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Printed in Canada
HUM/2603A01 – March 2014



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Juvenile Idiopathic Arthritis

A guide to your condition and its treatment

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You've been diagnosed with juvenile idiopathic arthritis (JIA)

In addition to information about JIA, this guide covers current medications and other important elements of treatment, such as physiotherapy and occupational therapy.

It also includes sections about lifestyle and other topics such as the special needs of teenagers with JIA. **Let's get started ..➤**

So you probably have a lot of questions.

This booklet is designed to answer many of those questions.

The idea is to help you and your family understand the information and get as involved as possible in making the most of the chosen

treatment plan. But the information may at times be technical,

so be sure to read it over with a parent, and to ask your health care team any questions that come up.



Many people think arthritis is an older person's disease. The facts tell a different story: about one in 1,000 Canadian children has JIA. It is also the most frequently occurring form of arthritis in children.

A coordinated management plan is key

Although there is no cure for JIA, therapies exist and can be effective.

Your rheumatologist plays a central role

After a diagnosis of JIA, your rheumatologist will coordinate the overall treatment plan.

The coordinated management plan may include medication and rehabilitation therapy

- **Medications** help reduce joint swelling, pain and stiffness.
- **Exercise** helps prevent the loss of joint movement and encourages normal growth.

Looking forward

- People who are well monitored and follow the treatment plan from their health care team tend to do well.

Who gets JIA?

JIA affects children aged 16 or younger. In Canada, about 10,000 (one in 1,000) children and teenagers are affected by JIA. Four times as many girls as boys get JIA.

Is JIA contagious?

No.

Who treats JIA?

A team approach is the best way to treat JIA. Ideally, the treatment plan will be managed by a pediatric rheumatologist (a doctor trained to treat these types of diseases in children). The health care team may also include some of the following specialists:

- Family doctor
- Nurse
- Physiotherapist
- Occupational therapist
- Social worker
- Psychologist
- Dietitian
- Orthopedic surgeon
- Ophthalmologist (or optometrist)
- Dentist
- Teacher

How can others help with JIA?

JIA can affect the whole family. It can also limit everyone's ability to take part in social and after-school activities, and can make schoolwork difficult.

Family members can help by doing the following:

- Learn as much as possible about JIA and its treatment.
- Make sure that the treatment plan is followed closely.
- Think about joining a support group.
- As much as possible, treat everyone in the family equally.
- Encourage exercise and physical therapy.
- Work closely with the school.
- Keep the lines of communication open.
- Work with therapists and/or social workers.

What is JIA?

JIA is medically defined as continuous inflammation in a child aged 16 or younger of one or more joints lasting at least six weeks for which no other cause can be found.

Greek origin of the word “arthritis”

The word arthritis means inflammation of the joint (“arth” meaning joint and “itis” which means inflammation).

Inflammation...

...is a medical term used to describe pain, stiffness, redness and swelling. With an inflammatory type of arthritis like JIA, a person’s own immune system (antibodies) attacks tissue in the lining of the joint, causing it to feel warm, stiff, swollen and, often, painful.



How does JIA affect the joints?

In a healthy joint

- A sac called the articular capsule surrounds the space between two bones.
- The inner lining of this sac is called the synovial lining. This lining makes a fluid that keeps the joint slippery; similar to the way motor oil keeps the parts of a car engine working properly.
- The ends of the bones are covered with a smooth substance called cartilage which allows the bone ends to glide easily across each other.

In arthritis

- Changes in the immune system cause the synovial lining to become inflamed and thicker.
- Extra fluid with inflammatory cells is made. These cells produce and release substances that can cause the symptoms of joint inflammation.
- The results are redness, swelling, warmth, stiffness, and pain. If left untreated, joint inflammation can damage the cartilage and underlying bone.



What causes JIA?

JIA occurs when the body's immune system attacks its own cells and tissues.

The immune system seems to be overactive. It could be overreacting in response to an infection, or treating something as an infection when it's not. Whatever the reason, there is a continuous inflammation in the tissues of joints.

.....> **JIA is NOT caused by...**

...a disease or an infection either parent may have had. It's also not connected to anything that may have happened during pregnancy. JIA is not caused by eating the wrong foods, and there's no medical proof that JIA can be improved by any specific diets.

A rash and a fever can accompany JIA; however, the disease is not contagious. JIA is not passed from generation to generation, and arthritis is almost never passed from a parent to a child.

Diagnosis of JIA

JIA can be difficult to detect and may be missed by even the most experienced doctor. Usually, the steps leading up to a diagnosis of JIA are as follows:

History

- Your doctor will interview you to obtain a complete health and symptom history.

Physical exam

- Your doctor will perform a physical exam to look for signs of joint swelling or loss of mobility, which indicate the joints are inflamed.

