Explore what's possible with treatment for adults with SMA

No matter where you are in your treatment journey, this guide is for you

Find thought-starters, reflection prompts, and questions to ask your doctor about treatment for SMA.



"Treatment is totally worth it as an adult. Since SMA is progressive, being on treatment has really helped me keep doing what I love."

–**Liz,** living with Type 3 SMA, started treatment at age 38

Ambassadors are compensated by Genentech.
SMA=spinal muscular atrophy.

What is Evrysdi?
Evrysdi is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adults.

Important Safety Information

- **Before taking Evrysdi, tell your healthcare provider about all of your medical conditions, including if you:**
  - are pregnant or plan to become pregnant, as Evrysdi may harm your unborn baby. Ask your healthcare provider for advice before taking this medicine

Please see accompanying full Prescribing Information for additional Important Safety Information.

Evrysdi®
risdiplam
60 mg powder for oral solution
5 mg tablet

Think about how far you've come

Living with SMA can require adapting as your symptoms change over time. Sometimes these changes are subtle and hard to notice. Ultimately, SMA symptoms can get in the way of your ability to complete daily tasks on your own.

Treatment is an important way to manage the progression of SMA. As you consider your treatment options, think about changes you've noticed in your abilities and how you've been feeling over the last few years. You can use the survey below to get started.

How are you doing with your SMA today compared to how you were feeling a few years ago?

A lot better | A little better | About the same | A little worse | A lot worse

Are there daily tasks that require more effort now than they did in the past? Check any that apply:

- ☐ Handwriting
- ☐ Getting dressed
- ☐ Typing or using a phone
- ☐ Cooking
- ☐ Showering
- ☐ Getting in and out of seats
- ☐ Something else:

_____

_____

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_____

Do you ever...

Find that it takes more time and effort to complete daily tasks than it did a few years ago?

☐ Yes ☐ No

Use workarounds or adjustments in response to your SMA symptoms?

☐ Yes ☐ No

"The progression of SMA can be slow. You don't realize that something is happening to you until you try to do something that you used to be able to do and go 'Oh, I can't do that anymore.'"

–**Angela**, living with Type 2 SMA, started treatment at age 40



Identify what matters to you

Speaking to your doctor with your goals in mind can help you have a productive conversation.

Not sure what your goals are? Use these prompts to think through what you're looking for in an SMA treatment.

What aspects of daily living do you value being able to do now?

- ☐ Walking
- ☐ Driving
- ☐ Eating and drinking
- ☐ Getting dressed
- ☐ Writing or drawing
- ☐ Bathing
- ☐ Typing or using a phone
- ☐ Something else: _____



"It takes courage to seek treatment, but I think the reward is worth it. I recommend talking with your doctor about what is best for you."

–**Ira**, an Evrysdi ambassador living with Type 2 SMA, started treatment at age 36

Why does preserving these activities matter to you?

_____

_____

_____

Who else are you thinking about when it comes to maintaining these skills and activities?

_____

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_____

More treatment options are available than ever before for adults with SMA

Explore an option designed to fit more easily into adult life



Evrysdi is a once-daily treatment option for all people with SMA

Evrysdi is approved across all ages, SMA types, and abilities

5+ years of results in adults and children

Evrysdi is made to fit your lifestyle

Evrysdi is non-invasive, so you have flexibility in how you plan your day

Delivered to your door—no visit to the pharmacy required

Comes in two oral options you can take everywhere—a liquid and a tablet*†

- Evrysdi tablets have the same demonstrated results and safety as the liquid form

"I haven't had issues swallowing the Evrysdi tablet and it can fit in a purse or backpack. I can take it to lunch or dinner. There's less planning and more peace of mind knowing it's simpler for me than liquid."

–**Zack**, living with Type 3 SMA, started treatment at age 28

*Evrysdi 5-mg tablets are approved for people aged 2 years and older who weigh at least 44 lb (20 kg).

†If refrigeration is not available, Evrysdi liquid can be kept at room temperature up to 104°F (40°C) for a combined total of 5 days. Store Evrysdi tablets at room temperature, between 68°F to 77°F (20°C to 25°C). Excursions permitted between 59°F to 86°F (15°C to 30°C). Keep the bottle tightly closed in order to protect from moisture.

Important Safety Information (continued)

- **Before taking Evrysdi, tell your healthcare provider about all of your medical conditions, including if you:**
  - are a woman who can become pregnant:
    - Before you start your treatment with Evrysdi, your healthcare provider may test you for pregnancy
    - Talk to your healthcare provider about birth control methods that may be right for you. Use birth control while on treatment and for at least 1 month after stopping Evrysdi

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Take the next step of your treatment journey

Understanding your priorities ahead of time will help you advocate for your needs as you decide on a treatment plan with your doctor

Use the prompts to figure out what you'd like to take away from your visit.

