SPINAL MUSCULAR ATROPHY

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THE LATEST ON
SPINAL MUSCULAR ATROPHY

CAN SPINAL CORD STIMULATION IMPROVE MOVEMENT?

Spinal cord electrostimulation may help children with SMA types 1 and 2 who are also getting medication. In a small, preliminary study, kids ages 6 to 13 who had gotten medication for two years got 30 to 40 minutes of physical therapy a day for up to 14 days. During the session, they received electrostimulation through a device implanted in their spine. After 14 days, each of the children had expanded their range of movements and learned at least one new motor skill.

SOURCE: *Life*

1 in 50

Number of Americans who carry the gene that causes SMA. In most cases, both parents have to carry it to cause the disease in a child.

SOURCE: Cleveland Clinic

UP TO 25,000

Number of children and adults living with SMA in the U.S.

SOURCE: Cleveland Clinic

RESEARCHERS FIND MORE GENES RELATED TO SMA

Researchers discovered another gene that may play a role in neurodegenerative diseases like SMA. Because SMA involves loss of nerve cells called motor neurons, genetic research has focused on nervous system genes. But this new study finds that defects in circulatory system genes that control blood vessel production and behavior play a part, too. When these blood vessel genes are defective, researchers found that newly created motor neurons cannot move out from the spinal cord and circulate to muscles throughout the body as they should. This discovery could be critical to the development of treatments that might help people with SMA produce new motor neurons.

SOURCE: *Neuron*

CAREGIVERS NEED CARE, TOO

If you take care of someone who has spinal muscular atrophy (SMA), it's important to take care of yourself, too. According to new research, caregivers for people with SMA are more likely to be depressed and anxious and have trouble sleeping. Both younger caregivers and those caring for older patients are the hardest hit. If you feel depressed, anxious, or have trouble sleeping, your doctor can help. There are effective treatments that will make you feel better so you can be a better caregiver.

SOURCE: *Pediatric Pulmonology*

HISPANOLISTIC/VIA GETTY IMAGES

STATS & FACTS

By Sonya Collins

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

1 in 10,000

Number of people who have spinal muscular atrophy (SMA).

4 NUMBER OF TYPES OF SMA

Type depends on when you develop symptoms and how severe they are.

6 in 10

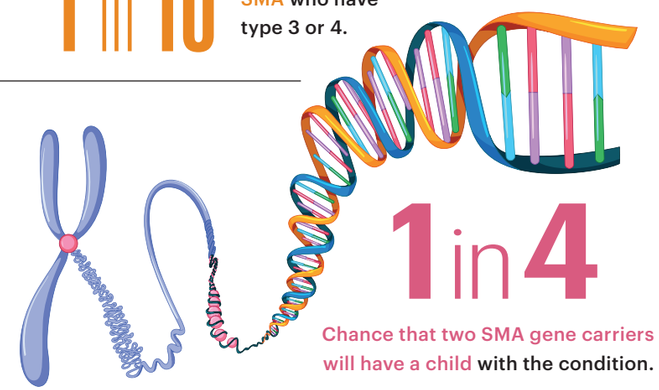
Number of people with SMA who have type 1.

3 in 10

Number of people with SMA who have type 2.

1 in 10

Number of people with SMA who have type 3 or 4.



1 in 47

Number of White people in the U.S. who carry the SMA gene—more than any other race or ethnicity.

1 in 4

Chance that two SMA gene carriers will have a child with the condition.

SOURCES: CDC, Cleveland Clinic, National Organization for Rare Disorders

FREEPIK.COM/GETTY IMAGES

MOVING AHEAD with Evrysdi® (risdiplam)

1,800+

people in the US with spinal muscular atrophy (SMA) are taking Evrysdi, including people up to 84 years old*†

*Number of people taking Evrysdi as of May 2022. Evrysdi approved in August 2020.

