



Enthesitis-related juvenile idiopathic arthritis

- Kids and teens get arthritis too – it's called juvenile idiopathic arthritis (JIA)
- There are several different types of JIA
- Enthesitis-related juvenile idiopathic arthritis causes one or more joints to become swollen and painful
- It's important you understand as much about your condition and treatments as possible so that you know what's happening and can be in control

Arthritis can affect anyone – from the very young to the very old. But the good news is that it can be treated well, and you can get on with doing the things you enjoy doing.

Juvenile idiopathic arthritis is a group of conditions that affect kids and teens under the age of 16. It causes one or more joints to become red, swollen, hot and painful for 6 weeks or more. There are several different types JIA.

You have enthesitis-related juvenile idiopathic arthritis.

That's a bit of a mouthful, so we'll call it ERA JIA for short.

To better understand your JIA, you need to understand a bit about how your joints and your immune system works.

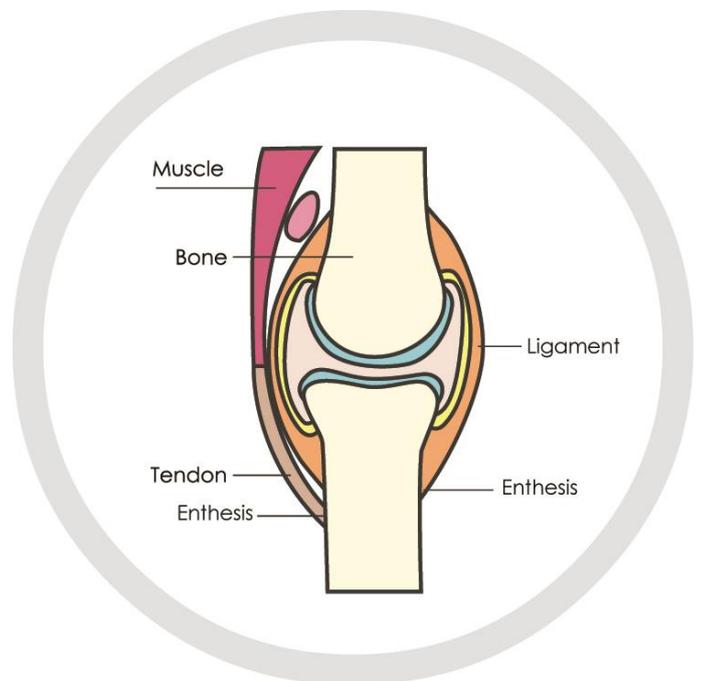
Your joints

Joints are places where bones meet. Bones, muscles, ligaments and tendons all work together so that you can bend, twist, stretch and move about.

The ends of your bones are covered in a thin layer of a smooth tissue called cartilage. It acts like a slippery cushion that helps your joint move smoothly.

Around most of your joints is a joint capsule. This keeps your bones in place. Inside the capsule is a thick fluid which nourishes and lubricates your joint (like oil for a squeaky hinge).

Ligaments hold the joint together by joining one bone to another. Your muscles are attached to the bones by tendons. As your muscles contract, they pull on the bones to make the joint move.



Entheses are the tissues that connect your ligaments or tendons to your bones.

Your immune system

There are many different types of immune cells and proteins doing many different jobs to protect you against disease and infection. When your body detects the presence of germs, such as a bacteria or virus, your immune system springs into action and defends your body against these invaders. Once they deal with the germs, they switch off. And everything goes back to normal.

However sometimes with conditions like ERA JIA, the immune system gets a little confused and attacks the healthy tissues it's supposed to protect, including your joints, tendons and entheses. Your immune system launches an attack and doesn't stop.

What is ERA JIA?

Let's break the name up so we can understand more about your condition.

- **Enthesitis-related** means that your type of arthritis is related to your entheses – or the tissue that connects your ligaments and tendons to your bones. The 'itis' part of enthesitis means inflammation. So enthesitis means inflammation of your entheses.
- **Juvenile** means that your condition affects people under the age of 16 years.
- **Idiopathic** means that we don't know what causes the condition to occur.
- **Arthritis** means inflammation of the joint.

When you put it all together, enthesitis-related juvenile idiopathic arthritis is a condition where one or more of your joints becomes red and swollen and your entheses will also become inflamed.

ERA JIA most commonly affects:

- boys (however girls can develop it)
- people aged between 9 and 12 years.

Most people who develop ERA JIA will have a positive blood test for the genetic marker HLA-B27. However some people can be positive for HLA-B27 and not develop ERA JIA. And some people can have ERA JIA and not be positive for HLA-B27. It's a bit confusing! But it's one of the things your doctor will check, to help them diagnose your condition.

What are the symptoms?

The symptoms experienced by people with ERA JIA varies. No one experiences the exact same set of symptoms. However it's important to be aware of different symptoms so that if you notice them, you can discuss them with your doctor.

