

# JUVENILE ARTHRITIS

# Live and Learn

FROM THE EXPERTS AT THE ARTHRITIS FOUNDATION



Arthritis  
Foundation®

# Understanding Juvenile Arthritis

People of all ages can and do have arthritis. Nearly 300,000 American children – from infants to teenagers – have some form of arthritis. In fact, arthritis is more common in children than type 1 diabetes and other childhood diseases that may be more familiar. The word “arthritis” means joint inflammation (arth = joint; itis = inflammation). Joint inflammation causes pain, stiffness, swelling, warmth and redness at the affected joint.

Over time joint damage can occur, leading to decreased function and mobility. Juvenile arthritis (JA) is an umbrella term, not a specific disease. It refers to a group of rheumatic diseases and conditions affecting children. Because arthritis affects every child differently, it’s important to recognize the signs so a timely and accurate diagnosis can be made to ensure the best possible outcome for your child’s health and well-being. With the proper medical care, your child can continue to live a productive and fulfilling life.

## Juvenile Idiopathic Arthritis

Juvenile idiopathic arthritis (JIA) is the most common type of arthritis in children. The term idiopathic means “of unknown origin.” JIA was previously called juvenile rheumatoid arthritis (JRA). However, JIA describes the disease more accurately and corrects the notion that JIA is a child-sized version of rheumatoid arthritis.

A healthy immune system protects the body from infection and disease. In JIA, the immune system mistakenly attacks the body’s tissue, causing inflammation in joints and potentially other areas of the body. That is why JIA is considered an autoimmune disease. JIA is not contagious.

The Arthritis Foundation is an excellent source of information and can connect you with other families in your area or to an online community of families dealing with JA.

Not all children have the same symptoms. Joint symptoms of JIA may include pain, swelling, stiffness, redness and warmth. Pain is often worse following sleep or periods of inactivity. Non-joint symptoms may include fever, fatigue, rash, poor sleep, swollen lymph nodes, pain at the points where bones and tendons connect, decreased hunger and weight loss. Symptoms can change from day to day or throughout a single day.

If you are reading this brochure, you or a health care professional must suspect your child has a rheumatic disease. If you have not already, you may want to find a pediatric rheumatologist – a doctor with special training to treat children with arthritis and other musculoskeletal diseases – for a diagnosis. If you are not able to find a pediatric rheumatologist practicing in your area, you may choose to travel to the closest one or your pediatrician may be able to do a remote consultation with one.

## Causes of JIA

Researchers are uncertain what causes JIA. There is no evidence that foods, toxins, allergens or lack of vitamins play a role in developing the



Visit the Arthritis Foundation's JA website at [arthritis.org/juvenile-arthritis](https://arthritis.org/juvenile-arthritis) to learn more and find resources.

disease. Current research indicates there is a genetic predisposition to JIA. More than a dozen genetic markers for JIA have been identified, and hundreds more are being considered. However, genetic markers alone can't determine who will get arthritis. Researchers believe that a trigger, like a virus, can start the disease process in those children with the genetic tendency.

## Diagnosing JIA

An early diagnosis followed by aggressive treatment are key to preventing or slowing joint damage and preserving function and mobility. Here are some of the steps your child's doctor will perform during the initial diagnosis period.

**Medical history.** The doctor will take your child's health history to document the symptoms experienced and the length of time they've been present. This helps rule out other possible causes, like trauma or infections. The doctor will also ask about your family's medical history.



**Physical exam.** The doctor will examine your child's joints for external signs of inflammation and test their range of motion.

**Lab tests.** Tests may include the following:

- Erythrocyte sedimentation rate (ESR or sed rate).
- Antinuclear antibody (ANA).
- Anti-cyclic citrullinated peptide (anti-CCP).
- Rheumatoid factor (RF).
- HLA-B27 typing (a genetic marker).
- Complete blood count (CBC).
- Urinalysis.

## Early Signs and Symptoms

The following list includes some of the most common early signs and symptoms of arthritis in children. Your child may not have all of these symptoms.

