

Santen

Imagine Your Happiness



LIVING WITH VKC

Tips for parents
from parents

 **AllergyUK**

We know how difficult it can be when your child has VKC (vernal keratoconjunctivitis).

The challenge of juggling treatments around everyday activities, managing your child's symptoms, and helping them live life to the full. We also know how hard it can be to find someone who is going through the same thing.

We are parents to children with VKC too. We hope this booklet will help you and your families to understand VKC better and to feel that you can get on top of it.

Having the support of your ophthalmologist is really important so please do speak to them if you aren't sure about anything, are struggling or want some more advice.

Natasha, Emma and Tracey

Content

What is VKC?	4
Managing VKC and its symptoms.....	4
Keeping on top of treatment	5
Eye drops	6
Managing medications when your child has multiple allergies	7
Spotting signs of a flare up	8
VKC and school	9
VKC “life hacks”	10
Sources of information.....	11

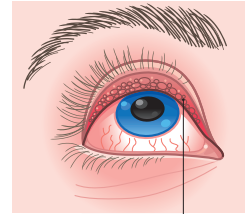
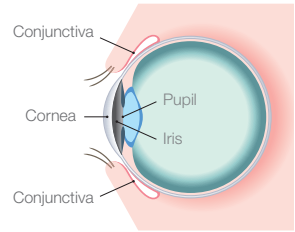
What is VKC?

Vernal keratoconjunctivitis, or VKC, is a form of allergic eye disease. The symptoms occur when children are exposed to environmental allergens like dust and pollen. These allergens cause an allergic reaction and inflammation on the front surface of the eye.

In mild cases of VKC this inflammation causes itching and redness. In more severe cases the surface under the top eye lid can become inflamed and

swollen bumps (called papillae) can form. These are sometimes known as cobblestones because of their appearance. When the eye closes these can rub on the front of the eye causing pain and irritation.

Children with VKC often have other allergic conditions like asthma, eczema or food allergies. In most cases children grow out of VKC by the time they reach adulthood.

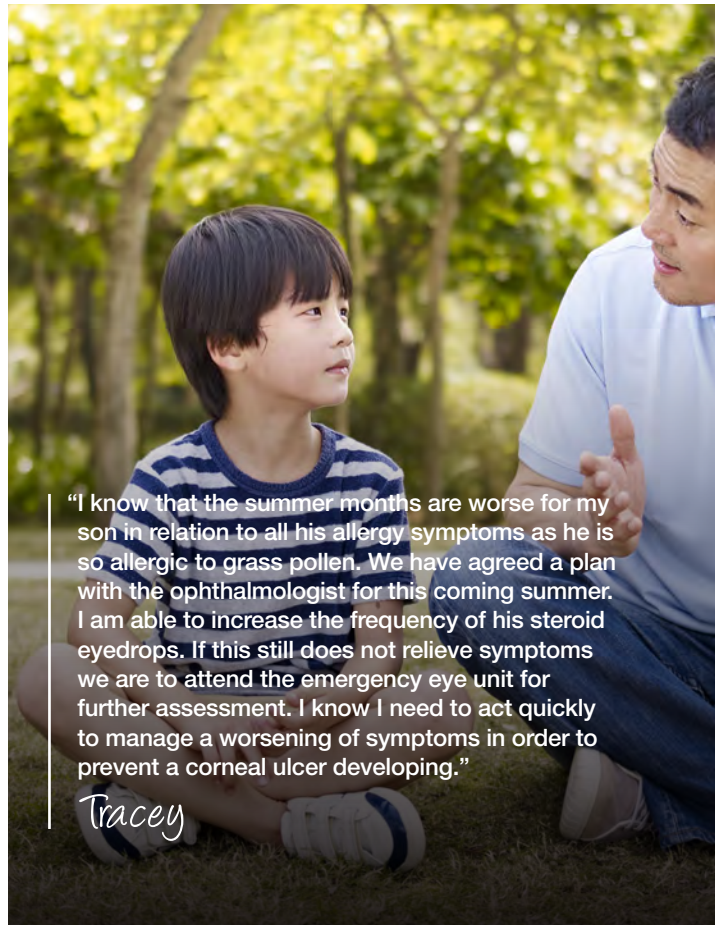


Papillae or "cobblestones"

Managing VKC and its symptoms

When your child is first diagnosed with VKC it can feel overwhelming. There can be a lot of information to take in. You might feel unsure if what you are doing is the right thing. Over time this does get easier.