†Clinical studies of Evrysdi did not include people aged 65 and older to determine whether they respond differently from those who are younger

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
- 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.** Talk to your healthcare provider right away if you become pregnant while taking Evrysdi. Ask about registering with the Evrysdi Pregnancy Registry, which was created to collect information about your health and your baby's health. Your healthcare provider can enroll you in this registry by calling 1-833-760-1098 or visiting 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

Genentech
A Member of the Roche Group

Studied in the **most inclusive** clinical study program in SMA‡§

- ✓ For newborns to adults with SMA — **later-onset, infantile-onset, and presymptomatic SMA**
- ✓ Designed to help the body **make more SMN protein**
- ✓ Safety profile that has been studied in **more than 490 people** from newborns to adults
- ✓ Oral treatment that **can fit into your day**

‡Studies included individuals with a broad range of physical ability, including those with and without the ability to walk, with and without scoliosis (mild to severe), with and without prior disease-modifying treatment (evaluated for safety).

§The efficacy and safety of Evrysdi was established in 3 main studies. SUNFISH is a 2-part, placebo-controlled study in 231 adults and children aged 2 to 25 years with Type 2 or 3 SMA. FIREFISH is a 2-part, open-label study in 62 infants aged 2 to 7 months with Type 1 SMA. RAINBOWFISH is an ongoing, open-label study in 26 newborns younger than 6 weeks (at first dose). These newborns were genetically diagnosed with SMA and had not yet shown symptoms (presymptomatic SMA). A fourth study, JEWELFISH, is an ongoing, open-label safety study in 174 people aged 1 to 60 years with Type 1, 2, or 3 SMA that was previously treated with approved or investigational SMA medications.

Important Safety Information (continued)

Tell your healthcare provider about all the medicines you take.

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 accompanying brief summary for additional Important Safety Information.

If you cannot afford your Evrysdi medication, visit MySMASupport.com for financial assistance information.

Talk with your doctor about Evrysdi
or visit **www.Evrysdi.com/Go** to learn more

Evrysdi® risdiplam 60 mg powder for oral solution

Patient Information
EVRYSDI® [ev-RIZ-dee]
(risdiplam)
for oral solution

What is EVRYSDI?

- EVRYSDI is a prescription medicine used to treat spinal muscular atrophy (SMA) in children and adults.

Before taking EVRYSDI, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. If you are pregnant, or are planning to become pregnant, ask your healthcare provider for advice before taking this medicine. EVRYSDI may harm your unborn baby.
- are a woman who can become pregnant:
  - Before you start your treatment with EVRYSDI, your healthcare provider may test you for pregnancy. Because EVRYSDI may harm your unborn baby, you and your healthcare provider will decide if taking EVRYSDI is right for you during this time.
  - 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. If you become pregnant while receiving EVRYSDI, tell your healthcare provider right away. Talk to your healthcare provider about registering with the EVRYSDI Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health. Your healthcare provider can enroll you in this registry by calling 1-833-760-1098 or visiting https://www.evrysdipregnancyregistry.com.
- are an adult male planning to have children: EVRYSDI may affect a man's ability to have children (fertility). If this is of concern to you, make sure to ask a healthcare provider for advice.
- are breastfeeding or plan to breastfeed. It is not known if EVRYSDI passes into breast milk and may harm your baby. If you plan to breastfeed, discuss with your healthcare provider about the best way to feed your baby while on treatment with EVRYSDI.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Keep a list of them to show your healthcare provider, including your pharmacist, when you get a new medicine.

How should I take EVRYSDI?

See the detailed Instructions for Use that comes with EVRYSDI for information on how to take or give EVRYSDI oral solution.

- You should receive EVRYSDI from the pharmacy as a liquid that can be given by mouth or through a feeding tube. The liquid solution is prepared by your pharmacist or other healthcare provider. 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.

