

**You,
Your Child
& Arthritis**

6th edition (2020)

Revised by Shirley ML Tse, MD, FRCPC , Associate Professor, University of Toronto, Program Director, Division of Rheumatology, SickKids. Review support by Pamela Jarvis, RSSW, Arthritis Society Canada and Michelle Bridge, OT Reg. (Ont.), ACPAC, Arthritis Society Canada.

Edition history:

5th edition (2009) and 4th edition (2005) revised by Shirley ML Tse, MD, FRCPC, Assistant Professor of Pediatrics, University of Toronto, Pediatric Rheumatologist, The Hospital for Sick Children

5th edition editing support from Michelle Batthish, MD, FRCPC, Michelle Anderson, B.Sc N, Kristi Whitney-Mahoney, M.Sc., B.Sc P.T., Christine O'Brien, M.Sc., O.T. ACPAC, Neely Lerman MSW, RSW, Nasrin Tehrani, MD, MB BCh, M.Sc., FRCS Ed and final editing by Jennifer D. Foster

3rd edition revised by Dr. Ronald Laxer

Original and 2nd edition produced by the late Dr. Abraham Shore and Dr. James E. Boone.

Table of Contents

| | |
|---|----|
| Introduction | 3 |
| Overview | 3 |
| What is Arthritis? | 4 |
| What Causes Juvenile Arthritis? | 5 |
| How is Juvenile Arthritis Diagnosed? | 5 |
| What are the Unique Features of Juvenile Arthritis? | 6 |
| • Growth | 6 |
| • Eye Problems and Care | 6 |
| • Dental Care | 6 |
| • Unpredictability | 7 |
| What are the Patterns and Types of Juvenile Arthritis? | 7 |
| • Oligoarticular-persistent JA | 8 |
| • Oligoarticular-extended JA | 8 |
| • Polyarticular-RF negative JA | 9 |
| • Polyarticular-RF positive JA | 9 |
| • Systemic JA | 9 |
| • Enthesitis-related arthritis | 10 |
| • Psoriatic arthritis | 10 |
| What Will Happen to Your Child? | 10 |
| Treating Juvenile Arthritis | 11 |
| • Aims of Therapy | 11 |
| Medication | 11 |
| • Non-steroidal anti-inflammatory Drugs (NSAIDs) | 12 |
| • Steroids (Cortisone-Type Drugs) | 12 |
| • Conventional disease-modifying anti-rheumatic drugs (DMARDs) | 12 |
| • Biologic DMARDs | 12 |
| Physiotherapy and Occupational Therapy | 13 |
| Exercise and Physical Activity | 13 |
| Comfort Measures | 14 |
| • When should you use heat? | 14 |
| • When should you use cold? | 14 |
| • Splinting, casting, and orthotics | 14 |
| • Massage | 15 |
| • Rest | 15 |
| • Relief of morning stiffness | 15 |
| • Improvement takes time | 15 |
| Surgery | 15 |
| Research | 16 |
| Your Family and Juvenile Arthritis | 16 |
| Independence and Coping with Life | 17 |
| Your Child and School | 17 |
| Adolescence | 18 |
| Note to Parents/Caregivers and a Word of Encouragement | 19 |
| Glossary | 20 |
| Notes | 22 |

Introduction

You, Your Child & Arthritis is a valuable resource for families of children with juvenile arthritis (JA). This guide provides the information parents/caregivers need to understand their child's disease and to feel comfortable caring for them. It also covers the different types of juvenile arthritis, current treatments including medications, and other important elements of treatment, such as physiotherapy and occupational therapy. In addition, there are important sections for parents/caregivers learning to cope with a child who has a chronic disease. Pediatric rheumatology teams across Canada recommend and endorse this resource for all families of children with arthritis.



Overview

Many people mistakenly think arthritis is just a disease of the elderly, but the statistics tell a different story. About three in 1,000 Canadian children have juvenile arthritis, which makes it more common than most chronic childhood diseases. You may have heard of the medical term "juvenile idiopathic arthritis" and wondered what it means. "Idiopathic" simply means "unknown". This word is used when other illnesses or triggers known to cause arthritis have been ruled out as the cause of a child's arthritis. Throughout this guide, juvenile arthritis (JA) will be used for the sake of simplicity. The term *Juvenile Arthritis* is an umbrella term that refers to seven different types of JA, which are discussed in the section on Patterns and Types of Juvenile Arthritis.



While there is no cure for JA, treatment options exist and can be effective. Once your child has been diagnosed, you will decide on the overall treatment plan with your child's doctor and arthritis healthcare team. This plan will include medication and rehabilitation therapy. The therapy program is one of the cornerstones of treatment: exercise helps prevent the loss of joint movement and encourages normal growth. Although JA may cause joint damage, the bones and cartilage of growing children have amazing abilities to heal.

The medications prescribed by your child's doctor act to reduce or stop joint swelling, pain and stiffness. They can also prevent joint damage and make your child's therapy program easier to do. The type and strength of medication will depend on your child's diagnosis.

Children who are well monitored and follow the recommended treatment provided by a healthcare team have the best outcomes overall. The majority of children with JA are able to participate in normal activities and have a bright future.

What is Arthritis?

