Kawasaki Disease Home Care Instructions



Symptoms may come back

Most patients will not have symptoms (fever, red skin, etc.) after leaving the hospital. Sometimes fever or other symptoms reappear a few days to a week after leaving the hospital. ***VERY IMPORTANT*** If your child begins to have fever again (100.5 or higher), call the Kawasaki Team right away. Failure to do so may result in heart damage.

Kawasaki Team:

Kawasaki Nurse Care Manager: (323)361-8638 or (323)361-4622

Cardiologist On- Call: (323)660-2450 and ask for the On-Call Cardiologist

When to take your child's temperature

Take your child's temperature between 4:00–6:00p.m. each day **before** giving the 6:00 p.m. aspirin dose. Write the temperature reading on your home log. You should also take your child's temperature if they feel warm or are acting sick or irritable.

Other Signs to Watch for:

If any of these signs appear or become worse notify the Kawasaki Team.



A. Rash on any part of the body including rash that comes and goes or moves from one part of the body to another



B. Redness of white part of the eyes

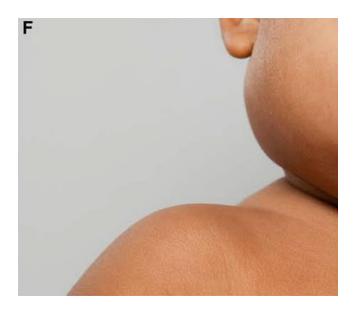


C. Red, dry lips and tongue (strawberry tongue)



D & E. Redness and puffiness of the hands and feet with soreness of the joints.





F. Swelling of the lymph nodes. Usually on one side and usually in the neck area but also can be under the arms or in the diaper/underwear area (groin).

Behavior

After your child leaves the hospital, you may see a change in behavior including:

- Irritability
- Different sleep patterns
- Bad dreams
- Return to more baby-like behavior

Medicines

Low Dose Aspirin

Give Aspirin with food or milk to prevent an upset stomach. Sometimes, there are side effects from taking aspirin such as nausea, vomiting, increased bruising and bleeding. Because your child may bruise more easily; avoid rough play and contact sports. If your child has any of these, you should call your doctor. Low dose aspirin used for antiplatelet effect has not been connected with the development of Reye syndrome.

Plavix or Warfarin

In a few patients who develop large aneurysms in the coronary arteries, they need stronger blood thinning drugs called Clopidogrel (Plavix) or Warfarin (Coumadin). Because special care is needed for these drugs, you will receive special training from a nurse.

Diet

Your child may eat whatever he or she normally eats. If your child's lips or tongue are sore or tender, softer, cool non-acidic foods and fluids are best until the lips and tongue are healed.

Immunizations

Most immunizations can be given to children who have had Kawasaki Disease. Live virus vaccines should be delayed for 11 months after treatment with IVIG (immune globulin or gamma globulin). The yearly FLU vaccination is recommended.

School/Day Care

Your child may return to school or daycare when he or she is:

- Free of fever, joint pain and other signs and symptoms of Kawasaki Disease.
- Back to normal energy level

It may take 1 to 2 weeks after discharge before he or she feels well enough to return to school or daycare.

What to Expect

Skin

Most children have peeling of the fingers, toes, palms of the hands and soles of the feet. This can last between two and six weeks. The peeling does not hurt. Your child's skin will be normal after the skin has finished peeling. You may also trim the fingernails and dead skin on the fingers to decrease scratches that could cause an infection.

When bathing, pat the skin dry. Skin does not need to be <u>completely / totally</u> dry.

If your child wears diapers

Use a cloth diaper inside of your child's disposable diaper to prevent irritation.

Your child may complain of itching. You can apply calamine lotion or lotion to the itchy areas.

Pain

Some children develop joint pain during the second and third week of illness.

If your child has joint pain, they may stay on high dose aspirin for a longer period of time. Using any Non-Steroidal Anti Inflammatory Drug such as Ibuprofen or Motrin with high dose aspirin may result in serious side effects including risk of bleeding. Call your doctor if joint pain occurs or lasts. The joint pain and stiffness do not last long. There are no known long-term problems from the joint pain. If your child has pain that does not get better after several weeks, call your doctor.

Signs of heart problems

Heart attack (Myocardial infarction) is the most serious problem of Kawasaki Disease. Your doctor uses a test called an Echocardiogram to learn who is at higher risk for a heart attack. Most children do not have to worry about heart attacks after Kawasaki Disease. High-risk patients are given blood-thinning medication (anticoagulant) to prevent a heart attack.

Caridology

A small number of high-risk children may develop coronary artery aneurysms. "An aneurysm (AN'urizm) is a bulge in a blood vessel, much like a bulge on an over-inflated inner tube. Aneurysms are dangerous because they may burst" (American Heart Association, 2007, www.americanheart.org). A coronary aneurysm is when it happens to a blood vessel of the heart.

Children with aneurysms and those that had changes in their coronary arteries during the Kawasaki illness will have a "Stress Echocardiogram Test" to find out the heart's response to heavy physical activity. This helps your doctor to know how the child's heart responds to competitive sports activity.

Call your doctor right away if your child has any of these:

Chest pain
Sweatiness
Sudden paleness
Blue grayish color around nose and mouth
Stomachache
Vomiting
Passing out
Seizures

If your child looks very sick you should take him or her to the nearest hospital emergency room or call 911.

It is very important that your child be seen regularly.

To make an appointment:

Monday thru Friday 8:00 a.m. to 3:00 p.m. call (323)361-2461 and ask for the Kawasaki Clinic.

To talk to a doctor after 5PM or on weekends and holidays:

Call (323) 660-2450 and ask for cardiologist on-call