My child has systemic JIA
A guide to the condition and its treatment

What is systemic JIA?
The word ‘arthritis’ literally means inflammation of the joints. Arthritis that affects children under the age of 16 is known as juvenile idiopathic arthritis, or JIA, and 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, affecting fewer than 1 in 10 children with arthritis. ‘Systemic’ means it affects 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 five years of age. 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 of arthritis may have different causes. (The word ‘idiopathic’ means of unknown cause.) JIA is thought to stem from a combination of genetic and environmental factors and is an immune system disorder. It is extremely rare for more than one family member to be affected.

What are the symptoms?
Children with systemic JIA may feel generally unwell, and may have a range of changing symptoms, including:
• a high fever that comes and goes regularly, sometimes more than once a day
• a rash with flat spots of red/pink skin, which may accompany the fever
• joint and muscle pains that come and go with the fever
• tiredness, caused by the arthritis and/or by associated anaemia
• loss of appetite and weight loss
• 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 systemic JIA.
How is it diagnosed?

There is no definite test to diagnose systemic JIA, and diagnosis can take a while. This is particularly the case if your child experiences a fever and rash some time before the arthritis becomes evident, as several other things can cause the same symptoms, such as viral or bacterial infections, and these will need to be ruled out. 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 worsen (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 monitor for signs of inflammation. It can be difficult to know what is an infection and what is a flare-up, so if you are at all concerned you should seek medical attention.

Systemic JIA differs in form and severity from one child to another. Your child may experience one or two episodes that settle with treatment. or they may have relapses and need intermittent treatment, or need ongoing treatment into adulthood and be at risk of joint damage.

How is it treated?

Although there is no cure for arthritis, there are many effective treatments that can enable your child to live a happy and healthy life. Medication for arthritis in children has improved a lot in recent years, and ongoing research is improving our understanding of the condition all the time.

Medication for systemic JIA can include:

- non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen or diclofenac to reduce pain and inflammation, taken in tablet or liquid form
- steroids to reduce inflammation, taken by mouth, injection or drip
- disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate to stop arthritis progressing, taken in tablet or liquid form or by injection
- biologic drugs (if methotrexate does not work by itself) such as etanercept (Enbrel) for children aged 2–17, adalimumab (Humira) for those aged 4–17, or tocilizumab (RoActemra) may also be given.

It is important that your child takes all medication as directed by your doctor but if you or your child do have problems or concerns, never hesitate to discuss these 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 medication, but the risks of these need to be balanced against the risk 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 ‘Coping with Pain’
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 your doctor what the treatment is, how it is to be administered and any possible side effects. Once children reach 16 years of age, they are able to 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 will come across 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 on the way healthcare services are structured in your region. Some of the key ones are:

- 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 monitoring 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 members on their own or at least for part of their visit. This 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 has been diagnosed in a paediatric rheumatology service and they are still requiring rheumatology care in their mid teens, 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 in the new situation.
Here at Arthritis Care we believe there is always something you can do to reduce the impact of arthritis, whether it’s finding out more about the type of arthritis your child has, meeting up with others at a parent group or by encouraging your child to attend one of our social weekends.

Talk to us

The Source is our free helpline for young people and their families. Talking about arthritis, sharing your concerns and how you feel can really help. The Source is run by people with experience of arthritis who are here to listen and help you find answers to your questions. You can call them on 0808 808 2000 (weekdays 10am–4pm) or email: TheSource@arthritiscare.org.uk

The Source can:
• help you with any questions you have about arthritis
• be there to listen if you need someone to talk to
• tell you more about the young people’s forum
• tell you about services, courses and support for you in your area.

We’re here with free, up-to-date information about arthritis. You can download leaflets on childhood arthritis including:
• My Child has Arthritis – a practical guide for parents
• My Child has Oligoarticular JIA – a guide to the condition and its treatment
• My Child has Polyarticular JIA – a guide to the condition and its treatment
• My Child has Systemic JIA – a guide to the condition and its treatment

There is also Kids with Arthritis – a guide for families by Carrie Britton PhD (4th edn, 2006), available by contacting The Source. A bilingual version in Welsh and English is also available.

Can you do something to help?

We hope this leaflet has been useful to you. It’s just one of our many publications that are free to anyone who is affected by arthritis. Every year over 1000 people under 16 will develop inflammatory arthritis in the UK. The challenges of living with arthritis are too often overlooked and underestimated. We’re here to change that. Now more than ever we need people like you to lend their time, experience and voice to help others.

To find out more go to arthritiscare.org.uk, call the free helpline weekdays on 0808 800 4050 or contact one of our offices.

Contact us

The Source helpline:
0808 808 2000
(weekdays 10am–4pm)

TheSource@arthritiscare.org.uk

Our offices:

England:
020 7380 6540

Northern Ireland:
028 9078 2940

Scotland:
0141 954 7776

Wales:
029 2044 4155

Our website:
arthritiscare.org.uk

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Please check our website for up-to-date information and reference sources or call 020 7380 6577.

Arthritis Care is a certified member of The Information Standard. This means that you can be confident that Arthritis Care is a reliable and trustworthy source of health and social care information.