

societi *We are the UK Foundation*
for **Kawasaki Disease**

Kawasaki Disease

*A guide for families
and carers*



*Reviewed and reprinted
August 2025*



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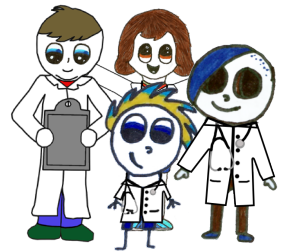
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This guide has been written to provide information for families and carers, who have just been told their child has Kawasaki Disease. It's been produced by Societi Foundation with clinical leadership from experts including Professor Robert Tulloh, Professor Paul Brogan, Dr Jethro Herberg and Dr Filip Kucera. Their contributions are gratefully acknowledged!



A huge thank you to our wonderful families who helped develop and review this booklet, especially Sammi, Laura, Lisa, Joanna, Jess, Sue and Suzanna.



Introduction

Facing a diagnosis of Kawasaki Disease can be an extremely difficult and upsetting time for families.

This guide is intended to help you understand more about Kawasaki Disease (pronounced “ka:wa’sa:ki”), and provide some sources of information and support which are available for you.

It has been written by doctors, experts in Kawasaki Disease, together with parents who have been through Kawasaki Disease, and led by Societi Foundation, the UK Foundation for Kawasaki Disease.

Kawasaki Disease mainly affects young children (under 5 years), but one quarter of patients are older. It is increasingly common in the UK with about 1,500 children admitted to hospital with Kawasaki Disease each year – and this number is rising.

Kawasaki Disease is an illness where there is inflammation of the blood vessels (arteries). This type of condition is called a vasculitis. Doctors still do not know what causes Kawasaki Disease – but we do know that it is not contagious (catching) to other children.

Kawasaki Disease needs to be treated quickly to try and prevent long-term damage to the blood vessels, particularly those around the heart (the coronary arteries).

Some key points:



Early treatment of Kawasaki Disease reduces the risk of heart damage



Most children recover well with rapid treatment



Treatment works by ‘switching off’ inflammation



Children with Kawasaki Disease are closely monitored



Societi Foundation is here to help, with lots of information for families affected





What are the symptoms of Kawasaki Disease?

Kawasaki Disease usually begins with a high temperature (fever), which continues for several days. Many, but not all, children develop other symptoms such as:



Persistent fever



**Cracked lips/
'strawberry' tongue**



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

Kawasaki Disease can be present with some or all of these symptoms. Doctors sometimes refer to 'incomplete Kawasaki Disease' or 'complete Kawasaki Disease' but most doctors today know this is just one illness where symptoms can vary, child by child. If your child has been given a diagnosis of incomplete Kawasaki Disease or complete Kawasaki Disease, don't worry about that - their treatment will be the same. It just refers to how many symptoms they showed at a particular time.

Most symptoms of Kawasaki Disease occur in the first few days of the illness, although they are often not all present at the same time. Other symptoms which can occur include irritability (children with Kawasaki Disease are characteristically irritable!), loss of appetite, moodiness, diarrhoea, tummy ache, vomiting, jaundice (skin and whites of the eyes going a little yellow in colour) and a new inflammation (redness) at the site of an earlier BCG immunisation more commonly seen on children outside the UK - generally at the top of the left arm.

Later, at between 14 and 21 days after the start of the fever, skin peeling on fingers and toes can occur, but this only happens to about half of children affected by Kawasaki Disease. Some doctors incorrectly still look for skin peeling very early on when a child has Kawasaki Disease, when in fact it is a sign of healing, and will almost always only come later, if it occurs at all.



What causes **Kawasaki Disease?**

There are lots of theories around the cause of Kawasaki Disease and much research ongoing across the globe to try and identify its cause. But at the moment, no-one is certain of the cause.

There is some evidence to suggest that some children are more likely because of their genes (a genetic predisposition) to be affected by Kawasaki Disease. Some researchers believe it could be a child's response to an infection or a number of infections although no infectious cause has been found. There are theories too that suggest an environmental agent – perhaps something which is airborne or related to water bodies, as the cause. Whilst there is much research ongoing, some of it appears contradictory – and the patterns of incidence of Kawasaki Disease (who gets it and where) are different in different places.