- Joints that are warm to the touch
- Swelling and tenderness at joints
- Fever
- Rash
- Favoring one limb over another
- Pain (at rest or with activity)
- Stiffness, especially upon waking in the morning
- Decreased physical activity
- Inability to bend or straighten joints completely

**Imaging.** The doctor may order imaging scans – X-rays, ultrasound, MRI or CT – of joints to identify joint damage.

The diagnosis of JIA is made by the presence of active arthritis in one or more joints for at least six weeks, after other conditions have been ruled out. The pediatrician and a pediatric rheumatologist may be involved in making the final diagnosis.

If you need more or don't understand information, ask questions. Your doctors should welcome an open dialog and make you feel comfortable discussing your child's diagnosis and treatment plan. Early diagnosis and treatment can preserve your child's mobility, function and overall health.

## Types of Juvenile Idiopathic Arthritis

If your child has been diagnosed with JIA, it's important to identify the type of JIA to ensure they receive the most effective treatment.

### Oligoarthritis

Oligoarthritis – oligo means few – is the most common form of JIA, particularly in young children. About half of all children with JIA have this subtype. Oligoarthritis affects four or fewer joints, often the knees, ankles, wrists or elbows. It's particularly common in white girls, age 6 or younger. Uveitis (chronic eye inflammation) is more common with oligoarthritis than with the other subtypes.

Children with oligoarthritis who test positive for antinuclear antibody (ANA) face the greatest risk of developing eye inflammation and should be monitored for eye problems. Children with oligoarthritis are less likely to have severe problems

with joint function than those diagnosed with other types of JIA.

## **Polyarthritis**

Polyarthritis – poly means many – affects five or more joints. About 25% of children with JIA have polyarthritis. Polyarthritis is more common in girls and can occur any time in childhood. It usually affects the small joints of the fingers and hands. It also can affect weight-bearing joints, such as the knees, hips, ankles and feet. A child may also have arthritis in the neck or the jaw, making opening the mouth and chewing more difficult.

Polyarthritis often affects the same joints on both sides of the body, such as the right and left knees. Children with polyarthritis face a lower risk of eye inflammation than with oligoarthritis. Annual visits to an ophthalmologist may be sufficient unless more frequency is advised.

Children with polyarthritis are either RF-positive (have the rheumatoid factor antibody in the blood) or RF-negative (no antibody). RF-positive polyarthritis is most similar to rheumatoid arthritis. Children with this form are more likely to experience severe joint disease and related erosion than those who are RF-negative. Other symptoms of polyarthritis may include low-grade fever, rheumatoid nodules (bumps under the skin, most often at the elbow) and anemia (low red blood cell count).

## **Systemic Arthritis**

Systemic means the entire body. Systemic arthritis occurs in roughly 10% of JIA cases. Classic symptoms of systemic arthritis include high, spiking fevers (103°F or higher) that may occur daily for weeks or even months and pale red spots that appear on the chest, thighs and

sometimes other parts of the body. The rash and fever often happen together and may come and go for several days in a row. Joint inflammation usually begins at the same time as the fever and rash, but may start weeks or months later.

Other possible signs include inflammation of the heart or lungs or their outer linings; anemia; or enlarged lymph nodes, liver or spleen. In many children, the systemic symptoms of the disease, like fever, go away completely. Eye inflammation isn't common with systemic arthritis, but it is important to have your child's vision checked regularly.

## **Enthesitis-related Arthritis**

Enthesitis-related arthritis involves inflammation of the joints and the entheses – the places where tendons attach to the bone. Between 10% and 20% of children with JIA have this subtype. The disease can be mild for some children, while for others it can be more severe. It most often affects the hips, knees, back and feet. Often referred to as spondyloarthritis, enthesitis-related arthritis usually begins after age 6. Frequently, children with enthesitis-related arthritis test positive for the HLA-B27 gene.

## **Juvenile Psoriatic Arthritis**

Juvenile psoriatic arthritis occurs with the skin condition psoriasis. However, the psoriasis may begin many years before or after the beginning of arthritis. Joint symptoms include pain and swelling in one or more joints, often the wrists, knees, ankles, fingers and toes. Symptoms of psoriasis include a scaling red rash commonly seen behind the ears; on the eyelids, elbows and knees; and at the scalp line



## Other Pediatric Rheumatic Diseases Related to JIA

**Juvenile lupus:** Lupus is an autoimmune disease that can affect joints, skin, kidneys, blood and other parts of the body.