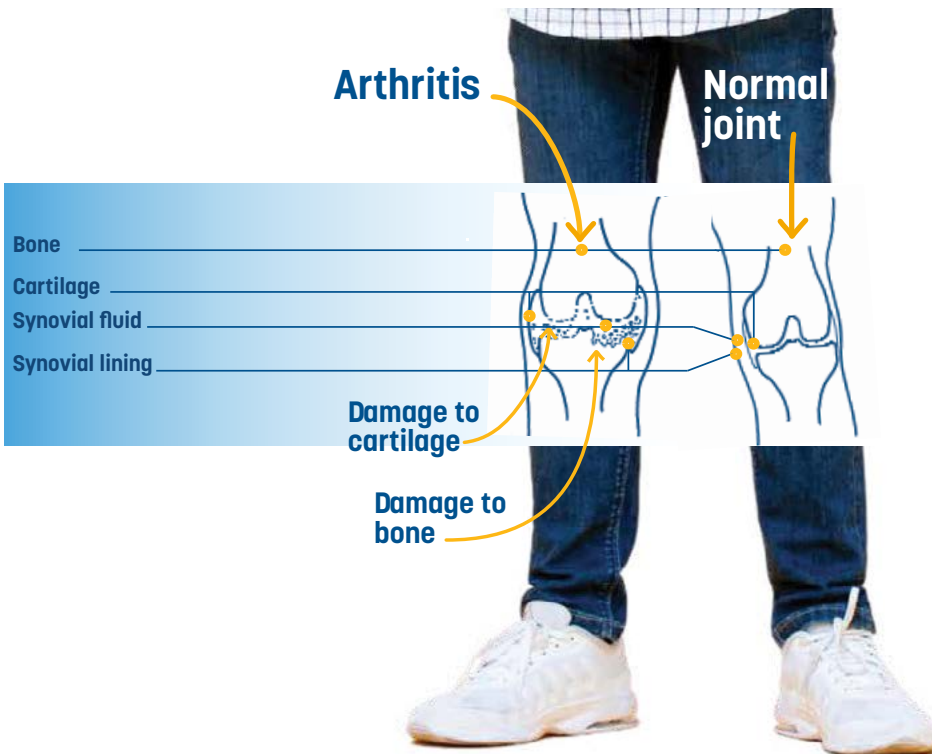
The word arthritis (arthro = joint, itis = inflammation) is a term referring to inflammation of the joint. Inflammation is a medical term that describes swelling, heat and redness which causes pain and, when in the joints, can also cause stiffness. In the case of inflammatory arthritis, like JA, an individual's own immune system attacks tissue in the lining of the joint, causing it to feel warm, stiff, swollen and, often, painful.



In the joint space between two bones, there is a lining called synovium, which produces a fluid that lubricates and nourishes the joints. The ends of the bones at the joint are covered with a substance called cartilage, which allows bone ends to glide smoothly across each other. In JA, and other forms of inflammatory arthritis, an imbalance in the immune system causes the synovium to become inflamed and thickened, leading to the production of extra fluid. This fluid contains inflammatory cells which secrete proteins and chemicals of inflammation. This causes increased warmth, stiffness, swelling and pain in the affected joint. If left untreated, the inflammation can damage the cartilage and the underlying bone.

Arthritis can involve almost any part of the body, most often affecting large joints such as knees, ankles, wrists and elbows. It can also be found in small joints such as the fingers and toes. Weight-bearing joints are sometimes affected more commonly than non-weight-bearing joints. Some forms of arthritis can also affect other parts of the body.

Juvenile arthritis is medically defined as continuous (also known as chronic) inflammation of one or more joints lasting at least six weeks, for which no other cause can be found in a child aged 16 or younger.



Did you know?

There are over 100 types of arthritis, with different causes and symptoms.

You can learn more at arthritis.ca

What Causes Juvenile Arthritis?

No one knows exactly what causes JA. It is not caused by any disease or infection that either parent may have had. It is not connected to any event during pregnancy. JA is not caused by eating the wrong foods, and there is no proof that JA can be improved solely by any specific diets. Many people feel their arthritis is better in warm, dry climates, but there is no proof that JA is improved by any particular climate.

JA may begin after an event that switches on the body's immune system, such as an ordinary infection or injury. The body's immune system normally fights these infections or injuries by causing inflammation, which signals to the body to heal damaged tissue. However, the immune system should return to a non-inflammation resting state when the event has resolved. With JA, the immune system seems to become overactive and causes continuous inflammation. This continuous inflammation affects the joints and sometimes skin and internal organs.

Most types of JA are not passed from generation to generation so the chance of your child passing arthritis on to their own child is extremely rare.

How is Juvenile Arthritis Diagnosed?

Children with arthritis do not always complain of pain, so it may be difficult to tell if a child's joints are inflamed (red, swollen and warm to the touch). Sometimes the only initial clues to arthritis may be that the child is stiff when waking up or there is some difficulty using an arm or leg. In some cases, there may be no signs other than a swollen joint or some loss of movement. As a result, JA can be difficult to detect and may go unrecognized by even the most experienced doctor or healthcare provider. Your child's doctor will look carefully for any signs of joint swelling or loss of mobility, which indicate that the joints are inflamed.

Arthritis or its symptoms may be a result of many different illnesses, including infection, injury, allergic/drug reactions or other autoimmune diseases (such as thyroid disease, diabetes, inflammatory bowel disease or lupus). Since there is no single test to diagnose JA, tests to rule out other causes of joint pain and swelling must be done. Your child will likely have X-rays as well as urine and blood tests.

Once a diagnosis of JA has been confirmed, routine tests (such as blood tests, X-rays and eye examinations) will need to be repeated from time to time in order to follow the illness and assess the effects of any medication. Your child's doctor will discuss with you how often these routine tests need to be done.

It is important to note that, depending on the type of arthritis, JA may be relatively mild or it can be progressive and disabling. The disease may be limited to the joints or affect the eyes and other organs. In some cases, with appropriate treatment JA can resolve by adulthood. With other cases, the disease and its effects are lifelong and require ongoing medical care.

The first several weeks following your child's diagnosis can be a difficult time for everyone in your family. Your child's condition may need to be reassessed in order for your child's doctor to be absolutely certain of the diagnosis. It may take several weeks - or sometimes even months - for the medicines and prescribed therapy program to have a noticeable effect. If your child has started on medications or other treatments, the doctor will monitor these regularly.



What are the Unique Features of Juvenile Arthritis?

Growth

Inflammation from JA affects the growth of a child, meaning the growth patterns of affected joints may change. Sometimes inflammation can lead to quicker growth. However, growth usually returns to normal once the arthritis is under control. Sometimes if the inflammation is not well controlled, growth may slow down and ultimately not reach the full growth potential of the affected limb or digit. This makes controlling the arthritis to the point of no or minimal inflammation very important.



If the arthritis is severe and requires medications, such as steroids, overall body growth may slow down. Growth usually returns to normal once the arthritis is controlled and the use of steroids is reduced or stopped. The healthcare team will pay careful attention to all aspects of your child's growth.

Eye problems and care

Many types of JA can involve inflammation inside the eye (called "uveitis"). This inflammation does not make the eye red, may not be painful and may not affect your child's vision, so he or she may not even be aware of it. That is why it is important for your child's eyes to be checked regularly by eye specialists. How often your child needs eye exams will depend on your child's risk of developing eye problems and will be determined by your child's healthcare team. If your child develops eye inflammation, then your child should be under the care of an eye specialist to receive appropriate treatment. Treatment may include eye drops, injections of steroids behind the eyes and other medications. Undetected or poorly treated eye disease can lead to vision loss or even blindness.

