window at the very front of the eye). The iris may be stuck to the lens (at the pupil margin) and the pressure in your eye may be normal, high or low.



Treatment

Acute anterior uveitis is usually treated with eye drops. These include:

Steroid eye drops

Steroid eye drops act to reduce inflammation. A range of different steroid eye drops may be used depending on the severity of your acute anterior uveitis.

Steroid drops will often need to be reduced gradually and not stopped suddenly (depending on how long you have been using them for). The doctor should give you more information about this.

It is important to realise that steroid drops do not cure the inflammation. They damp down the inflammation until your own body and immune system switches off the attack. They do, however, reduce the risk of damage to the eye in the meantime.

Even if your eye feels back to normal it is very important to complete your course of drops. If you stop too soon an attack can flare up again immediately.

Dilating eye drops

Dilating drops will make your pupil larger. This will reduce the risk of the iris sticking to the lens and break any attachments that have already formed.

They will help to relieve the pain and give rest to your eye.

As they enlarge your pupils, they will temporarily blur your vision, especially when reading. It is important that you persevere with them, but remember that they are only required in the early stages of treatment.

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*Steroid eye drops
act to reduce
inflammation.*

Eye pressure lowering drops

In some people, the inflammation causes the eye pressure to increase, and pressure-lowering drops may be needed until the inflammation is controlled.

Raised pressure can also be a side-effect of steroid drops, which also requires similar treatment.

If you've had high pressure in your eyes in the past, do mention it at every visit.

If the inflammation is intense steroid injections can be used around the eye to help. A small number of people will need a short course of steroid tablets or injections if the inflammation is not confined to the front of the eye, as steroid drops do not penetrate through to the back of the eye.

Chronic anterior uveitis

When an attack of anterior uveitis lasts for longer than 3 months it is referred to as chronic anterior uveitis.

Treatment of chronic anterior uveitis may need long-term use of steroid drops, treatment with steroid tablets or other immunosuppressive medication to suppress the immune system safely for a longer period of time.



Top tips for dealing with acute anterior uveitis

See an ophthalmologist urgently (within 24 hours) to make the diagnosis and start treatment without delay.

Carefully follow the instructions from your doctor about taking the medicine.


Return for follow-up checks as arranged.

Return to the hospital quickly if your symptoms return, if you notice any further deterioration in vision or if other symptoms such as pain or redness develop.

If you are sensitive to light, dark glasses will help. You can also try lying in a dark room with your eyes closed.

Anti-inflammatory type painkillers are useful, e.g. aspirin and ibuprofen, but always read the instructions carefully before taking any medication.

Studies have shown that smoking can increase your risk of an attack of uveitis. If you smoke do consider getting help to quit.

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*Smoking can
increase your
risk of an attack
of uveitis.*

Gilly's story

I had my first attack of uveitis in my 20's before I was even diagnosed with axial spA (AS). Then I've had quite a few attacks over the years. It's hard to find a cause but stress and hormones seem to play a role for me. I always had an attack during my pregnancies.

There's been times when I've not had an attack for years on end. That seems to coincide with times that I've felt I was very stable and doing well on my medication.

When I have an attack, the key for me has been to get to see an ophthalmologist in eye casualty as soon as I possibly can. As soon as I get to an eye casualty I know I'm in good hands and they know exactly how it should be treated. I've always found that if I have any delay in starting treatment, the uveitis will go on for longer before it clears.



Become a NASS member today!

Join the largest and most significant community of people with axial SpA (AS) in the UK.

Being a member makes you an essential part of the work we do.

You will be able to impact and influence where we focus our efforts. You can help us improve both your own well-being and that of everyone living with axial SpA (AS) in the UK.

Thanks to our members support, we are able to make guides like this available to anyone who need them.

Our Members also receive:

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- Access to our annual Members Day (free for a member and guest).
- Access to the Members only resources on our website.
- Access to our Members Forum.
- Voting rights at our AGM.
- Chance to contribute to cutting-edge research and campaigns.
- Exclusive guides to claiming disability benefits (on request).
- Members Pack (including Membership card).

**We are one connected community, transforming axial SpA (AS) futures.
All that's missing is You!**

**Simply call 020 8741 1515, or visit
www.bit.ly/JoinNASS to become a member today!**

Notes

Thank you

We distribute 40,000 guides to living with axial SpA (AS) each year.

Without your hard work and support NASS wouldn't be able to provide this vital information for people with axial SpA (AS).

Donate to the fight at
nass.co.uk/get-involved/donate/

Acknowledgements

NASS would like to thank all the rheumatologists, physiotherapists and other health professionals who helped to develop our NASS guides. We would also like to thank all the NASS members who commented on the text and design.



Keep in touch!



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