What is childhood arthritis?

Juvenile idiopathic arthritis (JIA)

Juvenile idiopathic arthritis, or JIA, is really a group of illnesses that share similar symptoms. Idiopathic arthritis is arthritis with no known cause and, just as in adult arthritis, it causes inflammation, pain and swelling in the joints.

Arthritis affects 1 in 1,000 children in the UK and can begin at any age. Most types of JIA are more common in girls.

Most children won't have lasting problems from childhood arthritis. JIA doesn't turn into rheumatoid arthritis in adulthood. And having juvenile idiopathic arthritis doesn't mean that your child will go on to develop adult forms of arthritis.

What types of juvenile idiopathic arthritis are there?

There are several different forms of juvenile idiopathic arthritis, with different patterns of symptoms. But some children have arthritis that doesn't exactly fit any one pattern.

Oligoarthritis

Oligoarthritis is the most common type of JIA – 60% of children with JIA have this type – and it's most common in girls under five. Overall, it is the mildest form of juvenile idiopathic arthritis and the most likely to clear up with little or no lasting damage. Oligoarthritis:

- affects between one and four joints in the first six months
- most often affects the knees, ankles and wrists, but sometimes the elbows, hands and feet
- causes morning stiffness in the affected joints
- can make children seem moody and difficult
- in young children, can cause difficulty in learning to walk.

Eye inflammation (uveitis) is a possible complication, affecting about 1 in 5 children with oligoarthritis. Children with oligoarthritis who carry antinuclear antibodies in their blood are most at risk of uveitis.

Extended oligoarthritis spreads after the first six months or so to affect more than four joints – about 2 in 5 children with oligoarthritis are affected in this way. Persistent oligoarthritis never affects more than four joints and usually clears up in 3 – 4 years with appropriate treatment.

Polyarthritis

Polyarthritis is the second most common type of juvenile idiopathic arthritis, affecting 20% of children with JIA, and is more common in girls than boys. Polyarthritis:

- affects five or more joints
- often affects the joints of the hands and feet, which become painful, swollen and stiff
- may also affect the knees, wrists, elbows, ankles, hips, neck or jaw
- may cause soreness in the tendons of the hands
- can affect a number of joints at once or one after another
- can cause children to feel generally unwell
- may be accompanied by a fever – usually when the joint symptoms are worse.

About 1 in 10 children with polyarthritis will test positive for rheumatoid factor, meaning that their blood contains an antibody similar to that often found in adult rheumatoid arthritis. Most children who are RF-positive are girls, usually aged 10 or over. Children who are RF-positive can have quite a severe form of disease, and early treatment is important to slow down the disease and prevent long-term joint damage.

Polyarthritis may continue into adult life, or the symptoms may disappear after a time (remission). Permanent remission is more likely in children who are RF-negative.

Systemic arthritis

Systemic arthritis (sometimes called Still's disease) accounts for about 1 in 10 cases of juvenile idiopathic arthritis, affects boys and girls equally, and often starts before the age of five. Systemic arthritis:

- affects the body as a whole, not just the joints
- can be difficult to diagnose – symptoms are sometimes confused with measles, meningitis or leukemia
- very occasionally affects the covering of the heart or lungs.

The most common symptoms of systemic juvenile idiopathic arthritis are a fever lasting several weeks, a blotchy rash on the thighs, arms or body, pain or swelling in the joints, swelling of the glands in the armpits, groin or neck and a poor appetite.

Some children recover after one bout of systemic arthritis. Others have symptoms that come and go for several years. Some children go on to develop polyarthritis but have no further fever attacks.

Psoriatic arthritis

Psoriatic arthritis is associated with the skin condition psoriasis, which causes a scaly skin rash. Less than 1 in 10 children with arthritis have this type. It is more common in girls and typically starts at around 8–9 years of age.

Sometimes the arthritis starts before the psoriasis, though doctors may spot signs of psoriasis in the fingernails or toenails. A family history of psoriasis can help with the diagnosis.