You get better at managing the condition and more in tune with your child's symptoms and what they mean. Many parents also find as their child gets older they become better at telling you when there's a problem.



"I know that the summer months are worse for my son in relation to all his allergy symptoms as he is so allergic to grass pollen. We have agreed a plan with the ophthalmologist for this coming summer. I am able to increase the frequency of his steroid eyedrops. If this still does not relieve symptoms we are to attend the emergency eye unit for further assessment. I know I need to act quickly to manage a worsening of symptoms in order to prevent a corneal ulcer developing."

Tracey

Keeping on top of treatment

Keeping on top of treatment is the key to living life with VKC. This can be easier said than done at times when life is busy or if your child has medications for other conditions. It is so important to make sure your child is having the treatment your doctor has given you. It's a good idea to talk to them about it too – to help them understand why treatment is important for keeping their eyes healthy so they can keep doing the things they love.

"I keep the eyedrops everywhere. They are in my handbag, in the glove compartment, at my mum's house. That way I always have them to hand and if I think my son might be starting a flare up I can act on it right away."

Natasha

Knowing when to see the ophthalmologist

Treatment of VKC needs to be a partnership between you, your child and the ophthalmologist. The more you tackle this all together the better. Agree a treatment plan together and discuss your role in making decisions about stepping up treatment.

Over time parents can learn how to manage and step up treatment themselves, but you need to agree with the ophthalmologist under what circumstances (e.g. a flare up or routine follow up appointments) they should see your child. If you are ever unsure what you should be doing then ask the ophthalmologist or another member of the healthcare team for help.

"You do learn what is best for your child. It starts to become second nature. If I think he is having a flare up I'll try increasing the drops. If I don't see an improvement within 48 hours then I take him to the eye hospital."

Natasha

"When my son was younger he would be in pain every night. I realise now that his VKC wasn't under control. I wish I had pushed to get another opinion about his treatment. We didn't need to be living like that. Too many sleepless nights are a sign that things are not ok."

Emma

Eye drops

The eye drops your child has will depend on their symptoms. The most common types of eye drops used for VKC are:

- 1** Lubricant drops: these help to sooth the eyes. Try putting these in first as they might help to relieve any itching.
- 2** Anti-allergy drops (known as mast cell stabilisers): these reduce the reaction your child has to allergens like pollen and dust.
- 3** Steroid drops: help to reduce inflammation in the eye. These are often given during a flare up. After the flare up is under control your doctor will usually try to reduce the dose.
- 4** Immunosuppressant drops: used to keep the inflammation under control and reduce the risk of having a flare up. These can sometimes sting when they go in but the feeling usually goes away quickly.

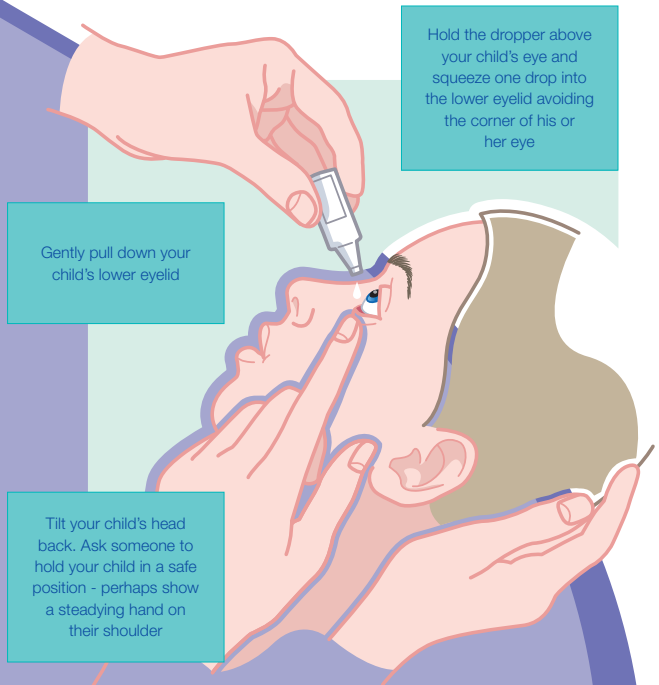
TIP: If you have to put several drops in then try doing them in the order above. Leave 5-10 minutes between each one if you can but if that is not possible don't worry about it. The most important thing is to get the drops in.

