

Patient information-corneal and external disease

Acanthamoeba keratitis (AK)

This leaflet is designed for patients, as well as their relatives, friends and carers, to help explain acanthamoeba keratitis (AK) and its impact.

What is AK?

AK is an infection of the cornea, the clear 'window' at the front of the eye that can be very painful. The infection is caused by a microscopic organism called acanthamoeba, which is common in nature and is usually found in bodies of water (lakes, oceans and rivers) as well as domestic tap water, swimming pools, hot tubs, soil and air. Many different species of acanthamoeba exist. Acanthamoeba organisms do not generally cause harm to humans (we come into contact with them when we wash, swim, drink water etc.), but they can cause a serious eye disease if they infect the cornea. Not all species of acanthamoeba have been found to cause corneal infections. AK is most common in people who wear contact lenses, but anyone with a corneal injury is susceptible to developing the infection.

Generally speaking, acanthamoeba has a life cycle of two stages: an active form (when the organism feeds and

replicates), and a dormant form (when the acanthamoeba protects itself from attack by developing into a cyst).

How is AK diagnosed?

Your ophthalmologist will use a standard slit lamp microscope to look for signs of inflammation in your cornea, including specific clinical signs characteristic of AK. This is sometimes followed by a corneal scrape and culture (a process by which some cells from the surface of your cornea are removed and sent to a laboratory for further analysis), or a swab of the cornea to check for acanthamoeba DNA, using a test called Polymerase Chain Reaction 'PCR'. Results for both these tests take a few days to come through. In some cases, AK can be detected using a confocal microscope, a powerful scanner that can see acanthamoeba cysts within the various layers of the cornea. Your ophthalmologist will use these tests together with other clinical signs and symptoms in order to decide on the appropriate treatment plan.

Why is it difficult to make a diagnosis?



In the early stages, AK and other microbial corneal infections have similar signs and symptoms, making it difficult to tell immediately which one you may have. This is why a variety of tests and clinical signs are observed. Sometimes the diagnosis can change when the doctor receives more information from laboratory tests. Diagnosis can also change depending on how your eye(s) respond to treatment.

The primary difference between AK and other microbial infections is that it is challenging to treat, due to its resistance to many forms of therapy. Acanthamoeba in the dormant cyst form can survive for long periods of time. AK cannot be treated with antibiotics because it is not a bacterial infection.

Why is my eye so painful and red?

AK can be extremely painful, although not all patients experience intense pain. The cornea is one of the most sensitive organs, with the highest density of pain receptors in the body. This means that any injury to the cornea can be very painful. Pain can also be triggered by the body's immune response to the infection in your cornea - this is called an inflammatory response and may be one of the reasons your eye is red as well as painful. The medicines used to treat AK can be quite harsh and, in some cases, can also irritate the surface of your cornea. Your doctor will try to strike a balance between effective treatment of the infection and preventing further irritation on the corneal surface.

Why am I so light sensitive and why is my eye watering so much?

Light sensitivity (also termed photophobia) is a symptom of the inflammation and infection in your cornea because the cornea, which is usually clear, turns cloudy and scatters the light around. You may also have light sensitivity because you have been given an eye drop that temporarily widens the pupil, the hole through which light enters the eye. Sometimes the iris (the coloured part of the eye) can go into spasm when the cornea is infected, which can also cause pain, so these drops may help relieve the pain but may also make you more light sensitive. Tears are a natural reaction to disruption of the corneal surface and are a reflex response to the infection. They act to remove irritants from the surface of the eye.

Why has my vision deteriorated so suddenly?

In the early stages of the disease, the cornea can become irregular due to the infection and inflammation, which can affect your vision. This can occur quite suddenly, and you should inform your ophthalmologist as soon as possible if this happens to you. As the infection responds to treatment, patients can notice their vision improve as the inflammation reduces and the surface heals. In later stages of the disease, scarring on the front of the cornea, resulting from long-term inflammation, is usually the reason for vision loss. In



some patients, scarring can be quite extensive and may need further therapy (e.g. a cornea transplant) to rehabilitate vision once the infection is over. A degree of permanent vision loss occurs in around a quarter of cases.

How could I have got AK?

Around 85% of cases of AK have been associated with contact lens wear. There are a number of different factors which are known to increase the risk of contracting AK. The biggest risk factor is exposure to water (generally through swimming or showering in contact lenses, rinsing or storing lenses in water and handling lenses with unwashed or wet hands). Improper contact lens hygiene, including not disinfecting lenses properly and not cleaning and changing contact lens cases regularly have also been shown to increase the risk of infection. Those who do not wear contact lenses may still contract AK, although it has a much rarer incidence than in contact lens wear.