Often psoriatic arthritis only affects the fingers and toes, but it may affect other joints as well. Eye inflammation (uveitis) is a possible complication.

Enthesitis-related arthritis

Enthesitis-related arthritis usually affects boys aged eight and over, but can occur in girls and in younger children. The main symptoms are arthritis in several joints at once, often located at the sacroiliac joint where the spine meets the pelvis and at the point where the tendons are attached to the bones.

Children with this type of arthritis can also get problems with their eyes – usually iritis or acute anterior uveitis, which causes pain and redness in the eye. This is less common than the eye disease associated with oligoarthritis, but still needs prompt treatment.

About 3 in 4 children with enthesitis-related arthritis carry a particular genetic marker, the HLA-B27 gene, which is also associated with some adult forms of arthritis. However, even those children with the HLA-B27 gene won't necessarily go on to have problems as adults.

What causes juvenile idiopathic arthritis?

It's not known exactly what causes juvenile idiopathic arthritis.

There's no clear evidence that JIA is passed down through families, although we do know that a child's genetic make-up is a factor. It's possible that certain illnesses act as a trigger, or that there is an interaction between genetic and other trigger factors.

How does juvenile idiopathic arthritis progress?

Every child's illness is different and responds differently to treatment, so it's very difficult to predict how arthritis will affect your child.

Some children may have joint damage that limits their daily activities to some extent, and some could develop osteoporosis when older. Others may need continuing medication, and a few may need joint replacements in adulthood.

However, many children go into what doctors call remission, which means their symptoms disappear, often permanently – about 60% of children with JIA have few or no further problems with arthritis as adults.

About a third of children with juvenile idiopathic arthritis will have some continuing problems as they become teenagers and young adults. The transition to adult life can be full of anxieties for any young person and having arthritis can bring additional challenges.

How is juvenile idiopathic arthritis diagnosed?

Juvenile idiopathic arthritis can be difficult to detect and there's no single test that can confirm the diagnosis. Doctors base their diagnosis on what you tell them, what they find by examining your child, and on tests they carry out to rule out other possible illnesses.
The most common blood tests are:

- full blood count (FBC) – to check for anaemia and signs of inflammation
- erythrocyte sedimentation rate (ESR) – to measure inflammation
- C-reactive protein (CRP) – to measure inflammation and disease activity
- urea and electrolytes (U&E) – to check how well the kidneys are working
- liver function tests (LFT)
- autoantibodies – to check for autoantibodies such as for rheumatoid factor (RF) and antinuclear antibodies (ANA), especially if your child has oligoarthritis and might be at greater risk of eye damage.

Some tests may need to be repeated after diagnosis to monitor the condition.

Some hospitals use magnetic resonance imaging (MRI) or ultrasound (US) scans to check how badly a joint is affected. MRI and US scans don't use harmful radiation and are safe for children. X-rays of affected joints are often done when the child first comes to hospital. If the diagnosis is unclear at the start of the condition, x-rays or a bone scan may help to rule out more serious illnesses.

If doctors suspect systemic arthritis your child may be admitted to hospital for tests, which may include taking a bone marrow sample to rule out leukaemia.

Eye tests

Children with arthritis are at risk of inflammation in the eye (uveitis). Uveitis can cause blindness if left untreated. As it is normally painless, regular tests are needed to spot it early on – these may be as often as every three months for children in higher-risk groups, for example those with oligoarthritis who carry the antinuclear antibody. It's very important to make sure your child has the eye checks that the specialist advises.

The ophthalmologist will check your child's general vision and examine the eyes using a special (slit lamp) microscope. Eye drops may be needed to enlarge (dilate) the pupil to allow examination of the back of the eyes.

Juvenile idiopathic arthritis treatments

Making sure your child has the best treatment early on will slow down the disease and minimize long-term damage to the joints. Regular exercises, started at an early stage, will also help your child's mobility and protect the joints from damage.

