

JUVENILE IDIOPATHIC ARTHRITIS



ARTHRITIS 
NEW ZEALAND

ENABLING A BETTER QUALITY OF LIFE

KAIPONAPONA AOTEAROA

Te whakapiki i te kounga ora



ARTHRITIS NEW ZEALAND

FINDING OUT YOUR CHILD HAS JUVENILE IDIOPATHIC ARTHRITIS (JIA).



INFORMATION FOR PARENTS, FAMILIES AND CARERS.

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HOW DID MY CHILD GET THIS DISEASE?

The causes of arthritis in children are unknown. Research suggests that for some types of JIA, genetics may be involved. However, these conditions are not regarded as hereditary. So if you have one child with arthritis, it does not mean that your other children will also have arthritis. It also does not mean that your child's children will develop JIA.

Another theory is that some form of infection may trigger the start of JIA. Dietary and emotional factors do not appear to play a role in the development of JIA. JIA cannot be spread from one child to another. It is not infectious.

ARTHRITIS IN CHILDREN IS AN AUTOIMMUNE ILLNESS.

While the cause is still unknown, there is nothing you could have done to prevent it.

What we know is that JIA is an autoimmune illness where, for unknown reasons, the immune system becomes confused and attacks normal healthy cells of the body rather than invading foreign bodies such as bacteria or viruses.

The cells the immune systems attacks (called connective tissue) are those that make up the lining of the joints (synovium).



As these types of cells also exist outside of the joints, JIA can affect other parts of the body as well.



DIAGNOSIS

There is no single test to diagnose JIA. Instead, it involves a number of steps. These include:

- Taking a detailed medical history of the child and their biologically related family members (where possible)
- Physical examinations
- Laboratory tests (eg. Blood and urine)
- Other tests such as x-rays of the joints

Some tests may be ongoing or have to be repeated several times. This helps the doctor look for changes to your child's symptoms over a time period.

If JIA is suspected, your child should be referred to a Rheumatologist (ideally a specialist in paediatric arthritis) who would confirm the diagnosis and then start treatment. Reaching a diagnosis can take time, and the 'waiting period' can be very frustrating. This is understandable, but it is important to keep on with the process until the diagnosis is made. The rheumatologist can then make sure that your child receives the best treatment to manage the symptoms and reduce the potential damage caused by JIA.

Remember, if you feel it is needed, you can seek a second opinion by asking your GP for another referral.



IS JIA CURABLE?

With appropriate management, most children with JIA will grow up without any lasting effects of their arthritis. However, it is not possible to determine who will or will not 'grow out' of their arthritis. For this reason, good medical care is vital for all children with any form of JIA.

Good overall care, both during and between flares, can minimize the effects of illness and help keep lives as 'normal' as possible, now and in the future.

The outlook for children with JIA is usually very positive. The good news is that most children with JIA will not have active symptoms by the time they become adults.

EVERY RESPONSE IS DIFFERENT

Each child has a slightly different illness that may respond differently to treatment. It is difficult to know how the arthritis will specifically affect your child. However, the treatments for JIA are constantly improving. There is still no cure for JIA, but for many children, treatment can cause the symptoms to disappear for a long period, if not forever. This is called remission.

For most children with JIA, the effects of their illness can be reduced to the point where they go on to a healthy adult life. For some, JIA can cause longer term problems, especially if they do not receive the right care for their joints and muscles. There is no way to predict which outcome your child will have. Some forms of JIA have a greater chance of permanent remission. Your child's rheumatologist can give you more information about this.

'FROZEN' JOINTS AND OSTEOPOROSIS

Arthritis affected joints that are not kept mobile can stiffen into abnormal positions and then will no longer work properly. This can also lead to joint damage and severely restrict your child's ability to do most normal daily activities for the rest of their life.

Children who have JIA are also more likely to experience a thinning of their bones as they get older. This is a condition called osteoporosis and it results in the bones being susceptible to breaking or fracturing.

Everyone is different and what works for one child may not work for another. Over time you will learn to understand how your child's JIA affects them and the non-verbal indicators of how they are feeling.