Eye disease can happen with any type of JA, and eye disease may begin before arthritis is even diagnosed. Eye disease is most common in children with inflammation in one or in only a few of their joints and having a positive marker in the blood known as antinuclear antibody (ANA). This antibody can be found in up to 25% of healthy children but can cause a higher risk of eye inflammation in children with arthritis. Testing for the ANA at diagnosis is important to decide how often your child will need to have a check up with an eye care expert.

Dental care

Arthritis of the jaw is seen in many children with all forms of JA. Your child may have no symptoms, or symptoms are felt as recurrent ear problems rather than arthritis of the jaw. If arthritis severely affects the jaw, the chin may not grow normally and rarely, surgery may be required. Parents/caregivers of children with JA should be aware of jaw problems, and they can occur at any time during their disease. If your child has trouble eating or complains about pain while eating, these symptoms should be reported to your doctor.

Treatment can include the usual rheumatology medications (see Medication section) as well as local treatments such as mouth splints if recommended by an orthodontist. Because the metal in orthodontics braces interferes with MRI scans needed to monitor the jaw, please ask your orthodontist about ceramic braces. Different specialists are included in the care of children with arthritis of the jaw. Your child's dentist should give your child's teeth special attention and your child should practice good dental care.

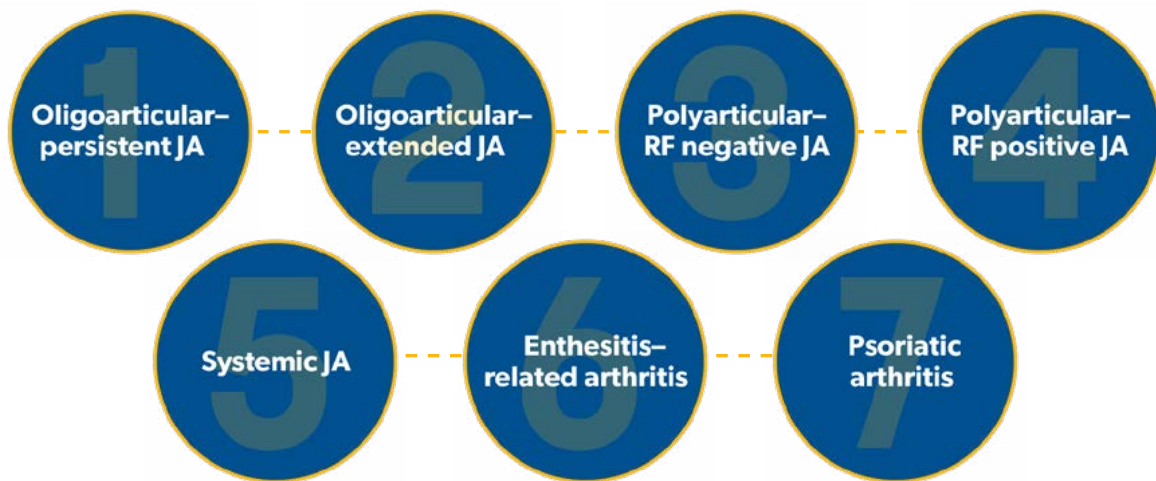
Unpredictability

Rarely JA can be active for as little as several months up to a year, then it goes into remission and seems to “disappear” forever. Many children, however, have an up-and-down course for many years, depending on what type of arthritis they have. Flares are those times when the arthritis seems to be getting worse. Remissions are times when the arthritis seems to have disappeared. Sometimes a mild infection, such as the stomach flu, may cause a flare but the reason for a flare is usually unknown. Parents/caregivers may be upset to see a flare when it seemed the disease had disappeared or greatly improved. Yet parents should remain hopeful and optimistic because most flares will resolve with appropriate care and treatment.

What are the Patterns and Types of Juvenile Arthritis?

The symptoms and nature of JA vary greatly. Once a doctor suspects JA, your child will usually be referred to a specialist, such as a pediatric rheumatologist (a doctor who is specially trained in the diagnosis, evaluation and treatment of joint, muscle and bone inflammation in children).

There are seven major types of JA:



Determining the form of JA your child has is mostly based on the information collected during the initial physical examination and tests. What happens with your child’s disease over the next six to twelve months is also important. It may take time for your child’s doctor to be absolutely certain which of these types of JA your child has. If the course of your child’s disease changes, a different, more appropriate form may be assigned. Your child’s healthcare provider can still begin treatment without knowing exactly what form of JA your child has. But confirmation of the form of JA will give you, your child and their healthcare providers the best information for creating a personalized treatment plan.

| Type of JA | How common is it? | Who's likely to get it? | When does it happen? |
|--------------------------------|-------------------|-------------------------|---|
| Oligoarticular - Persistent JA | Most common | Girls more than boys | Early childhood (usually under 4 years) |
| Oligoarticular - Extended JA | Common | Girls more than boys | After 6 months from diagnosis of oligo JA |
| Polyarticular RF negative JA | Common | Girls more than boys | 2 peaks: 2-4 years and 6-12 years |
| Polyarticular RF positive JA | Less common | Girls more than boys | Late childhood/early adolescence |
| Systemic JA | Less common | Girls = boys | Throughout childhood |
| Enthesitis-related arthritis | Less common | Boys more than girls | Boys over the age of 10 |
| Psoriatic arthritis | Less common | Girls more than boys | 2 peaks: 2-4 years and 9-11 years |

Oligoarticular-Persistent Juvenile Arthritis

This is the most common and mildest form of JA. Children are classified as having oligoarticular-persistent JA if no more than four joints are involved beyond six months after the diagnosis of JA. Although multiple joints are affected, not all joints may be inflamed at the same time. The most commonly affected joints are the knee, ankle, wrist and elbow, with little to no change in the overall health or growth of the child. Symptoms usually start in children four years old or younger, and girls are affected more often than boys.

Although oligoarticular-persistent JA may involve flares (when symptoms worsen) and remissions (when symptoms decrease or disappear), with the right treatment there is rarely permanent damage to the joints. Although the joint inflammation in this type of arthritis may be mild, up to 20% of children with this type of JA will develop uveitis (inflammation of the eye), so it is crucial that your child's eyes are examined at least three or four times a year for the first few years after diagnosis. The blood test for antinuclear antibody (ANA) is almost always positive with children who develop eye inflammation with JA. That's why the ANA blood test helps identify those children who will need more frequent eye checks.