Your child's response to treatment and the progress of his or her illness will be monitored over a long period, and will usually involve a team of specialists. Care may be shared between your local hospital and a specialist centre further away. The specialist centre is likely to have a team of specialists in childhood arthritis – including a paediatric rheumatologist as well as specialist nurses and therapists.

Drugs

There is no cure for juvenile idiopathic arthritis at present, but there are a number of drugs that can help to relieve your child's pain, reduce the swelling or inflammation in his or her joints, and slow down the advance of arthritis.

- **Non-steroidal anti-inflammatory drugs (NSAIDs)** – NSAIDs such as ibuprofen, diclofenac and naproxen help reduce pain, stiffness and swelling (inflammation), which helps to prevent lasting joint damage. Most children with juvenile idiopathic arthritis take NSAIDs, and if your child has only mild arthritis, this may be the only medicine they need.
- **Disease-modifying anti-rheumatic drugs (DMARDs)** – DMARDs are medicines including methotrexate, sulfasalazine and ciclosporin which slow down, and may even stop the progress of arthritis. They don't have an immediate effect on pain or inflammation so they are usually used alongside NSAIDs. Other DMARDs that are occasionally used include penicillamine, gold and hydroxychloroquine.
- **Steroids** – Steroids (usually prednisolone) reduce the inflammation caused by arthritis. Steroids can be given by injection into a painful joint or muscle, through a drip into a vein, or as a course of tablets.
- **Biologics** – New medicines called biologics, such as etanercept and adalimumab, are proving useful in treating JIA. They work by blocking the process of inflammation and are given as injections or via a drip.
- **Eye drops** will be used if your child has eye inflammation – these may be needed to reduce the inflammation, prevent the swollen iris from sticking to the lens and to reduce the pressure inside the eye. Some of the medicines used for the arthritis, such as methotrexate and the biologics, can be used to treat eye inflammation if the eye drops alone aren't sufficient.

Some of the drugs used to treat JIA, especially the DMARDs, require regular blood tests to monitor how well they are working and to check for potential side-effects. It's very important that your child has these tests on a regular basis as recommended by your doctor.

Physical therapies

Regular exercise helps to strengthen weakened muscles and build stamina. This will help your child to get swollen, painful joints moving again and slow down the effects of arthritis.

The physiotherapist will assess your child's movement and tailor an exercise programme to your child's needs. Your physiotherapist will show you initially how exercises should be done as well as give advice on equipment which may be useful. It's very important to continue these exercises at home. They may also recommend other therapies such as hydrotherapy or TENS (transcutaneous electrical nerve stimulation) for pain relief.

Surgery

A very few children, with severe arthritis, benefit from surgery when other treatments haven't helped.

- A soft tissue release can be helpful when muscles or tendons have become too tight around a joint. This is most often done for hip problems.
- A joint replacement may be necessary when a joint becomes very painful and deformed after many years of arthritis. Joint replacements are usually considered only after growing has stopped.
- A synovectomy, where the lining of a joint (synovium) is removed, can be useful for a child with one badly inflamed joint if local steroid injections have not worked well enough.

Self-help and daily living

Exercise is a vital part of your child's treatment, but it's important also to think about your child's diet and general health. And help is available to ensure that your child has as normal a family life as possible.

Exercise

Ideally your child should exercise every day, although some families prefer a Monday to Friday programme with weekends off. Your physiotherapist will show you how to supervise exercises at home. Stretches first thing may help to ease morning stiffness, especially in a warm bath.

You should encourage your child to take part in sports and to join in PE at school. Any physical activity, apart from contact sports, is good exercise. Swimming, cycling and walking are all useful.

Occasionally, children with juvenile idiopathic arthritis may need to rest if their arthritis flares up and they are feeling ill or particularly tired. Normally, however, they shouldn't need to rest any more than other children.