A small number of children with JIA may need to continue taking the medicines to control their arthritis into adulthood. Some may also need to have surgery if the damage to their joints becomes too severe or restrictive. This may include joint replacements, joint fusions, the realignment or reconstruction of damaged joints and surgery to release joints that have "frozen". Your child's rheumatologist can give you more information about this.



WHAT ARE THE NEXT STEPS AFTER DIAGNOSIS?

MEDICAL TESTS

At some point, your child will be asked to have a number of tests as part of the diagnosis or management of the arthritis. There is nothing to be alarmed about, these are routine. Some of the more common tests include:

- **FBC – Full Blood Count.** A blood test to check for anything abnormal that might be important in managing the illness.
- **RF – Rheumatoid Factor.** An antibody detected by a blood test. This is an indicator of the kind of JIA your child has.
- **ESR – Erythrocyte Sedimentation Rate.** A blood test that detects how much inflammation there is in the body.
- **CRP – C-Reactive Protein.** This is also a test that detects inflammation.
- **ANA – Ant-Nuclear Antibody.** This test is used to do two things. It helps identify the type of arthritis your child has and it is an important indicator for your child's risk of developing eye problems.
- **X-Ray** – Takes pictures of your child's joints to see how they change with time.
- **MRI OR CT SCANS.** They do much the same as X-ray but in greater detail. They can also show changes in non-bone structures around the joints (like ligaments and tendons).
- **HLA-B27** – A blood test that helps determine the type of arthritis that your child may have.



GOING TO HOSPITAL

Children with JIA may need to go into hospital from time to time. Your child's rheumatologist usually suggests this when special care is needed; it is not likely to be due to an emergency.

The management of JIA is a team approach. Take guidance from all members of the team to make the best decisions for your child.

MANAGEMENT AND TREATMENT OPTIONS

There are many different treatments available for JIA. What works for one child may not work for another. Finding the right treatment for your child can involve a process of trial and error. While this can be frustrating for all involved, it is important that you stick with the process to ensure your child gets the best possible treatment for their particular type of arthritis.

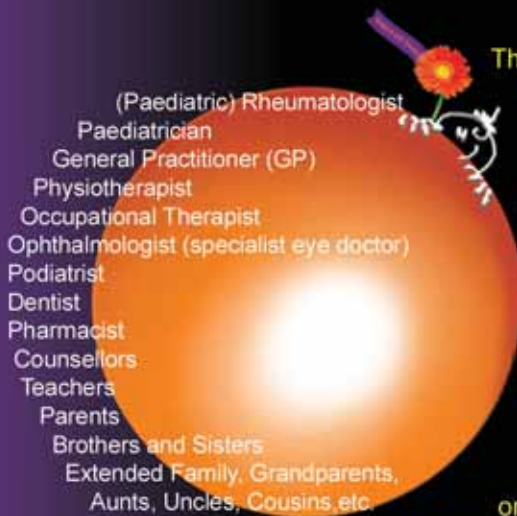
This process may need to be repeated if your child experiences a progression of the illness, a flare-up or just because their body has become use to a certain medicine and it no longer works as well as it did. Ultimate goals include putting the illness into remission and giving your child the greatest chance of entering adulthood with as little joint damage as possible.

The aim of any JIA treatment or management plan is to:

- Reduce the symptoms (such as stiffness, pain and inflammation).
- Enable your child to lead the most normal life possible.
- Slow or stop the progression of the illness.

THE TEAM APPROACH

To achieve the best possible outcome, the management of your child's arthritis will involve a team effort. This team may include:



The make-up of your child's team will depend on the type of JIA, how active the disease is, what joints are involved, and how the illness is impacting on your child's well being.

Your child's rheumatologist will usually coordinate this team, but other team members may also recommend specialists or healthcare professionals that they feel would help your child.

THE IMPORTANCE OF EXERCISE AND PLAY

Exercise is important for good health in all children, including those with JIA. However, the wrong exercises can result in increased pain, and cause further joint damage. Your child's doctors and therapists can advise you on suitable exercises.