Symptoms of ERA JIA include:

- pain and inflammation in one or more of your joints, usually in your hips, knees, ankles, feet
- inflammation of your entheses, most commonly in the knees, heels and bottom of your feet
- joint stiffness, especially when you get up in the morning
- an eye condition, called acute anterior uveitis, that makes your eye red, painful, watery and sensitive to light
- back pain and stiffness - some people develop this over time.

At times you may go through a period where your JIA is more painful, you experience more inflammation and fatigue (or tiredness). This is called a 'flare'. We don't always know what causes a flare, but we do know that

stress or an illness can trigger one. Flares are temporary, and will need to be managed by your doctor. But they can be frustrating and painful while they last.

Remember, everyone's different, and will have different symptoms. You may not experience all of the symptoms listed here. It's impossible to know. If you do notice any changes to your symptoms, talk with your doctor.

Why did I get ERA JIA?

No one knows what causes some people to develop ERA JIA. It's thought that it may be the result of genetic factors (or things you've inherited) and something from your environment (e.g. an infection that hasn't been identified).

Is ERA JIA contagious?

No, your condition isn't contagious. You didn't catch it from anyone, and no one can catch it from you.

What happens now?

You'll need to see your doctor regularly so that they can keep up with how you're doing. You'll see your usual GP for day-to-day stuff. However you'll also see a specialist - a paediatric rheumatologist – who's an expert in conditions that affect muscles, bones and joints.

You won't see your paediatric rheumatologist as often as your GP, but they'll work together to make sure you get the best possible care.

Your GP and paediatric rheumatologist will ask you:

- how you're feeling
- about your pain levels
- if you've had problems with your eyes
- if you're having any other problems (e.g. sleeping, being active, keeping up at school)
- if you're having problems with your medication (e.g. they make you feel unwell, you're forgetting to take them).

They'll also physically check out your joints by looking at them and feeling how they move.

Occasionally you may need to have tests (e.g. blood tests, x-rays) to see how your medications and other treatments are working.

Do I have to take medication?

Most people with JIA – regardless of the type – will have to take some form of medication at some time. It depends on the symptoms you're experiencing. There are many different types of medications that work in different ways.

Your doctors will always start with the simplest medications at the smallest doses and work their way

up to more complex medications and larger doses depending on how your JIA responds to the treatments.

Medications may include:

Pain relievers (or analgesics) - medications like paracetamol can provide temporary pain relief.

Non-steroidal anti-inflammatories (NSAIDs) - there are over-the-counter NSAIDs that you can buy at the pharmacy or supermarket, as well as prescription NSAIDs. They work to help control inflammation and provide temporary pain relief.

Corticosteroids - these medications are used to quickly control or reduce inflammation. They can be injected or swallowed.

- corticosteroid injections - if a joint is particularly painful and swollen, an injection directly into the joint can help to quickly relieve your pain and inflammation.
- corticosteroids (liquid or tablets) - such as prednisolone, are used in the early days of your condition, or if you're going through a flare, to get the inflammation under control. They do have side effects if used for long periods, so your doctor will closely monitor you while you're taking them.

Disease modifying anti-rheumatic drugs (DMARDs) - this group of medications work on controlling your overactive immune system. They help relieve pain and inflammation, and can also reduce or prevent joint damage. These medications can take months to kick in so you may also need to take other medications to help control pain and inflammation until then. A commonly used disease modifying drug for JIA is methotrexate.

Biologics (bDMARDs) - these newer medications are also a type of disease modifying drug, and they also work on controlling your immune system. However unlike other disease modifying drugs, biologics target specific cells and proteins that are causing the inflammation and damage, rather than hitting your entire immune system.

Depending on your particular symptoms, and how much pain and inflammation you have, you may take one medication or a combination of different medications.

All medications have side effects. Fortunately most of the side effects are mild. You may not even experience side effects. However if you do feel unwell or strange after taking any medications, talk with your parents, doctor or nurse immediately.

What other health professionals will I see?

Apart from your GP and paediatric rheumatologist, you'll work with other health professionals including:

Physiotherapists, or physios, may work with you from time to time to make sure your joints continue to move and work properly. They'll develop an exercise program that's specific to you. This will help you maintain the full range of movement in your affected joints and strengthen your muscles. Physios can also show you different things you can do to help manage your pain.

Occupational therapists, or OTs, help you learn better ways of doing everyday activities. Your JIA might make things like getting dressed and managing at school more difficult. OTs can help you find solutions to these problems.

Ophthalmologist/optometrist, or eye specialists, will monitor your eyes and take care of them if needed.

Podiatrists are experts in feet. If your condition is causing pain or inflammation in your feet, they can help. They can give you advice on shoes that'll be best for your feet, and can provide orthotics if needed. Orthotics are special inserts for your shoes that provide your feet with proper support.

You may also occasionally see other health professionals, especially if you need to talk about your emotions (psychologist or psychiatrist), get help with your diet (dietitian) or get advice on your medications (pharmacist).

All of these people will work together to help you live well with ERA JIA.

