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You, Your Child & Arthritis was created by The Arthritis Society in conjunction with leading experts in pediatric rheumatology, young adults with JA and parents of children with arthritis.



You, Your Child & Arthritis



Introduction

You, Your Child & Arthritis is a valuable resource for families of children with juvenile arthritis (JA). This guide provides the information parents 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 new biologic medications) and other important elements of treatment, such as physiotherapy and occupational therapy. In addition, there are important sections for parents learning to cope with a child who has a chronic disease. Pediatric rheumatology teams across Canada recommend and endorse this source for all families of children with arthritis.

Lori Tucker, MD

Chair, Pediatric Section of the Canadian Rheumatology Association

Foreword

In 2004, a book entitled *I am Brave: Children Living with Arthritis* was developed to give hope and inspiration to children living with arthritis.

During its development, children from across Canada were asked to draw pictures and write stories about the emotional and physical impact of the disease on their day-to-day life.

This edition of *You, Your Child & Arthritis* presented an opportunity to republish the compelling and creative artwork first showcased in *I am Brave*.



Artists

Bailey - pg 13

Brandon - pg 20

Callah - pg 44

Chesney - pg 25, 26

Ericka - pg 21, 25, 29

Jaclyn - pg 15

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5th Edition

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4th Edition

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You, Your Child & Arthritis was originally produced by the late Dr. Abraham Shore and

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We also thank Dr. Alex Levin and Dr. Nasrin Tehrani, for their contributions to the section on eye problems and eye care.

An Overview

Unfortunately, many people mistakenly think arthritis is just a disease of the elderly. But the statistics tell a different story: about one in 1,000 Canadian children has 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” in the medical community simply means “unknown.” This word is used when other illnesses known to cause arthritis, such as infections, injuries, cancers and other related rheumatic/autoimmune disorders (lupus, dermatomyositis, vasculitis), are ruled out as the cause of a child’s arthritis. For the sake of simplicity and clarity, juvenile idiopathic arthritis will be referred to as juvenile arthritis or JA throughout this guide.

While there is no cure for JA, therapies exist and can be effective. Once your child has been diagnosed, the overall treatment plan will be co-ordinated by your child’s doctor. The treatment plan will include medication and, potentially, rehabilitation therapy. The therapy program, specially designed by both your child’s doctor and therapists, is one of the cornerstones of treatment. Exercise helps prevent the loss of joint movement and encourages normal growth. And, 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 joint swelling, pain and stiffness.

The medications can also prevent joint damage and make your child’s therapy program easier to do. The choice, nature and strength of the medication will depend on the severity and type of arthritis, which will be discussed later in this publication.



Children who are well monitored and follow the recommended treatment provided by a health-care team fare the best overall. The majority of children are able to participate in normal activities and have a bright future. Expanding research initiatives and the availability of more effective therapies, including medications, promise better days ahead for children with juvenile arthritis.

→ Arthritis is not just a disease of old people.



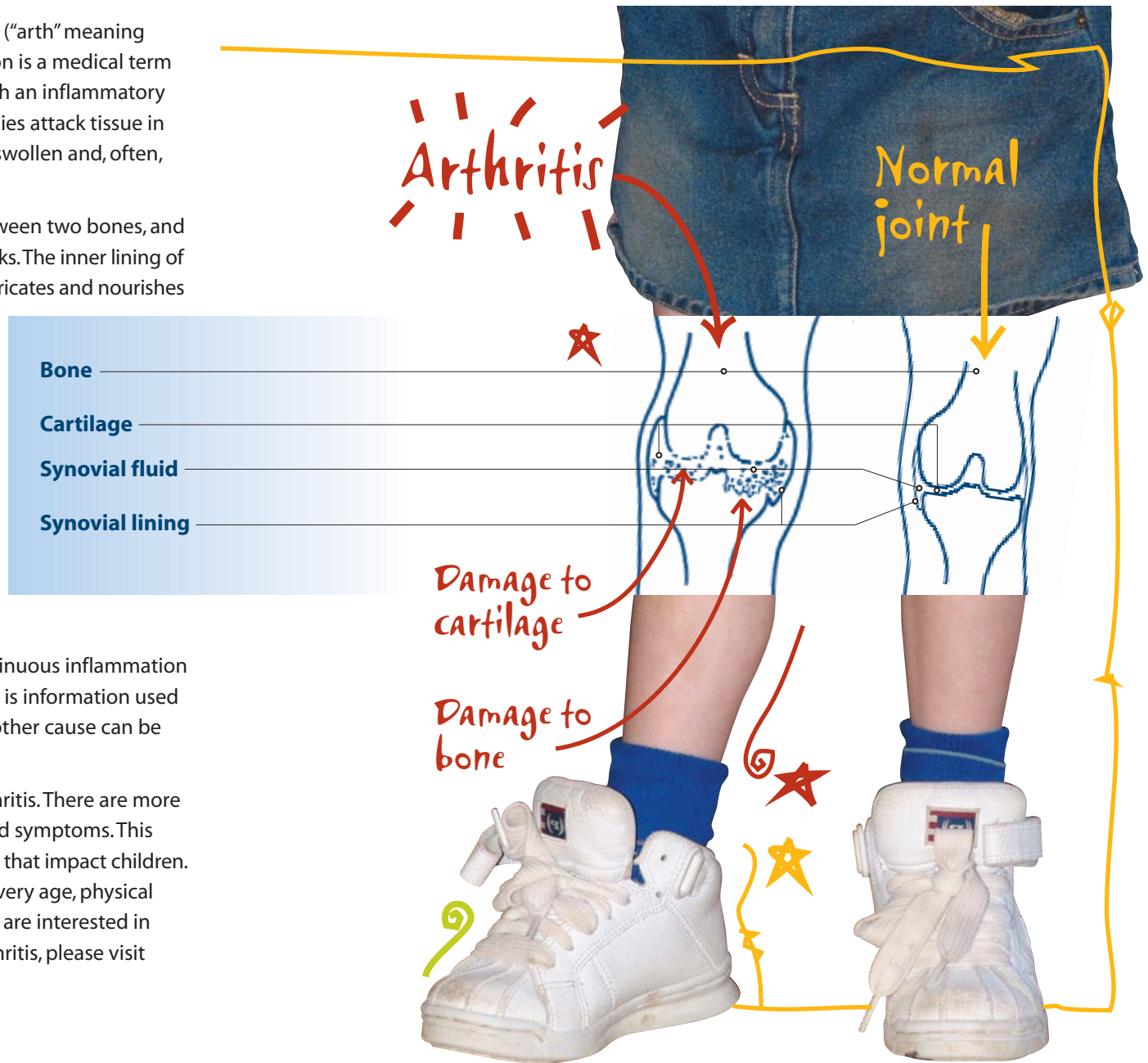
What is Arthritis?

