

Asfotase alfa for treating paediatric-onset hypophosphatasia

Information for the public

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Asfotase alfa (Strensiq) is available on the NHS as a possible treatment for paediatric-onset hypophosphatasia for people:

- who meet particular criteria for treatment (outlined in the 5-year [managed access arrangement](#)) and
- if they (or their parents or carers) agree to the conditions in this arrangement, such as attending clinics, data collection and assessment of how well the treatment is working.

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

NICE will take the information about how well the treatment works into account when the guidance on asfotase alfa is reviewed. If NICE does not recommend asfotase 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:

- [Metabolic Support UK](#), 0845 241 2173
- [Genetic Alliance UK](#), 0207 704 3141
- [Brittle Bone Society](#), 01382 204 446
- [Soft Bones UK](#), 02392 111 111

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

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