What can I do?

Follow your treatment plan. It's extremely important that you follow the plan that your health professionals have developed for you. That means taking your medications as they've been prescribed, doing the exercises your physio and OT have given you, using any gadgets you've been given to help protect your joints, and letting your doctor know of any changes to your symptoms and how you're feeling. All of these things give you a better chance of managing your ERA JIA well and reducing the risk of long-term problems.

Exercise and stay active as much as possible. Exercise has so many health benefits. It helps keep your bones, muscles and joints healthy, improves your mood, can help you sleep better and helps keep you at a healthy weight. It's also fun – especially when you're with friends and team mates.

Know what helps you manage your pain. Try different things so you know what works for you. For example you might find heat packs or ice packs help reduce joint pains, listening to your favourite music relaxes you and helps ease tense muscles, a warm bath or shower gets stiff joints moving and medicines can provide temporary pain relief. Don't rely on just one thing to help you deal with pain – have a few tricks up your sleeve to deal with different situations.

Eat well. While no foods can make your JIA better or worse, having a healthy, well-balanced diet with a wide range of foods is best for overall good health. Eating a nutritious diet will also help you to control your weight. This is important for many health reasons, but when it comes to your joints, being overweight puts extra strain on them, which will add to your pain.

Know what to do when you have a flare. Flares can occur out of the blue, so talk with your doctor and work out a plan for what to do when you have a flare. You may need to do things like take short rest breaks during the day or adjust your medications. Having a plan in place means you'll be prepared and know what to do.

Keep track of how you're going. Write down how your symptoms are, when you feel better or worse, how your activity levels are, if you're getting a good night's sleep, how the medications you're taking are going, and if you have any side effects.

Having this information in one place will help when you visit your doctor. Your doctor will be able to see how you're going and if your treatment is working or needs adjusting. You can write this information in a notebook, or download one of the many apps available for tracking this information.

Talk with your teachers. Many teachers have never met someone with JIA. They may not know that you can feel great one day, and terrible the next. You and your parents can talk with your teachers about how your condition affects you and how it may affect you at school. Your paediatric rheumatology nurse, OT and physio will also be able to provide information to your teachers and school.

Talk with your friends. It's up to you how much you want to tell your friends and classmates about your condition. It can be helpful if your close friends know what you're experiencing as they can be very supportive.

Don't be too hard on yourself and changes to your body. There are some things that you just can't control. Your arthritis may affect how you look from time to time. Some of your joints may look swollen or red and a bit different to how your friend's joints look. Some medications can make you put on a little weight and your face may get puffy. This won't last forever. Just keep following your treatment plan – take your medications, exercise, eat well, go to school and hang out with friends. If you're really worried about these changes, talk with your doctor, your parents or your nurse.

It's ok to feel sad. It's perfectly natural that from time to time you may feel sad, frustrated, anxious or angry about having ERA JIA. If you feel like these feelings are taking over, or they're happening more and more often, talk with someone you trust. This may be a parent, doctor, nurse, good friend, school counsellor, Kids Help Line, headspace or beyondblue. Don't keep these feelings bottled up.

Will I always have ERA JIA?

It's impossible to know whether you'll always have ERA JIA. Some people with JIA do go into remission and their arthritis goes away.

However others will continue to have JIA into adulthood and will need to continue working with their health professionals to manage it properly. This is one reason why it's so important that you understand your condition and your treatments. And that you follow your treatment plan.

The good news is that treatments have become much better and continue to improve. Research into understanding what causes JIA to occur and into finding new and improved treatments is making great progress all the time.

So even if you do have ERA JIA as an adult, there's no reason that it should get in the way of you doing the things you want to do – uni, travel, your dream job, having a family. You can still have a great life with lots to look forward to.

This information sheet was proudly sponsored by an unrestricted educational grant from Abbvie.

More to explore

There are a lot of people, organisations and websites where you can get help and more information including:

- Your parents/carers
- Your doctor
- Your paediatric rheumatologist and nurse
- Musculoskeletal Australia
MSK Help Line 1800 263 265

Websites

- Musculoskeletal Australia
www.msk.org.au
- Arthritis Ireland
www.juvenilearthritis.ie
- Kids get arthritis too (Arthritis Foundation USA)
www.kidsgetarthritis.org
- PainBytes
www.aci.health.nsw.gov.au/chronic-pain/painbytes

Useful resources

- Beyondblue
www.youthbeyondblue.com
24/7 help line 1300 224 636
- Headspace
www.headspace.org.au
9.00am to 1.00am/7 days 1800 650 890
- Kids Help Line
<https://kidshelpline.com.au/teens>
24/7 help line 1800 551 800
- Smiling Mind
Mindfulness and meditation
<https://smilingmind.com.au>
- Arthur's Place
A social network for young adults with arthritis
<http://arthursplace.co.uk>

Apps

- Track and React – Arthritis Foundation (USA)
Available through iTunes and Google Play
- iBeatPain for Teens
Available through iTunes

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