

## **Tocilizumab for systemic juvenile idiopathic arthritis**

*NICE 'technology appraisal guidance' advises on when and how drugs and other treatments should be used in the NHS.*

This leaflet is about when **tocilizumab** should be used to treat children and young people with systemic juvenile idiopathic arthritis in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for children and young people with systemic juvenile idiopathic arthritis, and their parents or carers, but it may also be useful for anyone with an interest in the condition.

It does not describe systemic juvenile idiopathic arthritis or the treatments in detail – a member of your healthcare team should discuss these with you. You can get more information from the organisations listed on page 4.

*This may not be the only possible treatment for systemic juvenile idiopathic arthritis. Your healthcare team should talk to you about whether it is suitable for you and about other treatment options available.*

### What has NICE said?

NICE recommends tocilizumab as a possible treatment for some children and young people with systemic juvenile idiopathic arthritis (see below).

NICE does not recommend tocilizumab for children and young people whose disease is improving with methotrexate treatment, or who have not yet been treated with methotrexate.

### Who can have tocilizumab?

Children and young people should be able to have tocilizumab if they have tried all of the following drugs but they have not worked: NSAIDs (non-steroidal anti-inflammatory drugs), systemic corticosteroids and methotrexate.

### Why has NICE said this?

NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE recommended tocilizumab because it is clinically effective and it is a cost effective use of NHS resources compared with other treatments currently used in clinical practice.

## Systemic juvenile idiopathic arthritis

Juvenile idiopathic arthritis is swelling of the joints in children and young people. As well as joint pain, children and young people with systemic juvenile idiopathic arthritis may have fever, rashes, swollen glands, tiredness and lack of energy, weight loss and muscle pain. It can lead to joint damage and permanent disability.

## Tocilizumab

Tocilizumab is a drug that helps to reduce the pain and swelling caused by systemic juvenile idiopathic arthritis. It may slow down the progression of the condition and help to prevent permanent joint damage.

### What does this mean for me?

When NICE recommends a treatment, the NHS must make sure it is available to those people it could help, normally within 3 months of the guidance being issued.

So, if a child or young person has systemic juvenile idiopathic arthritis, and they (and/or their parents or carers) and their doctor think that tocilizumab is the right treatment for them (see 'What has NICE said?' on page 2), they should be able to have the treatment on the NHS. Please see [www.nice.org.uk/aboutguidance](http://www.nice.org.uk/aboutguidance) if you think they are eligible for the treatment but it is not available.

If a child or young person is already taking tocilizumab for systemic juvenile idiopathic arthritis but their circumstances do not meet the criteria given on page 2 (see 'What has NICE said?'), they should be able to continue taking it until they and their healthcare professional decide it is the right time to stop. This decision should be made jointly by the clinicians, and the child or young person and/or their parents or carers.

### More information

The organisations below can provide more information and support for people with systemic juvenile idiopathic arthritis. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- [National Rheumatoid Arthritis Society](#) 0800 298 7650
- [Versus Arthritis](#) 0800 520 0520

[NHS Choices](#) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

## About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts, including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

*To find out more about NICE, its work and how it reaches decisions, see [www.nice.org.uk/aboutguidance](http://www.nice.org.uk/aboutguidance)*

*This leaflet and other versions of the guidance aimed at healthcare professionals are available at <http://guidance.nice.org.uk/TA238>*

*The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.*

*We encourage NHS and voluntary organisations to use text from this leaflet in their own information about systemic juvenile idiopathic arthritis.*

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