The word arthritis means inflammation of the joint (“arth” meaning joint and “itis” meaning inflammation). Inflammation is a medical term describing pain, stiffness, redness and swelling. With an inflammatory type of arthritis like JA, an individual’s own antibodies attack tissue in the lining of the joint, causing it to feel warm, stiff, swollen and, often, painful.

Picture a capsule that encloses the joint space between two bones, and this will help to better understand how arthritis works. The inner lining of this capsule, the synovium, produces a fluid that lubricates and nourishes the joint. The ends of the bones are covered with a smooth substance called cartilage, which allows the bone ends to glide smoothly across each other. Inflammatory arthritis creates imbalances in the immune system and causes the synovium to become inflamed and thickened, producing extra fluid. This fluid contains inflammatory cells. These inflammatory cells produce and release substances that cause the warmth, stiffness, swelling and pain. If left untreated, the inflammation can damage the cartilage and underlying bone.

Juvenile arthritis, then, is medically defined as continuous inflammation of one or more joints lasting at least six weeks (this is information used by doctors to properly diagnose JA), for which no other cause can be found in a child aged 16 or younger.

It is important to know that not all joint pain is arthritis. There are more than 100 types of arthritis, with different causes and symptoms. This publication will discuss the various forms of arthritis that impact children. Arthritis affects more than four million people of every age, physical condition and ethnic background in Canada. If you are interested in learning more about the various adult types of arthritis, please visit www.arthritis.ca.



What Causes Juvenile Arthritis?

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

The onset of JA may follow an event that turns on the immune system, such as a routine infection or injury, but these common events do not cause chronic arthritis. Current research points to the body's own immune system being responsible for the inflammation. The human immune system is a complex and finely tuned defence mechanism that fights infection by causing inflammation. In juvenile arthritis, there is inflammation in one or more joints. With JA, the immune system seems to be overactive, perhaps responding inappropriately to an infection or mistakenly identifying something as an infection, thereby causing continuous inflammation. Although some children may get a rash and a fever with JA, the disease is not contagious.

Most types of JA are not passed from generation to generation, and arthritis is almost never passed from a parent to a child. The chance of your child passing arthritis on to his or her child(ren) is extremely rare.

Diagnosis

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 rare cases, there may be no signs other than a swollen joint or

some movement loss when the child is examined. As a result, JA can be difficult to detect and may go unrecognized by even the most experienced physician. Your child's doctor will look carefully for any signs of joint swelling or loss of mobility, which indicate 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, urine and blood tests. Lab tests may help determine the type of arthritis your child has and if he or she is at risk of getting a more severe type of arthritis or developing inflammation in other joints and organs. Once the diagnosis of JA has been confirmed, routine tests, such as blood tests, X-rays and eye examinations, will need to be repeated in order to monitor the illness and the effects of medication. Your child's doctor will discuss with you how often the routine tests need to be done.

It is important to note that, depending on the type, 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, JA is gone 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. This may include blood and other laboratory tests.



Unique Features of Juvenile Arthritis

Growth

Inflammation from JA affects the growth of a child, meaning the growth patterns of arthritic joints may change. Sometimes inflammation can lead to quicker growth. For example, knee inflammation may cause the inflamed leg to grow slightly faster than the non-inflamed leg. However, growth usually returns to normal once the arthritis is under control. Sometimes if the inflammation is not well controlled, growth may slow down. For example, ongoing jaw inflammation may result in a small chin. 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. A health-care team will pay careful attention to all aspects of your child's growth.

Eye Problems and Care

Sometimes a child with JA may have inflammation inside the eye. This eye disorder has many technical names: uveitis, iritis, iridocyclitis, anterior uveitis and nongranulomatous iritis. The inflammation often occurs without symptoms or visible signs, so you and your child may not even be aware of it. That's why it's important for your child's eyes to be checked regularly, even if they aren't red or sore.

In the early stages, this inflammation can only be detected by a special examination (slit-lamp examination), which must be done by an ophthalmologist (a physician specially trained in eye care and treatment) or an optometrist (a non-physician who has special training in performing eye examinations). The slit-lamp examination is a simple and painless procedure, except for the eye drops needed to dilate the pupils; these sting for 10 to 20 seconds. The frequency of the eye exams will depend on your child's risk of developing eye problems and will be determined by your child's pediatric rheumatologist and ophthalmologist/optometrist. Please ensure you, your child and the rheumatologist are informed and updated with the results of the eye examinations performed by the ophthalmologist/optometrist.

If your child develops uveitis, then your child should be under the care of an ophthalmologist to receive appropriate treatment. Treatment of uveitis may include eye drops (for example, steroids, drops to dilate the pupil),



injections of steroids behind the eyes (subtenon injections) and other oral or injectable medications.

A listing of the common medications used during examination and treatment of uveitis can be found online at www.arthritis.ca.

Undetected or inadequately treated uveitis can lead to a cataract (a cloudiness in the lens of the eye), glaucoma (high pressure inside the eye) and/or band keratopathy (calcium deposition on the surface of the eyeball). All of these can lead to vision loss or even blindness. Sometimes scar tissue forms at the edge of the pupil (called posterior synechiae), which causes the pupil to become

irregularly shaped. This doesn't affect vision, but it means your child has or had active uveitis. For more information about the complications of uveitis, visit the website of the Pediatric Glaucoma and Cataract Family Association at www.pgcfca.org.

It's important to know uveitis is not related to the degree of inflammation in your child's joints. Eye disease is most common in children with inflammation in only one or a few joints. And the eye disease may begin before arthritis is diagnosed. Although uveitis can happen with any type of JA, it is most common in ANA positive, rheumatoid factor negative, young girls with oligoarticular JA and older boys with polyarticular JA. (Note: the different types of arthritis are covered in "Patterns and Types of Arthritis in Childhood", pages 14-19). Uveitis can happen in one or both eyes. If after six to 12 months the uveitis has only affected one eye, the other eye will most likely not be affected. But regular visits to an eye doctor are still essential.

Some children have only one episode of uveitis that easily responds to treatment. Others may have ongoing uveitis that responds to treatment, with periods of no inflammation. About 10 per cent of children with JA will have chronic uveitis that may require months or years of treatment. These children are most at risk for other eye problems and vision loss.

Unpredictability

Sometimes JA may last for as little as several months up to a year, then disappear forever. Some children, however, have an up-and-down course for many years, depending on what type of arthritis they have. Flares (also known as flare-ups or exacerbations) are those times when the arthritis seems to be getting worse.

