

Eculizumab for treating atypical haemolytic uraemic syndrome

Information for the public

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What has NICE said?

Eculizumab (also called Soliris) works well enough and is recommended as a possible treatment for people with atypical haemolytic uraemic syndrome (aHUS). It should only be used if certain conditions are in place. These include that an expert centre oversees your treatment, and that there is monitoring and research on the dose of eculizumab and when, whether and why the drug is stopped.

What does this mean for me?

If you have aHUS, and your doctor thinks that eculizumab is the right treatment, you should be able to have the treatment on the NHS. Eculizumab should be available on the NHS within 3 months of the guidance being issued. Your doctor should ask you if details of your treatment can be collected.

The condition and the treatment

Atypical haemolytic uraemic syndrome (aHUS) is a very rare, life-threatening condition. It causes blood clots to form in small blood vessels throughout the body and also severe inflammation of blood vessels. This can damage vital organs such as the kidneys, brain and heart.

Eculizumab (also called Soliris) works by stopping blood clots from forming and preventing the inflammation.

Source of advice and support

- aHUS UK, voice@ahusuk.org, www.ahusuk.org

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