In the UK, what we do know is that Kawasaki Disease is more common in children who live in rural areas – and children of black and minority ethnic backgrounds are more likely to be affected than those of Caucasian (white) backgrounds.





How is **Kawasaki Disease** diagnosed?

There is currently no specific test for Kawasaki Disease and it can be difficult to make a diagnosis, as many symptoms are common to other childhood infections. The diagnosis is made by recognising the symptoms and signs in a child with persistent fever, with no other likely explanation. A test is however being developed and in future this should help families get a rapid diagnosis.



Not all symptoms have to be present for a diagnosis to be made.

Kawasaki Disease symptoms can appear one after the other, so may not be present all at the same time. In very young children (babies under one year old) we know that often, there are very few symptoms.

As well as listening to you about your child becoming unwell, and looking at their symptoms, doctors will probably do some blood tests, which might help them decide whether it is Kawasaki Disease making your child unwell, or another illness.



We know that can be distressing and concerning, but until there is a specific test for Kawasaki Disease, we rely on the expertise of doctors and the need to piece together key bits of information to diagnose Kawasaki Disease.



Are there any complications?

UK studies have shown that about 1 in 4 children with Kawasaki Disease will develop some heart damage. Some of these will have damage to the blood vessels that supply the heart muscle itself (coronary arteries), resulting from inflammation (swelling). This heart damage is a worry to all parents. It's important to know though that this damage ranges from mild to severe. For many children, they can recover, but for a few there may be long term damage to their heart.

Problems with the coronary arteries can be detected on a heart scan (an echocardiogram) which your child will have during their stay in hospital. A common type of change which happens in Kawasaki Disease is a swelling of the blood vessels supplying the heart with blood (coronary arteries). This is called a coronary artery aneurysm.

If an aneurysm is found during a heart scan, it might be helpful to know that most of these changes settle over the following two years. This does depend on the nature of any damage caused to a child's heart by Kawasaki Disease, and of course, how serious the damage is to start with.



But it is important to say that even for those children who do go on to have a long-term problem, whilst they will have to take medication and be monitored closely by doctors, almost all lead a normal life. The diagram over the page explains a bit more about what a coronary artery aneurysm is.

In the months after having Kawasaki Disease, some children can continue to be tired, be "out of sorts" or moody, have joint pain or tummy upsets that take some time to settle down.

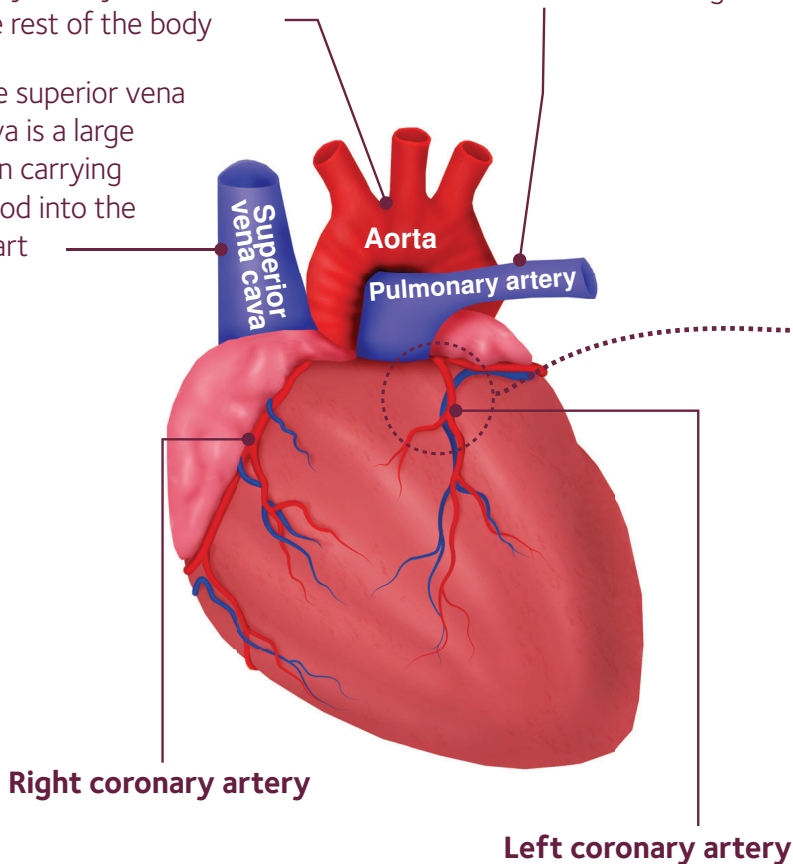
What is a coronary artery aneurysm?