Swimming can be excellent as the buoyancy provided by the water takes most of the weight off the painful joints, and allows greater freedom of movement. Swimming can improve muscle strength and joint movement. Added to this, in water your child doesn't feel as if they are exercising. It's fun and they can do it with friends and family. Warm water pools or spas are best as the warm water also helps the muscles relax.



Overall, your child should be encouraged to live their life as normal as possible. This helps increase their self-esteem and feelings of control over their illness. Bad experiences do not always mean that you should stop any particular activities. Talking with your child about possible changes is always recommended. This shared decision making adds to the child's feelings of control over the disease and their commitment to the path ahead. Ideally, the eventual goal is to teach the child to manage their own illness.



THE IMPORTANCE OF REST

JIA can cause tiredness, so it is important that your child gets rest, including a good night's sleep and maybe a rest period during the day.

Rest does not necessarily mean lying in bed. Rest can be listening to music, reading a book, drawing a picture or any other non-physical activity. Alternating between active and passive activities throughout the day can help your child to participate in their normal daily routines.

MEDICINES

Medicines play a major role in the management of JIA. Some are tablets taken by mouth, while others are given as an injection. In some cases this injection may be directly into the joint. Medicines are a major part of the treatment of JIA and your child may need to take more than one type of medicine.

PRESCRIPTION MEDICINES

Most medicines will need to be prescribed by your child's doctor. But some, such as simple pain relievers, may be purchased at a pharmacy or supermarket ('over-the-counter').

The medicines used to treat JIA aim to:

- Alter or slow the progression of the illness
- Control inflammation
- Relieve pain
- Reduce fever
- Reduce other symptoms of the disease
- Assist in the maintenance of your child's 'normal' growth.



As a parent you may feel anxious about the prospect of your child taking these medicines. This is natural and understandable. Your child may not want to take these medicines either, particularly when their symptoms improve. However, many of the medicines used today not only reduce the symptoms but also slow the progress of the illness. For these medicines to be effective, it is important they are taken exactly as your child's doctor prescribes. Many of them need to continue even when the child's symptoms improve so that they maintain the improvement and also lessen the risk of damage to the joints.

Like all medicines, they can have side effects. These are usually easily recognised. While your child is on these medicines, the doctors will be closely watching for any of these side effects. To make sure that any potential problems are detected and rectified as early as possible, your child may need to have regular tests, such as blood tests.

You should always tell your child's doctor about any new symptoms or changes in your child as well as anything else that concerns you.

Many of the medicines used today not only reduce the symptoms but also slow the progress of the illness.





NON-PRESCRIPTION MEDICINES

Some medicines can interact with other medicines. It is important that you tell each doctor or health care professional that your child sees about each and every medicine they are taking, even if the medicine is not being used to treat JIA. This also includes any medicine that is available without prescription, such as 'over the counter' pharmacy medicines, natural, herbal and complementary medicines. *All medicines have benefits as well as side-effects but without medicines, permanent joint damage and a poorer prognosis is more likely.*



Until recently, the medicines that have been available to treat JIA have been limited. However, new medicines are now being developed so that doctors have a much larger choice. As JIA can vary greatly from child to child, the larger number of available medicines means that doctors are now better able to manage each child's specific symptoms over time. The downside is that it can take longer to find the best medicines for your child.

The type of medicine(s) recommended for your child will depend on a number of factors including the:

- Type of JIA
- Severity of the illness
- Child's ability to tolerate the medicine

MOST COMMON TYPES OF MEDICINES USED TO TREAT JIA

PAIN RELIEVERS (ANALGESICS)

Analgesics are medicines that can relieve mild to severe pain by blocking pain signals from being sent to the brain or by preventing the brain from receiving or working out what these signals mean. They typically take effect within ½ to 1 hour of taking the dose. Each dose usually provides relief for between 4 and 6 hours.



These medicines do not reduce the inflammation present in JIA.