Are there many other people who have AK?

Due to the way that UK domestic water is stored and supplied, incidence of the disease is generally higher in the UK than in other parts of the world. Studies suggest that AK affects around 2 in 100,000 contact lens wearers per year in the UK, which is around 20 times less than the number of daily wear soft contact lens wearers with bacterial infections. Since 2011, Moorfields Eye


Hospital and other centres in the UK and USA have reported a three-fold increase in the number of cases of disease, although it still remains rare.

I have AK in one eye. Can it spread to the other eye or to other parts of my body?

At Moorfields Eye Hospital, we have only seen cases of bilateral AK (affecting both eyes) where the patient has been infected in both eyes at the same time rather than it spreading from one eye to the other. Acanthamoeba is an opportunistic organism in that it is widespread in the environment, but fortunately only rarely invades human tissue to cause disease. It's extremely unlikely for acanthamoeba to spread from person to person. There are some extremely rare strains of acanthamoeba that can affect the brain; most of these cases occur in immunocompromised patients and are not related to contact lens wear. However, it's still a good idea to take sensible precautions to ensure that other bacteria or germs do not spread between your eyes or from your nose/mouth to your eyes. Always wash your hands and dry them thoroughly before and after putting in your eye drops. Also make sure that you don't touch your eye with the dropper or bottle top when applying eye drops.

How am I going to be treated?

Typically, treatment is with antiseptic drops which include Polyhexamethylene Biguanide PHMB,



Chlorhexidine, Brolene and Hexamidine. These are used either individually or in combination.

Usually you'll need to take these eye drops every hour for the first few days (including overnight), reducing to 2-hourly by day only, and then less frequently depending on your response to treatment. It can be quite difficult to take eye drops through the night during the first few days, but it's very important to try and stick to the regime outlined by the doctor as best you can.

In addition to the anti-amoebic eye drops, you may be given anti-inflammatory or painkillers to help with the pain. You may also be given a dilating drop early in the infection to stop painful spasms of the coloured part of the eye, the iris. Around 10% of acanthamoeba infections have dual pathology, which means that another infection, usually bacterial, is also present. If this is the case for you, you may also be prescribed with antibiotics as well as your other drops. Sometimes these are also given to guard against a secondary bacterial infection while the eye surface is disrupted in the early stages of the disease. Patients with severe inflammation or scleritis (inflammation of the white part of the eye) are sometimes prescribed steroid eye drops, although not every patient requires these, and their use needs to be carefully managed.

As all patients react differently to the infection, your doctor will assess the most appropriate treatment regime for you. The treatment may change depending upon how your eye responds. If you have any concerns about your treatment then make sure you ask the doctor at your clinic appointment.

Please bring all your eye drops to your clinic appointment and please do not stop taking them on the day of the outpatient visit. The nurse or pharmacist will show you how to use the drops properly.

Is AK treated the same in other countries as in the UK?

There are currently no licensed medicines approved for the treatment of AK in any country. Most ophthalmologists use the same group of antiseptic eye drops that have been shown to kill acanthamoeba both in the laboratory and are effective in treating patients in large case series. Some case reports have indicated successful treatment with other types of treatment such as collagen cross-linking, antifungal drugs, and a newer drug called Miltefosine. Although the results have only been reported in a few individual cases, more extensive studies are required to determine whether any of these therapies are suitable options or alternatives to existing treatments. Your team will be happy to discuss your treatment plan and answer any questions or queries you have. You are strongly advised to come in for recommended follow-up



appointments even if your eye/s is/are feeling completely better.

How long can I expect to be treated for?

Although each patient is different, generally speaking those who are diagnosed and receive appropriate treatment quickly can expect their treatment to last three to six months. Some patients recover sooner, and more complicated cases can last for over a year. Although the early stages of the disease can be very difficult and can limit your ability to do your day to day activities, as the infection comes under control you should be able to continue many of these whilst continuing to receive treatment.

Can steroid drops cause any complications?

Although steroid drops can both aid healing and make the eye more comfortable by reducing inflammation, using steroids may also delay the clearing of the infection and cause other complications including cataract (clouding of the lens) and glaucoma (raised eye pressure). The use of steroids will therefore need to be carefully managed by your ophthalmologist.