Taking EVRYSDI

- Your healthcare provider will tell you how long you or your child needs to take EVRYSDI. Do not stop treatment with EVRYSDI unless your healthcare provider tells you to.
- For infants and children, your healthcare provider will determine the daily dose of EVRYSDI needed based on your child's age and weight. For adults, take 5 mg of EVRYSDI daily.
  - Take EVRYSDI exactly as your healthcare provider tells you to take it. Do not change the dose without talking to your healthcare provider.
- Take EVRYSDI 1 time daily after a meal (or after breastfeeding for a child) at approximately the same time each day. Drink water afterwards to make sure EVRYSDI has been completely swallowed.
- Do not mix EVRYSDI with formula or milk.
- If you are unable to swallow and have a nasogastric or gastrostomy tube, EVRYSDI can be given through the tube.
- If you miss a dose of EVRYSDI:
  - If you remember the missed dose within 6 hours of when you normally take EVRYSDI, then take or give the dose. Continue taking EVRYSDI at your usual time the next day.
  - If you remember the missed dose more than 6 hours after you normally take EVRYSDI, skip the missed dose. Take your next dose at your usual time the next day.
- If you do not fully swallow the dose, or you vomit after taking a dose, **do not take** another dose of EVRYSDI to make up for that dose. Wait until the next day to take the next dose at your usual time.

Reusable Oral Syringes

- Your pharmacist will provide you with the reusable oral syringe(s) that are needed for taking your medicine and explain how to use them. Wash the syringes per instructions after use. Do not throw them away.
- Use the reusable oral syringe(s) provided by your pharmacist (you should receive 1 or 2 identical oral syringes depending on your prescribed daily dose) to measure your or your child's dose of EVRYSDI, as they are designed to protect the medicine from light. Contact your healthcare provider or pharmacist if your oral syringe(s) are lost or damaged.
- When transferred from the bottle to the oral syringe, take EVRYSDI right away. Do not store the EVRYSDI solution in the syringe. If EVRYSDI is not taken within 5 minutes of when it is drawn up, EVRYSDI should be thrown away from the reusable oral syringe, and a new dose should be prepared.

What are the possible side effects of EVRYSDI?
The most common side effects of EVRYSDI include:

- **For later-onset SMA:**
  - fever
  - diarrhea
  - rash
- **For infantile-onset SMA:**
  - fever
  - runny nose, sneezing, and sore throat (upper respiratory infection)
  - diarrhea
  - lung infection (lower respiratory infection)
  - rash
  - vomiting
  - cough
  - constipation

These are not all of the possible side effects of EVRYSDI. For more information, ask your healthcare provider or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store EVRYSDI?

- Store EVRYSDI in the refrigerator between 36°F to 46°F (2°C to 8°C). Do not freeze.
  - If necessary, EVRYSDI can be kept at room temperature up to 104°F (up to 40°C) for a combined total of 5 days. EVRYSDI can be removed from, and returned to, a refrigerator. The total combined time out of refrigeration should not be more than 5 days.
- Keep EVRYSDI in an upright position in the original amber bottle to protect from light.
- Throw away (discard) any unused portion of EVRYSDI 64 days after it is mixed by the pharmacist (constitution) or if EVRYSDI has been kept at room temperature (below 104°F [40°C]) for more than a total combined time of 5 days. Discard EVRYSDI if it has been kept above 104°F (40°C). Please see the Discard After date written on the bottle label. (See the **Instructions for Use** that comes with EVRYSDI).

Keep EVRYSDI, all medicines and syringes out of the reach of children.

General information about the safe and effective use of EVRYSDI.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use EVRYSDI for a condition for which it was not prescribed. Do not give EVRYSDI to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for information about EVRYSDI that is written for health professionals.

What are the ingredients in EVRYSDI?

Active ingredient: risdiplam

Inactive ingredients: ascorbic acid, disodium edetate dihydrate, isomalt, mannitol, polyethylene glycol 6000, sodium benzoate, strawberry flavor, sucralose, and tartaric acid.

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EVRYSDI® (risdiplam)

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For more information, go to www.EVRYSDI.com or call 1-833-387-9734.

This Patient Information has been approved by the U.S. Food and Drug Administration. Approved: 10/2022

RAISING A CHILD WITH SMA

WHAT TO EXPECT AS YOU LOOK AHEAD

By Rachel Reiff Ellis
Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

There's a lot to wrap your head around after you receive a spinal muscular atrophy (SMA) diagnosis for your child. Along with the emotional aspects, there's a lot to learn about the disease and how to support and care for your child. The best place to start is with your child's care team.

WHO YOU'LL SEE

Over the course of your child's care, you'll see many different specialists, including pulmonologists; neurologists; rehab specialists; physical, occupational, and speech therapists; and nutritionists.

