



ARTHRITIS CARE

*Empowering  
people with arthritis.*

# My child has systemic JIA

A guide to the condition and its treatment



Arthritis means inflammation of the joints. The most common type in people under 16 is known as JIA (juvenile idiopathic arthritis). There are 12,000 children with JIA in the UK.

This leaflet outlines only the medical aspects of systemic JIA. Remember, there is a lot you can do to manage the effects of arthritis on your lives. Arthritis Care has a booklet on this – see the information section at the end.

### **Why does arthritis occur?**

The cause of JIA has not been clearly identified but it is thought to occur as a result of genetic and environmental factors. It is rare for more than one family member to be affected.

### **What is systemic JIA?**

Systemic JIA (previously known as Still's disease) is one of the rarer forms of JIA, affecting fewer than 1 in 10 children with arthritis. It affects about the same number of boys as girls, and usually starts before five years of age.

### **What are the symptoms?**

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

- a high fever which regularly comes and goes, sometimes every evening
- a rash with flat spots of red/pink skin may accompany the fever
- joint and muscle pain that come and go with the fever
- tiredness, caused by arthritis or by anaemia (low levels of iron in the blood)
- loss of appetite and weight loss
- possible swelling around the glands, liver, spleen or heart, but this is usually painless and rarely causes other problems.

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



## How is it diagnosed?

Diagnosis can take a while as there is no definite test for systemic JIA. Several other things, such as viral and bacterial infections, can cause the same symptoms. Your child may be given blood tests, be scanned or have an X-ray to rule out other causes before being diagnosed with systemic JIA.



## What is the outlook?

The sooner your child is treated, the better. A third of children with systemic arthritis will have one or two episodes and settle with treatment, a third of children will have relapses and need intermittent treatment and a third will need ongoing treatment into adulthood.

Having more joints affected increases the likelihood of joint damage, which may require joint replacements. More frequent relapses are associated with more serious disease.

## How will it affect my child?

All children are different, but it is common to experience pain and fatigue.

There will be times when your child's symptoms worsen. These are known as flare-ups, which can be unpredictable and be made worse by other infections.

Your child will need regular blood tests and check-ups to monitor for signs of inflammation. It can be difficult to know what is an infection and what is a flare-up, so you should seek medical attention if you are concerned.

Severe forms of JIA may make children short for their age.

## How is it treated?

JIA cannot be cured, but treatment can help to reduce your child's arthritis, prevent additional problems and enable them to lead as normal a life as possible. Medication for arthritis in children has improved a lot in the past 10 years, and there is ongoing research into treatment options.

Physiotherapy and regular exercises are also an essential part of treatment.

Medication for systemic JIA can include:

- **non-steroidal anti-inflammatory drugs (NSAIDs)** such as ibuprofen or diclofenac to reduce pain and inflammation. They may be taken in tablet or liquid form
- **steroids** taken by mouth, injection or drip to reduce inflammation
- **disease-modifying anti-rheumatic drugs (DMARDs)** such as methotrexate, taken as a pill, liquid or an injection to stop arthritis progressing
- **biologic drugs** may be used if methotrexate does not work by itself. These include **anti-TNF drugs** – etanercept (Enbrel) may be given to children aged 2-17, and adalimumab (Humira) to those aged 4-17. The biologic tocilizumab (RoActemra) may also be given. The availability of these drugs will vary across the UK.

## The right treatment for your child

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 they understand your child's needs, and you understand the treatment options.

You may want to refer to the Arthritis and Musculoskeletal Alliance (ARMA) *Standards of Care for Children and Young People with Juvenile Idiopathic Arthritis* to check that all your child's needs are being considered by doctors – download from [www.arthritiscare.org.uk/Youngpeopleandfamilies](http://www.arthritiscare.org.uk/Youngpeopleandfamilies)

Some children experience side effects from medication, but the risks of these need to be balanced against the risk of untreated arthritis, which can lead to permanent joint damage. Discuss the potential benefits and risks of medication with doctors and/or nurse specialists before making a decision.

It is important that your child takes all medication as directed by your doctor but if you do have problems or concerns, never hesitate to discuss these with your rheumatology team. As well as medication, hot and cold packs, warm baths, and gentle massage may all reduce your child's pain or discomfort.

## Your child's healthcare team

You and your child may see the following professionals:

- general practitioner (GP)
- rheumatology consultant
- specialist nurse
- occupational therapist (OT)
- physiotherapist
- podiatrist (also called a chiropodist)
- ophthalmologist
- orthopaedic consultant.



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## Where can I get more information and support?

**Arthritis Care is here to help you and your family.**

The Source is a helpline service which offers confidential information and support for young people with arthritis and their families. Call free on 0808 808 2000 (10am-4pm weekdays) or email [TheSource@arthritiscare.org.uk](mailto:TheSource@arthritiscare.org.uk)

Our website ([www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)) has sections for young people and for parents plus:

- separate online discussion forums for young people and for parents
- details of a range of personal development and confidence building workshops and weekends
- films and stories from young people to help you understand the impact of JIA.

You can also download our booklet *My Child has Arthritis – a practical guide for parents* which has information on managing the effects of JIA on family life.



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Arthritis Care is here for everyone with arthritis but we rely on the support of people like you. If you would like to make a contribution to our work, please phone us on **020 7380 6540** or you can donate online via our website.



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The Source is our free helpline for young people and their families.

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Our information is regularly reviewed. This leaflet will be reviewed in 2013. Please check our website for up-to-date information and reference sources or call 020 7380 6577.

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