Remissions are times when the arthritis appears to have disappeared. Sometimes a mild infection, such as the flu, may cause a flare. The reason for a flare is usually unknown. Parents may be upset to see a flare when it seemed the disease had disappeared or greatly improved. Yet parents should remain hopeful and optimistic. Fortunately, these flares tend to become less severe and occur less often with time.



Patterns and Types of Arthritis in Childhood

The symptoms and nature of juvenile arthritis vary greatly. Once a doctor has diagnosed or suspects arthritis in your child, your child will usually be referred to a specialist, such as a pediatric rheumatologist, who is a physician specially trained in the diagnosis, evaluation and treatment of disorders of joints, muscles and bones in children. A specific diagnosis is important, allowing for a specially designed treatment program to be created for each child.

There are seven major types of JA:

- Oligoarticular–persistent JA
- Oligoarticular–extended JA
- Polyarticular–RF negative JA
- Polyarticular–RF positive JA
- Systemic JA
- Enthesitis–related arthritis (ERA)
- Psoriatic arthritis

Determining the type of JA your child has is, for the most part, based on the information collected during the diagnosis stage (physical examination findings, blood, urine and imaging tests). What happens with your child's disease over the next six to 12 months is another important factor. It may take time for your child's doctor to be absolutely certain of the subtype of JA. And if the course of your child's disease changes, a different, more appropriate subtype may be assigned.

Remember, though, the initial management of your child's arthritis will not be hindered or delayed by an unconfirmed subtype. Confirmation of the subtype of JA will give you, your child and his or her health-care providers the information needed to create a specially designed treatment plan.

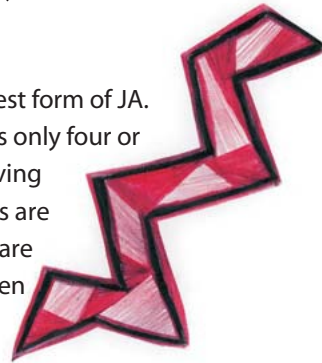


Type of JA	How common is it?	Who's likely to get it?	When does it happen?
Oligoarticular JA	Most common	Girls > Boys	Early childhood (usually < 4 years)
Polyarticular RF negative JA	Common	Girls > Boys	2 peaks: 2-4 years and 6-12 years
Polyarticular RF positive JA	Less Common	Girls > Boys	Late childhood/early adolescence
Systemic JA	Less Common	Girls = Boys	Throughout childhood
Enthesitis-related arthritis	Less Common	Boys > Girls	Boys over the age of 10
Psoriatic arthritis	Less Common	Girls > Boys	2 peaks: 2-4 years and 9-11 years

Oligoarticular–Persistent Juvenile Arthritis

This is the name given to the most common and mildest form of JA. Oligoarticular (sometimes called pauciarticular) means only four or fewer joints are involved. Children are classified as having oligoarticular–persistent JA if no more than four joints are involved beyond six months after the diagnosis. Girls are affected more often than boys, usually starting in children aged four or younger. 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. Although oligoarticular-persistent JA may involve flares and remissions, there is rarely permanent damage to the joints with the right treatment. Many affected children are in permanent remission within a few years after the onset of the disease.

Up to 20 per cent of children with oligoarticular-persistent JA will eventually develop uveitis, so it's crucial a slit-lamp examination of the eyes is arranged 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. That's why the ANA blood test helps identify those children who will need frequent eye checks.



Oligoarticular–Extended Juvenile Arthritis

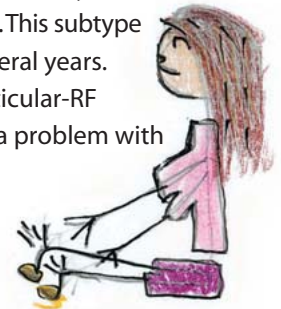
As described above, oligoarticular means the involvement of four or fewer joints. Children are classified as having oligoarticular–extended JA if four or fewer joints are involved within the first six months after the initial diagnosis, but the child develops arthritis in five or more different joints at any time during the course of the disease. The key here is to remember not all joints need to be inflamed at the same time. Importance here is placed on the number of locations of the affected joints. Large and small joints may be affected, and flares and remissions may occur. With the appropriate treatment, however, permanent damage to the joints can usually be prevented. Associated eye disease can also be present, so it's important for children to have slit-lamp examinations of their eyes at least three or four times a year for the first few years after diagnosis. As mentioned above, the blood test for antinuclear antibody (ANA) is almost always positive in children who develop eye inflammation. The ANA blood test helps identify those children who will need 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 don't test positive for rheumatoid factor (RF). This type of JA can begin at any age, and it usually starts in several joints at the same time. It's more common in girls than in boys. Occasionally, it will begin in only one or two joints, then spread to other joints.

The temporomandibular joint (TMJ or jaw) and the cervical spine (neck) are two joints that may be involved. TMJ arthritis can lead to a limited ability to open the jaw. It may also affect chewing and cause abnormal growth of the jaw, leading to a small chin. Your child's doctor will check if these two joints are affected by doing a physical examination and taking X-rays. Your child's doctor will then inform you and your child of any further management and necessary precautions. This subtype of JA may last only six months, but usually lasts several years. Inflammation of internal organs is rare with polyarticular-RF negative JA. A change in growth patterns is less of a problem with this type of arthritis than it is with systemic JA.

On a bad day, my arthritis hurts.



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 rheumatoid factor (RF). This type of juvenile arthritis 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 polyarticular-RF positive in teenagers may closely resemble adult rheumatoid arthritis (RA). Occasionally it will begin in only one or two joints, then spread to other joints. It can affect both the small (especially hands and fingers) and large joints (knees, hips, ankles), 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. This subtype causes severe joint damage more often than other types of arthritis. Because of this, stronger medications are recommended at an early stage.

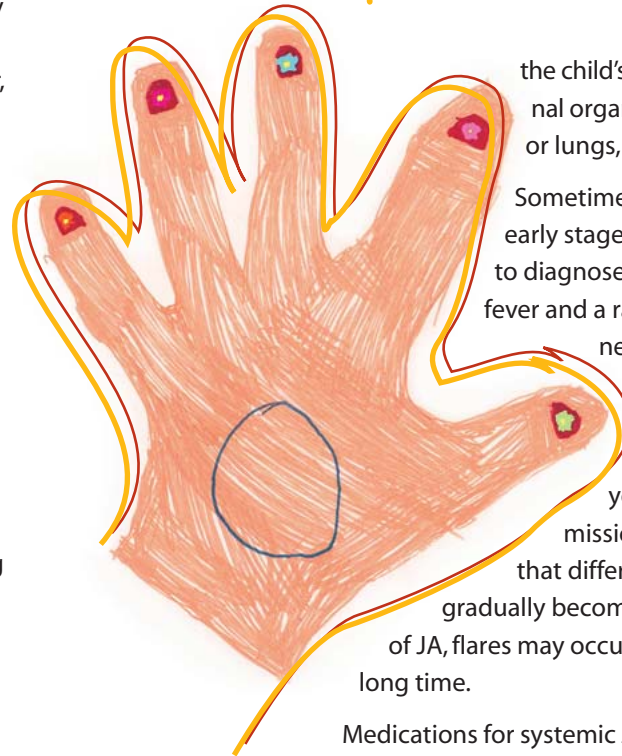
Systemic Juvenile Arthritis

This form of JA affects the body in a general way with a fever and can also 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 usually involves many different joints, and some joints may be affected to a severe degree. Children with systemic JA have a spiking (rapidly rising and falling) fever that usually occurs once (or sometimes twice) a day. A rash frequently comes and goes with the fever. The rash usually appears as pale red spots on the child's chest, upper arms, thighs and other parts of the body (see picture below).



