Juvenile Idiopathic Arthritis (JIA)

Parent information leaflet

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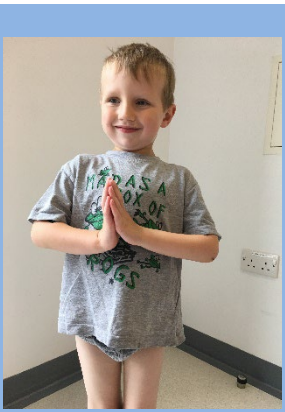
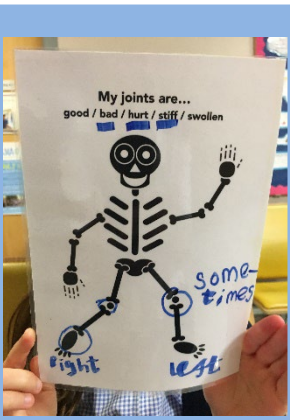
NHS

JUVENILE IDIOPATHIC ARTHRITIS (JIA)





NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

This guidance has been review and adapted by healthcare professionals across North East and North Cumbria with consent from Newcastle Hospitals

Juvenile idiopathic arthritis (JIA)

What is juvenile idiopathic arthritis?

Juvenile idiopathic arthritis (JIA) is inflammation (swelling) of one or more of your joints it first occurs before you/ your child’s 16th birthday.

JIA is slightly more common in girls. It most commonly occurs in pre-school age children or teenagers.

There are different types of JIA and symptoms vary between the different types. Knowing which type you/ your child’s has helps assess the likelihood they will grow out of JIA.

JIA may be difficult to control in some people, but most cases will be well controlled with treatment most of the time. If arthritis is part of another condition, it's often managed in a very similar way to JIA.

What should I look out for?

If you/your child has any of these symptoms for more than a couple of weeks, this will be why referral is sent to a paediatric rheumatology consultant

- painful, swollen or stiff joint(s)
- joint(s) that are warm to touch
- increased tiredness
- a fever that keeps returning
- a limp but no injury.

They will consider:

Causes

We don't completely understand what causes JIA. In fact, that's what ‘idiopathic’ means.

What we do know is that JIA is an autoimmune disease. The immune system is the body’s way of defending itself against injury, illness or bacteria.

The body can defend itself by causing inflammation or swelling. But when you have JIA, the body creates inflammation in a joint or joints when it doesn’t need to. This inflammation then causes stiffness and pain.

Is JIA genetic?

It's very rare to have two people in the same family with JIA, but we do know that genetic factors are involved. This is to do with the genes that are passed down from your parents.

JIA is thought to be due to a combination of genetic factors and trigger factors from the environment, for example the infections that the immune system has been in contact with.

There’s no evidence that a specific infection causes JIA, but an infection may trigger the immune system's response that then carries on and affects the joints.

Different types of JIA

There are several different types of juvenile idiopathic arthritis (JIA), some of which are milder than others.

You need to know which type you/your child has because this will help your doctor plan your treatment and give you advice.

Type of JIA	What is it?	What are the symptoms?	How will it affect me?	What else should I know?
Oligoarticular JIA	The most common type – affects about two thirds of young people with arthritis. It's often mild.	Most commonly affects one or both knees. Most likely type to cause eye inflammation (chronic anterior uveitis) – you'll need regular eye checks.	Most likely type to go away leaving little or no joint damage.	If you develop problems with five or more joints after six months, this is called extended oligoarthritis. This can cause joint damage. Your doctor may suggest early treatment with drugs like methotrexate to keep the damage to a minimum.
Polyarticular JIA	The second most common type of JIA. It may come on suddenly or can steadily involve more joints over a period of months.	Painful swelling in fingers, toes, wrists, ankles, hips, knees, the neck and jaw. You may feel unwell and tired and occasionally develop a slight fever.	Symptoms may continue into adult life, but it can go into remission, where all the symptoms disappear.	A blood test will show whether a marker called rheumatoid factor is present in your blood.
Enthesitis-related JIA	Affects the places where the tendons attach to the bone (entheses), causing inflammation.	Often affects the joints of the leg and spine. Associated with a red painful eye condition (acute uveitis).	You may develop stiffness in your neck and lower back in your teens.	There may be a family history of ankylosing spondylitis or inflammatory bowel disease because of a particular genetic marker called HLA-B27.