Lab tests

- To determine the type of arthritis and whether there is a risk of developing a more severe type of arthritis or developing inflammation in other joints and organs.
- **Erythrocyte sedimentation rate (ESR):** Sedimentation rate is the speed at which red blood cells settle to the bottom of a tube of blood. An elevated rate may indicate inflammation.
- **C-reactive protein:** Measures levels of general inflammation in the body.
- **Anti-nuclear antibody:** Proteins often produced by the immune system of people with certain autoimmune diseases, including arthritis.
- **Rheumatoid factor:** An antibody that is frequently found in the blood of adults who have rheumatoid arthritis.
- **Cyclic citrullinated peptide (CCP):** Like the rheumatoid factor, the CCP is another antibody that may be found in the blood of adults with rheumatoid arthritis.

.....> **In many people living with JIA, the results of these blood tests will be normal.**

Diagnosis of JIA

Imaging scans

- X-rays
- Bone scan
- Bone density test
- Ultrasound
- Magnetic resonance imaging (MRI)

...> **After diagnosis of JIA, monitoring is important.** After diagnosis, 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 prescribed medication. Your doctor will let you know how frequently the routine tests need to be done.



Signs and symptoms of JIA

The most common signs and symptoms of JIA are listed below:

- **Pain:** While you may not actually complain of your joint pain, your parents may notice that you are limping – especially first thing in the morning or after a nap.
- **Swelling:** Joint swelling is common and is usually noticed first in larger joints like the knee.
- **Stiffness:** You and your parents may notice that you are clumsier than usual, mainly in the morning or after a nap.

...> **JIA can affect one or more joints.** In some cases, JIA affects the entire body (including swollen lymph nodes, rashes and fever). Symptoms flare up at times and go away at other times.

Complications of JIA

A few serious complications can result from JIA:

- **Eye problems:** Some forms of JIA can lead to eye inflammation (uveitis). Untreated, this condition may result in cataracts, glaucoma and even blindness.

...> **Eye inflammation frequently occurs without symptoms, so it's important to have your eyes checked regularly by an ophthalmologist (eye doctor).**

- **Changes in growth patterns:** JIA can affect growth and bone development.

Members of your health care team

Tracking the pattern of JIA is important

Once the disease has formed a pattern, the health care team will be better able to give you a general idea of the possible future impact of JIA.

Working with the JIA health care team is key

- Working very closely with the JIA health care team is a great way to help achieve the best possible outcome. The team may include: a rheumatologist, family doctor, nurse, physiotherapist, occupational therapist, social worker, psychologist, dietitian, orthopedic surgeon, ophthalmologist or optometrist, dentist and even teacher(s).
- The team members who will be involved in care will depend on the nature of the arthritis and any special needs.

The most important members of the team are you and your family!

With the help and guidance of the team, you and your family can manage your arthritis.

...> **Being proactive counts.** *With JIA, the longer the disease remains active, the greater the risk of joint damage. This is why it's important to seek treatment early to help achieve the best possible outcome.*

Treating JIA

You and your family's attitude and emotional response to JIA and the treatment plan are very important.

Persistence is important

Persistence with prescribed treatment and a positive approach from you and your family are the keys to success.

Everyone has unique needs and reactions

Aims of therapy

- Achieve normal physical, social and intellectual development.
- Achieve and maintain an acceptable and functional range of joint movement.
- Attend school regularly.
- Relate to other kids.
- Be a happy and productive member of society.



Although there is no cure for JIA, there are medications that can reduce the inflammation and relieve the pain and swelling.

For best results, medications must always be taken regularly and exactly as prescribed.

Typical medications used for JIA include:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs)**
 - Used to reduce pain and swelling.
 - NSAIDs are available in a liquid or pill form.
 - Some are available over the counter at the pharmacy while others need a prescription.
- **Disease-modifying antirheumatic drugs (DMARDs)**
 - DMARDs are used when NSAIDs alone fail to relieve symptoms of joint pain and swelling.
 - May be taken in combination with NSAIDs.
 - Several DMARDs may be combined together to manage severe cases of JIA.
 - DMARDs can be administered orally or as an injection under the skin (subcutaneously or SC).
 - DMARDs are available by prescription.

- **Biologic agents**
 - Help reduce the symptoms and inflammation that can cause joint damage.
 - Used when other treatments have not controlled the disease adequately.
 - Biologics are either injected under the skin (subcutaneously or SC) or infused in a vein in the arm (intravenously or IV).
 - Available by prescription.
- **Corticosteroids**
 - Corticosteroids (also known as steroids) are anti-inflammatory drugs.
 - Corticosteroids may be administered by mouth or by injection directly into a joint.
 - Available by prescription.

Physiotherapy and occupational therapy

Physiotherapists and occupational therapists design exercise programs that help keep joints flexible and maintain range of motion and muscle tone. Such a program helps maintain physical abilities so you can participate in school, sports and recreational activities.

With a proper exercise program, a therapist can help:

- Reduce pain and stiffness.
- Help keep muscles strong and flexible.
- Offer advice about exercise, activity and rest.
- Discuss approaches to protect joints.
- Provide advice to teachers and coaches about arthritis.
- Offer instruction on the use of splints, orthotics and proper footwear.

The specialist may also recommend using splints and other devices to help maintain normal bone and joint growth.

Comfort measures

Heat and cold are often used to manage arthritis pain and discomfort.