“Articular” means relating to a joint.

“Oligoarticular” refers to a few (2-4) joints.

“Polyarticular” refers to many (5 or more) joints.

Oligoarticular-Extended Juvenile Arthritis

Children are classified as having oligoarticular-extended JA if four or fewer joints are involved within the first six months after the initial diagnosis, but the child develops arthritis in five or more different joints at any time during the course of the disease. Large and small joints may be affected, and flares and remissions may occur. With the appropriate treatment, permanent damage to the joints can usually be prevented. Eye disease often occurs so it is important for children to have their eyes examined at least three or four times a year for the first few years after diagnosis. The blood test for antinuclear antibody (ANA) helps to identify those children who will need more frequent eye checks.

Polyarticular–Rheumatoid Factor Negative Juvenile Arthritis

Children with polyarticular-RF negative JA have five or more joints involved within the first six months of diagnosis, but they do not test positive for rheumatoid factor (RF). The rheumatoid factor is an antibody or protein produced by the immune system that can attack healthy tissue in your body such as the joints. Consequently, children with many affected joints that test negative for RF may have a less aggressive arthritis compared to those who test positive for RF. This type of JA can begin at any age and is more common in girls than in boys. It usually starts in several joints at the same time but may begin in only one or two joints and then later involve other joints. The joints of the jaw may be affected and this can lead to a reduced ability of the child to open their mouth or chew, and may cause abnormal growth of the jaw. The joints of the neck may also be affected. Your child’s doctor will check these joints by doing a physical examination and may do X-rays or other tests such as an MRI (magnetic resonance imaging) scan.

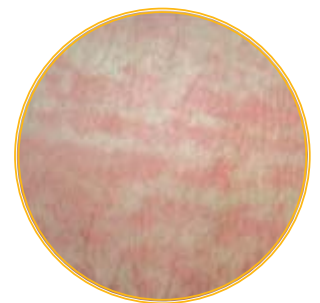
Polyarticular–Rheumatoid Factor Positive Juvenile Arthritis

Children with polyarticular-RF positive JA have five or more joints involved within the first six months of diagnosis and test positive for a blood protein called rheumatoid factor (RF). The rheumatoid factor is an antibody or protein produced by the immune system that can attack healthy tissue in your body such as the joints. Consequently, children with many affected joints that test positive for RF may have a more aggressive arthritis compared to those who test negative for RF. These children will likely need stronger and longer courses of medications to control the arthritis. This form of JA can begin at any age, but it occurs more often in girls during their pre-teen or teenage years. Usually, the arthritis starts in several joints at the same time. The onset of this form of JA in teenagers may closely resemble adult rheumatoid arthritis (RA). Occasionally it will begin in only one or two joints, then spreads to involve other joints.

It can affect both the small (especially hands and fingers) and large (knees, hips, ankles) joints, usually on both sides of the body. Some children may also experience a low-grade fever, rheumatoid nodules (bumps under the skin, especially in the hands or along tendons), anemia (a low red blood cell count or a fall in the hemoglobin level), significant fatigue, poor appetite and an overall feeling of being unwell. Severe joint damage is a concern, so stronger medications are recommended at an early stage.

Systemic Juvenile Arthritis (Systemic JA)

This form of JA affects the body in a general way (for example, frequent fevers) and can affect not only the child’s joints and skin, but also the internal organs. Systemic JA can begin at any age and affects boys and girls equally. It often involves many joints, and some joints may be affected to a severe degree. Children have a spiking (rapidly rising and falling) fever that usually occurs once or twice a day until medications for this type of arthritis manages it. A pale red rash frequently comes and goes with the fever.



The arthritis usually appears within the first six months after the start of the fever and can persist even when the fever settles. Children may have swollen lymph glands and an enlarged liver and spleen. They appear listless and unwell during the fever, only to brighten up when their temperature returns to normal. When fever continues on and off for several weeks, the child may become weak, lose weight or become pale from anemia (a fall in the level of hemoglobin in the blood). Flares that last a long time may also interfere with the child’s growth, but growth usually improves as the child’s condition improves. Inflammation of the internal organs may cause stomach pain or affect the heart or lungs but will not cause permanent damage. Sometimes there is no sign of joint inflammation in the early stages of this

form of JA. This can make it very difficult to diagnose, as there are many other illnesses that cause a fever and a rash in children. Because of this, many tests may need to be done.

The course of systemic JA can be unpredictable. With newer medications, even severe cases may go into remission within a few years; however, flares may occur even after the disease has been inactive for a long time.

Medications for systemic JA include drugs that control not only the arthritis, but also the systemic part of the illness, such as the fever and the anemia. Inflammation of the eye is uncommon in this form of JA, but children should still have their eyes examined annually.

Enthesitis-Related Arthritis

Children with enthesitis-related arthritis have inflammation both in their joints (arthritis) and in the spots where tendons attach or insert to bones (entheses). This form of JA generally affects children over the age of 10 and is more common in boys. This is one of the few types of arthritis that may run in families. The legs and hips are usually affected, especially around the knees, ankles and bottoms of the feet. Children may complain of knee, heel or foot pain, which may improve with activity. Joint inflammation often continues into adulthood, sometimes progressing into joints in the back and often leading to pain and stiffness. It may also occur with inflammation of the eyes or the bowel (intestines). Many children with this form of JA carry a specific gene marker (called HLA-B27) and lab testing for this gene may help in diagnosis.

Psoriatic Arthritis

This type of JA is characterized by the occurrence of arthritis with psoriasis, a skin disease that appears as a scaly red rash. Psoriatic arthritis affects both boys and girls, and it can happen at any age. Often only a few joints are affected, but the hips, back, fingers or toes can be affected. The fingers or toes of some children may look sausage-like because of extreme swelling. The arthritis starts before any sign of skin disease in about half of children with psoriatic arthritis. For this reason, knowledge of a family history of psoriasis may help with the diagnosis.

What Will Happen to your Child?