Psoriatic arthritis	Psoriasis is a skin rash. A combination of joint pain and the rash is known as psoriatic arthritis.	Usually affects fingers and toes but may affect other joints too. Joints may be affected before the psoriasis appears – your doctor may look closely at fingernails and toenails for early signs. Uveitis is fairly common but it's the painless type that doesn't look red.	It's difficult to predict, but between 30-40% have ongoing disease into adulthood.	Your doctor may ask if anyone else in your family has the condition.
Systemic-onset JIA	Your doctor may ask if anyone else in your family has the condition.	Enlarged glands in your neck, under your arms and around your groin. Your doctor may find your spleen and liver are enlarged, and, very occasionally, the covering of your heart is inflamed (pericarditis). In the first few weeks there may be no sign of swollen joints, and the diagnosis may be uncertain.	It can be difficult to predict how it'll affect you but usually the fever and rash will settle, although the arthritis may continue for several years before settling.	Lots of tests may be needed to confirm the diagnosis and this can be a worrying time.

How will JIA affect me/my child?

Many children who have JIA won't have any symptoms when they're adults, but it's not possible to accurately predict this. In most cases, childhood arthritis has a good outcome.

In at least 30% of cases, however, arthritis can remain active into adult life. Some young adults with JIA have joint damage that limits their daily activities to some extent and a few may need joint replacements. Other problems can sometimes occur. Some people are physically smaller than average or have osteoporosis as a result of their arthritis and/or treatment with steroids.

A successful outcome in JIA requires many things, including:

- a positive approach
- an experienced team working alongside your GP
- a caring, helpful environment with support from family, friends and teachers.

You also need to know how to get help that you can understand, know who to approach and be confident enough to ask for support and advice.

Diagnosis

To make a diagnosis of JIA, a paediatric (young person's) rheumatologist will examine the joints and ask questions.

There isn't a specific test for JIA, but your doctor will take blood tests and x-rays. They may also do other tests, including:

- ultrasound or MRI scans to try to see if there's arthritis and to rule out other conditions
- removing fluid from a joint (aspiration) to rule out joint infection
- bone marrow examination to rule out some rare conditions, especially if they think you/your child has systemic-onset JIA.

You/ your child will be diagnosed with JIA if:

- They have had arthritis for six weeks or more
- The symptoms started before their 16th birthday
- The doctor has ruled out other conditions that can cause arthritis.

Treatment

The aim of treatment for juvenile idiopathic arthritis (JIA) is to:

- control the symptoms of arthritis
- enable to lead an active life at school or college
- enable to enjoy an active family and social life
- help you/your child to become an independent adult.

It's important to do all of these things but at the same time try to reduce any side-effects caused by the medicines.

Drugs

Drugs can't cure arthritis, but they can control the symptoms and help to reduce the possibility of joint damage. An increasing number of medicines are now available.

Painkillers

These drugs help to control the pain of arthritis.

- Common painkillers include paracetamol, codeine or combinations e.g. co-codamol.
- They have to be taken regularly for maximum effect, which lasts hours not days.
- Side-effects include constipation, drowsiness and feeling a bit spaced-out.

Non-steroidal anti-inflammatory drugs (NSAIDs)

Non-steroidal anti-inflammatory drugs (NSAIDs) often help to reduce pain, stiffness and swelling.

Examples of the many NSAIDs include ibuprofen, piroxicam, naproxen and diclofenac. These have to be taken regularly to get maximum effect, which lasts hours not days.

Side-effects include indigestion and other stomach problems. The risk of this happening can be reduced by always taking them with food.

Disease-modifying anti-rheumatic drugs (DMARDs)

Disease-modifying anti-rheumatic drugs (DMARDs) dampen down inflammation and can reduce the joint damage caused by arthritis.

Methotrexate is the most commonly used DMARD in JIA. It can be given as a weekly dose by mouth or injection.

Side-effects of methotrexate are rare, but you'll need regular blood tests to check for them.

DMARDs are slow to become effective and you may not notice any benefit for several months.

Biological therapies

Biological therapies is a name given to some newer drugs that have been available for about 10 years. Just like DMARDs, they slow down the progress of arthritis and reduce pain, swelling and stiffness.

Like DMARDs they work by suppressing the immune system, and they're called biological therapies because they were developed from research into the biology of arthritis.

The main biological therapy used for JIA are etanercept, infliximab and adalimumab.

Steroids

These drugs control inflammation, pain and stiffness. They can be given as tablets, by injection into a joint or by a drip into a vein.

A common treatment for young people is a steroid injection into the affected joint.

- Injections are very effective for many months, are very well tolerated and cause very few side-effects.
- In younger children these injections will be done under general anaesthetic, but as you get older these may be done under sedation, with gas and air (entonox) or awake with a local anaesthetic. In adult clinics, joint injections are always given with a local anaesthetic when you're awake.

Steroid tablets are used less for young people than steroid injections.

