



# Polyarticular juvenile idiopathic arthritis (rheumatoid factor negative)

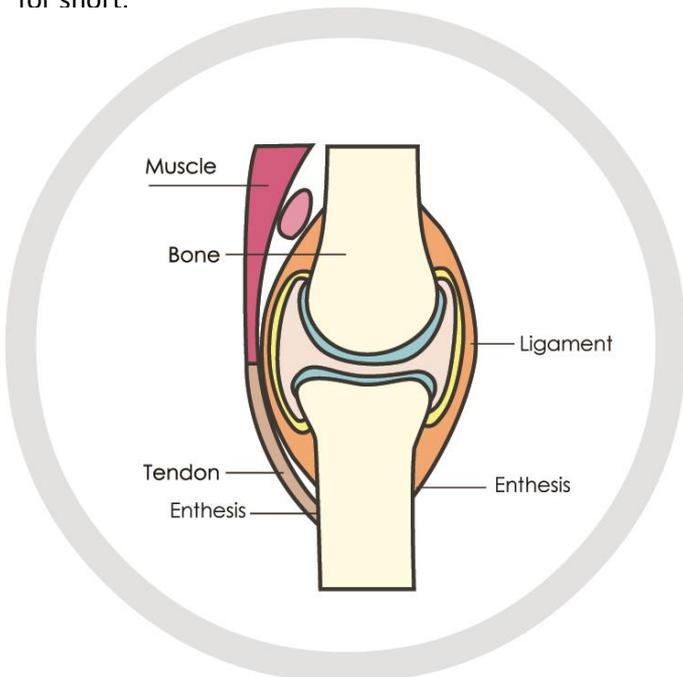
- Kids and teens get arthritis too – it's called juvenile idiopathic arthritis (JIA)
- There are several different types JIA
- Polyarticular juvenile idiopathic arthritis (rheumatoid factor negative) causes five or more joints to become swollen and painful
- It's important you understand as much about 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 of JIA.

You have polyarticular juvenile idiopathic arthritis (rheumatoid factor negative). That's a long and complicated mouthful, so we'll just call it PolyJIA (RF-) for short.



To better understand your arthritis, 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.

## 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 PolyJIA (RF-), the immune system gets a little confused and attacks the healthy tissues it's supposed to protect, including your joints. Your immune system launches an attack and doesn't stop.

### What is PolyJIA (RF-)?

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

- **Poly** means many. In PolyJIA (RF-), five or more of your joints will become red, swollen and painful within the first 6 months of your developing it.
- **Articular** refers to joints.
- **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.
- **Rheumatoid factor** is a protein that the immune system produces that can attack healthy tissue in your body.
- **Negative** means the blood test looking for the protein rheumatoid factor didn't find it present in your body. The absence or presence of rheumatoid factor helps your doctor work out which type of JIA you have and how best to treat it.

So PolyJIA (RF-) is a condition that affects many joints, causing pain and inflammation, and the blood test looking for the presence of rheumatoid factor was negative.

PolyJIA (RF-) most commonly affects girls under the age of 12, however boys can also get it.

### What are the symptoms?

The symptoms experienced by people with PolyJIA (RF-) varies. No one experiences the exact same set of symptoms and to the same degree.

Some people may get a lot of pain and inflammation. Others may not have as much. Some may have lots of joints involved, while others may only have five.

It's impossible to know how your condition will develop over time.

Symptoms of PolyJIA (RF-) include:

- pain and swelling in your joints – especially those in your hands and feet – though it can also affect your bigger joints (e.g. knees, hips)
- different joints affected on one side of the body to the other (e.g. right knee, not left knee, left elbow, not right elbow). This is called asymmetrical
- joint stiffness, especially when you get up in the morning
- inflammation of the tissues surrounding tendons (tenosynovitis) particularly in the wrist, ankle and hand
- an eye condition called chronic anterior uveitis may occur in a small number of people with PolyJIA (RF-)
- a low fever and feeling generally unwell may occur.

At times you may go through a period where your arthritis 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. 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 PolyJIA (RF-)?

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

### Is PolyJIA (RF-) 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'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 (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 can 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 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, particularly if it affects your hands. Some people may also need to use splints (special braces made of plastic or other materials) at times to relieve inflammation and help prevent future joint problems. OTs can help you deal with all of this.

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

**Podiatrists** are experts in feet. Because PolyJIA (RF-) often affects the joints in feet you may need to see a podiatrist. 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 our diet (dietitian) or get advice on your medications (pharmacist).

All of these people will work together to help you live well with PolyJIA (RF-).

### 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 PolyJIA (RF-) 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 (especially the joints in your hips, knees and feet) 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 sometimes 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 PolyJIA (RF-). 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 PolyJIA (RF-)?

It's impossible to know whether you'll always have PolyJIA (RF-). 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, and into finding new and improved treatments is making great progress all the time.

So even if you do have PolyJIA (RF-) 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](http://www.msk.org.au)
- Arthritis Ireland  
[www.juvenilearthritis.ie](http://www.juvenilearthritis.ie)
- Kids get arthritis too (Arthritis Foundation USA)  
[www.kidsgetarthritisoo.org](http://www.kidsgetarthritisoo.org)
- PainBytes  
[www.aci.health.nsw.gov.au/chronic-pain/painbytes](http://www.aci.health.nsw.gov.au/chronic-pain/painbytes)

## Useful resources

- Beyondblue  
[www.youthbeyondblue.com](http://www.youthbeyondblue.com)  
24/7 help line 1300 224 636
- Headspace  
[www.headspace.org.au](http://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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