Although the long-term outlook for most children with arthritis is usually good, it's impossible to predict exactly what will happen to your child. It is true that the longer the disease remains active, the greater the risk of joint damage, which means controlling the inflammation early is very important. Once the disease has established a pattern, your healthcare team will be better able to give you a general idea of your child's future. To achieve the best possible outcome, you and your child will need to work very closely with the arthritis treatment team, which may include some or all of the following: a doctor, nurse, physiotherapist, occupational therapist, social worker, psychologist, dietitian, orthopedic surgeon, ophthalmologist (or optometrist, if your child does not have active uveitis or related eye problems needing treatment), dentist and your child's teacher(s). The team members who will be involved in the care of your child will be determined by the nature of the arthritis and your child's unique needs. The most important members of the team are you and your child. Together, a personalized plan to manage your child's arthritis will be put in place. With the help and guidance of the team, your child can manage even severe arthritis.



Treating Juvenile Arthritis

Treatment includes medications and therapy programs. Persistence with the suggested treatment and a positive attitude from you and your child are the keys to success. This will make your child feel better and help to prevent joint damage. Sometimes joints may be damaged from inflammation, but an exercise program and the use of splints can help to prevent deformities. It may take time to notice the benefits of therapy.



It's vital that your child's social development be as normal as possible. Children who cannot participate in all the activities their friends enjoy may become depressed and feel isolated. Children with arthritis should be encouraged to attend school and participate in appropriate activities with friends to promote independence and build self-esteem. Speak to your child's teacher about ways to adapt activities so that your child can participate fully.

Aims of Therapy

Each child with arthritis is an individual with their own unique needs and reactions. That is why the treatment program must be designed for your child with you and the entire arthritis team. Overall, the treatment plan aims to help your child:

- Reduce and stop the pain and discomfort from their arthritis
- Achieve normal physical, social and intellectual development
- Achieve and maintain an acceptable and functional range of joint movement
- Achieve emotional acceptance of any physical limitations
- Attend school regularly
- Relate to other children
- Assume responsibility for their own health
- Establish and be proactive and purposeful in healthy coping strategies
- Be a happy and productive member of society

Medication

There is no cure for juvenile arthritis. However, currently we have many medications available to treat JA. The healthcare team's goal is to achieve remission, in other words to have no swollen, stiff or painful joints. The good news is that remission is frequently achieved while taking medications. To be fully effective, medication must always be taken regularly and exactly as prescribed. A personalized medication program will be designed together with you and your child's doctor, according to your child's weight and disease activity. To explore this area of treatment, Arthritis Society Canada has developed a [**comprehensive expert guide**](#) that delivers detailed information on medications used to treat JA.



Non-steroidal anti-inflammatory drugs (NSAIDs)

NSAIDs help to reduce the levels of proteins that cause joint inflammation (known as prostaglandins), similar to a sponge mopping up water. By reducing pain, swelling and stiffness, NSAIDs allow a child with arthritis to participate in everyday activities. They are not addictive and their effect on inflammation does not wear out over time. They are also not a steroid and do not affect growth or bone development. Some of the more commonly prescribed NSAIDs include naproxen and ibuprofen. The choice of medication is based on the disease type, how easy it is to take and the doctor's recommendations. NSAIDs are available in a liquid or pill form and are usually given one to four times per day, depending on the prescription.

Steroids (Cortisone-Type Drugs)

Cortisone is a steroid hormone produced naturally by the body. It is necessary for normal body metabolism but also can fight inflammation. Unfortunately, your child's own body cannot make enough cortisone to control the arthritis on its own. Corticosteroids (or steroids) are very powerful anti-inflammatory drugs and improvement can be seen as quickly as 48 hours after the first dose. These steroids are very different from the anabolic steroids sometimes taken by athletes. This arthritis medication can be given by mouth (oral) or injected into a vein or into the joint itself. Oral or injected steroids are used for severe arthritis that has not responded to other drugs. Injections of steroids directly into a joint (intra-articular) can be very helpful if only a few joints are involved or for persistent arthritis in joints that does not respond to initial drug treatments. This procedure is done with strict attention to your child's age and tolerance level.

Conventional disease-modifying anti-rheumatic drugs (DMARDs)

For children who have ongoing arthritis in several joints, or arthritis that isn't controlled with NSAIDs or joint injections, a second line of drugs is often prescribed. These medications, called disease-modifying anti-rheumatic drugs or DMARDs, are slow-acting drugs that can take up to six months to work. They can lead to better control of the arthritis compared to just using NSAIDs because they stop or reduce the number of cells in the immune system that are causing the inflammation.

DMARDs are often used in combination with NSAIDs and joint injections. It may be necessary to try different DMARDs to find which one works best for your child. Several DMARDs may be combined together to manage severe cases of arthritis. DMARDs can be given orally or as an injection under the skin. Treatment with these drugs must be continued for months or years, even after the disease is controlled, in order to avoid a recurrence.

Biologic DMARDs

Biologics are a type of disease-modifying anti-rheumatic drug that "target" only arthritis proteins and the cells that produce them while leaving healthy immune cells alone. Some examples of arthritis proteins (or cytokines) that cause inflammation include tumor necrosis factor (TNF), interleukin-1 (IL-1) and interleukin-6 (IL-6). These cytokines are known to promote inflammation and are found in high levels in the blood and joints of children with arthritis. Biologics can dramatically reduce inflammation and, in some cases, prevent joint damage. They are used when other treatments have not controlled the disease adequately.

Biologics work quickly, and improvement may be noticed within one to two weeks of starting the biologic, but it may take three to six months to feel the full effect. Your child's doctor will recommend which biologic is best suited for your child based on the type of arthritis, other medical problems and medications being taken.

Learn more about [biologics](#).