- Side-effects are more common with large doses and longer courses (over weeks and months).
- Short courses (for a few days or up to a week) or low doses tend to have few or no side-effects. Your doctor will try and limit side-effects by putting you on a low dose or short course.
- Your doctor will give you a steroid card which tells people you're on steroids. Always carry this with you.
- Steroids should never be stopped suddenly (except if you've only been on them for under 2 weeks) as you can become very ill.

Eye drops

These will be used if you have eye inflammation. They're used to reduce the inflammation, prevent the swollen iris from sticking to the lens and to reduce pressure inside the eye.

Some of the medicines used for the arthritis, such as methotrexate and the biological therapies, can be used to treat eye inflammation if the eye drops alone aren't enough.

Key points about your drug treatments

The risk of **chickenpox**. Chickenpox can be more severe if you're taking steroids, methotrexate or biological therapies.

If you/your child hasn't had chickenpox (or aren't sure) then tell your doctor or rheumatology nurse. They'll give you advice on what to do if you get chickenpox or have been around someone with the condition. You may be able to have a vaccine.

If you need to have a **vaccination**, talk to your rheumatology team or GP. You might need to avoid some live vaccines if you are taking certain DMARDs or biological therapies. For more information about individual drugs, visit our drugs content and search by the name of the drug you are taking. There is a section on vaccinations for each drug.

Avoid drinking **alcohol.** Alcohol makes your liver more sensitive to the effect of methotrexate, which increases the risk of liver damage. You may be advised not to drink alcohol at all, but in truth many young people do drink some alcohol without apparent side-effects with their liver.

It's important to discuss what safe limits are with your doctor as this will vary with your age and size.

If you're sexually active, there are some things you should know about certain drugs.

Women shouldn't take methotrexate if they are pregnant or trying for a baby, as it can be harmful for an unborn baby.

Women taking methotrexate should use contraception or encourage their partner to do so, and should carry on using contraception for three months after stopping methotrexate. If you become pregnant while taking methotrexate, you should stop taking it and see your doctor as soon as possible.

Previously it was recommended that men stop taking methotrexate three months before trying for a baby, but research has now been done that suggests that they may not need to.

Talk to your rheumatology team if you have any questions or concerns about having sex while on drugs for arthritis.

There are drugs for arthritis that are safe to take during pregnancy, and it's important that if a woman is pregnant, her arthritis is under control.

If you'd like to start a family, it's a good idea to talk to your rheumatology team before about what drugs you can take. For more information about individual drugs, visit our drugs content and search by the name of the drug you are taking. There is information about this topic for each drug under the section 'Fertility, pregnancy and breastfeeding'.

Other treatments

Physiotherapy and occupational therapy

Physiotherapy and occupational therapy can:

- help your arthritis
- relieve pain
- improve your ability to get on with life
- provide exercises to stretch soft tissues and build up muscles
- improve your heart and lung fitness.

Your physiotherapist and occupational therapist will assess you and will develop a programme for your individual needs so that you're able to do the activities you want and need to be able to do in your daily life. They may give you exercises and coping strategies and sometimes they may provide equipment to make daily activities easier.

Physiotherapists will help you with daily exercise by giving you a plan to follow that suits your needs. Your exercise plan will aim to make your muscles stronger and more flexible, which may help prevent damage to your joints and improve your movement. If you have a flare-up or a specific joint problem your physiotherapist will help you to improve or regain your strength.

Your therapists can provide equipment to help with your daily routine of washing and getting ready. An occupational therapist can give advice and provide equipment to help you be independent – for example, an aid to get in and out of the bath, if necessary.

Pain relief

There are various ways to relieve pain, such as hot and cold pads, TENS, acupuncture, massage, hydrotherapy and relaxation. Your physiotherapist will be able to advise you on these.

If your sleep is affected, it's good to have a regular routine and some method of pain relief before bed.

Posture

A good upright posture is important to keep your body working efficiently. This means keeping the muscles strong enough to keep the back straight, with the shoulders relaxed but held back and the head up. This is particularly important when you're sitting using a computer.

Your therapists can give you tips to improve your posture and exercises to strengthen the 'core' of your body (the muscles of your stomach and back).

Splints and insoles

Splints will help stabilise your joints and give support to allow you to keep going for longer periods.

A podiatrist will be able to provide you with insoles, which will give added support to your feet and ankles and can often help to relieve pain in your knees and hips.

Protecting your joints

It's important to be aware of joint protection. The muscles and soft tissues which hold your joints in place can be put under strain as you use them. Use supports for the joints if necessary and ensure that your muscles are as strong as possible. Your therapists will give you advice about the best ways to protect your joints when out and about or performing certain tasks.

Mobility

Most young people with JIA have normal mobility. However, you may need to allow extra time to get from place to place, especially if you have to use stairs. You may need crutches to help with walking, or a wheelchair if walking distances becomes a problem.

Your therapy team will advise you on what mobility aids you may need and give you tips for getting about.

