

Adult onset Still's disease (AOSD)

1

What is adult onset Still's disease?

Adult onset Still's disease (AOSD) is a form of inflammatory arthritis usually seen in children, but which occasionally develops in adults. Like other forms of inflammatory arthritis, AOSD is caused by the immune system starting to attack the body. It affects the joints and can also cause swelling in the lymph nodes, liver and spleen.

AOSD is rare, with just a few hundred people likely to be affected in the UK, compared with more than 700,000 with rheumatoid arthritis. It affects men and women equally. Three quarters of people who develop AOSD are under 35 years. AOSD can take some time to diagnose because the symptoms could be the result of many other things, which need to be ruled out before AOSD can be clearly identified.

REAL LIFE STORY

‘ I was diagnosed with AOSD when I was 39, after six months of investigations into other causes for my symptoms. These included bone marrow biopsies and CT scans. The low points at first were the night sweats, joint pain and extreme fatigue – all very stressful.

I was glad to eventually be diagnosed and my treatment with steroids (Prednisolone) started immediately. Although I had lost a lot of weight it soon came back once I was treated with steroids. Eventually the dosage was reduced and I learned to manage my condition. I take painkillers for my wrist and hand pain. I have lost a lot of power in my hands, which is a bit difficult for a big guy like myself. The worst part is the combination of low level background pain combined with general fatigue.

However, life continues. I have benefited from using walking poles, wrist supports and hand therapy. My employers have been very supportive in changing how I work and by providing equipment. AOSD has had a big impact on me but it will not detract from the important things in life – being a husband and father. ’

How will it affect me?

AOSD often begins with a high fever that goes up and down during the day for several days or longer. A pink rash usually comes and goes with the fever, along with a feeling of being achy and tired. The fever and rash usually occur before the joints are affected. Once the fever and symptoms have died down, joint problems can develop.

With AOSD you could experience:

- loss of strength in your wrists and hands; joint pains in the shoulders, neck, elbows, hips and knees
- night sweats

- a salmon-pink rash that can come and go
- a sore throat experienced as an intense burning feeling for a few days
- abdominal pain due to swelling of the liver and spleen
- inflammation of the lining of the lungs
- chest pain and rapid pulse because of inflammation and fluid around the heart – not heart problems. Contact your doctor if you develop it.

You may need to have several tests to rule out other causes before being diagnosed. These can include a CT scan, MRI scan, bone marrow tests, X-rays and ultrasound.

What is the treatment?

- **Non-steroidal anti-inflammatory drugs (NSAIDs).** These can reduce inflammation and pain. Ibuprofen (Nurofen) is available without a prescription. Diclofenac (Voltarol) may be more effective and require a prescription. Take them with or after food. You may need to take these drugs during bad patches, or possibly over a longer period after symptoms have disappeared.
- **Steroids** such can be taken orally – starting with a higher dose then reducing this as much as possible to minimise side effects, especially weight gain. Steroids are used where symptoms are more severe, and can also be injected into a joint to reduce pain and swelling.
- **Disease-modifying anti-rheumatic drugs (DMARDs)** like methotrexate are very successful in treating some forms of arthritis, including AOSD. These drugs may have side effects and each person responds to them differently.
- **Anti-TNFs** (also known as biologics) such as infliximab (Remicade), etanercept (Enbrel) or adalimumab (Humira) can be used though are not available for everyone.

What can I do to help myself?

- Good and bad days are common. Learn how to pace yourself and not to overdo it on days when you are feeling better.
- Balance activity and rest each day, and within each week.
- Plan and prioritise tasks each day and each week.
- Learning how to relax and get enough rest will help to manage stress.
- Understand what your medication does – particularly the need to keep taking it on days when you feel better.
- Try to use larger joints to move and lift things.

- Reorganise workspaces, such as the kitchen, so objects that are heavy and/or frequently used are within easy reach at waist or shoulder level.
- Move your body every couple of hours to avoid becoming too stiff. Gentle exercise can help to keep your muscles strong and your joints flexible.
- If your hands are painful, placing them in warm water can help.
- If your hands or wrists are weak, squeeze and manipulate something with your hands to help maintain strength.
- Supplement your diet, especially with calcium and vitamin D supplements if you are taking steroids.

Who will I see?

Your GP will probably refer you to a rheumatologist – a consultant based at a hospital – for a full diagnosis and treatment. AOSD is usually diagnosed by ruling out many other diseases, so it will help to keep a record of all your symptoms and how you are affected.

Rheumatologists work with a healthcare team, which could include:

- a nurse practitioner who can help you learn about the disease and how to live with it
- a physiotherapist who may give you exercises to strengthen your wrists and hands
- an occupational therapist who can help you to find special equipment such as hand and wrist splints, and advise on how to protect your joints and conserve energy.

What is the likely outcome?

AOSD is unpredictable. If more joints are affected, there is some evidence that the disease will be more severe. Flare-ups are a normal part of Still's disease, but the severity and frequency of these will be different for each person. There can be months or even years between flare-ups.

There is no sure way of predicting if AOSD will go into remission or how many flare-ups there will be, but there are drug treatments which can greatly minimise the symptoms. There is a risk of developing long-term inflammatory arthritis.

Is it hereditary?

The cause is unknown. Current thinking is that something triggers the immune system to over-react. No hereditary link has been identified.

Where can I get more information and support?

Arthritis Care is the UK's largest charity working with and for all people who have arthritis.

We are here to help you make positive choices through our information, website, self-management training, and professional helpline. Call the free helpline for confidential support on 0808 800 4050 (10am-4pm weekdays) or email: Helpline@arthritiscare.org.uk

You can find support from others with arthritis by joining our online discussion forums.

We rely on donations to fund our vital work in supporting people living with arthritis. If you would like to make a contribution, please phone us on 020 7380 6540 or you can donate online.

www.arthritiscare.org.uk

Our factsheets are reviewed every 18 months. Please check our website for up to date information and reference sources or call 020 7380 6577.

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Contact us

For confidential information and support about treatments, available care and adapting your life, contact the Arthritis Care Helpline

Freephone: 0808 800 4050

10am-4pm (weekdays)

Email: Helplines@arthritiscare.org.uk

For information about Arthritis Care and the services we offer, contact us at: **www.arthritiscare.org.uk**

You can also talk to other people who are living with arthritis, through the discussion forums on our website.

Arthritis Care UK office and England regional services:

Tel: 020 7380 6500

Central England email: CentralEngland@arthritiscare.org.uk

North England email: NorthEngland@arthritiscare.org.uk

South England email: SouthEngland@arthritiscare.org.uk

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Tel: 028 9078 2940

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Arthritis Care in Scotland

Tel: 0141 954 7776

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Arthritis Care in Wales

Tel: 029 2044 4155

Email: Wales@arthritiscare.org.uk

Other organisations

www.Stillsdisease.org