

Cerliponase alfa for treating neuronal ceroid lipofuscinosis type 2

Information for the public

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Cerliponase alfa (Brineura) is available on the NHS as a possible treatment for neuronal ceroid lipofuscinosis type 2 (also known as tripeptidyl peptidase 1 deficiency) if the conditions in the [managed access agreement](#) are followed.

If you are not eligible for cerliponase alfa but are already taking it, you should be able to continue until you and your doctor decide when best to stop.

The managed access agreement includes rules for starting and stopping treatment with cerliponase alfa, and for assessing how well the treatment is working. NICE will take the information about how well the treatment works into account when the guidance on cerliponase alfa is reviewed.

If NICE does not recommend cerliponase alfa for NHS funding when a review of the guidance is published, it will no longer be available for any patient.

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. Read more about [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

These organisations can give you advice and support:

- [Batten Disease Family Association \(BDFA\)](#), 0800 046 9832
- [Genetic Alliance UK](#), 0207 831 0883

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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