**Juvenile scleroderma:** Scleroderma is the medical name for a group of conditions that can cause the skin to tighten and harden on the fingers, hands, forearms and face. It can affect other parts of the body, such as blood vessels, the digestive system, lungs, kidneys, muscles, nerves and joints.

**Juvenile myositis:** Juvenile polymyositis is an inflammatory disease that causes muscle weakness. Juvenile dermatomyositis combines muscle weakness and a skin rash on the eyelids and knuckles.

**Juvenile vasculitis:** There are several forms of vasculitis, or inflammation of blood vessels. Joint symptoms may occur with each type.

**Noninflammatory conditions in children:** Noninflammatory musculoskeletal conditions (e.g., fibromyalgia, amplified musculoskeletal pain syndrome) can cause chronic or recurrent muscle or joint pain in children.

or sometimes in the belly button. Fingernails or toenails may split, crumble or develop ridges. People with psoriasis typically have a family history of the disease. Roughly 10% of children with JIA have juvenile psoriatic arthritis.



Learn more about the types of juvenile arthritis and their treatments at [arthritis.org/juvenile-arthritis](https://arthritis.org/juvenile-arthritis).

## Undifferentiated Arthritis

Any arthritis of unknown cause with symptoms continuing for at least six weeks that doesn't meet criteria for any one type of JIA or that involves symptoms spanning two or more types falls into the category of "undifferentiated arthritis."

## Juvenile Idiopathic Arthritis Treatments

Early diagnosis and aggressive medical care give children with JIA the best opportunity for a good outcome. The goal of any treatment plan is to achieve remission by controlling inflammation, relieving pain, preventing joint damage and preserving function and mobility.

Your child's treatment plan will vary depending on the subtype of JIA they have and may include medication, exercise, eye care, dental care and proper nutrition. In some cases, surgery may become necessary at later stages to help with pain or joint function. Providing your child with optimal care will require a team of health care providers. These specialists may include a pediatric rheumatologist, dietician, ophthalmologist, dentist, orthopaedic surgeon and psychologist as well as nurses and physical and occupational therapists.

## Access to Care

Dealing with an arthritis diagnosis and figuring out treatment options are enough to deal with day to day. But navigating a complex health care system adds additional burden. The Arthritis Foundation has resources to help you. Visit [arthritis.org/rxforaccess](https://arthritis.org/rxforaccess) to learn how to get the

arthritis care you need and manage claim denials. Or contact the Arthritis Foundation Helpline for personalized support at 800-283-7800 or [helpline@arthritis.org](mailto:helpline@arthritis.org).

## Medication

The initial goal of drug therapy is to reduce inflammation and relieve pain. Long-range objectives are to prevent disease progression and destruction of joint, bone, cartilage, muscles, tendons, joint capsules and internal organs. More than one medication may be prescribed to treat your child's disease. The idea is to hit the disease hard and fast to prevent joint damage and stop the disease in its tracks as much as possible.

### Understanding Remission

Children do not usually outgrow arthritis. JIA is a chronic disease. But the goal of treatment is to achieve remission, or the absence of arthritis symptoms. Remission may occur while on medication (most likely) and without medication (less frequent and usually brief). With recent developments in medication and treatment approaches, children with arthritis can have fulfilling and productive lives.

To help your child achieve remission, closely follow the treatment plan that may include medication, exercise, physical therapy and nutrition recommendations, among other tools.

The following information provides a broad overview of the most common classes of medications the doctor may prescribe. If you have questions about these or other treatments for JIA, ask your child's doctor or pharmacist. The Arthritis Foundation does not endorse any brand name or generic medication.

Dosages (how much of a medicine and how often it is taken) are set by your child's doctor and are often based on your child's height and weight.



