

## ABOUT THIS LEAFLET

### About this leaflet

This leaflet has been written for young people who have been affected by Kawasaki Disease. The information it contains has been reviewed by doctors from Societi Foundation's Scientific Advisory Board. It is designed to be shared with school teachers or care givers to explain more about some of the longer term issues which some young people with Kawasaki Disease may experience.

### See a doctor if you have concerns!

This leaflet does not provide medical advice. It is intended to be a guide for general information purposes only. If you have concerns, please contact your usual doctor or GP.

### Important points:

- 1. Whilst you'll read about a range of possible longer term issues in this leaflet, following Kawasaki Disease most children experience just one or two, if any of these issues.**
- 2. It's important to know that the majority of longer term issues will resolve within one to two years or well before then, on their own without additional treatment for most children. If you have concerns, please see your usual doctor or GP.**
- 3. If a young person has serious, lasting complications following Kawasaki Disease, a medical care and action plan should be put in place at school/nursery. If this is necessary, your doctor will provide guidance for this.**



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## ABOUT KAWASAKI DISEASE

Kawasaki Disease is a serious disease which affects hundreds of children in the UK each year. Most children affected are under 5 years but about 25% of patients are older children. Kawasaki Disease has a range of symptoms including:



**Persistent fever**



**Bloodshot eyes**



**Swollen fingers/toes**



**Swollen glands**



**Rash**



**Cracked lips/  
strawberry tongue**

Kawasaki Disease can be present with some or all of these symptoms. If a child has a persistent fever with any two or more of these symptoms please THINK Kawasaki Disease.

Most of these symptoms occur in the first few days of the illness, although they are often not all present at the same time. There are sometimes other symptoms too - loss of appetite, diarrhoea, tummy ache, vomiting and jaundice. Typically, children with Kawasaki Disease are very irritable.

Kawasaki Disease is a serious illness as it can cause coronary artery damage – damage to the blood vessels in the heart. Early treatment is key to reduce the risk of lifelong serious heart damage. Kawasaki Disease is the leading cause of acquired heart disease in children in the UK.

### THANK YOU

If you have found the information in this leaflet helpful, please consider making a donation to Societi Foundation. Your donations support our work to share information about Kawasaki Disease and protect children's hearts.

Societi is a registered charity in England & Wales (no.1173755)

# societi

The UK Foundation for  
Kawasaki Disease



Understanding  
some of the

## LONGER TERM ISSUES



A short guide for young  
people affected by  
Kawasaki Disease.



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## LONGER TERM ISSUES



### **Eczema & Skin peeling**

After Kawasaki Disease, some children have ongoing problems with occasional dry skin areas and skin peeling. Dry lips can be treated with Vaseline, this does help. Creams such as E45 can be used on dry, peeling skin if it is uncomfortable. Whatever cream you choose to use, pick one without antibiotics or perfumes as these ingredients can irritate the skin. Try not to pick the affected areas, as this could lead to infection.

### **Exercise**

All young people can exercise after Kawasaki Disease, in fact regular exercise is important! Some young people may be advised by their doctor to avoid certain types of exercise if they have very serious heart damage. This would include those taking blood thinning medicines like warfarin and clexane where a doctor may advise that they should not take part in contact sports, for instance. If there needs to be any restrictions on exercise, your doctor will advise you in detail. If you have any questions about exercise after Kawasaki Disease, discuss these with your doctor.

### **Joints**

Nearly half of children affected by Kawasaki Disease have some initial issues with joint pain or swelling in the first few weeks. Areas most affected include large joints - elbows, knees or ankles. This can be quite painful but over the counter painkillers can be given to help (ibuprofen should be avoided in young people who are already taking aspirin.) Very occasionally joint pain can continue for longer – if this happens, discuss it with your doctor.

### **Tummy pain**

Many children complain of tummy pain and possibly have vomiting and/or diarrhoea when first ill with Kawasaki Disease - this doesn't usually last long. Ongoing tummy pain could however be linked to other issues, for instance it can sometimes be caused by some types of medicines (see also Treatments & precautions). Speak to your doctor if this is a concern.

### **Tiredness**

Having been seriously ill with Kawasaki Disease, many children experience tiredness and for some this can last a few weeks or months. After Kawasaki Disease, the recovery process will be different for each child and some may have low levels of energy for some time after being initially unwell. If tiredness is not improving and is affecting school (for instance) discuss it with your doctor.

### **Behaviour**

Some children will have difficulty concentrating, be more restless or have trouble sleeping for a short time after Kawasaki Disease. Some will experience anxiety linked often to awareness of a difficult period in hospital and older children may be alert to having been seriously unwell. This can lead to worries about health or a more generalised anxiety. This shouldn't present lasting difficulties for most young people and studies show that this improves, with almost all children recovering within 1 to 2 years. If other mental health issues emerge, these are probably not linked to Kawasaki Disease and a doctor should be consulted.

### **Treatments & precautions**

The main approach to treating Kawasaki Disease initially is with two medicines called immunoglobulin and aspirin. After treatment with immunoglobulin, your child's doctor will advise that for a period of 6 months, they will need to avoid having live vaccinations. This is simply because the antibodies in immunoglobulin may mean that vaccination might not be effective.

All children with Kawasaki Disease will also be treated initially with low dose aspirin for about 6 weeks. After 6 weeks an echocardiogram (ultrasound of the heart) will be done to check for any damage to the heart. Aspirin will be stopped in children with no lasting heart damage. In children who develop lasting heart damage, low dose aspirin may be continued longer term.

Some young people 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, following their initial illness with Kawasaki Disease, to stop this for a few days if there is a high fever (39°C+) This is to reduce the risk of Reyes syndrome, a rare but potentially very serious illness.



### **Other treatments**

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 young people, avoiding contact sports (see also Exercise).

### **Bruising**

Following Kawasaki Disease, if a child is taking aspirin and blood thinning medicines, they may bruise much more easily. It is important that school is aware of this and it is noted in the young person's individual record.

### **A repeat of some symptoms?**

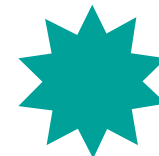
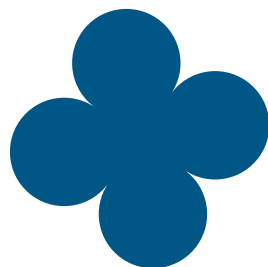
Many children will experience repeated symptoms or "reactivation". This might happen when they have a cold, and they get a very high fever, red eyes or a rash, or peeling skin. This happens very frequently in children who have had Kawasaki Disease but almost always, it is not another episode of Kawasaki Disease. It's the child responding differently to a bug or infection after Kawasaki Disease. These symptoms can be worrying 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 2% of children. Speak to your doctor if you have concerns.

### **Flexibility & support**

After a serious illness like Kawasaki Disease, 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 mentioned above or regular medication.

Some young will need routine follow up medical appointments and may miss some school because of this. Working together between schools and families is important to help minimise any negative impact of necessary changes like these.



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