Putting eye drops in

Make sure you wash your hands first. Ask your child to put their head back and hold the bottom eye lid down while you put the drop in.

Have a tissue or cold cloth at the ready to hold over the eye but take care not to wipe the eye drop out. You might find it hard to begin with but it is important to persist. It does become second nature over time.

Some of the eye drops might sting a little. If it seems like they are stinging a lot then that drop might not be in the right form for your child. Talk to your ophthalmologist about whether there is a different one they could try.



Hold the dropper above your child's eye and squeeze one drop into the lower eyelid avoiding the corner of his or her eye

Gently pull down your child's lower eyelid

Tilt your child's head back. Ask someone to hold your child in a safe position - perhaps show a steadying hand on their shoulder

How to encourage kids to have their eye drops

Encouragement and praise and maybe the odd little treat helps! At least to get you through the early stages when you and your child are getting used to the routine. Explain to your child why they need to have the drops and how it will make them feel better and protect their eyes. As they get older they will understand more about why they need the drops.

“Mornings used to be a massive stress point for us. In the end we found a better routine. These small changes help to make mornings as stress free as possible. In the end we played around with our routine until we found one that worked for us.”

Emma

Managing medications when your child has multiple allergies

Often children who have VKC also have other allergic conditions like asthma, eczema or food allergies. It can be really hard on kids and families if they have lots of other treatments like inhalers and creams as well as eye drops. Working out a good morning routine that fits in with your life can help. But we know it can be really tough. Here are some ideas from other parents that might help you.

- Prepare as much you can the night before to give you less to think about in the morning.
- If you have several eye drops to give your child get the first drop in early (as soon as you both wake up).
- Put all the medicines you need to give them in one box and as you are finished with each one take it out of the box. This will help you to keep track of them.

“I find it easier to apply the eczema creams as soon as my son wakes (we often do these in bed whilst he lies there). We then apply an eyedrop and he then gets himself dressed. By the time he arrives downstairs, at least 5 mins has elapsed and we can do another eyedrop. He then has his inhaler followed by breakfast and a third eyedrop. It’s about building the treatments into your morning routine just as you would with getting dressed or cleaning your teeth.”

Tracey



Spotting signs of a flare up

These are some signs that parents have noticed in their own children. Every child is different and it is important that you get to know how your own child reacts and the signs they show when they are having a flare up.

Signs that your child might be having a flare up of VKC

- Droopy eye
- Discharge from the eye
- Sticky or watery eyes
- Soreness/itchiness when blinking
- Prolonged or unusual blinking
- Pressing on the eyes
- Difficulty opening eyes, especially in the morning
- Difficulty going out in the light
- Blurred vision

Keeping a note of these can help. The important thing is that if you are worried your child might be having a flare up then get in touch with your ophthalmologist right away.

Talk to your child about the symptoms they experience. Help them to recognise these too and to talk to you about how their eyes are feeling. Sometimes there might not be many signs on the outside but your child might be feeling that their eyes are itchy or scratchy. If they can tell you about it then you can get the help you need when you need it.



“Sometimes I’d notice that my son was showing some signs of a flare up, but I’d worry that I was imagining it or being over anxious and I didn’t want to waste anyone’s time. But I didn’t want to risk things getting worse either. It can be really hard to know the right thing to do. Over time we both got better at recognising the signs of a flare up and getting him to the ophthalmologist quickly. I think trusting your instincts is really important.”

Emma

VKC and school

Some schools are great at supporting kids with VKC and will be happy to put eye drops in. Others might not feel confident in supporting your child with their VKC or have policies which mean they can't administer medicines. Help teachers understand the condition and why it's so important to keep it under

control. Help them to recognize the symptoms of a VKC flare-up and ensure they know to inform you if your child's eyes seem to be getting worse. Share this booklet with them.

