

Nusinersen for treating spinal muscular atrophy

Information for the public

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Nusinersen (Spinraza) is available on the NHS as a possible treatment for 5q spinal muscular atrophy (SMA) if:

- people have pre-symptomatic SMA, or SMA types 1, 2 or 3 and
- the conditions in the [managed access agreement](#) are followed.

More evidence on nusinersen (Spinraza) is being collected, which will be reviewed. A review of the guidance will then be published after 5 years. The drug will be available through the managed access agreement 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. 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

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

These organisations can give you advice and support:

- [Spinal Muscular Atrophy UK](#), 01789 267520
- [Muscular Dystrophy UK](#), 0800 652 6352
- [TreatSMA](#), 0300 800 0202

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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