The coronary arteries are the blood vessels that supply oxygen and nutrients to the heart muscle. This image represents the human heart and shows the left and the right coronary arteries at a normal size. These arteries can be affected by Kawasaki Disease in some children.

The aorta is the main artery that carries blood away from your heart to the rest of the body

The pulmonary artery carries blood from the heart to the lungs

The superior vena cava is a large vein carrying blood into the heart

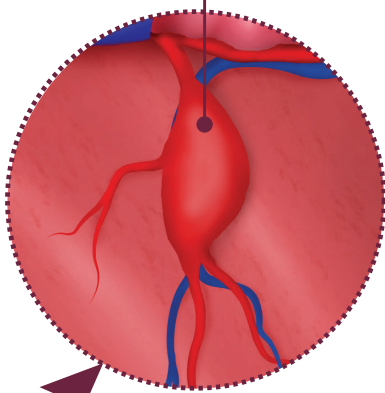


What is an aneurysm?

An aneurysm is a swelling in the artery. This image represents an aneurysm that could be caused by Kawasaki Disease.

Aneurysms vary in size and can be a small, medium or large/giant. Doctors use something called a “z score” to help to describe the size of an aneurysm.

Coronary artery aneurysm



What is dilatation?

Sometimes the inflammation of coronary arteries leads to a slight widening of these blood vessels, although they don't get inflamed enough to cause an aneurysm. Your doctor might describe this change as “dilatation”. If this happens, your child may have additional scans until their coronary arteries have returned to their normal size.

What is a z score?

A z score allows doctors to understand the size of an aneurysm, relative to the size of the child. This is helpful because a small baby would usually have small blood vessels, but an older child would be bigger and have bigger blood vessels. So, the z score helps doctors to know if the measurements of the blood vessels are healthy for the size of the child or whether there is an aneurysm.

What about blood clots (thrombosis)?

Blood clots can sometimes occur in Kawasaki Disease where coronary artery aneurysms have developed. Their risk is minimised by using medication such as aspirin or clopidogrel, and with ‘blood-thinners’ such as heparin or warfarin.

Can aneurysms rupture?

This is very rare indeed, but very occasionally an aneurysm can rupture. This usually happens early during the disease process.



How is **Kawasaki Disease** treated?

Early treatment of Kawasaki Disease reduces the risk of heart damage and treatments focus on 'switching off' the inflammation by calming the body's immune responses.

Most children respond to the treatments described below. Successful treatment leads to a rapid end of the symptoms, including fever. Early treatment can significantly improve the chances of a good recovery. Research shows that treatment should be given as early as possible.

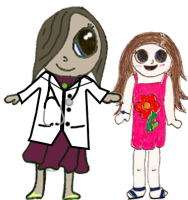
Medicines used - IVIG and aspirin

Intravenous Immunoglobulin - IVIG

The main treatment for Kawasaki Disease is called immunoglobulin which is given into a vein through a drip over 12 hours (IVIG). Sometimes the time varies depending on how your child responds and their particular situation. IVIG is made from the plasma in donated blood, and is rich in antibodies - the molecules that the body makes to fight against infection. It is generally safe with side effects being rare. Expert doctors administer the treatment too and your child will be carefully looked after.

In some cases, your child could be given a second infusion of IVIG, if they remain very unwell and doctors don't see the improvement they expect. Once again, your child will be closely cared for throughout the treatment.

IVIG can interfere with the ability to respond to vaccinations, particularly live vaccination including MMR, chicken pox, rotavirus, BCG and yellow fever. If your child is due to have a live vaccine, this will need to be delayed for several months. You should discuss the best time to have vaccines with your child's GP or doctor. If your child received a live vaccination in the three weeks before receiving IVIG, they may need a booster vaccine nine months after IVIG.