My priorities for this visit are:

- ☐ Understanding my treatment options
- ☐ Finding a treatment that's right for me
- ☐ Making sure my questions are answered
- ☐ Something else:

_____

_____

_____

_____

It's important to me that my treatment:

- ☐ Helps me retain abilities, such as:

_____

_____

_____

_____

- ☐ Has manageable side effects
- ☐ Doesn't require a hospital stay
- ☐ Is easy to take on the go
- ☐ Fits in with my lifestyle long term
- ☐ Something else:

_____

_____

_____

_____



"If you think there's a chance of improving your symptoms, I would say take the leap. Put the fear aside as much as you can. I have no regrets about starting treatment as an adult."

–**Marianne**, living with Type 2 SMA, started treatment at age 22

Make your needs known at your appointment

Use these tips to advocate for yourself during your visit



Bring this guide and any resources you've used to learn about SMA treatment so far. Ask your doctor to walk you through any parts you had questions about.



Know your options. It's good to have an idea of which SMA treatments are available, so your doctor can go into more detail about them.



Ask questions. Your doctor wants to help you understand your treatment options and how they can address your SMA symptoms.



Not sure what to ask? Try these questions:

- I haven't noticed my symptoms changing in a while—does treatment matter for someone like me?
- What are the potential risks that come with delaying treatment?
- How are SMA treatments administered?
- What can I expect in terms of side effects with SMA treatments?
- What could treatment with Evrysdi look like for me?

Use this space to add any additional questions or notes from your appointment:

Resources for your journey

Find more information about SMA treatment

Explore treatments

Find an overview of SMA treatments from Cure SMA, an advocacy organization

Find doctors

See clinics that treat SMA near you with Cure SMA's treatment center locator

Discover Evrysdi

Learn about a non-invasive treatment for SMA at **Evrysdi.com**

Talk to peers

Connect with people who know SMA through Evyrsdi's SMA Peer Connect program*

*Participation is free and open to anyone living with SMA, or caring for someone who is. There's no requirement to be taking Evrysdi to join.

Questions about accessing Evrysdi?

Evrysdi's Parternship and Access Liaisons (PALs) are here to provide support with access, navigating insurance, and next steps.

You can contact a PAL **here**.

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  - are pregnant or plan to become pregnant, as Evrysdi may harm your unborn baby. Ask your healthcare provider for advice before taking this medicine
  - are a woman who can become pregnant:
    - Before you start your treatment with Evrysdi, your healthcare provider may test you for pregnancy
    - Talk to your healthcare provider about birth control methods that may be right for you. Use birth control while on treatment and for at least 1 month after stopping Evrysdi
    - **Pregnancy Registry.** There is a pregnancy registry for women who take Evrysdi during pregnancy. The purpose of this registry is to collect information about the health of the pregnant woman and her baby. If you are pregnant or become pregnant while receiving Evrysdi, tell your healthcare provider right away. Talk to your healthcare provider about registering with the Evrysdi Pregnancy Registry. Your healthcare provider can enroll you in this registry or you can enroll by calling **1-833-760-1098** or visiting **https://www.evrysdipregnancyregistry.com**.
  - are an adult male. Evrysdi may affect a man's ability to have children (fertility). Ask a healthcare provider for advice before taking this medicine
  - are breastfeeding or plan to breastfeed. It is not known if Evrysdi passes into breast milk and may harm your baby
- **Tell your healthcare provider about all the medicines you take**
- If you were prescribed Evrysdi for Oral Solution, you should receive Evrysdi from the pharmacy as a liquid. If the medicine in the bottle is a powder, **do not use it**. Contact your pharmacist for a replacement
- Avoid getting Evrysdi on your skin or in your eyes. If Evrysdi gets on your skin, wash the area with soap and water. If Evrysdi gets in your eyes, rinse your eyes with water
- **The most common side effects of Evrysdi include:**
  - For later-onset SMA: fever, diarrhea, rash
  - For infantile-onset SMA: fever; diarrhea; rash; runny nose, sneezing and sore throat (upper respiratory infection); lung infection (lower respiratory infection); constipation; vomiting; cough

These are not all of the possible side effects of Evrysdi. For more information on the risk and benefits profile of Evrysdi, ask your healthcare provider or pharmacist.

You may report side effects to the FDA at **1-800-FDA-1088** or **www.fda.gov/medwatch**. You may also report side effects to Genentech at **1-888-835-2555**.

Please see additional Important Safety Information throughout and accompanying full Prescribing Information.

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