A small percentage of patients experience scleritis (inflammation of the white part of the eye) which is usually treated using steroid drops and, in more severe cases, additional oral medication is also given.

Are there any other complications I may experience from AK treatment?

Some patients experience complications including a fixed dilated pupil due to damage to their iris. Vascularisation of the cornea (growth of blood vessels into the cornea) and secondary bacterial infections sometimes also occur. Other complications such as cataract and glaucoma can form as part of severe AK, which is why, at each clinic appointment, your doctors will perform thorough checks on your eye(s) to look out for signs of these complications.

Why do some people with AK need a cornea transplant?

Around 25% of cases of AK seen at Moorfields result in a corneal transplant. There are different types of transplant – and these carry different risks. Some are carried out to improve your vision at the end of infection. Other transplants are carried out, on actively inflamed eyes, as part of therapy.

The therapeutic transplants are usually for corneal perforations, although the success rate of these is poorer than the transplants to improve vision, therefore the procedure is rarely used unless absolutely necessary.

There is also a risk of a recurrence of AK post-surgery and this is one reason why corneal transplants are generally delayed until the eye has been infection free for some time. Your doctor will discuss what's right for you and separate information will be provided if





you are a possible candidate for a corneal transplant.

For patients who have poor vision but do not require a transplant, vision can be improved using a rigid contact lens. Your ophthalmologist will discuss all options with you at the appropriate time.

Why am I asked the same questions each time I visit the clinic?

In order to provide you with the best care, we need to re-review your situation, especially any changes since your last appointment, as it may have an effect on your current treatment.

A. Coping with AK at home

Can I shower as normal and wash my hair?

Yes, although if you have recently had a corneal scrape or if you have been told you have an epithelial defect (a breakdown on the surface of your affected cornea) you may wish to avoid getting water in your eye for a few days as a precautionary measure. Swimming should definitely be avoided during this time. Ask your doctor at your next clinic appointment if you are worried about this.

Can I wear eye makeup?

Eye makeup should be avoided in the early stages of your treatment, as this can sometimes be a source of additional bacteria entering the eye. You should be careful not to rub your

affected eye(s) too much and removing eye makeup should be done as carefully as possible with gentle cleanser so as not to irritate the cornea. Once your infection has started to settle, it may be ok to wear non-waterproof eye makeup. Ask your doctor at your next appointment.

I am very light sensitive. What can I do?

You may want to buy a pair of prescription sunglasses to help you cope with daylight. Drawing curtains and blinds at home can help. It's also possible to buy a shade or eye patch to wear over glasses – this can help if you want to watch TV or work at a computer. Most people feel self-conscious at first, but it can provide a relief for your symptoms. Try not to wear the patch all the time, so that fresh air can circulate around the eye. Many patients find it helpful to wear a hat and sunglasses when they go out. Check with your doctor before wearing any type of patch that sticks to the eye itself.

Can I continue to go to the gym/play sports?

Yes, you can. Many patients have found exercise is a good way of helping them to relax and to cope with the infection. It has also been shown to help improve self-esteem, mood, sleep quality and energy, as well as reducing your risk of stress and depression. You should do as much as you feel like doing, although you should take care

with contact sports such as rugby. Ask your doctor if you have any concerns.

Can I continue to drive?

You must tell the DVLA if you have any problem with your eyesight that affects both of your eyes, or the remaining eye if you only have one eye. Non work-related drivers must be able to read (with glasses or contact lenses) a car number plate made after 1 September 2001 from 20 metres. You must also meet the minimum eyesight standard for driving by having a visual acuity of at least 6/12 measured on the Snellen scale (the standard test chart used at hospital eye units) with both eyes together or, if you have sight in one eye only, in that eye. You must also have adequate peripheral vision (field of vision). It may be helpful to remember that around 1 in 20 people in the general population have poor vision in one eye. Ask your doctor at your clinic appointment whether you meet the minimum standards of vision for driving. You may need to inform your car insurer too.

Some people with AK have found a book, "A Singular View: The Art of Seeing with One Eye" by Frank B. Brady helpful when first dealing with poor vision in one eye. This book can be purchased online.

When can I start wearing contact lenses again?

This will depend on the extent to which your cornea has been affected by the infection. For those who wish to return

to contact lenses after AK, daily disposables are usually the most suitable option. Most patients will need to wait several weeks or months to ensure they are clear of infection and their eye(s) are healthy before wearing contact lenses again. Ask your doctor what's right for you.