## **Nonsteroidal Anti-Inflammatory Drugs (NSAIDs)**

NSAIDs (such as ibuprofen and naproxen) are a mainstay of early therapy for children with JA to ease pain and inflammation; however, they do not prevent joint damage. Not all children respond to NSAIDs the same way, so your child's doctor may try different ones for your child. Laboratory tests help doctors monitor side effects.

## **Disease-Modifying Antirheumatic Drugs (DMARDs)**

DMARDs affect the way the immune system functions. They can prevent joint damage, such as cartilage and bone destruction, but can take a month or more to have an effect. They are often used in combination with other medications, like NSAIDs, corticosteroids or biologics. Children taking DMARDs need regular lab tests to monitor possible side effects.

Methotrexate is the most commonly prescribed nonbiologic DMARD in both children and adults with arthritis. It can be taken orally or by injection. It has been used for nearly 30 years to treat JIA. Other nonbiologic DMARDs used to treat JIA include sulfasalazine, leflunomide and hydroxychloroquine.

### **Arthritis Foundation Supports CARRA**

We partner with the Childhood Arthritis and Rheumatology Research Alliance (CARRA, [carragroup.org](http://carragroup.org)) to address the most pressing needs of those living with pediatric rheumatic diseases. We've been involved with CARRA since it started in 2002, focused on getting answers to the questions that matter most to young people and their families — and finding solutions.

Children taking certain medications may need to avoid live vaccines (such as the measles-mumps-rubella vaccine and the chickenpox vaccine). Talk to your doctor before your child receives vaccinations.

### **Biologics**

Biologics, or biologic response modifiers, are a subset of DMARDs. They are used to treat a number of autoimmune diseases, including JIA. These medications help to correct a faulty response by the immune system that causes arthritis inflammation. Biologics are given by injection at home or infusion at a doctor's office or clinic.

Biologics suppress the immune system. This can make your child more likely to develop infections, so you should look for signs such as fever, sore throat, chills or cough and notify your doctor if they occur. Before your child receives a biologic, the doctor should order a TB test because biologics may activate old tuberculosis infections.

### **Corticosteroids**

Corticosteroids (such as prednisone) are strong anti-inflammatory medicines that work quickly compared to DMARDs. The doctor may prescribe small doses of corticosteroids to help quickly control inflammation while waiting for DMARDs to do their work. Corticosteroids can be given orally or by injection. Injections into the joint are preferred when only a few joints are involved or when a single joint is particularly bothersome. Because of the potential side effects, corticosteroids are used at the lowest dose for the

shortest length of time as possible. Your child's doctor will help you determine if the benefits of treatment outweigh the risks.

## Surgery

Surgery is rarely used to treat JIA early in the course of the disease. However, it can be used to correct leg length discrepancy, straighten a bent or deformed joint or replace a badly damaged joint.

## Eye Care

Eye inflammation (uveitis) can occur in children with JIA, particularly in those with oligoarthritis. It is very important for children with JIA to have their eyes checked by an ophthalmologist at diagnosis and regularly as recommended by their

### FDA Approval: What Does It Mean?

Many medications have been approved to treat JIA by the U.S. Food and Drug Administration (FDA). Still, a doctor may prescribe a medication to treat JIA that was not approved for this purpose by the FDA. This is called an "off-label" use. Unapproved does not mean disapproved. There are many effective arthritis medications that have not been submitted to the FDA for testing in children. Based on their FDA approval for adults and demonstrated benefits, they are used to treat childhood arthritis. Prednisone, a corticosteroid, is an example of a medicine used off-label for JIA.

The Best Pharmaceuticals for Children Act and the Pediatric Research Equity Act were designed to encourage more pediatric studies of drugs used in children.

doctor to reduce the chance of vision loss. Uveitis does not necessarily cause symptoms such as pain or red eye. The only way to confirm uveitis is by eye examination. Uveitis can occur even if arthritis flares are under control.

## Dental Care

JIA may affect the temporomandibular (jaw) joint, causing pain, stiffness and altered growth. This can make brushing and flossing difficult. Your child's dentist may suggest assistive devices or rinses to help your child keep their teeth and gums healthy. More frequent, shorter dental visits can help children who are unable to keep their mouths open for long periods during dental work. Jaw exercises and therapy can help pain and stiffness. Injections with corticosteroids or surgery are sometimes needed.