Physiotherapy and Occupational Therapy

Physiotherapists (PTs) and Occupational Therapists (OTs) can be important members of your child's healthcare team. Therapists help children restore their physical abilities and function, as well as participate in school and extracurricular activities. Your child's therapist can:

- Provide education about disease process and management
- Reinforce pain and stiffness self-management techniques
- Prescribe exercises to improve joint range of motion, muscle stretch and strength, endurance, and balance
- Discuss ways to protect joints (i.e., ergonomics, posture, pacing)
- Provide advice about healthy lifestyles, sleep, and fatigue management
- Recommend accommodations to facilitate independence at school/home/work/activity
- Instruct in the use of splints, orthotics, supportive footwear, and mobility aids
- Refer to appropriate community resources
- Teach skills for transition to adult care



Exercise and Physical Activity

Exercise and physical activity are important for children with arthritis. Therapeutic exercises may be prescribed to your child by their PT or OT when your child is first diagnosed with arthritis and throughout their arthritis journey. When joints are actively inflamed, the focus of exercise is on gentle range of motion for pain relief and to help prevent joint contractures. The program is progressed to stretching and strengthening exercises when there is improvement in the inflammation. Engaging in regular therapeutic exercises and daily physical activity as tolerated can help:

- Reduce pain
- Keep joints flexible
- Keep muscles and bones strong
- Improve energy and sleep
- Improve confidence and mood
- Restore fitness level



Helpful hints for your child:

- Encourage your child to manage their own activity levels on sore days
- Avoid high-impact activities (i.e., running, jumping, hopping) when weight-bearing joints are sore and swollen
- Discourage handstands and pushups on inflamed wrists
- Swimming, walking, and biking are good alternatives
- Participate in activities and sports with friends and family

Comfort Measures

When should you use heat?

Using heating pads and warm packs or taking a warm shower are great ways to help manage chronic arthritis symptoms. Always use a protective barrier, such as a towel, between the warm pack and the skin. Heat dilates blood vessels which increases the flow of oxygen and nutrients to the area. Moist heat penetrates better than dry heat. Heat is ideal for:



- Soothing painful joints
- Decreasing morning stiffness
- Relaxing tense muscles
- Improving circulation and warming up muscles before activity

When should you use cold?

Using a commercial or homemade cold pack (i.e., from crushed ice, ice cubes or a bag of frozen vegetables) can be helpful. Do not eat frozen vegetables after use. Always use a protective barrier, such as a towel, between the cold pack and the skin. Cold constricts blood vessels which is ideal for:

- Blocking pain signals associated with acute inflammation (i.e., hot swollen joint)
- Reducing swelling and inflammation
- Decreasing muscle spasm
- Helping muscle contraction

For further details and safety tips on using heat and cold to manage arthritis, speak with your child's healthcare team.

Splinting, casting, and orthotics

The need for splinting and casting has decreased significantly over the years as medication protocols have included earlier use of disease modifying anti-rheumatic drugs, which have generally been effective in reducing pain and joint deformities. However, some children do not respond to the revised standards of care and continue to benefit from off-the-shelf or custom splints to:

- Reduce pain
- Rest a swollen or sore joint
- Stabilize the joint during activity

Your child's OT or PT may recommend the use of specific functional (daytime) or nocturnal (nighttime) splints. In the case of joint contractures, serial casting, which involves putting a series of temporary casts on an affected joint to gradually straighten it, or gentle stretching devices may be recommended by the therapist for realigning/stretching the joint and reducing deformity. Foot orthotics, worn inside the shoe, may be needed for lower limb alignment, and work optimally with supportive footwear.

Massage

Massage, or rubbing, is another way to help manage pain. Massage can stretch and loosen stiff muscles and help decrease stress. Rubbing a sore joint will help to block the pain signals from reaching the brain.

Here are some ways a child can use massage:

- Treatment from a Registered Massage Therapist; however, frequency may be limited by finances or extended healthcare benefits
- Massage of sore muscles and joints from a parent/caregiver
- Self-massage by rubbing the painful areas
- Use a hand-held massage device, massage pillow, or massage chair

Rest

Chronic diseases can cause fatigue and children require extra rest when their arthritis is very active; however, a child with active inflammation should be encouraged to engage in gentle range of motion exercises. Bed rest is not advised, as this leads to stiffness and loss of mobility. An OT or PT will be able to advise regarding activity modification to protect the joints and optimize energy levels. When sleeping, a supportive mattress and a single pillow for the neck are best. Children with arthritis are commonly good judges of their abilities and tolerances and are encouraged to self-limit their activities when they are sore.

Relief of morning stiffness

Many children feel stiff when they wake up in the morning or after sitting for long periods of time. There are several ways to help relieve the stiffness your child may experience, including taking a hot bath or shower, using a hot pack or heating pad, and doing range of motion and stretching exercises. Most children with chronic symptoms fare better with heat; although, some children may respond better to cold therapies.

Improvement takes time

An overall improvement in arthritis symptoms can take time. The exercises may be unpleasant for your child in the beginning for a variety of reasons, and it is normal to regularly remind your child to do them. Therapists rely on parents and caregivers as part of the care team. Encourage your child to continue with all their normal activities and chores, to promote normal development. It may be difficult to remain positive about the future when your child has an arthritis flare, but parents and caregivers are encouraged to share their doubts, fears and questions with the child's circle of care. You know what motivates your child best and your optimism will set the stage for a successful outcome.

Surgery

Surgery is not common but may be required after many years of severe arthritis causing significant joint damage. Surgery may be needed to relieve pain, straighten out a bent or deformed joint, restore mobility or to replace a damaged joint. Sometimes the tendons and ligaments around joints, such as the hips, may need to be lengthened. When arthritis affects one knee more than the other, the more affected side may grow faster, temporarily increasing the length of that leg. But this usually improves by itself and surgery is rarely needed.



As JA can affect the neck and jaw, it may make general anesthesia challenging. This is because JA can lead to a reduced jaw opening and inability to extend the neck, which can affect airway control. Please

Let the anesthesia doctors know if these areas are affected in your child and special measures can be put in place to ensure that everything is safe while your child receives general anesthesia. Eye surgery is sometimes needed if a child develops eye complications due to ongoing or repeated inflammation. Jaw surgery is sometimes needed if a child develops severe growth deformities due to arthritis of the jaw.

Research

Advances in research are bringing scientists closer to finding causes, cures and perhaps even a form of prevention for JA.

Research into JA is important to help understand how the body and disease mechanisms work, determine the “natural” history of diseases, develop and test new treatments and improve the quality of life for children with JA. Remember, your child’s current care is the result of previous research. Arthritis Society Canada funds leading-edge research projects that bring new insights into the disease and lead to new and better treatments for JA. To learn more about research funded by Arthritis Society Canada and how you can contribute, please visit arthritis.ca.



Your Family and Juvenile Arthritis

Fear of the future is a common experience of parents/caregivers following a diagnosis of JA. Individual parents may have very different coping styles. These can affect how even the strongest family works together. Open communication between parents and their partners or other adults about their fears and coping needs is helpful. All family members should involve themselves in the child’s treatment program, so they can provide each other with the support needed to deal with a chronic illness.