Using heat

Taking a warm shower and using warm packs help reduce pain and stiffness.

Heat can help:

- Relieve pain.
- Relieve muscle spasms and tightness.
- Enhance range of motion.

...> **Heat should NOT** be applied to an already inflamed joint since it can make the symptoms worse.

Using cold

Using a commercial cold pack or a homemade one (from crushed ice, ice cubes or a bag of frozen vegetables) can help relieve certain symptoms. Cold can help:

- Reduce swelling.
- Decrease pain.
- Limit blood flow to an inflamed joint.

...> **Always use** a protective barrier, such as a towel or cloth between the warm or cold pack and the skin.

Splints

An occupational therapist or physiotherapist may recommend the use of splints which may be worn during the day or at night. Splints are often used for the wrists, knees or in shoes (foot orthotics). Splints help:

- Reduce pain.
- Rest or support a swollen or sore joint(s).
- Position and stretch a joint.
- Provide support during activity.

Exercise and physical activity

Therapy exercises, given by a physical or occupational therapist, may be needed right after diagnosis or during a period of increased disease activity (a flare).

When joints are actively inflamed, the exercises will focus on pain relief and gentle range of motion. Further exercises to stretch and strengthen can be done when the inflammation improves.

Exercises prescribed by a therapist as well as regular daily physical activity help:

- Keep muscles and bones strong and joints flexible.
- Decrease pain.
- Improve confidence, mood, energy and sleep.
- Improve or maintain fitness levels.

...> Tips

- Change positions often.
- Get up and stretch at home and at school.
- Take rest breaks when you are tired or sore. Frequent, short periods of activity are just as good as longer ones.
- Limit activities on days when you are sore.
- Avoid activities such as running, jumping and hopping when your joints are swollen or sore. Swimming, walking and tricycle or bike riding can be done even if you are feeling sore.
- Avoid carrying heavy books or bags.
- Ask for a second set of school books to be used at home.
- If you use a knapsack, make sure it goes over both shoulders.

Rest

Although extra rest can be needed when JIA is very active, moving around and stretching is important even during periods of inflammation.

...> **Bed rest is NOT recommended.** *It can lead to stiffness and loss of mobility.*

For sleeping...

A supportive mattress and one pillow for the neck are best.

Relieving morning stiffness

Stiffness from JIA is common first thing in the morning or after sitting for long periods.

There are several ways to help relieve stiffness:

- Hot bath or shower.
- Hot pack or heating pad.
- Range-of-motion exercises.

If you are like most kids, you'll prefer warmth – but your joints may prefer cold treatments (see the section on “Comfort measures”).

Be patient! Improvement can take time

- Some medications can take two to three months for you to see the full effect.
- Even the benefits of exercise will take time.
 - At first, the exercises may be painful.
 - It may mean constant, even annoying reminders.

...> **Stay positive.** *Make sure to share your doubts, fears and questions with your parents, family, friends and/or caregivers. This can help you and your family keep up the positive attitude that is key for the best possible outcome.*

Surgery

Surgery is not common, but may be needed after many years of severe JIA.

Surgery is used to:

- Relieve pain.
- Straighten out a bent or deformed joint.
- Restore mobility.
- Replace a damaged joint.
- Lengthen tendons and ligaments around joints, such as the hips.

Eye surgery may be needed if you develop a complication, such as:

- Cataract (cloudiness in the lens of the eye)
- Glaucoma (high pressure inside the eye)
- Band keratopathy (calcium deposition on the surface of the eyeball caused by uveitis)

Dental care

If arthritis has severely affected the jaw, there could be poor chin growth. This may require a visit to an orthodontist who may recommend a splint to be worn in the mouth.

...> **Alert your dentist to JIA. JIA of the jaw can make complicated dental work a problem. Make sure to tell your dentist that you have JIA. You should also practice good dental care.**

Adolescents

Adolescence can be a challenging time for everyone. Teenagers have an increased desire for independence and want to fit in with their peer group.

Having a chronic disease like JIA, needing to miss classes or activities for appointments and taking medications may increase feelings of being different from peers.

...> **Friends and social support. It's important to pursue and enjoy active friendships, as these can help during difficult times.**

Being independent means taking responsibility...

It's also important to assume more responsibility for your JIA:

- For taking medication on time
- Reporting any joint symptoms or medication side effects
- Following an exercise program

Your doctor will help you decide what to do next

We hope you have found this information helpful and suggest that you speak to your doctor and the rest of your health care team about the most appropriate treatment for your condition. Don't hesitate to ask questions and get involved in decision-making regarding your JIA. And keep in mind there are many options available to you, so if one approach doesn't work, another one might.

Suggested resources

For more information about JIA, visit:

Canada

The Arthritis Society
www.arthritis.ca

SickKids
www.aboutkidshealth.ca/En/ResourceCentres/JuvenileIdiopathicArthritis

International

National Institute of Arthritis and Musculoskeletal and Skin Diseases
www.niams.nih.gov

Arthritis Foundation
www.arthritis.org

Pediatric Rheumatology International Trials Organisation
www.printo.it/pediatric-rheumatology

