

Nusinersen and risdiplam for treating spinal muscular atrophy

Information for the public

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Nusinersen (Spinraza) and risdiplam (Evrysdi) are available on the NHS as possible treatments for spinal muscular atrophy (SMA).

Nusinersen is a possible treatment for 5q SMA.

Risdiplam is a possible treatment for 5q SMA type 1, 2 or 3, or with 1 to 4 copies of a gene called SMN2. But risdiplam should not be used when the SMA is not yet causing any symptoms and onasemnogene abeparvovec (OA) is suitable.

Nusinersen and risdiplam should not be used together, or when the SMA has been successfully treated with OA.

Nusinersen or risdiplam may be used as a bridging therapy (that is, used as a temporary treatment until treatment with OA is possible) by people with or without symptoms.

You or your child's healthcare professional might decide to stop nusinersen or risdiplam if the SMA gets worse and the treatment is not providing benefit. But this decision will be taken based on clinical judgement and individual needs.

If you or your child are not eligible for nusinersen or risdiplam but are already having it, you should be able to continue until you and your healthcare professional decide when best to stop.

Is this treatment right for me or my child?

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

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 SMA](#) 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
- [Treat SMA](#), 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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