Sometimes the parent(s)/caregiver(s) of a child with a chronic health problem become overly involved with that child, excluding other aspects of their lives. Yet it’s important for parents to make time for themselves: exercising, maintaining friendships (as these are key supports) and pursuing other interests are essential. This “me” time helps parents keep a balanced perspective, allowing them to continue providing the optimism and strength their child needs. Remember, children learn how to care for themselves by watching their parents/caregivers, so modelling a balanced lifestyle will help your child do so in the future. This is a very important part of living successfully with arthritis.

It is also important to allow children living with JA to have their own time and play with family and friends. Encourage your child with JA to pursue hobbies and interests as you would any other children in your family. The emotional stress of an ongoing illness like arthritis can be keenly felt by other children in the family. Brothers and sisters are often confused about how to feel for the child with arthritis. They want to help, but sometimes – understandably – they are jealous of all the extra attention the child with arthritis seems to receive. Brothers and sisters may have difficulty understanding why there is so little time left for them. Let them openly discuss their own efforts and struggles to adjust to their sibling’s arthritis. Make sure their interests are not overlooked and encourage them to get involved. For example, it may be helpful to have the other children participate in the exercise program, so they feel as though they’re helping their sibling. Children who grow up with a chronically ill brother or sister often develop compassion for the problems of others and benefit from the experience.

Independence and Coping with Life

As the parent/caregiver of a child with arthritis, it's important to think in terms of what your child can do. Encourage your child to work within their own limits from the start. For example, encouraging your child to participate in age-appropriate chores helps instill family values and will prevent resentment from any siblings who may also have chores. Pick chores your child with arthritis can do or adapt chores to their ability. Folding laundry or setting the table are good examples. Let your child dress and undress on their own, even if this seems to take too long. An occupational therapist can design physical tool aids, such as orthotics, reachers and dollies, that will help children manage. This, in turn, will help them develop competence and confidence with self-care activities. Be prepared to set limits and discipline your child with arthritis, just as you would your other children. Parents tend to excuse the child with arthritis for inappropriate behaviour or from doing chores because they may feel the child has enough to deal with. Yet this may encourage the child to use their condition as an excuse or to their own advantage, both inside and outside the home. This can lead to behaviour problems later on in life. Parents may find they need the help of a social worker or a psychologist in learning how to best deal with some of these issues. Ultimately, it's crucial to keep in mind that your child with arthritis is a child first, who happens to be living with a chronic disease. You will have many conversations with your child that centre on arthritis and treatment but remember to make time each day to talk about non-arthritis related topics. This will help your child feel like a "regular" kid.



Your Child and School

It's crucial your child's life remain as "normal" as possible, and regular school attendance should be a main goal of the treatment program. If your child's arthritis is active, this will require the encouragement, help and understanding of the school's staff. Talk with the principal, teachers, nurse and any others in the school who may be in contact with your child. Share with them your child's condition and treatment program, limitations, strengths and special needs. During certain times of a severe flare, it may become necessary for your child to engage in home schooling. If the school staff has further questions, it may be helpful for members of your child's arthritis team to speak with them.



Early morning stiffness can be the greatest problem in getting to school. During the night, fluid accumulates in the joints, making them stiff. The stiffness will decrease as your child gets moving in the morning. Your child may have to wake up early so the stiffness improves enough to move comfortably.

Be sure to tell teachers your child may arrive late at times, since early morning joint stiffness may vary in degree and duration from day to day. Most children with arthritis attend school full-time, but if your doctor and therapist decide on half-days, afternoons may be better.

Another challenge at school may be the need for frequent eye medications, sometimes as often as hourly. No special training is needed to put in eye drops. The school nurse or teachers may do this. Although older children can instill their own eye drops, they may need a reminder. A child should never miss school just because of a need for eye drops.

Many parents/caregivers have found it helpful to teach their child's classmates about arthritis. Getting them involved – assisting with boots and clothing, holding heavy doors, carrying books, taking notes and so on – can promote understanding and co-operation, and make your child's school days much easier and more enjoyable. If your child cannot sit on the floor, it can be helpful to have others sit on a chair beside them. Be sure to talk with your child first about what information can be shared with classmates and how your child would like this information to be shared. Your child may also be able to suggest other ways classmates can help.

Some classmates may be curious about hand splints in treating arthritis. If the teacher treats your child's splint(s) in a matter-of-fact way, so will the class. With your child's permission, a simple explanation to the class about the use of splints would probably be helpful. Splints are similar to braces on teeth, which are temporarily used to make sure that a body part grows straight. Painful wrists may make carrying books a problem. Children may find a backpack is helpful.

Children with arthritis often get stiff if they sit for too long. Teachers can help by allowing your child to get up and move around in the classroom. If the arthritis is very active, the child may be unable to participate in regular gym classes. Arrangements can be made for the child to do physiotherapy during gym. At times, your child may also need the gym teacher to help adapt gym activities, and/or to find alternate ways to participate/be tested. Request that the gym teacher trust your child's judgment, as the ability to fully participate can change daily. If your child's knees or ankles are very swollen, it is best to avoid sports that require a lot of jumping or jarring movements, such as basketball or downhill skiing. However, in general, your child should not be restricted. Unless the arthritis is severe, they should be encouraged to participate in activities and set their own limits.

Students are often expected to rotate from class to class in high school. This may pose special problems for teens with arthritis. It may be beneficial to have your teen excused from class a few minutes early to "beat the rush" to the next class. If possible, request to have classes scheduled on one level and/or with as little distance as possible between different classrooms to make travel between classes easier.

This is best arranged at the end of the previous school year. Use of a school elevator (if needed), having access to a locker on each floor and having a second set of textbooks at home are additional accommodations that can be helpful.

It's important for you and your child to work together with school staff in order for your child to both enjoy and succeed at school.

Adolescence

Adolescence can be a particularly challenging time for all teens. They have an increased desire for independence and a desire to fit in with peers. Having a chronic disease, needing to miss classes or activities for appointments, and taking medications may increase feelings of being different from one's peers. It's important to allow and encourage your child to pursue and enjoy active friendships, as these can help during difficult times.