Diet and nutrition

There's no evidence that any special diet or avoiding certain foods help JIA directly. However:

- Calcium and vitamin D are important to build bone strength and help guard against osteoporosis in later life.
- Iron-rich foods can help to prevent anaemia, which can sometimes be a problem in childhood arthritis.
- Some children benefit from food supplements, like Complan, to maintain calorie intake while they are ill.

Putting on weight can be a problem if your child is inactive for a long time, and steroids can increase your child's appetite. Putting on weight puts extra strain on your child's joints, so it's important to keep an eye on this. Your hospital dietician can offer more advice.

Pain management

Medications and exercises should help to control pain, but if additional pain relief is sometimes needed you can try applying heat or cold packs. Always wrap the packs in a cloth to protect the skin from burns. If the pain is very bad, you can alternate the packs (hot and cold) for 10 minutes each.

Complementary therapies

There are very few studies that test the safety or effectiveness of complementary therapies for JIA. So far, there's no evidence that any complementary therapies definitely help juvenile idiopathic arthritis.

It could be dangerous to stop some of your child's medicines suddenly, and some complementary therapies may interact with their drugs, so we recommend that you discuss this with your doctor before trying any complementary therapies.

Relaxation therapies like yoga, t'ai chi or aromatherapy may be helpful, and massage by a child's parents can also help to reduce pain, stiffness and stress.

Supports, aids and gadgets

The use of special equipment should ideally be kept to a minimum for children with arthritis. It's better to strengthen the muscles through appropriate exercises. However, the following can sometimes be helpful, in particular when the arthritis is very active and before the medicines bring it under control:

- a wheelchair to manage long walks or shopping trips when your child gets tired
- a wrist splint to rest the wrist while keeping the fingers free to write
- a splint for the back of the leg to keep the knee stretched, especially at night
- crutches – usually only after surgery
- special seating or a tilting desk.

An occupational therapist can advise on equipment and how your child can manage day-to-day activities with minimal joint strain.

Dental care

Regular dental check-ups are especially important for children with juvenile idiopathic arthritis, who tend to have more trouble with their teeth – partly because of difficulty with brushing. If your child's arthritis has affected the jaw they may need orthodontic advice.

Hospital visits

Your child will need to visit hospital regularly for check-ups, usually every 3–6 months at an outpatients department. Your child may see physiotherapists, occupational therapists and podiatrists in between times.

Children with arthritis rarely have to stay overnight in hospital. This usually only happens if a child is very ill with systemic arthritis or if it's more convenient to stay a few days while having various tests and treatments.

Family life

Looking after a child who is ill, for a short or a longer period, can be hard on the whole family, and it's a good idea to take up any offers of help from relatives or friends. Encourage your child to take part in ordinary childhood activities.

Hospital appointments will make demands on your time. And because arthritis can be unpredictable it can be difficult to plan family days out. It's often best to decide on the day. Brothers and sisters can be very supportive but it's important to find time for family activities.

Your hospital team can help you cope with all aspects of your child's illness. The team may include a psychologist who can help you talk through any worries, and a social worker who can help with finding out about benefits and parental support.

You may find it helpful to talk to another family who have already been through the experience. Your hospital team or the Children's Chronic Arthritis Association (CCAA) can put you in touch with a local family; the CCAA also organises family events.

What help is available?

You may be entitled to certain benefits. Your social worker should be able to advise you. Otherwise visit your local Citizens Advice Bureau or Jobcentre/Jobcentre Plus office, or ring the Benefit Enquiry Line for advice. You may also be able to get grants for certain items and expenses through the Family Fund.

Other help you or your child may be entitled to includes:

- adaptations to your home (through your local social services department)
- a 'Blue Badge' for preferential parking
- road tax exemption on your vehicle if your child has the higher rate Disability Living Allowance
- help with travel to school
- parental leave from work
- support at school from a Special Educational Needs Coordinator, or in some cases a Statement of Special Educational Needs.

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