

## Understanding NICE guidance

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Information for people who use NHS services

# Trabectedin for the treatment of advanced soft tissue sarcoma

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

This leaflet is about when **trabectedin** should be used to treat people with advanced soft tissue sarcoma 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 people with advanced soft tissue sarcoma but it may also be useful for their families or carers or anyone with an interest in the condition.

It does not describe advanced soft tissue sarcoma or the treatments in detail – your specialist should discuss these with you. You can get more information from the organisations listed on the back page.

*This may not be the only possible treatment for advanced soft tissue sarcoma. Your specialist should talk to you about whether it is suitable for you and about other treatment options available.*

## What has NICE said?

Trabectedin is recommended as a possible treatment for people with advanced soft tissue sarcoma if:

- treatment with anthracyclines and ifosfamide has failed, **or**
- they cannot tolerate anthracyclines and ifosfamide, **or**
- anthracyclines and ifosfamide are unsuitable.

The manufacturer of trabectedin has agreed to a 'patient access scheme', which means that when a person needs more than five trabectedin treatments, it provides the sixth and any further trabectedin treatments to the NHS free of charge.

## Advanced soft tissue sarcoma

Soft tissue sarcoma is a tumour (cancer) affecting tissues, such as muscles or blood vessels, that connect, support or surround other structures and organs of the body. It is described as advanced when it is so large that it cannot all be removed by an operation and it has spread to other parts of the body.

## Trabectedin

Trabectedin (also known as Yondelis) is a drug that slows down the rate at which a tumour grows. It is given through a drip into a vein.

## 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 you have advanced soft tissue sarcoma and treatment with anthracyclines and ifosfamide has failed, you cannot tolerate these treatments or they are unsuitable, you should be able to have trabectedin on the NHS if your specialist thinks that it is the right treatment for you.

If you need more than five cycles of treatment you will be asked to be part of a 'patient access scheme'. Your specialist should talk to you about this.

Please see [www.nice.org.uk/AboutGuidance](http://www.nice.org.uk/AboutGuidance) if the treatment is not available.

## More information

The organisations below can provide more information and support for people with advanced soft tissue sarcoma. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- CancerHelp UK (the patient information website of Cancer Research UK), 0808 800 4040  
[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)
- Rarer Cancers Forum, 0800 434 6476  
[www.rarercancers.org.uk](http://www.rarercancers.org.uk)
- Sarcoma UK, 01588 674757  
[www.sarcoma-uk.org](http://www.sarcoma-uk.org)

NHS Choices ([www.nhs.uk](http://www.nhs.uk)) may be a good place to find out more. Your local patient advice and liaison service (usually known as 'PALS') may also 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, 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 [www.nice.org.uk/guidance/TA185](http://www.nice.org.uk/guidance/TA185)*

*You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and quote reference N2105). 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 advanced soft tissue sarcoma.*