

# Let's talk about treatment

SPINRAZA facts and stories to help prepare for your first dose

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## INDICATION

SPINRAZA® (nusinersen) is a prescription medicine used to treat spinal muscular atrophy (SMA) in pediatric and adult patients.

## SELECTED IMPORTANT SAFETY INFORMATION

**Increased risk of bleeding complications** has been observed after administration of similar medicines. Your healthcare provider should perform blood tests before you start treatment with SPINRAZA and before each dose to monitor for signs of these risks. Seek medical attention if unexpected bleeding occurs.

**Please see additional Important Safety Information on page 15 and click for full Prescribing Information.**



**LAUREN // AGE 20**  
LATER-ONSET SMA  
TREATED WITH SPINRAZA

Individual results may vary based on several factors, including severity of disease, initiation of treatment, and duration of therapy.



## FAQs about treatment

Inside these pages, you will hear what some people with SMA have to say about their dosing days. **Of course, everyone's individual experience with SPINRAZA will be different and your healthcare provider (HCP) should always be your primary source for information.** We hope hearing from the community is informative nonetheless.

**SPINRAZA is given via intrathecal injection** by a specially trained HCP with expertise in administering these types of procedures. It's important to keep in mind that this is a significant procedure with associated risks. As a reminder, we have included some frequently asked questions (FAQs) about intrathecal administration. This information is not intended to be taken as medical advice, and you should always consult with your HCP on any treatment-specific questions. If you have any immediate questions about treatment logistics, your Family Access Manager (FAM) is also able to help.

### SELECTED IMPORTANT SAFETY INFORMATION

**Increased risk of kidney damage, including potentially fatal acute inflammation of the kidney**, has been observed after administration of similar medicines. Your healthcare provider should perform urine testing before you start treatment with SPINRAZA and before each dose to monitor for signs of this risk.

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**CARLEE // AGE 11**  
LATER-ONSET SMA  
TREATED WITH SPINRAZA

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**SPINRAZA**<sup>®</sup>  
(nusinersen) injection  
12 mg/5 mL

## FAQs about administration



For more information about intrathecal administration, go to [SPINRAZA.com/dosing](https://www.spinraza.com/dosing) to download the Intrathecal Discussion Tool

### What is an intrathecal injection?

An intrathecal injection or lumbar puncture is a method to deliver medication into the fluid of the spine, also known as cerebrospinal fluid (CSF). The injection is always given by a specially trained healthcare provider (HCP).

### Why is SPINRAZA given intrathecally?

SPINRAZA is injected into the CSF, which circulates around the spine and the brain. SPINRAZA is delivered directly to the central nervous system (CNS), which allows it to be distributed to the survival motor neurons located in the spinal cord.

For additional information about intrathecal injections with SPINRAZA, please talk to your healthcare provider.

### SELECTED IMPORTANT SAFETY INFORMATION

The most common side effects of SPINRAZA include lower respiratory infection, fever, constipation, headache, vomiting, back pain, and post-lumbar puncture syndrome.

These are not all of the possible side effects of SPINRAZA. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

### Who will administer SPINRAZA?

Administration will be performed by, or under the direction of, healthcare professionals experienced in performing lumbar punctures for SPINRAZA. The procedure is performed in a designated treatment center with expertise in intrathecal injections.

### How often will I receive SPINRAZA?

You will receive SPINRAZA according to the SPINRAZA dosing schedule. The schedule begins with 4 initial loading doses; the first 3 occur in 14-day intervals, and the fourth dose occurs 30 days after the third dose. After these initial doses, SPINRAZA is administered 3 times a year. For more information about the dosing schedule and treatment procedure, please talk to your HCP.

### Are any tests required before SPINRAZA treatment?

Certain laboratory tests are required before starting treatment and before each dose of SPINRAZA as determined by your/your child's HCP. Because of an increased risk of bleeding, blood tests are required. Because of a risk of renal (kidney) toxicity, urine testing is required.

[Hear what the community has to say >](#)

Please see additional Important Safety Information on page 15 and click for full [Prescribing Information](#).



## I have read online that some people have good and others have bad experiences. What will my SPINRAZA treatment experience be like?

It's important to remember that everyone's experience will be different. Just because some people have had a good or bad dosing day, it doesn't necessarily mean that you will, too. If you have any questions about dosing day in particular, you should always discuss them with your doctor before your first SPINRAZA dose.

### SELECTED IMPORTANT SAFETY INFORMATION

Before taking SPINRAZA, tell your healthcare provider if you are pregnant or plan to become pregnant.

This information is not intended to replace discussions with your healthcare provider.

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ASHLEY // AGE 7  
LATER-ONSET SMA  
TREATED WITH SPINRAZA



"It's hope. You know, we are very realistic.

My biggest thing is to make sure people know that our experience with SPINRAZA is our experience, and theirs could be similar, could be different, but everybody reacts differently to every medication."

ANTONIA  
ASHLEY'S MOM

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## As I continue my treatment, how will my site of care keep me informed?

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Every site of care has a team in place who will have their own process for coordinating care. They may call you with reminders or provide other helpful information prior to your upcoming appointment.

Your site of care team may also work with you and your FAM to help manage any logistics related to your dosing days.

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### Hear from one site of care:

**"I inform patients and families of upcoming appointments 2 weeks prior to the date of their injection**

and provide basic instructions regarding their treatment day, such as lab information and any requirements and precautions.

Additionally, given that our dosing days are on Mondays, I call families on Thursday or Friday to ensure the patient is confirmed."

SITE OF CARE, SAN ANTONIO, TX

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12 mg/5 mL

## What is a dosing day like?

Every dosing day is unique based on the unique needs of each person and the policies each treatment center has in place. It's important to talk to your doctor about what to expect before your first SPINRAZA dose.

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**NICOLE // AGE 45**  
LATER-ONSET SMA  
TREATED WITH SPINRAZA

## "SPINRAZA treatment day starts early.

I get up around 5:30 and pack everything I'll need: water, snack, and food for my amazing service dog who always comes with me. I drop my daughter off at school and finally, I pick up my mom. My mom is the reason I am who I am today. She is the one who taught me to persevere and achieve mind over matter every day, so who better to accompany me on my treatment day?"

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**SPINRAZA**<sup>®</sup>  
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## Can a parent or caregiver be present during the procedure?

Each treatment center will have its own policies regarding the presence of caregivers during the injection. Please discuss this concern with your HCP prior to the injection.

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**CAMDEN // AGE 4**  
PRESYMPTOMATIC SMA  
TREATED WITH SPINRAZA

**"We try to go together so that we have one parent for each child during the dose. We live far enough where we have to stay the night. It's a lot of waiting around, and they have physical therapy days as well, so our kids get tired."**

**CHRISTINE**  
CAMDEN'S MOM

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## When should I expect to see improvements on SPINRAZA?

Everyone's journey on SPINRAZA is different, and individual results may vary based on disease progression, timing of treatment initiation, and duration of therapy. Remember, SPINRAZA is only one part of a holistic treatment plan. Discuss your goals and expectations with your HCP so that together, you can create a plan that works best for you.

### SELECTED IMPORTANT SAFETY INFORMATION

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**IAN // AGE 36**  
LATER-ONSET SMA  
TREATED WITH SPINRAZA

**“What I know  
for sure is  
that I am worth  
the effort,  
and I will continue to  
fight for my health.”**



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225 Binney Street, Cambridge, MA 02142

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