Many patients are interested in whether they can have laser surgery on an eye affected by AK, to avoid wearing glasses or lenses after the infection has cleared. This is a decision that has to be taken on a case by case basis and is dependent on any damage left behind by the infection. Ask your doctor what might work for you.

Are there any signs I should look out for in between clinic appointments?

Any sudden increase in pain, redness or loss of vision should be treated as an emergency. You should attend Moorfields A&E department in City Road for a further examination (open 24/7 for emergency eye problems only), or contact your clinic to arrange to be seen urgently.

B. Keeping on top of eye drops and other medicines

Can I get any help with the cost of NHS prescriptions?

If you usually pay for NHS prescriptions, prescription prepayment certificates are available in England and they can save you money. Certain individuals, such as those under 16 or



over 60, or those in possession of a valid HC2 certificate (full help with health costs) are also eligible for free NHS prescriptions. Speak to the pharmacy to find out more.

How long should I leave in between putting in eye drops?

Generally speaking, you should try to leave around five minutes between drops. This can be difficult when you are using a number of different drops every hour or every two hours, so try and leave at least two minutes between each one if using more than two. Setting alarm clock reminders or using smartphone apps can help you keep track.

Most of the eye drop liquid falls out of my eye. Is that ok? How do I stop it from happening?

Do not worry if some of the eye drop falls out – this is perfectly normal. It is a good idea to tilt your head back and keep your eye closed for a minute or so after you've put the drop in – to ensure all the medicine has got into your eye – although this can be impractical if you're on the move or in a public place. Try your best to do this at least when you are able to. If you miss your eye completely, do the drop again. If a small amount goes in, then wait till your next drop and try and ensure it goes in properly the next time. If a friend or family member is able to help put drops in, this can sometimes be useful, particularly if you have reduced vision in the affected eye(s).

Why do some eye drops sting so much?

If your eye is very inflamed, red or irritated, or if you have an epithelial defect, you may find the drops sting a lot. Different formulations of eye drops designed to kill acanthamoeba can also sting when they go in and when they mix with the previous one used, so try and keep a decent gap between drops. Keeping drops in the fridge can help ease the stinging. Perhaps try a cold compress or ice pack on your forehead or down the side of your face after the drop has been done. Tell your doctor if you have any concerns.

I have spilt my eye drops! What shall I do?

Contact the hospital pharmacy as soon as possible. Moorfields Pharmacy's direct line is 020 7566 2362.

I keep missing drops because I lose track of time. What can I do?

If you have a number of different drops to take at different times of the day, set an alarm clock and keep a notebook handy to help you tick off the ones you've done. There are quite a few helpful 'reminder' apps for smart phones, which can also help you keep on top of taking your medication.

My eye drops need to be kept refrigerated, but I'm not at home. What can I do?

Many patients carry a cool bag with ice packs in it to keep their drops cold



when they are out. Others use a thermos flask filled with ice cubes. There are many options available to buy on the internet. Remember, during the summer months non-refrigerated eye drops can also be affected by high temperatures.

I am out and cannot wash my hands before getting drops in. What can I do?

Carry a small bottle of alcohol based antibacterial hand gel with you for times when you are not able to wash your hands.

C. Resuming regular activities

How long can I expect to be off work?

This varies enormously and also depends on the type of work you do. Some patients have worked throughout their illness; others have found it necessary to take sick leave. You should return to work when you feel able to perform your duties appropriately. Some people return to work with reduced working hours or duties for a period of time. Ask your ophthalmologist for a letter/certificate for your employer if you feel unable to return to work in full capacity or to explain the importance of taking medication etc. Advice on dealing with the impact of illness on employment is available from RNIB, Citizens Advice Bureau and The Money Advice Service. At Moorfields, you can talk to one of our eye clinic liaison officers (ECLO's), who

are available at City Road as well as our other networked sites.

Can I still use a computer?

Yes, as long as you feel able to. Reducing the brightness on your screen or wearing an eye patch or shield can also help.

Am I allowed to fly?

Yes, although you should discuss any foreign travel plans with your doctor in order to ensure you will continue to receive appropriate treatment whilst away.

D. Emotional support

If I am finding it difficult to cope with my illness, what help can I get?

The impact of AK on those affected can be extremely difficult. Some patients feel they need additional emotional support, in particular with adjusting to fluctuating vision and changes in appearance as a result of the infection.