Aspirin

Aspirin is also given to help switch off the inflammation, reduce your child's fever and lower the chance of blood clot forming, if there is any damage to their heart.

'High dose' aspirin is usually used during the first 10–14 days of illness to help reduce inflammation. This is then usually switched to 'low dose' (or anti-platelet dose) aspirin which has a blood thinning effect. 'Low dose' aspirin will be given for 6 weeks and can then be stopped if everything is OK.

It's helpful to remember that 3 out of 4 children will not have any heart damage. If there is no damage to the coronary arteries, aspirin is stopped 6 weeks after the start of Kawasaki Disease symptoms. Because aspirin can cause a sore tummy in some children, doctors may give a medicine to protect their tummy, alongside aspirin.

Children who do have changes to their coronary artery may be given additional 'blood thinning' medicines. If these are needed, your child's doctors will explain what is involved in greater detail.



Other treatments

Most children respond well to IVIG and aspirin, and this combination can be very effective in stopping the inflammation caused by Kawasaki Disease. However, some children require additional treatments, to help fully 'switch off' the inflammation happening in their body. These are different types of medicine, but work by doing the same thing as IVIG and aspirin – they stop inflammation.

Some of these medicines may reduce your child's ability to fight infection, and if your child is given one of these medicines, your doctors will talk to you about this. They will let you know that if your child has a fever or is unwell during or shortly after taking these medicines (within 3 months), that you should take them to your GP or local hospital and show them the hospital discharge summary which explains what medicines they have been taking.

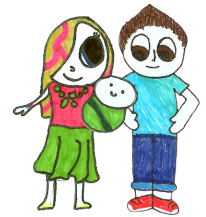
Corticosteroids

Corticosteroids reduce inflammation. Sometimes referred to just as ‘steroids’, these are not the same medicine that you might have heard about used in bodybuilding. Corticosteroids are given to children to treat a wide range of inflammatory illnesses and have been shown to be safe and effective as a treatment for children.

Corticosteroids can be given daily, either through a drip (if your child is still in hospital) or as a tablet by mouth.

Corticosteroids will make your child temporarily more vulnerable to some infections, especially if high doses have been given. This effect lasts for up to three months after finishing treatment.

If your child has had direct contact whilst, or immediately after, taking corticosteroids, with someone with chicken pox, shingles, or measles, contact your GP or your local hospital. Your child may need a blood test and an injection to protect them against chicken pox or measles. If your child has been on corticosteroids for a long time, the dose will slowly be reduced over time. They should not be stopped suddenly without advice from your doctor. Children taking corticosteroids may be given an additional medicine to protect their tummy from possible irritation.

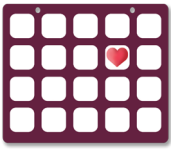


Anti-TNF medicines

These are medicines which also work to ‘switch off’ inflammation. Infliximab and etanercept are types of these medicines and they work in a different way to IVIG and aspirin by blocking a chemical in the blood called TNF-alpha. These medicines are generally well tolerated, with few side effects. They are given as a one-off intravenous infusion (through a drip).



Your child should not be given any live vaccines until 6 months after infliximab or etanercept treatment. Your doctor will tell you more about dietary restrictions and extra vaccinations which might be needed if your child has these treatments.



How long will it take for my child to get better?

Your child will need to stay in hospital for at least a few days, until the inflammation has stopped and their symptoms are better. It is difficult to know the exact length of time your child will be in hospital because it depends on the severity of the Kawasaki Disease and how they responded to treatment.

Once you go home, you may notice that your child is tired and may have a poor appetite. It can take several weeks for them to be fully back to normal. Do not worry if there is skin peeling from the hands, feet or groin area. This happens to almost half of children who have Kawasaki Disease and some Vaseline can help keep skin moisturised and stop any mild discomfort. However, if other symptoms return it is important to let your doctor or the hospital know.