The arthritis usually appears within the first six months after the start of the fever, and it often persists even when the fever settles. Children also often have swollen lymph glands and an enlargement of the liver and spleen. They appear listless and unwell during the fever (most

Even severe forms of arthritis sometimes go into remission within a few years.



often in the late afternoon or evening), only to brighten up by the next day when their temperature returns to normal. When fever in systemic JA persists 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 systemic 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 need to be done. The arthritis may be mild or severe, and only a few or many joints may be involved. Yet even severe forms of arthritis sometimes go into remission within a few years. If the child's arthritis doesn't go into remission, it will follow a pattern of ups and downs that differs for each child. In most cases, the pattern will gradually become less severe. Occasionally, as with all forms of JA, 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. Uveitis is uncommon in systemic JA, but children should still have their eyes examined annually.

Enthesitis–Related Arthritis

Children with enthesitis-related arthritis (ERA) have inflammation both in their joints (arthritis) and in the spots where tendons attach or insert to bones (entheses). This type of JA generally affects children over the age of 10, and it is more common in boys. The lower limbs are usually affected, especially around the knees, ankles and bottoms of the feet.

Children may often complain of knee, heel or foot pain, particularly with activity. The hips are also commonly affected.

Joint inflammation in ERA often continues into adulthood, sometimes progressing into the spine or sacroiliac joints and often leading to pain and back stiffness. ERA is one of the few types of arthritis that may be hereditary or run in families. It may also occur with inflammation of the eyes or the bowel, either in the child or in other family members. Many children with ERA carry a protein called HLA B-27 in their cells. Lab testing for this protein may, in some cases, help in the diagnosis.

Psoriatic Arthritis

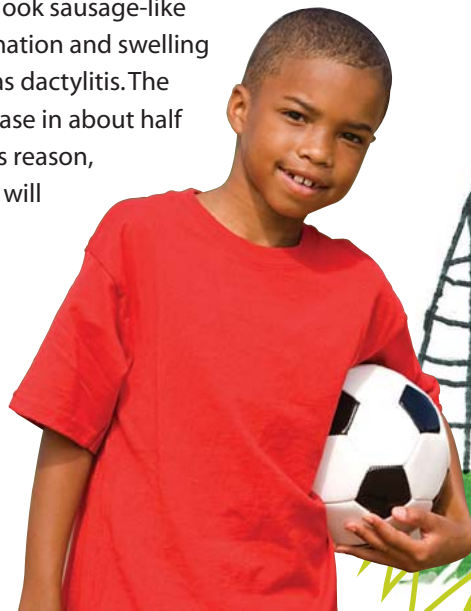
Psoriasis is a skin disease often accompanied by arthritis. Psoriasis appears as a scaly red rash, usually on the scalp, behind the ears, on the eyelids, elbows, knees, buttocks or in the belly button (see picture, left).



Some children may also have pitting or ridging on their fingernails. When arthritis and psoriasis occur together, the disease is called psoriatic JA. This type of arthritis affects boys and girls, and it can happen at any age.

Only one or a few joints are usually affected, but the hips or back (like in enthesitis-related arthritis), or the fingers and toes can be affected.

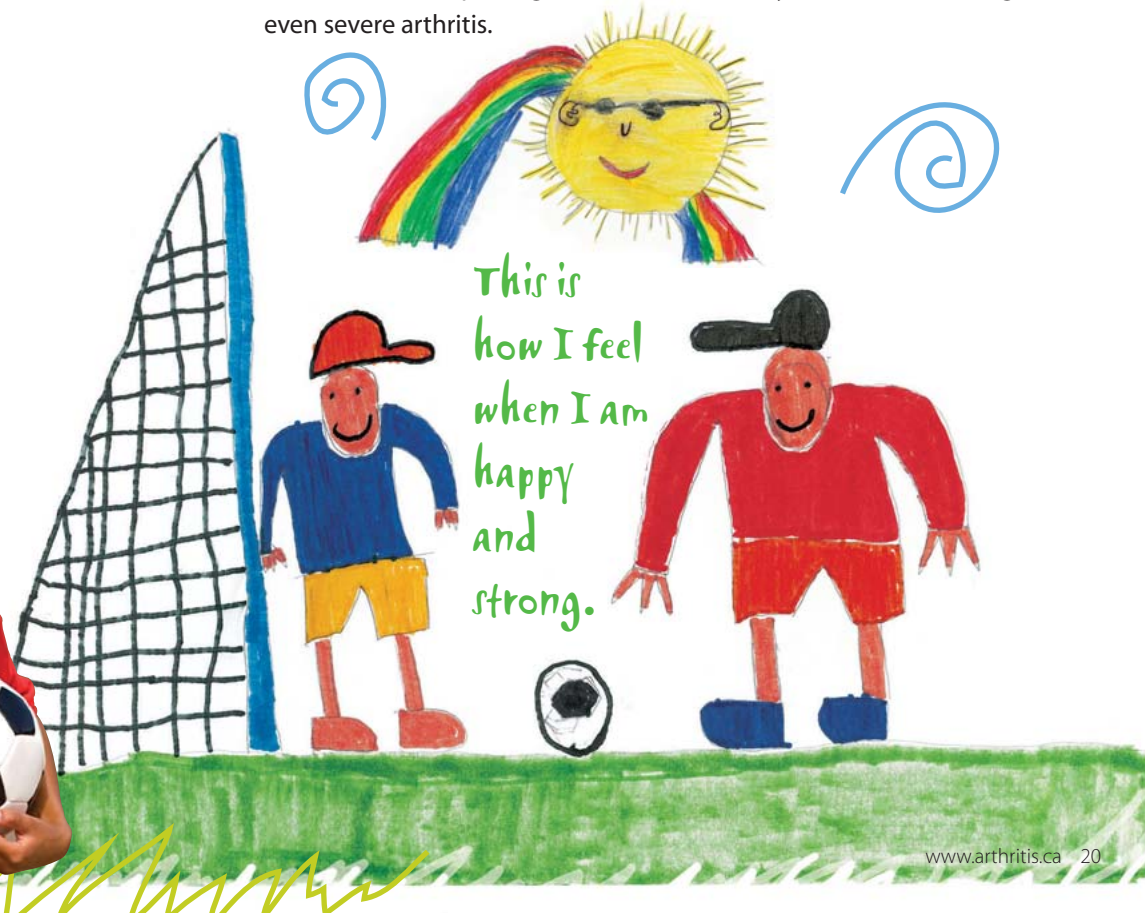
The fingers or toes of some children may look sausage-like because of extreme swelling. This inflammation and swelling in the tendon of a finger or toe is known as dactylitis. The arthritis starts before any sign of skin disease in about half of children with psoriatic arthritis. For this reason, knowledge of a family history of psoriasis will 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. Once the disease has established a pattern, your health-care 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: 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 special needs. The most important members of the team are you and your child. With the help and guidance of the team, your child can manage even severe arthritis.