To ensure you get the right wheelchair for your needs an assessment will be necessary. Remember that a wheelchair is an aid to your mobility, not a replacement for it.

Surgery

Some young people with severe arthritis will benefit from surgery when other treatments haven't helped. However, such procedures are now much rarer due to the more effective drug therapies available.

Please note that the information on our drugs pages has been written for adult use and may be different for young people. Speak to your rheumatologist for more specific information about medication and young people.

Managing symptoms

The first thing you can do to help yourself is to find out as much as you can about your condition so that you know what to expect and how it could affect you in the future.

Another really important thing you can do to help yourself is to improve your general health. You can do this by:

- eating healthily
- getting lots of exercise
- getting enough sleep
- not smoking
- avoiding illegal drugs and too much alcohol.

Exercise

Exercise is important for general fitness, protects against osteoporosis and helps you to relax. Weight-bearing exercise (such as walking) will help prevent osteoporosis and keep you fit. Try to set aside 15–20 minutes each day to work out. This doesn't need to be too energetic but you should check that each joint in your neck, spine, arms and legs moves fully. As your arthritis becomes controlled and your general fitness improves you can make the exercises a bit harder.

Diet

Your diet is very important when you're growing up as it keeps you healthy and makes your bones strong. It's important to take steps when you're young to help prevent osteoporosis in the future. Eating plenty of dairy products (for example milk, cheese and yoghurt) will help. Generally speaking, you should aim for a well-balanced diet with plenty of fruit and vegetables and a high fibre content, avoiding too much fat.

The effects of JIA

JIA can have different effects on your body, though your symptoms may vary from day to day.

Flare-ups

Flare-ups of JIA (where symptoms get worse) can happen after:

- infections
- periods of stress
- changes in medication.

But they can often happen for no apparent reason.

Flare-ups can:

- reduce your appetite
- reduce energy levels
- cause joint pain, swelling and stiffness.

Sometimes you'll be able to manage the symptoms with a non-steroidal anti-inflammatory drug (NSAID) such as ibuprofen for a few days or weeks. But if your symptoms are troubling you or carry on you should contact your rheumatology team.

Stiff joints

Your joints may feel stiffer after resting, for example first thing in the morning.

To help with stiffness, you should do some gentle activity. Swimming can be very good, especially in a warm pool. You might need to adapt this if you're having a flare-up.

Mood

JIA can affect sleep patterns. You may also feel fed up as a consequence of joint pains, frustrated at not being able to do everything you want to, or due to difficulties with medication. It's very important to share these concerns with the paediatric/adolescent rheumatology team.

Puberty

JIA probably won't affect puberty, but sometimes arthritis or some medications (for example steroids) can make the changes of puberty happen later.

In girls, periods can become irregular if arthritis is very active. Some of the medications, such as methotrexate, can have the same effect.

If you're worried about how you look or about changes happening to your body, discussing this with your family, friends, school nurse or rheumatology team can be helpful.

Growth

JIA probably won’t affect your growth, but sometimes having severe arthritis and/or being on steroid tablets can slow growth. If your growth is slower than normal for a time, it can often catch up later, especially when arthritis is well controlled.

If active arthritis is left untreated in a joint, the growth of that joint can be affected. It’s important to get control of the arthritis before that happens.

Teeth

You may have trouble with your teeth if you have difficulty brushing, but also because of effects of medications. It's important to have regular dental check-ups. You may need orthodontic advice if arthritis has affected your jaw.

You might find that an electric toothbrush is helpful. They can do some of the work for you to help make sure you clean your teeth thoroughly.

If possible, ask for sugar-free drugs. If you take medications by mouth, brushing your teeth after is a good idea.

Related eye condition – uveitis

If you have JIA, you are at a slightly higher risk of getting an eye condition called uveitis.

This involves inflammation in part of the eye, known as the uvea.

Early treatment can keep it under control and should prevent serious problems. If it isn't treated, uveitis can cause permanent sight loss.

It can cause pain and redness in the eyes or blurred vision, but it can also develop without any noticeable symptoms.

Children and young people with JIA are offered screening by a hospital eye specialist to detect uveitis at an early stage. They'll check your sight and look at your eye with a bright light. This test is painless.

The treatment for uveitis is steroid eye drops. The drugs methotrexate and adalimumab can also treat it.

Steroid tablets and steroid drips may be used in some cases.

If you have any changes to your vision, or your eyes are painful or red, tell your rheumatology team or GP straight away.

Useful Resources

My JIA – Juvenile Arthritis Research have produced a booklet for young people, parents, carers and schools about living with JIA.

CCAA – Kids with arthritis, family information, support weekends, award badges and lots of information.

JIA at NRAS – Information and support for JIA