



Adult onset Still's disease (AOSD)

What is adult onset Still's disease?

Adult onset Still's disease (AOSD) is a form of inflammatory arthritis. Like other forms of inflammatory arthritis, AOSD is caused by the immune system 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. It affects men and women equally and approximately, 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 conditions which would 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. The fever is often accompanied by a pink rash, as well as a general tiredness and achiness. The fever and rash may 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 these symptoms.

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

What is the treatment?

- **Non-steroidal anti-inflammatory drugs (NSAIDs).** These can reduce inflammation and pain. Ibuprofen (for example, Nurofen) is available without a prescription. Diclofenac (for example, Voltarol) may be more effective and require a prescription. These should be taken 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** can be taken orally — starting with a higher dose then reducing this as much as possible to minimise side effects. 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 can be very effective in treating some forms of arthritis, including AOSD. These drugs may have side effects and each person responds to them differently.
- Biologics, such as anti TNFs can help. Other biologics such as anikinra (IL-1 inhibitor) and tocilizumab can also be used.

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 where possible.



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- 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 suggests 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 (09:30-17:00 weekdays) or email: Helpline@arthritiscare.org.uk

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



Arthritis Care and Arthritis Research UK have joined together to help more people live well with arthritis. Read how at arthritisresearchuk.org/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.

Registered Charity Number 207711, SC041156.

www.arthritiscare.org.uk

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

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Note

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Contact us

For confidential support and information about treatments, available care and adapting your life, contact the Arthritis Care Helpline **Freephone: 0808 800 4050**
09:30-17:00 (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.

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Other organisations

www.Stillsdisease.org