Moorfields Eye Hospital provides a dedicated patient support and counselling service and can provide information, advice and counselling at the time of diagnosis, throughout your treatment and during your follow-up. You can contact the team by calling 020 7566 2385 or by emailing moorfields.referralscounselling@nhs.uk. You may be prompted to leave a voicemail but please be assured that this line is confidential. It is helpful to





keep the message short and clear, including your contact details. You can also contact the corneal nursing team on 020 7566 2405.

Eye clinic liaison officers (ECLOs) are available at Moorfields Eye Hospital in City Road to assist those living with sight loss. This includes patients, their relatives and carers. For more information about ECLO services at City Road, please ask a member of staff for the information leaflet, which is also available at the health hub, located at the main entrance of the hospital.

Phone: 020 7566 2355 or email: moorfields.cityroadECLO@nhs.net

D. Information and research on AK

Is there anywhere else I can find accurate information to share with others about AK?

You may find some other information about AK on the internet, but please bear in mind that much of this information may be inaccurate or out of date. Instead, please share this leaflet, (which is regularly reviewed and updated) with friends/family and others, to help them understand AK better. There are also a number of social media forums where AK patients from all over the world talk and provide support to each other. Talk to your doctor if you require more detailed information about your specific case to give to your employer.

I'd like to meet or talk with others about my experience of AK. Is there anywhere I can do this?

There are regular informal meet ups for AK patients and their friends and families in London, which are also live streamed online for those who do not live nearby. We try and arrange this meeting once a year outside of working hours, and often have expert speakers and group discussions on how to raise awareness of AK, or how to participate in research. If you'd like to get more information on future meet ups, please contact the patient author of this leaflet, Irenie Ekkeshis: irenie_ekkeshis@yahoo.co.uk.

Is there any research being done to help improve treatments for AK?

There are several promising new drugs being developed, but it is likely to be years before they are used on patients. There are a number of studies currently being undertaken by centres including Moorfields Eye Hospital and the UCL Biomedical Research Centre (BRC) to better diagnose, treat and prevent AK. A clinical trial is also currently underway to develop the first properly licensed treatment for the infection. If you'd like to know more about the ongoing research on AK, or if you're interested in getting involved, please contact Dr Nicole Carnt: n.carnt@unsw.edu.au.

Can I do anything to help prevent AK occurring in future?

The UK's Medicines and Healthcare Products Regulatory Agency (MHRA)



suggest all contact lens-wearing patients report their case of AK via their Yellow Card reporting scheme. It is important for people to report problems experienced with medical devices as these are used to identify issues which might not have been previously known about. The MHRA will review the product if necessary and take action to minimise risk and maximise benefit to the patients. You can do this at yellowcard.mhra.gov.uk. Other countries have similar reporting schemes, so please check with your doctor for details.

Where can I find out more about getting involved in research, or helping others who are going through AK?

Please email moorfields.resadmin@nhs.net if you would like to be involved in future research projects. We'd love to hear from you.

Moorfields patient counselling service is also interested in hearing from patients who would like to help support other patients experiencing AK. Please email jasmine.thombs1@nhs.net or louise.deboard@nhs.net Melanie.mason5@nhs.net to find out more.

Authors: Ms Irenie Ekkeshis, Dr Nicole Carnt, Dr Martin Watson, Melanie Mason
Revision number: 3
Approval date: September 2019
Review date: September 2022

Moorfields Eye Hospital NHS Foundation Trust
City Road, London EC1V 2PD

Phone: 020 7253 3411
www.moorfields.nhs.uk

Moorfields Direct telephone helpline

Phone: 020 7566 2345
Monday-Friday, 8.30am-9pm
Saturday, 9am-5pm
Information and advice on eye conditions and treatments from experienced ophthalmic-trained nurses.

Patient advice and liaison service (PALS)

Phone: 020 7566 2324/ 020 7566 2325
Email: moorfields.pals@nhs.net
Moorfields' PALS team provides confidential advice and support to help you with any concerns you may have about the care we provide, guiding you through the different services available at Moorfields. The PALS team can also advise you on how to make a complaint.

Your right to treatment within 18 weeks

Under the NHS constitution, all patients have the right to begin consultant-led treatment within 18 weeks of being referred by their GP. Moorfields is committed to fulfilling this right, but if you feel that we have failed to do so, please contact our patient advice and liaison service (PALS) who will be able to advise you further (see above). For more information about your rights under the NHS constitution, visit www.nhs.uk/choiceinthenhs