"We try to give people as much information as we can from a lot of different perspectives with our treatment teams," says John Brandsema, MD, pediatric neurologist at Children's Hospital of Philadelphia. "A whole village of people gets together to work to optimize care."

WHAT SMA LOOKS LIKE

SMA is different for every child. "There's a huge range of severity in terms of how people experience the disease depending on when they receive the diagnosis," Brandsema says.

If your child is showing symptoms before 6 months, this is the most severe form of SMA, type 1. Your child likely has problems holding their head, sucking, feeding, and swallowing, and they typically move very little. This type has the shortest life expectancy.

Type 2 SMA appears from ages 6 months to 18 months. Your child will have muscle weakness that affects walking and eating, especially at first. With treatment, children live into adulthood with this type.

Type 3 is mild SMA that appears after 18 months. You may notice clumsiness and trouble walking.

"No matter what form of SMA your child has, after a certain point, they're going to be relentlessly losing strength," Brandsema says. "That is the hallmark of the disease."

A HOPEFUL OUTLOOK

It can be difficult to hear that your child has a disease that will take away their abilities over time, but treatments have made leaps and bounds in recent years.

Though the disease doesn't have a cure, the introduction of a new targeted medication that doctors inject into the spinal cord to increase production of the SMN protein has helped stabilize and slow the disease. Gene therapy is another breakthrough option for children under 2 with promising results in clinical trials.

"In a very short period of time, we've seen a nearly 180-degree shift in what we're talking about in the clinic," Brandsema says. "Instead of relentless loss, there's a lot of hope and celebration. I'm not trying to minimize the significance of it. It's still a very severe disorder, and we need to do our best standard of care for it. But the outcomes are different now that we have these treatments. It's a very different story."

INFORMATION AND CONNECTION

John Brandsema, MD, shares a few sources you can turn to as a parent of a child with SMA.

+ **Cure SMA**
  A national organization with extensive information and support for families.
  CureSMA.org
+ **Muscular Dystrophy Association**
  Offers information about many different neuromuscular disorders.
  MDA.org
+ **Social Media**
  There are many online groups that are very helpful for peer connection.

JILL LEHMANN PHOTOGRAPHY/VIA GETTY IMAGES

MY LIFE WITH SMA

By Kayley Shade

Reviewed by Melinda Ratini, DO, MS,
WebMD Medical Reviewer

WESTEND61/VIA GETTY IMAGES; INSET PHOTO BY JURGENS PHOTOGRAPHY

I was diagnosed with SMA type 2 at 16 months old. I never walked or crawled, so my parents started taking me to doctors, but it took a while to figure it out.

I got my first wheelchair when I was 2 years old. I was the youngest person in South Dakota to have that chair. I drove it with a joystick. It was challenging for my parents to help a 2-year-old learn how to operate an electric wheelchair.

I need help with every aspect of daily living: eating, bathing, getting dressed.

The only area where I am super independent is on my computer and phone. I use a MacBook with a regular mouse and an onscreen keyboard, so I can click the keys on the screen rather than type on a keyboard. Typing would take me hours and be very exhausting.

I'm director of media for the Indoor Football League [IFL] and a freelance graphic designer. This is my dream job. I always knew I wanted to be a graphic designer and I'm a huge football fan.

I got an internship with the Sioux Falls Storm in 2015. I wasn't even going to apply at first. I thought, 'I'm in a wheelchair. What could I do for a football team?' But with my family's support and hearing that the team would be willing to work with me, I ended up applying. I was going to let my wheelchair hold me back. But then I said, 'If I don't put myself out there now, when am I going to do it?' It was the best decision I've ever made.

The Storm looked more at my abilities than my disability. I was an intern for 10 months and then they hired me full-time. That led to my current job with the IFL. I've moved up over the years and made awesome connections in the business world and lifelong friends.

At work, I mainly focus on social media. I do graphics for our social media channels. I make flyers and posters. I work for a great organization. They understand my disability, that I get sick very easily, and that it may take me a couple of days to get back. They work with me on deadlines or handle the project while I'm out.

