

**Uveitis Information Group Factsheet** 

Frequently asked questions about Uveitis

Written by Prof. Susan Lightman, of Moorfields Eye Hospital, London, this section has answers to commonly asked questions that are asked either at clinics or are asked of the UIG.

# What is Uveitis?

The term uveitis really means that you have inflammation inside the eye. There are lots of different types of uveitis with many causes so the term itself does not say anything about this. It is not one disorder.

# Why Me?

We do not know why most people get uveitis. There is an association with some infections (eg toxoplasmosis) and with certain diseases (such as sarcoidosis and Behcet'sdisease) in some patients and some patients have an increased likelihood due to the genes they carry (eg some types of uveitis are associated with certain gene types such as HLA B27 and HLA A29). But in many patients, we do not find a cause.. We think that uveitis falls into the group of diseases known as autoimmune in which the body reacts against itself. The trigger for this is unknown but might be infection in susceptible individuals. Treating for infection even if we knew what is was, is unlikely to help as the immune system is already activated and causes the damage.

# What types of Uveitis are there?

Uveitis is divided initially into anterior in which only the front part of the eye is involved (this is also sometimes called iritis and iridocylitis), posterior in which the back of the eye is involved and panuveitis in which the front and the back of the eye are both involved. Within each type, there are several subtypes. Anterior uveitis can be subdivided into acute disease which lasts a few weeks and chronic disease which is defined as lasting more than 3 months and can last many years. Posterior uveitis is usually chronic and can last a long time except in patients with toxoplasmosis when it may settle in a few weeks. It is important to know which type of uveitis you have as this determines the type of investigations and treatment you need and well as the complications.

# Can it be cured?

No it cannot and the treatment only suppresses the inflammation until the disease process burns itself out. The treatment needs to be continued as long as the inflammation is active. In any patient, it is not possible to know how long the disease will last and when it will go away. There is nothing we know that you can do to really influence it either.

# Is it caused by stress?

A lot of patients tell us that stress can bring on an attack or cause a relapse. There is a relationship between stress and the immune system but it not an easy one to understand. Unfortunately removing stress does not guarantee the disease will go away but luckily not all patients find stressful events have any effect on the disease either.

#### Why do I have to use drops?

Inflammation at the front of the eye (anterior uveitis) can be treated with drops as the drugs in them penetrate well into the front of the eye. Steroid drops come in a variety of types and strengths and are given to suppress the inflammation until it goes away. The more intense the inflammation you have, the stronger the steroid drops and the more frequently you have to put them in. As the inflammation is brought under control, the frequency and strength of the steroid drops can be reduced. Steroid can also be given as an ointment used at night – this releases steroid into the eye keeping it "marinaded" in steroid overnight Dilating drops are given to stop the iris (the coloured part of the eye), which becomes sticky when it is inflamed, sticking to the lens which is right behind it. If it sticks a lot, there is increased likelyhood of cataract and other complications in the long term. Again there are a variety of types of dilating drops which last different lengths of time –atropine can last several weeks, cyclopentolate most of a day and tropicamide a few hours. Often the pain of acute inflammation is helped by dilating the pupil as spasm of the iris can contribute to the discomfort.

#### Are steroid drops dangerous - do they cause cataracts?

It is true that steroid drops can cause cataract but uncontrolled inflammation can also cause it and will do more harm to the eye. It is therefore best to get the inflammation under control with the lowest amount of steroid required.

# Will I have to take tablets?

Patients who have inflammation at the back of the eye which is causing trouble cannot use drops to control it as the drops do not get to the back of the eye. Sometimes steroids can be given by injection under the eye in a depot slow release form an this is useful if only one is involved. Most patients who have both eyes involved take steroid tablets to control the inflammation. As we all know steroids have lots of side effects which are mainly dose dependent but in this day and age it is unnecessary for someone to have to stay on high doses of steroids in the long term. Other drugs such as cyclosporin, azathioprine and mycophenolate can work with the steroids enabling them to be effective at a lower dose, although they do have side effects of their own. The tablets don't cure the disease either and have to be taken for as long as the disease is active.

#### How will I know the uveitis is over?

Treatment can bring the inflammation under control and it is only possible to know whether the treatment is still required when you start to withdraw it. If all remains quiet, the uveitis is in remission but may relapse later. If the disease activity increases as the treatment is reduced, the disease process is still active and treatment needs to be continued.

# Will I go blind?

If by going blind you mean will you wake up in darkness, no you won't. Most patients with acute uveitis do not lose vision and treatment is aimed to control the inflammation to prevent it causing visual loss. The main causes of visual loss in patients with chronic uveitis are cataract (which can be removed), glaucoma or damage to the back of the eye from high pressure inside the eye, and macular oedema or 'waterlogging' of the retina due to the chronic inflammation. Control of the inflammation on the lowest dose of drugs possible and ensuring the intraocular pressure is not raised are key to reducing the chance of permanent visual loss.

# Should I worry if a cause cannot be found for my uveitis?

In many people, no obvious cause is found for their uveitis. In many diseases associated with inflammation, no underlying cause can be found either – the most common example being rheumatoid arthritis. In some patients, inflammation can be detected elsewhere such as in the lung and the disease process may be called sarcoidosis, but we do not know the cause of that either. In some patients infection is the cause such as that associated with toxoplasma or toxocara but these have very distinct clinical appearances allowing them to be easily detected on eye examination.

Current theories of why people get these autoimmune diseases such as rheumatoid arthritis, insulin dependent diabetes in young people, thyroid disease and uveitis include certain infections in which the immune system responds by producing cells to fight the infecting which also react incidentally with self tissue. This would not happen in everyone but only in patients with a certain genetic make-up which would form these crossreactive cells. By the time the uveitis occurs, there is no place for treatment of the infection as it has long gone-it is the immune response which causes the damage and this is what is treated.

# How will my uveitis and the medication used to treat it affect my pregnancy/breastfeeding?

Drops are the most frequent type of therapy used to treat uveitis and are not a threat as only very low doses get into the bloodstream if any does.

Drugs taken by mouth include steroids, azathioprine, cyclosporin, methotrexate, mycophenolate, tacrolimus and Diamox amongst others used less commonly. Of these Diamox is definitely contraindicated in pregnancy but the others are less clear cut. There is a risk with any drugs you take in pregnancy and although the risk is small, it is not zero. It is better not to be pregnant or breastfeeding on anything. However, this is not always realistic and most of the experience comes from patients who have had kidney transplants, are on similar medications and have had successful normal pregnancies. If you are contemplating getting pregnant or become pregnant while taking these type of drugs, it is very important that you discuss the situation with your ophthalmologist as quickly as possible. In this way, everything can be discussed and a plan that is best for you sorted out.

Further information can be obtained from:

Uveitis Information Group South House, Sweening Vidlin Shetland Isles ZE2 9QE Tel: 0845 6045660 email: info@uveitis.net website: www.uveitis.net