Adolescence is a time of separating from family and learning to become much more independent. That's why it's important to encourage an older child with arthritis to assume more responsibility for taking medication on time,



“It’s sort of difficult not to know if...today or tomorrow...my joints will be okay. That’s what’s a bit difficult...never knowing. You have to do it day by day”

– Young person with arthritis

reporting any joint symptoms or medication side effects and following an exercise program. Adolescence is the time for parents to begin “letting go” and for teens to take more responsibility for their treatment plan. These responsibilities will help prepare your teen for the transition to the adult healthcare system.

Note to Parents/Caregivers and a Word of Encouragement

Parents/caregivers are an important part of the team and should be as well informed as possible. When you have questions, write them down before a doctor’s appointment. Please bring or have available a list of all your child’s medications and supplements (including the name, dosage and frequency of administration) for the appointment. Feel free to question the doctor about medications and other parts of the treatment plan, and make sure you understand the reasons behind all the recommendations. You may also gain a great deal of insight by talking to other families of children with arthritis. Your clinic will likely have many resources for learning more about JA. Arthritis Society Canada will also be able to provide you with helpful information.



In the majority of children with mild forms of arthritis, there is almost no impact on lifestyle at school or at home. For some, impacts may include physical, emotional, as well as social aspects. Children with more severe arthritis must learn to cope with health difficulties at an early age. They may have to overcome pain, take medications, do exercises and experience limitations on certain activities. It’s also important to recognize the emotional impact this may have on the child. Living with JA may trigger feelings of anger, isolation, and hopelessness. Feeling a lack of validation from others can cause a challenge, as the effects of arthritis are not always visible to others, so a child may feel judged or misunderstood by their peers and classmates. They may also be unable to partake in social activities at times. However, with guidance, support and encouragement from their family, friends and the arthritis team, these experiences can help them develop into unique, compassionate and strong individuals with a bright future.

Glossary



- ▼ **Arthritis:** Inflammation of the joint (“arthro” meaning joint and “itis” meaning inflammation).
- ▼ **Cartilage:** A smooth, glistening structure that lines the ends of bones, allowing them to glide smoothly.
- ▼ **Enthesitis-Related Arthritis:** A form of JA in which arthritis is associated with inflammation of entheses (where tendons insert or attach to bones). The medical term is enthesitis. It is more common in boys over the age of 10 and can affect the back or spine.
- ▼ **Flare (or flare-up or exacerbation):** The term used for those times when arthritis acts up or is at its worst. Flares are common in juvenile arthritis, but usually become less severe over time.
- ▼ **Immune System:** The body’s defence system against infection; it is overly active in some forms of arthritis. Instead of turning off when you have cleared an infection or recovered from an injury, it remains hyperactive and continuously produces chemicals and proteins that cause ongoing inflammation.
- ▼ **Inflammation:** The body’s protective response to injury or infection characterized by redness, swelling, heat and pain. JA involves inflammation of the joints that is not caused by any injury or known infection.
- ▼ **Joint:** The site where two or more bones meet, binding the bones firmly together and permitting movement between them. A joint may be a hinge (elbow or knee) or a ball-and-socket (shoulder or hip). The ends of the bones are covered with cartilage, so they can glide over each other easily. Most joints are surrounded by a thin lining (synovium). In arthritis, this lining becomes inflamed.
- ▼ **Juvenile Idiopathic Arthritis (JIA):** The term commonly used to describe chronic arthritis in childhood. JIA generally has a much better outcome and is very different from adult rheumatoid arthritis.
- ▼ **Ophthalmologist:**
As a medical doctor who has completed specialized training, an ophthalmologist is licensed to practice medicine and surgery. An ophthalmologist diagnoses and treats eye diseases, performs eye surgery and prescribes and fits eyeglasses and contact lenses to correct vision problems.
- ▼ **Optometrist:** A university/college graduate who goes on to have special training in performing eye examinations, prescribing glasses and fitting contact lenses. They are not physicians/medical doctors and do not perform surgery. In some areas, they may be allowed to prescribe medications. We recommend that treatment for uveitis and related eye problems requiring medications, once diagnosed, be conducted under the care of an ophthalmologist.

- ▼ **Orthodontist:** A dentist who specializes in preventing and treating problems with the development of the teeth and jaw.
- ▼ **Orthopedic Surgeon:** A medical doctor with specialized training in the examination, diagnosis and treatment of bone and joint disorders, with special expertise in the surgical treatment of these disorders.
- ▼ **Pediatrician:** A medical doctor with specialized training in the examination, diagnosis and treatment of disorders of childhood and adolescence.
- ▼ **Pediatric Rheumatologist:** A medical doctor with specialized training in the examination, diagnosis and treatment of disorders of childhood and adolescence. As well, they have specialized training with the examination, diagnosis and treatment of bone and joint disorders in childhood and adolescence, with special expertise in diseases of inflammation.
- ▼ **Physiotherapist (PT):** A specialist in physical therapy and splinting, who will help design an exercise program for you. The physiotherapist will also monitor the movement in individual joints, as well as the strength of the muscles around the joints. The physiotherapist will continually modify the exercise program to meet your needs.
- ▼ **Psychologist:** A member of the healthcare team with specialized training in the diagnosis and evaluation of emotions and the role that emotions play in people with chronic illness.
- ▼ **Rheumatologist:** A medical doctor with specialized training in the examination, diagnosis and treatment of bone and joint disorders, with special expertise in diseases of inflammation.
- ▼ **Social Worker:** A member of the healthcare team who specializes in helping you and your family adjust to a chronic disease. Social workers also have particular expertise regarding community resources (i.e., educational, transportation, financial) that can benefit you and your family.

About Arthritis Society Canada

Arthritis Society Canada is dedicated to extinguishing arthritis. We represent the six million Canadians living with arthritis today, and the millions more who are impacted or at risk. Fueled by the trust and support of our donors and volunteers, Arthritis Society Canada is fighting the fire of arthritis with research, advocacy, innovation, information and support. We are Canada's largest charitable funder of cutting-edge arthritis research. We will not give up our efforts until everyone is free of the scorching pain of arthritis. Arthritis Society Canada is accredited under Imagine Canada's Standards Program. For more information, to make a donation or to volunteer, visit arthritis.ca.

CONNECT

arthritis.ca | 1.800.321.1433

Join Our Social Community



™ and © are trademarks of Arthritis Society Canada.