Analgesics for milder pain are available as non-prescription (over-the-counter) brands. In the case of severe pain, your doctor will prescribe a pain relief medicine. Your doctor can also advise you which analgesic medicines are appropriate for your child. Analgesics are generally well tolerated and can be used for longer periods as long as they are taken as directed on the pack or by the doctor.

Pain may also be caused by the inflammation itself. A group of medicines called non-steroidal anti-inflammatory drugs (NSAIDs) can be very effective in reducing this form of inflammatory pain. This group of medicines should only be used in children when recommended by your child's doctor. You also need to be careful what cold and flu medicines you give your child as many of these also contain an analgesic or a NSAID medicine.

NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)

NSAIDs are a widely prescribed group of medicines for JIA. They can have significant advantages over analgesics because they can relieve both the inflammation and consequently the pain around the joint. However NSAIDs do not slow the progression of the illness or reduce the risk of joint damage.

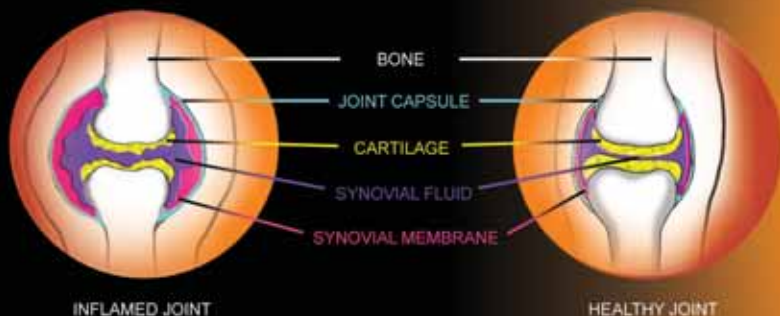
As everybody reacts differently to medicines, your child may need to switch to a different NSAID to find the one that best controls their symptoms with the least side effects. Your doctor or pharmacist can advise you on how these medicines may affect your child.

DISEASE MODIFYING ANTI-RHEUMATIC DRUGS (DMARDs)

DMARDs can slow or inhibit the progression of JIA. Although researchers don't fully understand how some DMARDs work, they believe that they hinder the immune system's attack on joint tissues, which in turn may slow the destruction of joints.

DMARDs are often used as an initial treatment for JIA – in combination with an NSAID. Like NSAIDs, the DMARDs do not stop pain mechanisms, but they do act against the underlying inflammation – and so indirectly reduce the levels of pain.

These medicines can take some time to have an effect on your child's pain and inflammation. It can take several weeks for DMARDs to reach their maximum effectiveness. Your child's rheumatologist will tell you more about this. Providing there are no serious side effects your child will need to stay on the medicine at least that long before its success can be assessed.





CORTICOSTEROIDS

Corticosteroids are man made forms of the naturally occurring hormones produced by the body. They can provide rapid and powerful reduction of pain and inflammation for children with arthritis.

Steroids are sometimes injected directly into the joints for local relief during flare-ups. Steroids are usually prescribed in low dose in tablet form. This type of steroid is quite different to the other types of anabolic steroids used in bodybuilding. You and your child's doctor will discuss and monitor your child's progress while on this medicine.





BIOLOGICAL MEDICINES

These are a class of medicines that have opened the door to a new era in the treatment for JIA. Unlike the older, more traditional DMARDs, these medicines have been developed specifically for the treatment of arthritis. These medicines are injected just below the skin or they can be injected directly into a vein using a slow infusion (a specialized infusion bag on a stand).

Biologic medicines work by directly targeting the inflammatory process that has become over-stimulated and is attacking the joints of children with arthritis. Some biologic medicines do this by blocking the effects of a chemical called tumor necrosis factor alpha (TNF- α). This is a protein found naturally in the body that helps control the cells involved in causing inflammation. In healthy children the level of TNF- α in the joints is balanced, but for children with JIA the level of TNF- α can increase dramatically.

Etanercept is the first and currently only, biologic medicine approved for JIA in New Zealand. This medicine has significantly changed the ability to treat JIA.

