



What is Kawasaki Disease?

Kawasaki Disease (also known as Kawasaki syndrome) is an acute childhood illness that hits out of the blue. It can affect children of all ages, although those age five or under are primarily affected. Boys are almost twice as likely as girls to be affected by Kawasaki Disease. It is an inflammatory process that can affect almost every system in the body, although the arteries that supply blood to the heart (the coronary arteries) appear specifically affected.

Why is it called Kawasaki Disease?

Dr Tomisaku Kawasaki of Tokyo, Japan, first described the group of symptoms associated with the illness in 1967. Since then it has been diagnosed in virtually every country in the world.

What are the symptoms ?

- **A persistent high temperature for 5 days or more**
- **Sore mouth / and cracked red lips**
- **Red tongue (often strawberry like)**
- **Skin rash**
- **Swollen glands in the neck (can be in the stomach)**
- **Red eyes - not sticky**
- **Swollen often red and painful hands and feet**

Although diagnosis of Kawasaki Disease requires fever plus at least four of the features above, doctors should consider Kawasaki Disease as a possible diagnosis even if not all features are present. This is known as incomplete Kawasaki Disease and is most common in very young children.

Other typical features are extreme irritability, joint pain, loss of appetite, moodiness, vomiting and diarrhea. The symptoms of Kawasaki Disease are similar to other illnesses but for Kawasaki Disease to be diagnosed, it will need a medical opinion. The symptoms often occur one after the other rather than all at the same time.

In less than half of children, between 14 days and 21 days after the start of fever, skin peeling can occur in Kawasaki Disease on the hands and feet. This is not a 'symptom' of the acute phase of the disease though - if it appears, it comes much later.

What causes Kawasaki Disease?

The cause is unknown. It seems to be the way certain children react to an unknown environmental factor or an infection - there are many theories and to date no-one has found a cause. It could be an abnormal response by the immune system. Research is taking place throughout the world to find the cause.

What is the treatment for Kawasaki Disease?

Immunoglobulin (antibodies from donated blood) given as an infusion, usually over 12 hours with aspirin. Aspirin is given initially as a higher dose and then low dose when the temperature settles and the inflammation has resolved for a total of about 6 – 8 weeks. This may be for longer if any heart damage has occurred.

How long does Kawasaki Disease last?

The initial stage (**acute**) is about the first **14 days**. Children will feel very unwell, especially whilst the **fever** is still high. During the convalescent stage, which will progress over the next **6 – 8 weeks**, your child will begin to feel 'better' as symptoms will be clearing, but they may still be very irritable and tired. Treatment can help make them more comfortable but cannot lessen the time that Kawasaki Disease takes to run its course.

What tests will be done?

Initially, blood tests will probably be needed to rule out other illnesses and to check blood counts but once diagnosed there is generally no need to repeat them very often. There will be an ECG to check the heart rhythm. There is always a cardiac ultrasound scan – an echocardiogram or "echo", which is done during and after the acute illness. This scan is painless and similar to those used during pregnancy. It can be tricky for the doctors to perform as unwell children can be uncooperative! Don't worry - staff are used to this. This test shows the coronary arteries of the heart and these can be checked for any changes caused by Kawasaki Disease.

What happens if a problem is found?

About a quarter of children currently treated sustain some damage to their coronary arteries. The majority of these children can lead quite normal lives though many will need to stay on medication and be seen regularly by a cardiologist. Aspirin is the mainstay but other drugs may also be required. There will be regular check-ups and echocardiograms.

In most children the shape of their coronary arteries with return to their earlier size within about two years but for others it can take a lot longer, if at all. Once damage to the coronary arteries from Kawasaki Disease has occurred, even after the coronary arteries have returned to their former size, regular checks with a cardiologist are important - for life.

Can Kawasaki Disease recur?

Kawasaki Disease can happen more than once, there is no natural resistance built up as happens with some other illnesses. The recurrence rate in the UK is about 1 in 50 cases.

Other useful points

It is vital for any child with (or suspected to have had) Kawasaki Disease to have a heart scan even if they no longer have any symptoms of the initial illness.

There are some children who have mood swings, sleep problems and/or behavioural problems after Kawasaki Disease. These problems have been shown to settle down for the majority of children within a couple of years.

Families of children who have had immunoglobulin treatment and are due their routine vaccinations, should talk with their doctor about the timing of these vaccinations.

We know there are adults presenting with problems which can be traced back to having undiagnosed and therefore untreated Kawasaki Disease as children. Adult cardiologists are increasingly aware of this illness.

Who are the Kawasaki Support group?

The group was established in June 1994 by three mothers of children with Kawasaki Disease. It is still run by two of them - Sue Davidson and Nicky Clements. We have support from the medical profession and have a telephone help line and Facebook group. We currently have over 1600 families in the support group and it is expanding.

The group can be contacted by post, email or phone at the address and number below.

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Who are Societi Foundation?

Societi Foundation is the **UK Foundation for Kawasaki Disease** and a registered charity no. 1173755. We work in partnership with KSSG and together we raise awareness of Kawasaki Disease. For more information and our combined website go to **www.societi.org.uk**

This information booklet was updated in 2018 by Societi Foundation, the UK Foundation for Kawasaki Disease www.societi.org.uk

