

Etranacogene dezaparvovec for treating moderately severe or severe haemophilia B

Information for the public

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Etranacogene dezaparvovec (Hemgenix) is available during the [managed access](#) period. It is a possible treatment for moderately severe or severe haemophilia B (also known as congenital factor IX [FIX] deficiency) in adults who do not have anti-FIX antibodies.

More evidence on etranacogene dezaparvovec is being collected. After this NICE will decide whether to recommend it for routine use on the NHS and update the guidance. It will be available with managed access until then.

Is this treatment right for me?

Your healthcare professionals should give you clear information, talk with you about your options and listen carefully to your views and concerns. Your family can be involved too, if you wish. See [our webpage on making decisions about your care](#).

Questions to think about

- How well does it work compared with other treatments?
- What are the risks or side effects? How likely are they?
- How will the treatment affect my day-to-day life?
- What happens if the treatment does not work?
- What happens if I do not want to have treatment? Are there other treatments available?

Information and support

The [NHS webpage on haemophilia](#) may be a good place to find out more.

[The Haemophilia Society](#) (020 7939 0780) can give you advice and support:

You can also get support from your local [Healthwatch](#).

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

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