Treating Juvenile Arthritis

You, your child and your family's attitude and emotional response toward arthritis and the treatment plan are extremely important in determining the future. Some 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. Persistence with the suggested treatment and a positive attitude from you and your child are the keys to success. Remember, children take their cues from their parents and they will often look to you to figure out how to respond to any challenges. They will learn from you to view their arthritis as either a devastating change in lifestyle or as a challenge the family will face and manage together. It's vital 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.

Aims of Therapy

Each child with arthritis is an individual with his or her own unique needs and reactions. And that is why the treatment program must be designed for your child by the entire arthritis team. Overall, the treatment plan aims to help your child:

- 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 his or her own health.
- Be a happy and productive member of society.

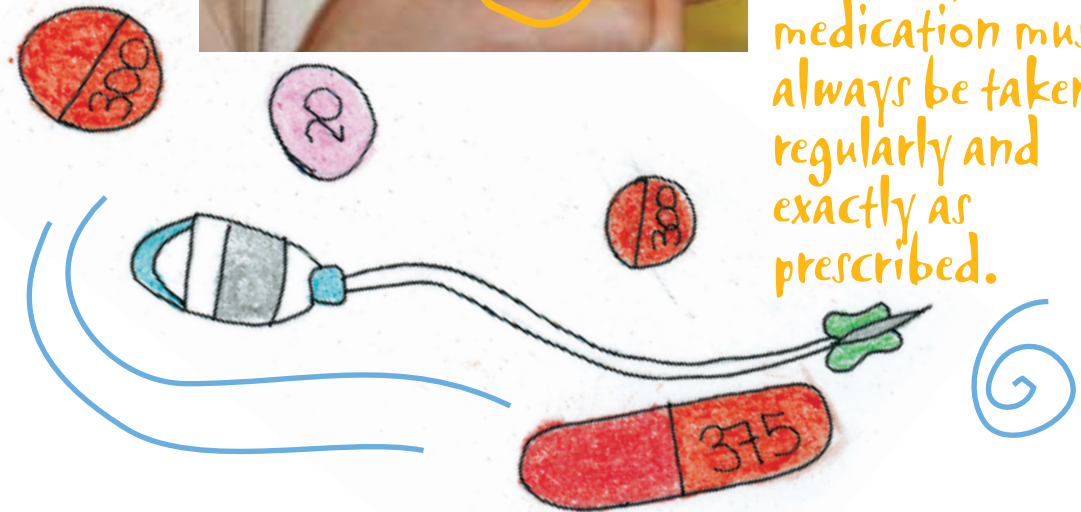
Medications

There is no cure for juvenile arthritis. Yet there are medications that can reduce the inflammation and relieve the pain and swelling. To be fully effective, medication must always be taken regularly and exactly as prescribed. A specific medication program will be designed by your child's doctor, according to your child's weight and disease activity. It's important not to change the dosage, delivery schedule or method of delivery without the doctor's knowledge.

Below are some descriptions of medications used to treat juvenile arthritis. A more comprehensive list is available at www.arthritis.ca.



←
To be fully effective, medication must always be taken regularly and exactly as prescribed.



Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

Most treatment plans will start with anti-inflammatory medications. These medications do not contain cortisone (steroids). The medical term for this kind of medication is non-steroidal anti-inflammatory drugs or NSAIDs. By reducing pain, swelling and stiffness, these medications allow a child with arthritis to participate in everyday activities. NSAIDs are not addictive and their effect on inflammation does not wear out over time.

Some of the more commonly prescribed NSAIDs include naproxen, indomethacin and ibuprofen. The choice of medication is based on the disease type, how easy it is to take and the doctor's choice. Sometimes it may take eight to 12 weeks to see any improvement, and it may be necessary to try several different NSAIDs to figure out which one works best for your child. 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. 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. They are also used for moderate to severe inflammation involving other body systems.

Steroid Joint Injections (Cortisone-Type Drugs)

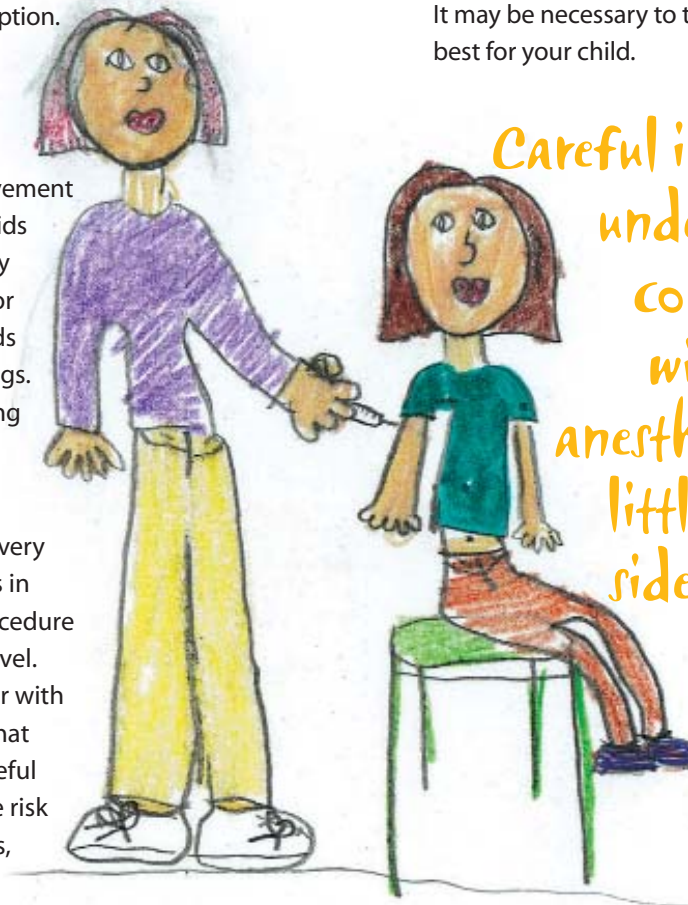
Injections of steroids directly into a joint (intraarticular) can be very helpful if only a few joints are involved or for persistent arthritis in joints that does not respond to initial drug treatments. This procedure is done with strict attention to your child's age and tolerance level. The known side effects of steroids taken by mouth do not occur with this type of treatment, and one joint injection does not mean that injections will have to be repeated frequently, if ever again. Careful injection under sterile conditions with local anesthetic has little risk of side effects and may improve the injected joint(s) for months,

sometimes even longer. The initial improvement is often dramatic, occurring within days to a week following the joint injection. If effective, other medications may be stopped early.