Follow-up after discharge

Children with Kawasaki Disease are followed-up with a heart scan (echocardiogram). You should receive an appointment for this at hospital. Most children with Kawasaki Disease have normal coronary arteries during and after their illness. Damage to coronary arteries can develop in the first few weeks of Kawasaki Disease, so your child will be given an appointment for a heart scan after 2 and 6 weeks, even if their first scans were normal. If the scan is normal at 6 weeks, then aspirin is usually stopped.

Children with damage to their coronary arteries require a longer period of follow-up with more frequent scans. They may need longer-term medicines, such as low-dose aspirin. They may need to attend a specialist Kawasaki Disease clinic. Your doctor will talk to you and explain more about treatment and next steps if this is needed for your child.



When can my child go back to their normal routine?

Flexibility and support

Your child can go back to nursery or school as soon as you feel they are well enough to. However, after a serious illness like Kawasaki Disease, some children and their families may need support as normal routines such as nursery and school are resumed. Some flexibility will be essential to help children settle back in – especially if there are significant adjustments now needed, like protective safety helmets or regular medication.



Some children will need routine follow up medical appointments and may miss school / nursery because of this.

Working together between schools and families is important to help minimise any negative impact of necessary changes like these.



Longer term issues following Kawasaki Disease

After a child has had Kawasaki Disease, you may read or hear about possible longer-term issues that can sometimes follow the illness. It's important to know that most children are only affected by one or two of these issues, if any at all – and many children won't have any at all.

The majority of problems that do occur settle within one to two years, and often much sooner. Most will resolve on their own, without the need for additional treatment. However, if you are concerned about anything after your child has recovered from Kawasaki Disease, you should speak to your GP or usual doctor.

When additional support is needed

In some cases, if a child has serious or lasting complications, your child's doctor may advise that a medical care and action plan is needed. This will help nursery or school staff to understand any

precautions that might be necessary, and your child's doctor will support with this if required.

Eczema & skin peeling

Some children continue to have dry or peeling skin in the weeks or months after Kawasaki Disease, particularly on their hands or feet. This can be irritating, but it usually gets better over time.

Dry lips are also common and Vaseline can help soothe and protect them. For dry or peeling skin, gentle creams like E45 can also be used if the skin is uncomfortable. It's best to avoid creams that contain antibiotics or perfumes, as these can irritate the skin. Children should be encouraged not to pick at dry or peeling areas, as this can lead to infection.

You might find it helpful to take a copy of this leaflet into school/nursery as you make a plan for your child to return.

Exercise

Exercise is important for all children, and getting back to regular activity is a good part of recovery.

Most children can safely return to all normal activities. However, if a child has had significant heart damage and is taking blood-thinning medicines like warfarin or clexane, their doctor may recommend that contact sports are avoided. If any restrictions are needed for your child, your doctor will explain these clearly.

If you're ever unsure, it's a good idea to ask your doctor about what types of exercise are safe.

Joints

Many children affected by Kawasaki Disease will experience some joint pain or swelling in the first few weeks after becoming unwell. This is most often felt in larger joints like the knees, elbows or ankles, and can be uncomfortable.

Simple pain relief can be used to help – but ibuprofen should be avoided in children who are already taking aspirin, as the two medicines don't mix well. If joint pain continues beyond the early recovery period, it's important to talk to your doctor.





Tummy pain

Tummy aches, diarrhoea and vomiting are quite common in the early days of Kawasaki Disease, especially when children are first unwell. These symptoms usually settle quickly.

However, if your child has ongoing tummy pain, it could sometimes be linked to their medicines. For example, aspirin can sometimes cause an upset stomach. If you're worried about persistent tummy symptoms, it's always best to check with your doctor.

Behaviour

It's not unusual for children to seem more restless, have trouble sleeping, or find it harder to concentrate after being seriously unwell, no matter what illness they have had.

Some children, especially older ones, may become anxious or worried. This can be linked to their time in hospital or an increased awareness that they have been seriously ill.

These changes are usually short-lived, and studies show that most children are back to their usual selves within a year or two. If new or ongoing mental health issues arise, it's unlikely these are linked directly to Kawasaki Disease, and you should speak to your doctor for advice.

Tiredness

Children recovering from Kawasaki Disease often feel tired or have low energy levels. This can last for a few weeks or sometimes longer.