Etanercept is approved for the treatment of severe active polyarticular-course juvenile chronic arthritis, but only in children (aged 4-17 years) who have had an inadequate response to one or more of the non-biologic older DMARDs.

Etanercept is subsidized through the Pharmac for patients who meet the qualifying criteria. Your doctor can give you a lot more information on this.

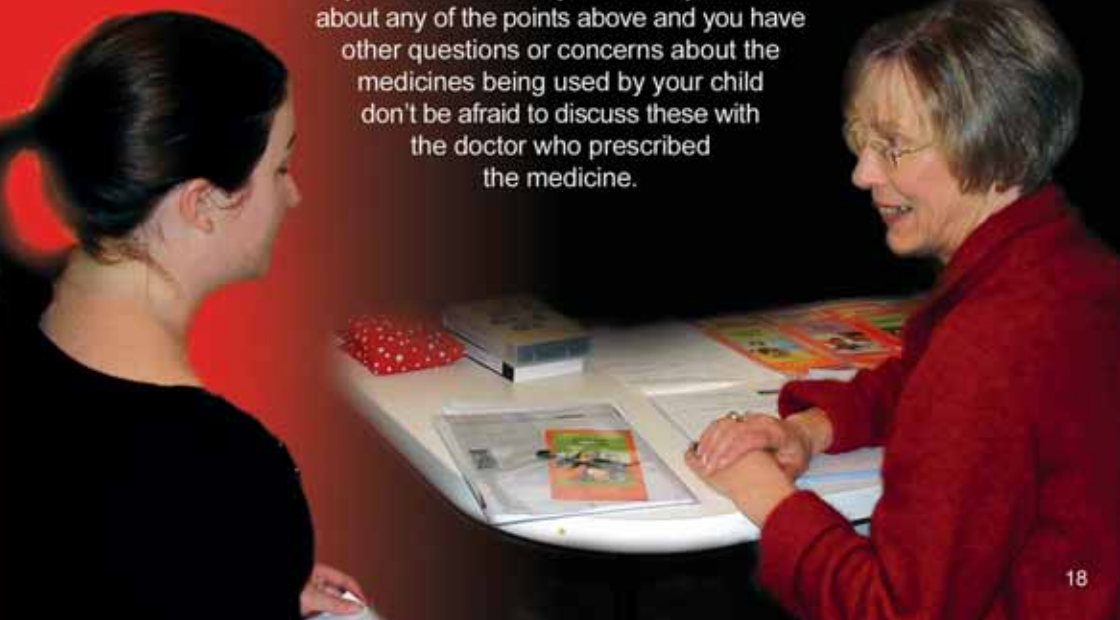


KNOWING ABOUT THE MEDICINES

For each medicine prescribed, your child's rheumatologist should talk to you about:

- Risks and benefits
- What the medicine is called
- Why the medicine is needed and how it can benefit your child
- How it works
- How the medicine should be taken (the dose, frequency, etc.)
- What side effects it may have and what to do if they occur
- What tests (if any) are needed while taking this medicine
- How long it takes to achieve the maximum benefit
- How long your child will need to stay on the medicine
- When and how the doctor will review the progress of the medicine.

If you don't feel that you are fully informed about any of the points above and you have other questions or concerns about the medicines being used by your child don't be afraid to discuss these with the doctor who prescribed the medicine.



MAKE A LIST OF QUESTIONS

It may be helpful to write down your questions as you think of them, rather than trying to remember them at the next appointment.

QUESTIONS



WHERE CAN WE GET MORE HELP?

Your child's doctors and the other members of the healthcare team are the best people to help with questions about your child's JIA. Talking with your doctor, specialist or pharmacist is always recommended.

IMPORTANT TELEPHONE NUMBERS:

RHEUMATOLOGIST:

GP:

PHYSIOTHERAPIST:

PHARMACY:



FOR FURTHER INFORMATION

Contact your local Arthritis New Zealand Centre

Ring our toll free number:

0800 663 463

Visit the Arthritis New Zealand website:

www.arthritis.org.nz





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