Disease-Modifying Anti-Rheumatic Drugs (DMARDs)

For children who have prolonged arthritis in several joints or arthritis that isn't controlled with NSAIDs or joint injections, a second line of drugs is often prescribed. This is because continued inflammation within an affected joint may lead to permanent damage. These medications, also 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.



Careful injection
under sterile
conditions
with local
anesthetic has
little risk of
side effects.

Several DMARDs may be combined together to manage severe cases of arthritis. DMARDs can be given orally or as an injection under the skin (subcutaneously or SC). Treatment with these drugs must be continued for months or years, even after the disease is controlled, in order to avoid a recurrence. Each drug has its own side effects that require careful monitoring by regular physical exams and lab tests. These will be carefully reviewed with you and your child by the health-care team.

Biologic Agents

Biologic agents (biologics) are the newest group of medications that help reduce the symptoms and inflammation that can cause joint damage. They are used when other treatments have not controlled the disease adequately. Biologics are designed to target specific components of the body's immune system, such as cytokines or receptors, which play a role in the disease process. Cytokines are active chemicals produced by your body's immune system that can cause or control inflammation. Tumor necrosis factor (TNF) and interleukin-1 (IL-1) are two cytokines 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. 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 the type of arthritis, other medical problems and medications.

In general, biologics are effective in treating arthritis in children who have not improved on standard therapy. Biologics are often helpful in the treatment of uveitis (eye inflammation) and systemic JA features, such as fever, rash and organ inflammation. Prior to the start of any biologic therapy, your child must be tested to ensure there is no tuberculosis (TB) infection present. This is done by a TB skin test and a chest X-ray. It is not safe to give an anti-TNF agent to children who also have other medical conditions, including severe chronic infections, heart failure, neurologic diseases (such as multiple sclerosis, neuropathies) and malignancies.

A more detailed description of what biologics do and which ones are available to treat JA in Canada can be found at www.arthritis.ca.

Biologics are used when other drugs have not controlled the disease adequately.

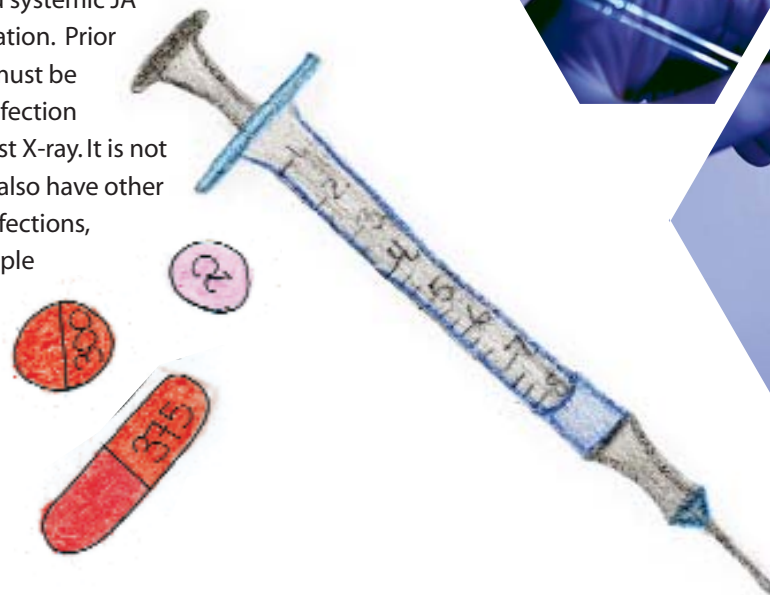
Newer Therapies

As this edition goes to press, ongoing research is taking place in the development of new biologic treatments (such as blocking IL-6 or antibody-making immune B cells). These newer biologics, such as monoclonal antibodies, receptor inhibitors and peptide vaccines, are designed to modify the body's immune response and effectively control the arthritis with fewer side effects. Ask your health-care team about these newer agents.

Alternative Therapies

You may have heard some people swear by many remedies for arthritis. Some examples include avoidance of certain foods, new medications and reflexology. While some of these may have merit, others make exaggerated, unproven claims of a cure. It's understandable some may want to try "alternative medicine," especially when standard medications haven't worked too well. Make sure your child's doctor and other members of the health-care team are aware you may be seeking such remedies for your child. They'll explore the potential risks and benefits with you, making sure there are no adverse drug interactions with your child's medications and the alternative therapy or therapies.

More information about complementary therapies can be found at www.arthritis.ca.



Physiotherapy and Occupational Therapy

Physiotherapists and occupational therapists can be important members of your child's health-care team. Therapists help children maintain their physical abilities and participate in school, sports and recreational activities.

Your child's therapist can help:

- Decrease pain and stiffness.
- Keep muscles strong and flexible.
- Provide advice about exercise, activity and rest.
- Discuss ways to protect joints.
- Provide advice for teachers and coaches about arthritis.
- Give instruction for the use of splints, orthotics and proper footwear.



Exercises should be done every day to be effective.

Exercise and Physical Activity

Exercise is safe and important for a child with arthritis. Therapy exercises, given to your child by a physical or occupational therapist, may be required when your child is first diagnosed with arthritis or when he or she is experiencing a flare. These exercises should be done every day to be effective. When joints are actively inflamed, exercises focus on pain relief and gentle range of motion. Further stretching and strengthening exercises are done when there's an improvement in the inflammation. Prescribed exercises and regular daily physical activity help:

- Keep muscles and bones strong.
- Keep joints flexible.
- Reduce pain.
- Improve confidence and mood.
- Improve energy and sleep.
- Improve or maintain your child's fitness level.

Helpful Hints for Your Child:

- Change positions often. Get up and stretch at home and at school.
- Encourage rest breaks when your child is tired or sore. Frequent, short periods of activity are as beneficial as longer ones.
 - Limit activities on days when your child is sore.
 - Avoid high-impact activities (running, jumping, hopping) when joints are swollen or sore. Swimming, walking and tricycle or bike riding are good alternatives.
- Request a second set of school books to be used at home.
- Participate in sports and activities with friends.
 - Avoid carrying heavy books or bags. Use a good backpack, positioned over both shoulders.