Children don't like feeling different at school so if they do need to have eye drops during school hours, then try to find a

way to do it with as little fuss as possible. Help them to be able to tell their friends what is happening and why they need the drops. Encourage the teachers to explain the condition and help the children understand and accept others for who they are.

School residential trips

For any parent the idea of their child going on their first residential school trip is daunting. It's even harder if your child has a medical condition and they rely on you to give them medication. Having VKC does not mean your child has to miss out on these important experiences. Talk to the school about how to handle this and make sure they feel confident to administer the medicines

and know what to do if they are unsure and how to contact you if they want more information. If your child is older then help them to play a bigger role too – that will help them to feel more in control.

“When my son goes on a school residential trip I write out a detailed treatment plan saying what medicine he needs at specific times. Then I organise a meeting with the teachers to talk it all through.”

Emma

Going to secondary school

Starting secondary school can be a good time to begin letting your child take more control of their treatment. It's also a time when your child can explain much more clearly what's going on and take more notice when their eyes are getting worse.

“At this point I had a few more battles with my son about how to manage treatment at school. He didn't want me coming in, but his Consultant wanted me to make sure he was getting the 2 or 3-hourly drops he needed during a flare. In the end we compromised on me coming in once a day and Harry setting alarms on his phone at school to put his own drops in.”

Emma

VKC “life hacks”

There is no reason why your child or your family should stop doing the things you enjoy. Keeping your child away from anything that could irritate their eyes is difficult and not really practical. Occasionally, you might have to make some compromises like avoiding swimming during a flare-up or wearing completely watertight goggles, but on the whole, there’s no reason your child should be missing out on normal life. They need to have as normal a childhood as possible and do the things that other children do. Here are our top VKC “life hacks”!

- 1** Encourage your child to wash their hands regularly to stop things from getting in the eyes and irritating them.
- 2** Lots of children with VKC struggle on sunny days – sunglasses and hats do help.
- 3** On holiday make sure you’ve got a good supply of all your child’s medicines. Sun, sand and sea can irritate eyes but our kids still love a day at the beach!
- 4** Get them to wear science goggles when baking. It stops flour dust from getting in the eyes.
- 5** Sleepover and playdates: Talk to the friends and parents of the friends explaining the condition isn’t contagious and can be managed well with medication.
- 6** Some children may find that swimming makes their eyes feel worse. If their VKC is well-controlled they shouldn’t have to miss out. But if they are having a flare up swimming could aggravate it.
- 7** If their eyes are hurting a cold cloth or eye mask that you keep in the fridge can help.
- 8** Artificial tears lubricate the eyes and kids may find them soothing. You can put them in as often as you like, although do wait a few minutes after putting in other eye drops.
- 9** Don’t let your child rub their eyes as this can make it worse. Help them find other ways to relieve the itch like a cold cloth or gently pressing a palm over the eye.
- 10** Try to create a calm environment at bedtime. If your child’s eyes are uncomfortable at night time use wet tissues to sooth the eyes – hold them in place with an eye mask. Silk eye masks can feel cold and soothing.





“Minimizing stress is important. When my son was younger we had so many typical stresses like being late for school (which is exacerbated with this condition) or getting to bed late. But when he was stressed he always started crying and rubbing his eyes, so then I’d get stressed about him rubbing his eyes and tell him to stop rubbing, and the whole situation would spiral. We’ve learnt to both be calmer and not worry about the small things.”

Emma

“It’s been important for us to try and maintain a ‘normal’ life by allowing my son to participate in activities just like any other child. This has been so important for his mental health and increasing his self-esteem. It would be all too easy to let allergies rule your life as opposed to you having control over them.”

Tracey

“At the beginning you do whatever you need to get them into a routine. You are both learning together and you might need to try different things. The important thing is to try to accept the changes from the routine you had before. The quicker you can do that the easier it becomes.”

Natasha



The development of this booklet
was funded by Santen UK Ltd.

In partnership with Allergy UK
www.allergyuk.org

Job code: NP-VKC-UK-0072 Date of preparation: August 2021