Medications may affect your child's oral health as well. Always inform your dentist about your child's JIA and medications. Older children who have had joint replacements may require an antibiotic before dental work.

### Managing Medication Side Effects

All medications have potential side effects, whether minor or more serious. Some children may never experience any side effects. Talk with your child's pediatric rheumatologist about the benefits and risks of each medication and how to alleviate side effects. Some may be avoided or minimized, for example, by taking medications with food. To learn more about the possible side effects and precautions for specific drugs, check out the Arthritis Foundation's Drug Guide at [arthritis.org/DrugGuide](http://arthritis.org/DrugGuide).



## Splints and Orthotics

Splints help keep joints in the correct position and relieve pain. They can be used to correct a deformity (bending in the wrong position). Splints are commonly used for knees, wrists or fingers. Orthotics, or shoe inserts, may help with differences in leg length and balance problems.

An occupational or physical therapist can make a custom splint for your child. Bring your child's splint to all clinic appointments so its fit can be checked.

## Lifestyle Modifications to Help Manage JA

Getting plenty of physical activity, eating well and learning how to cope with the challenges of the disease will benefit your child.

### Morning Stiffness Relief

Morning stiffness is one of the easiest ways to measure how active your child's arthritis is: The longer the stiffness lasts, the more active the disease. Taking a hot bath or shower, sleeping in a sleeping bag or sweat suit, doing range-of-motion exercises and using a hot or cold pack can help relieve stiffness. Although most children do better with warmth, there are a few who do well with cold treatments.

### Physical Activity

Exercise is an essential part of your child's treatment plan. It helps keep bones and muscles strong and preserves range of motion. Physical activity will also help your child achieve and maintain a healthy weight, relieving added pressure on weight-bearing joints like knees, hips and ankles.

## **Therapeutic Exercise**

Physical and occupational therapy can help to restore and maintain joint movement. Therapeutic exercise is the best way to preserve range of motion and strength and can help make it easier for children to perform activities of daily living. Range-of-motion exercises help with joint stiffness to prevent joints from becoming fixed in a bent position. Joints with poor movement are at increased risk of osteoarthritis, even if inflammation is controlled. Strengthening exercises build muscles that can help support weak joints.

A physical or occupational therapist will teach you and your child how to perform therapeutic exercises at home. Most exercises must be done daily. Hot baths, hot packs or cold treatments help to prepare joints for exercise. Family support can be very important when you need to keep your child motivated to be physically active.

## **Sports and Recreational Activities**

Recreational activities help your child have fun and spend time with family and friends while exercising. They help build confidence in physical abilities. However, these activities should not take the place of therapeutic exercise.

Encourage activities such as swimming and bike riding, which exercise the joints and muscles without putting too much weight-bearing stress on the joints. Activities such as jumping on a trampoline or jogging are not often recommended. However, sports like basketball or soccer may not be off limits for your child if his or her arthritis is well controlled.

Special exercises and protective equipment further reduce risk of injury. Be sure to work with your child's doctor and sports coaches to find the ideal activity for your child.

## Nutrition

A healthy diet is important for all children. While some people have reported improved symptom relief from eating or eliminating certain foods, there is no specific diet that can cure arthritis. Following a diet low in processed foods and saturated fat and rich in vegetables, fish, fruit, nuts and beans can be beneficial for your child's overall health and may ease inflammation.

Weight loss can be associated with JIA. Weight loss may occur due to a loss of appetite or because chewing may be painful if the jaw joints are affected. Eating small, frequent, nutritious

### Coping With a Flare

A flare is when arthritis is more active than usual. Your child may feel especially fatigued and have painful, swollen, pink and stiff joints. Call your child's doctor if you suspect your child is having a flare. Here are ways you can help your child:

- Make sure your child takes medicine on time to avoid flares caused by lack of medicine.
- Apply ice to sore joints for 20 minutes at a time with 10-minute breaks.
- After the first 24 hours, heat may be soothing for sore joints.
- Modify your child's activities but maintain joint flexibility and range of motion.
- Make sure your child rests when he or she is in pain.
- Ask your child's doctor about using splints at night.
- Keep your child connected with friends to help take the focus off the pain.

meals and snacks may help your child get the proper number of calories. Try to increase the nutrient content of each bite in order to reduce the amount of food at each meal.