Surgery

Surgery is not common, but may be necessary after many years of severe arthritis. Your child's doctor may seek the advice of an orthopedic surgeon to help plan future treatments and surgical procedures. 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 lengthening. When arthritis affects one knee more than the other, the more affected side may grow faster, temporarily increasing the length of that leg.

Over time, though, growth in the other leg will often catch up. Surgery is rarely needed to correct the difference in leg lengths. The orthopedic surgeon may also be asked to make recommendations on splinting and rehabilitation.


As JA frequently affects the neck and jaw, it may make general anesthesia difficult. It's advisable that an anesthesiologist see children with JA before any type of operation is planned.

Eye surgery is sometimes needed if a child develops a complication, such as a cataract (a cloudiness in the lens of the eye), glaucoma (high pressure inside the eye) and/or band keratopathy (calcium deposition on the surface of the eyeball due to the uveitis).

Dental Care

If arthritis has severely affected the jaw, there may be poor chin growth. An orthodontist may recommend a splint to be worn in the mouth. Surgical procedures can correct this problem once the disease is in remission. Your doctor may seek the advice of an orthodontist to make recommendations regarding these procedures.

Arthritis of the jaw can make complicated dental work a problem. Be sure to tell your dentist your child has arthritis, so the dentist can give your child's teeth special attention. You should also strongly encourage your child to practice good dental care.



Children with oligoarticular JA are at highest risk of developing chronic eye inflammation or uveitis, especially young girls.

Research

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

Now that JA is recognized as a unique disease, research is even more important in understanding how the body and disease mechanisms work, determining the “natural” history of diseases, developing and testing new treatments and improving the quality of life for children with JA. Remember, your child’s current care is the result of previous research.

Canadian pediatric rheumatologists across the country are at the forefront of many of the research efforts into the causes and management of juvenile arthritis. The Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI) is devoted to research in arthritis and improving the lives of children with JA. To learn more about current JA studies, please visit www.icaare.ca. The Arthritis Society 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 The Arthritis Society and how you can

contribute, please visit www.arthritis.ca.



Your Family and Juvenile Arthritis

Fear of the future is a common experience of parents following a diagnosis of juvenile arthritis. Individual parents may have very different coping styles. These can affect how even the strongest family works together.

Open communication between parents 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.

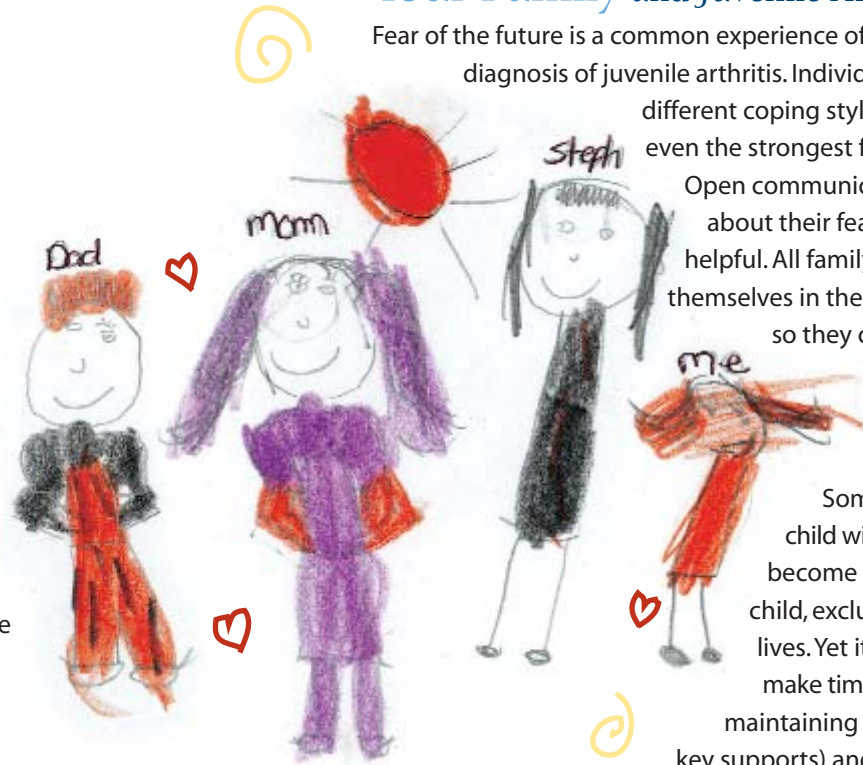
Sometimes the parents of a child with a chronic health problem become overly involved with that child, excluding other aspects of their lives. Yet it’s important for parents to make time for themselves: exercising,

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, 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 Learning to Cope with Life

As the parent of a child with arthritis, it's important to think in terms of what your child can do. Encourage your child to work within his or her 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 his or her ability. Folding laundry or setting the table are good examples. Let your child dress and undress himself or herself, 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 the disability as an excuse or to his or her 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 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. If the school staff has



Since  early morning joint stiffness may vary in duration from day to day, teachers should be told that your child might sometimes be late. 

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 have found it helpful to teach their child's classmates about arthritis. Getting them involved – assisting with boots and clothing, holding heavy doors, 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 him or her. Be sure to talk with your child first about what information can be shared with classmates and how he or she 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 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, he or she should be encouraged to participate in activities and set his or her 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 son or daughter 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, 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 health-care system.

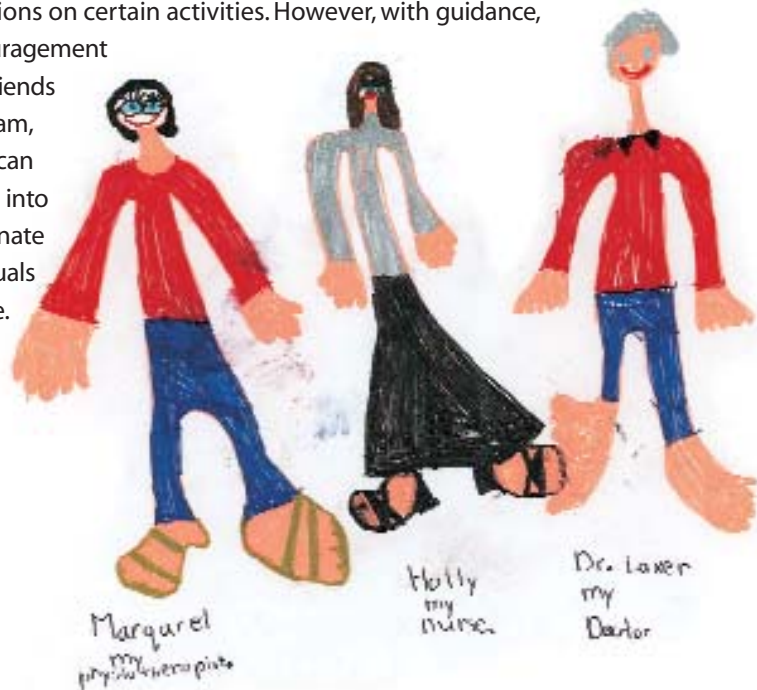
A group of diverse teenagers, including boys and girls of various ethnicities, are posing together in a pyramid formation. They are smiling and looking towards the camera. Some are wearing athletic gear like caps and tank tops.