Every child is different and recovery may take time. If tiredness goes on for a long time or starts to affect things like school or play, speak to your doctor. They can check if any extra support is needed.





What else to know about treatment

After treatment with IVIG, your child's doctor will usually advise that your child should not have live vaccines for six months. This is because IVIG can make these vaccines less effective. More information about this can be found in the treatment section of this guide on page 10.

Aspirin is given to all children with Kawasaki Disease for around six weeks, and if their heart scan (echocardiogram) shows no lasting heart damage, aspirin will be stopped.

If heart damage is found, aspirin may be continued long term. Some children may experience side effects whilst taking aspirin long term. These can include headaches, tummy pain and tiredness. Medicines to protect the tummy are often given with aspirin to limit side effects (see also Bruising).

Parents will be advised if a child is taking aspirin long term, to stop this for a few days if there is a high fever ($39^{\circ}\text{C}+$). This is to reduce the risk of Reye's syndrome, a rare but potentially very serious illness.

Other medicines may also be given to those with the most serious heart damage, for instance children with giant coronary artery aneurysms. Treatments may include warfarin or clexane to help thin the blood. For these children, precautions may be needed such as safety helmets for playtimes, which help to avoid knocks to the head and for older children, avoiding contact sports.

Bruising

Following Kawasaki Disease, if a child is taking aspirin and blood thinning medicines, they may bruise much more easily. It is important that nursery/school is aware of this and it is noted in the child or young person's individual record. Sharing a copy of this booklet with school/nursery might be helpful.





Can my child get **Kawasaki Disease** again?

It is unusual for a child to have Kawasaki Disease again (this only happens to fewer than 1 in 50 children). However, a few children have a repeat of some symptoms within the first few weeks, or a new episode later in childhood. If your child develops symptoms of Kawasaki Disease, take them to your local hospital to be reviewed and say that they have had Kawasaki Disease before.

Many children will experience repeated symptoms or “reactivation”. This might happen when they have a cold, and they get a very high fever, red eyes or a rash, or peeling skin. This happens very frequently in children who have had Kawasaki Disease but almost always, it is not another episode of Kawasaki Disease. It’s the child responding differently to a bug or infection after Kawasaki Disease. These symptoms can be worrying for parents even though it’s not Kawasaki Disease.

It’s important to know that actually getting Kawasaki Disease again is very rare - and only happens in less than 2% of children. Speak to your doctor if you have concerns.





Where can I find more information?

We hope the information contained in this booklet has been helpful to you. We know that a diagnosis of Kawasaki Disease within your family can be a very worrying and stressful experience. Being able to access reliable, expert backed information is very important to families during this difficult time.

Societi Foundation is a registered charity and is the UK Foundation for Kawasaki Disease. We are supported by a Scientific Advisory Board, a team of expert doctors, who review and inform all our work.

To support families during and after a Kawasaki Disease diagnosis, we provide information and resources aimed at answering your questions and supporting you. They include stories from other families – because you are not alone going through this. Our website also includes interviews with doctors who answer common questions, frequently asked questions in our Q&As, information on long term care and much more. You can access all this and much more at **www.societi.org.uk**. Please take a look.

If you find you still have questions after checking out our website, please get in touch: **info@societi.co.uk**. As a charity, we don't give medical advice, but we will always try to help where we can.



“ GILLIAN

I want Kawasaki Disease known - we were fortunate, the paediatric A&E team at Addenbrookes recognised the symptoms and were able to give my child the life saving treatment that was so desperately needed. I want this to be the case in all cases. Thank you Societi, I know you made the difference for us.

”

“ EMMA

Many thanks for all you do. My son was diagnosed with Kawasaki Disease last year and it's so important we raise awareness.

”

“ KAT

A year ago we were in hospital with our 15 week baby. It took a while for the diagnosis to be made but her tiny heart is still beating. THANK YOU for all you do.

”



societi We are the UK Foundation
for **Kawasaki Disease**

Our charity supports families affected by Kawasaki Disease, improves awareness, improves the care children receive and provides the most up to date information for doctors looking after children with Kawasaki Disease. If you'd like to help us in our work or donate, contact us info@societi.co.uk. Find out more www.societi.org.uk

Updated August 2025



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