I'm very immunocompromised. A common cold can turn into pneumonia very fast. When I'm healthy, I spend the night on a ventilator. When I'm sick, I'm on the ventilator 24/7. I do extra nebulizer treatments. I have a cough assist machine, a vest machine—pretty much every machine you can imagine.

My treatment for SMA includes an injection into my spinal column every 4 months. It's supposed to help stop disease progression and hopefully help me gain some strength. I haven't noticed any gains, but I haven't gotten any weaker either. I recently started physical therapy to see if I can build some muscle. I also have speech therapy to try to improve my swallowing, which can get pretty weak with SMA.

I'm good at managing my mental health. My parents, sister, and nurses are my support system. My nurses are like friends. I talk to my sister every day. If I need her, she'll come see me. When I'm sick for months on end, that's the only time I struggle with mental health, so I lean on my support system.

If I didn't have them, I'd probably have a totally different lifestyle.

KAYLEY'S TIPS

+ Don't let your disability hold you back.
+ Put yourself out there.
+ Lean on your support system.

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Read this article on **Being Independent When You Have Type 3 SMA.** Use your mobile phone camera to activate the QR code.

HOW THERAPY CAN HELP WITH SMA

KNOW YOUR OPTIONS

By Kendall K. Morgan

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

WERA RODSAWANG/VIA GETTY IMAGES

In spinal muscular atrophy (SMA), your body makes too little of an essential protein. This survival motor neuron (SMN) protein normally keeps motor neurons in your spinal cord healthy. When you don't have enough SMN, muscles in various parts of the body weaken over time.

There's no cure for SMA. But there are multiple proven treatments. They all work by increasing SMN.

"We see really remarkable results with early treatment intervention," says Jackie Glascock, PhD, vice president of research for the nonprofit Cure SMA.

TREATMENT OPTIONS

The first proven medicine for kids and adults with SMA has been around since 2016. When injected into your cerebrospinal fluid, it makes more working SMN protein from a backup copy of the gene. Another drug you take by mouth each day works the same way.

Children under age 2 have a third option. It's a gene therapy to replace the gene that's most often missing or broken in SMA.

"Now we have people who've had this all their lives," Glascock says. "The treatments are wonderful and have really changed the natural history of this disease. Now, with any treatment, kids [with the most severe type of SMA] achieve walking, sitting, and standing—and within pretty normal time frames of development."

TIMING MATTERS

With newborn screening for SMA now in most states, kids born with SMA today often are diagnosed in infancy and can start treatment right away. There's no consensus among experts about which of the three treatments to go with. Talk to your child's care team about the pros and cons of each option, considering your own preferences and values.

It's best to start treatment as early as you can. While timing is important, Glascock says that older people, for whom medications weren't always available, also stand to benefit from treatment. You can't get motor neurons back once they're lost, but she says older teens and adults can see their symptoms stabilize. Sometimes you may even notice some small improvements.

Many people with later onset or less severe types of SMA are opting to start on proactive treatment, Glascock says. Physical or occupational therapy and rehab also help.

EXPERIMENTAL THERAPIES

New drugs are being tested. These include gene therapies as well as medicines that aren't designed to boost SMN. One day you might take two or more medicines at once to treat SMA in different ways at the same time.

"There's a big push to try to identify other targets that could be druggable," Glascock says. "There's still unmet need across the patient population, especially for older people who didn't have early access to treatment."

SUPPORT SYSTEM

HOW TO WORK WITH YOUR CHILD'S SMA CARE TEAM

By Kendall K. Morgan

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

HISPANOLISTIC/VIA GETTY IMAGES

SCAN ME

For more ways to advocate for your child, read this article on **Taking Control of Your Child's SMA in the Doctor's Office.** Use your mobile phone camera to activate the QR code.

A neurologist is likely the first person on your child's care team you'll meet, says Diane Murrell, a social worker who works with kids with spinal muscular atrophy at Texas Children's Hospital in Houston.

"You can think of the neurologist as the quarterback," she says. "They'll look at the genetics, send tests, do the clinical exam."