Some children with JIA may gain excess weight due to side effects of corticosteroids or limited physical activity. Being overweight puts extra stress on joints like the knees and hips. A registered dietician can teach you ways to improve your child's diet.

### Treating the Emotional Side Effects of JA

Having JIA has a big impact on a child's life, both physically and emotionally. Helping your child learn to cope with the emotional aspects of arthritis will benefit the entire family.

Your attitude toward arthritis will set the tone for your child. Encourage them to learn as much as possible about the disease and its treatment so they can feel part of the decision making and in control of the disease. Talk to your child about how they feel about arthritis. Let your child express anger or sadness.

Expect your child with arthritis to behave as well as your other children and share in household responsibilities. Avoid making JA the center of attention.

Coping with the challenges of a chronic illness can be difficult. Professional counseling may help to facilitate the adjustment. Your child's doctor or a medical social worker can refer you to other sources of help.

## School and Social Issues

Most children with JA can expect the typical school experience and social life of any other child. While you might be tempted to keep your child with arthritis at home under your watchful care when they are in pain, it's important that they attend school and other activities as consistently as possible. If your child experiences stiffness after waking up, work some extra time into the morning routine to loosen up for the



day. Meet your child's teachers, school administrators and activity leaders to educate them about arthritis and its effects on your child. If your child agrees, offer to speak to their class or even to the parent/teacher association to spread the word about JIA.

It's important to know your child has educational rights. Several federal laws bar discrimination against children with disabilities in public schools and require private schools to be accessible.

**Section 504 of the Rehabilitation Act of 1973** requires schools to provide physical accommodations for students with disabilities. Setting up a 504 plan with your school allows the institution to make necessary accommodations, such as obtaining an extra set of books to keep at home, grouping classes in the same location, allowing extra time to switch classes or allowing for absences and late arrivals.

The Arthritis Foundation offers a free brochure for teachers called *Juvenile Arthritis: A Teacher's Guide*. The brochure educates your child's teacher about JA, its challenges and educational rights as well as how he or she can help your child in the classroom. To order a free copy, visit [www.afstore.org](http://www.afstore.org) or call 800-283-7800.

## Meeting Other Kids With JA

One of the best ways for your child to combat feelings of isolation that having arthritis may bring is to meet other children with arthritis. Often, shared experiences or perspectives can make for fast friendships and shared information about growing up with JA.



For more information about educational rights and setting up a 504 plan for your child, visit [arthritis.org/juvenile-arthritis](http://arthritis.org/juvenile-arthritis), and go to "Set Your Child Up for Success."

Get connected through the Arthritis Foundation. Events for juvenile arthritis families, such as Live Yes! JA Connect Groups, JA days, summer camps or teen activities, are held virtually and/or in person locally when it's safe to do so. The Arthritis Foundation hosts annual national conferences for families. Arthritis Champion Scholarships are offered to selected college students..

## Transitioning to Adulthood

Young people with rheumatic diseases have to take on new responsibilities as they enter the world of adult medical care. The Arthritis Foundation Transition Toolkit is designed to help youth and their families develop the skills they need to successfully make the leap to independence. Find it at [www.jatransition.org](http://www.jatransition.org).



Connect with other JA parents through Arthritis Foundation Live Yes! Connect Groups. Find one by visiting [connectgroups.arthritis.org](http://connectgroups.arthritis.org).







# Live Yes! <sup>SM</sup>

## Arthritis Network

We realize you didn't sign up for arthritis. Our family is probably one you never planned to join. But our special community is where you'll find strength, support and solutions to live life to the fullest. Here are a few ways to start your journey:

**WANT TO CONNECT** with people going through a similar experience. **Go to** [connectgroups.arthritis.org](https://connectgroups.arthritis.org)

**NEED HELP NOW?** Call our toll-free Helpline at 800-283-7800 or email [helpline@arthritis.org](mailto:helpline@arthritis.org)



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