



My child has systemic JIA

A guide to the condition and its treatment

► Other forms of JIA are: Oligoarthritis JIA, Polyarthritis JIA and Entesitis-related JIA. For further information and factsheets on these, visit arthritiscare.org.uk

What is systemic JIA?

The word 'arthritis' means inflammation of a joint. Arthritis that develops before the age of 16, and is not due to another identifiable condition, is known as juvenile idiopathic arthritis, or JIA. In the UK, there are around 15,000 children with some form of JIA. Systemic JIA (previously known as Still's disease) is one of the rarer forms of JIA, making up less than 1 in 10 children with JIA. 'Systemic' means it can affect many different parts of the body (or system), not just the joints.

Systemic JIA affects about the same number of boys as girls, and usually starts before the age of five. It is rare for more than one family member to be affected.

Why does arthritis occur?

It is not clear exactly what causes arthritis, and different types may have different causes. It is extremely rare for more than one family member to be affected.

What are the symptoms of systemic JIA?

Children with systemic JIA may feel generally unwell, and have a range of changing symptoms, including:

- a high fever that comes and goes regularly, usually once per day, but this can be more frequent
- a rash with flat spots of red/pink skin, which may occur at the same time as the fever
- joint and muscle pain that come and goes with the fever
- tiredness, caused by the arthritis and/or by associated anaemia
- weight loss and lack of appetite
- possible swelling around the glands, liver, spleen or heart (this is usually painless and rarely causes other problems).

Unlike in other forms of childhood arthritis, eye inflammation (uveitis) is rare in people with systemic JIA.

► This factsheet outlines only the medical aspects of systemic JIA, See the Arthritis Care resource *My Child has Arthritis* for more information on the other aspects of the condition.

How is it diagnosed?

There isn't a test that can diagnose systemic JIA. This means that diagnosis can take a while, particularly if your child experiences a fever and a rash before the condition becomes obvious. Viral or bacterial infections can also cause the symptoms of systemic JIA, so these need to be ruled out first. Your child may be sent for blood tests, X-rays or other types of scans, before a diagnosis of systemic JIA is confirmed.

How will it affect my child?

Systemic JIA affects different people in different ways, but it is common to experience pain and fatigue. Typically, there will be times when the symptoms of arthritis improve or even disappear (referred to as going into remission), and times when they get worse (known as flare-ups).

Flare-ups tend to be unpredictable and can be made worse by other infections. Your child will need regular blood tests and check-ups to check for signs of inflammation. It can be difficult to know what is an infection and what is a flare-up – seek medical help if you become concerned.

Your child may experience one or two episodes that settle with treatment, or have relapses and need intermittent treatment, or need ongoing treatment into adulthood and be at risk of joint damage.

How is it treated?

Medication for systemic JIA can include:

- non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or diclofenac to reduce pain and inflammation; these can be taken in tablet or liquid form
- antacid medications to reduce the chances of NSAIDs and steroids irritating the stomach
- steroids to reduce inflammation, taken intravenously or orally
- disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate to stop arthritis progressing, taken in tablet or liquid form, or by injection
- methotrexate is the standard drug that is tried first. However, if methotrexate alone is ineffective, biologics may be used. Examples of biologics used for the treatment of JIA include tocilizumab (RoActemra) and anakinra (Kineret).

It is important that your child takes all medication as directed by their doctor. However, if you have any concerns or questions, share them with your healthcare team. As your child grows up it is increasingly important that they are also involved in this shared decision-making process. Some children experience side effects from their medication, but the risks of these need to be balanced against the risks of untreated arthritis, which can lead to permanent joint damage.

Physiotherapy and regular exercises are also an important part of treatment for systemic JIA. And the use of hot and cold packs, warm baths and gentle massage may all help reduce your child's pain or discomfort.

► See our booklets *Exercise and Arthritis* and *Managing Pain for arthritis* for more advice on how to live well with arthritis.

The availability of biologic drugs may vary across the UK. These are all approved by The National Institute for Health and Care Excellence (NICE).

► If you want to check that all your child's needs are being considered by doctors, you can view and download the Arthritis and Musculoskeletal Alliance (ARMA) Standards of Care for Children and Young People with Juvenile Idiopathic Arthritis. Go to: arma.uk.net

Would you like to help us further our understanding of systemic JIA?

Many paediatric rheumatology units take part in clinical research programmes. This can include basic scientific research looking for biological causes or cure; clinical research looking for better treatments; research seeking to improve psychological and social outcomes; or health service research to improve care management at a service level.

If you and your child are interested in taking part in a research programme, you can find further information at: nihr.ac.uk/nihr-in-your-area/children/

Taking part in such research can play an invaluable part in furthering our understanding of arthritis in childhood. It is completely voluntary and you and your child will be given all the information you need to make a decision as to whether or not to take part.

How do I find the right treatment for my child?

Before your child is given any treatment, you should have the opportunity to discuss with their doctor what the treatment options are, and how it is to be administered and any possible side effects. Once children reach 16 years of age, they can consent to their own treatment.

The right treatment for your child may change over time. You will need to work closely with your child's healthcare team on an ongoing basis, so that they understand your child's needs, and you understand all the treatment options available.

Your child's healthcare team

You and your child may meet numerous health and care professionals. Which specialists you meet and how they work together will depend on your child's particular needs and circumstances, as well as how healthcare services are structured in your region. Healthcare professionals you may work with include the following:

- general practitioner (GP)
- rheumatology consultant
- specialist nurse
- occupational therapist (OT)
- physiotherapist
- podiatrist
- orthotist
- ophthalmologist
- orthopaedic consultant
- psychologist

You will meet some of these people regularly over several years, often acting as a link between them, sharing information and chasing up actions. Developing good, positive relationships with them can be hugely beneficial.

Transition

As your child grows up, it is important that they begin to take charge of their own healthcare, including managing their arthritis. As they get older, they will be encouraged to see their healthcare team on their own, or at least for part of their visit, which will help them begin to look after their own medication, and to become more knowledgeable and more involved in decision-making around their arthritis and treatment.

This move into adult healthcare services is sometimes called transitional care and usually starts in early adolescence. It can feel like quite a leap, because adult healthcare usually involves seeing different doctors and nurses, often in different hospitals.

If your child's arthritis was diagnosed in a paediatric rheumatology service and they are still requiring rheumatology care in their teenage years, the rheumatology team will also discuss with them and you about the transfer of their care to an adult rheumatology service. Research has shown that when young people and their carers are well prepared for this move, they find it easier to cope with their new situation.



ARTHRITIS CARE

How Arthritis Care can help you

Want to talk to someone about your arthritis?
Or read more about the condition?

Call our free, confidential Helpline on 0808 800 4050 for information and support. We're open weekdays from 09:30 to 17:00 – we'd really like to hear from you.

We have over 40 free booklets and factsheets on various aspects of arthritis, from diet and surgery, to managing pain and fatigue. These can be sent to you in the post – just ask our Helpline staff for details.

Go online

You can download all our booklets and factsheets as PDFs from arthritiscare.org.uk/information

We also have an Online Community, where you can chat to others with arthritis, and can be reached at arthritiscareforum.org.uk



Arthritis Care and Arthritis Research UK have joined together to help more people live well with arthritis. Read how at arthritiscare.org.uk/merger. All donations will now go to Arthritis Research UK and be used to help people with arthritis live full and active lives in communities across England and Wales, Scotland, and Northern Ireland.

Thank you

Contact us

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Latest version: October 2017. Due for review: December 2019. ISBN: 978-0-99 55836-8-9

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