It's important to encourage older children to assume more responsibility for taking their medications on time.

A Note to Parents and a Word of Encouragement

Parents 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. Your local branch of The Arthritis Society 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. 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. 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.



Common Arthritis Terms

I. GENERAL

Arthritis: Inflammation of the joint ("arth" 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 usually affects boys over the age of 10 and can affect the back.

Flare (or flare-up or exacerbation): The term used for those times when arthritis 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. It may respond the wrong way to infection or mistakenly identify something as infectious or foreign, causing 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 Arthritis (JA): The term commonly used to describe chronic arthritis in childhood. JA generally has a much better outcome and is very different from adult rheumatoid arthritis.

Leg-Length Discrepancy: A difference in the length of the two legs that may be caused when arthritis affects one knee more than the other, causing the more affected leg to grow faster.

Morning Stiffness: Joint stiffness occurring after the joint has been kept immobile overnight. The duration of the morning stiffness is one indication of how much inflammation the child has in the joints.

Oligoarticular Juvenile Arthritis: A form of JA in which four or fewer joints are affected.

Polyarticular Juvenile Arthritis: A form of JA in which five or more joints are affected.

Prognosis: The best estimate of the course of a disease and how its progress may affect a child's growth and development.

Psoriatic Arthritis: A form of JA in which arthritis occurs in association with psoriasis (scaly, red rash).The arthritis may start before the skin rash.

Remission: A term used to describe the times when the arthritis seems to have disappeared.The first remission may be permanent,and the child may never have arthritis again.

Synovium: The inner lining of the joint that produces synovial fluid, bathing and nourishing the cartilage. In JA, it is actually the synovium which is inflamed.This is called synovitis.

Systemic Juvenile Arthritis: The form of juvenile arthritis that also produces high fevers, a rash, swollen glands and an enlarged liver and spleen. It may involve inflammation of the lining of the heart or lungs.

Tendon: A band of tough, rope-like tissue that attaches muscle to bone, so muscles can move the joint.

Uveitis (also known as iritis or iridocyclitis): Inflammation inside the eye(s) that can cause damage to the iris, without any pain or evident redness.

II. MEMBERS OF THE HEALTH-CARE TEAM

Dietitian: A member of the health-care team who specializes in the evaluation of nutrition, ensuring an appropriate dietary program best suited to the individual child's needs.

Occupational Therapist (OT): A specialist who will help your child adjust to the demands of living, school and play. An OT can show your child how to perform ordinary tasks and activities with ease of movement and minimal pain and discomfort. When necessary, an OT can also provide your child with devices (such as modified pencils and eating utensils) to make things easier.

Ophthalmologist: A medical doctor with specialized training in the examination, diagnosis and treatment of eye diseases.

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, 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 the exercise program for your child.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 child's needs.

Psychologist: A member of the health-care 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 health-care team who specializes in helping you and your family adjust to a chronic disease. Social workers also have particular expertise regarding community resources (for example: educational, transportation, financial) that can benefit you and your family.

III. COMMON LABORATORY AND DIAGNOSTIC TESTS

ANA (antinuclear antibody): A protein detected by a blood test that is useful for identifying children who are at risk of developing uveitis (inflammation of the eye).

Arthroscopy: A procedure done while the patient is under general (or occasionally local) anesthetic. A small tube is inserted into the joint, allowing the surgeon to actually look inside and take a small snip of synovium (this procedure is called a biopsy). Arthroscopy is sometimes needed to help diagnose the cause of the child's arthritis.

CRP (C-reactive protein): A blood test that often is a measure of the total inflammation in the body.

ESR (erythrocyte sedimentation rate): A blood test that often is a measure of the total inflammation in the body.

HLA B27: A genetic marker that may be helpful in diagnosing enthesitis-related arthritis.

MRI: A type of X-ray (but without radiation) that examines joints and surrounding structures using magnetic fields. Excellent pictures of the inside of the joint are obtained. The test takes about one hour, and the child has to lie still. Sometimes the doctors and nurses in the MRI unit will have to give your child a mild sedative to allow them to remain still for the test.

Rheumatoid Factor: A blood test that is positive in adults with rheumatoid arthritis and in a very few older children who have polyarticular JA.

Slit-Lamp Examination: A special eye exam given by an ophthalmologist / optometrist to check for uveitis. The exam is painless and simply requires having the patient put their chin on the chin rest of a machine that shines a special light into the eye.

IV. COMMONLY USED TREATMENTS AND MEDICATIONS

Anti-Inflammatory: A medication that helps to reduce inflammation in the joints.

Insoles: Devices placed in shoes to keep the foot in a position of improved function.

Lift: A raise put in or on the shoe worn on the shorter leg, so the legs are of equal length when walking.

Orthotics: A term that includes devices that keep bones and joints in good positions (for example: splints, insoles).

Splints: Devices made of special plastic designed to help hold joints in the proper position during day or evening activities.

V. OTHER DISORDERS TREATED IN A PEDIATRIC RHEUMATOLOGY CLINIC

Dermatomyositis: A disorder with inflammation of the muscles and skin that results in muscle weakness.

Fibromyalgia: A painful disorder defined as generalized aching in many areas of the body, with specific tender spots that hurt when pressure is applied.

Growing Pains: A disorder in which young children awake during the night complaining of severe calf, shin and thigh pains. There is no relation to growth. Arthritis does not occur together with growing pains.

Lyme Disease: A disease caused by a bacterium transmitted by a tick bite. The arthritis of Lyme disease is usually mild and short in duration.

Reactive Arthritis: A form of arthritis that occurs one to several weeks after an infection somewhere in the body other than in the joints. This form of arthritis is usually of a short duration.

Rheumatic Fever: An inflammation of the joints and heart that is a complication from an infection with the bacteria streptococcus (or "strep") that infects the throat.

Systemic Lupus Erythematosus (SLE or Lupus): A chronic, rheumatic disease, which causes inflammation of the body's tissue and can affect any organ of the body. Arthritis is common in SLE.