Your neurologist is most likely the one who'll confirm your child's diagnosis. Your child will then see a pulmonologist, or lung specialist, to look at how they're breathing. A physical therapist also is a key player on the team, along with many others. For instance, a social worker like Murrell or perhaps a nurse coordinator can help you understand how all the pieces fit together and help relay your wishes to the larger team.

WHAT TO EXPECT

At first, your child may have appointments often as you work out a treatment plan. Later, it's likely you'll go for regular visits twice each year. Unlike a regular doctor appointment, however, these visits may last half a day or perhaps longer. You may see multiple doctors and other specialists one after another.

Murrell recommends packing snacks, drinks, and small activities so your child isn't bored. Bring a notebook along with any questions and write things down.

"It's normal to forget half of what's told," Murrell says.

Consider bringing someone else along. That person could take notes for you while you listen. Or they may help to entertain your child.

ASK THESE QUESTIONS

Murrell recommends letting your care team know from the start what you want for your child. Don't hesitate to ask the tough questions such as, "How will this play out for my child in the long term?" or "How will this intervention impact every aspect of my child's life and care?"

Such questions can help to avoid a breakdown in your communication. You will avoid misunderstandings and disappointment later by clarifying the goals of each treatment or intervention.

YOU'RE THE EXPERT

And if you're overwhelmed or feel like you aren't being heard? Ask if there's a dedicated social worker you can talk to. Murrell says social workers are trained to understand differences related to culture, education, or other factors. Another option is to request a "family meeting" with the team in which they'll set aside time to listen to you.

"A good physician will rely on the parent's input," Murrell says. "They are the expert; they see their child day to day, not just in the secluded setting of the clinic."

THE LINEUP

Your child's care team may include experts in many areas, including:

- + Neurology
- + Genetics
- + Orthopedics
- + Physical therapy
- + Pulmonology
- + Nutrition
- + Gastroenterology
- + Anesthesiology
- + Surgery
- + Social work

ASSISTIVE DEVICES FOR CHILDREN WITH SMA

THESE TOOLS HELP YOUR CHILD MANAGE LIFE MORE SMOOTHLY

By Rachel Reiff Ellis

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

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For more on this topic, read this article on **Assistive Devices for Children With Spinal Muscular Atrophy.** Use your mobile phone camera to activate the QR code.

Kids living with the muscle weakness of spinal muscular atrophy (SMA) often need specialized devices to help them navigate the world. The specific assistive equipment your child will need will depend greatly on their type and severity of SMA as well as their age.

"Infants with type 1 SMA often need the greatest assistance, usually with basics such as breathing and feeding to avoid tracheostomy, lung collapse, or hospitalization," says Meagan Hainlen, MD, pediatric neurologist at UT Southwestern Medical Center in Dallas.

Older children with type 2 or type 3 SMA may need wheelchairs or other mobility aids for support as they move around. These devices can give your child more independence and access to the world around them.

TYPES OF DEVICES

The most common kinds of tools you can use for your child include aids that help with moving, breathing, eating, and positioning.

Mobility aids. Depending on your child's age and ability, you may need an adaptive stroller (also called a medical stroller), walker, or wheelchair.

Adaptive strollers are designed for children with special needs, and come with extra support, storage for medical supplies, and multiple options for positioning. Once your child is older, you may transition to a wheelchair.

"Wheelchairs come in a variety of styles, from those you push yourself to power chairs you control with your hands or mouth," Hainlen says. You can also get chairs that change position or rise to standing.

Breathing aids. The muscles involved in breathing can get weak, especially over time. A bilevel positive airway pressure (BiPAP) machine increases the volume and pressure as your child breathes so they get enough oxygen. Other machines can help your child cough so their airways stay clear.

"These machines force air into the lungs and draw it back out at a specific pressure so their cough is more productive," Hainlen says.

Feeding aids. Trouble swallowing is a common problem in kids with SMA, which puts them at risk for choking. You can use a special feeding seat to help your child be upright while you feed them. Or they may need a feeding tube to maintain their nutrition.

"Feeding tubes deliver nutrition directly into the stomach or small intestine," Hainlen says. They enter your child's body through the nose, throat, or small incision in their abdomen.

Aids that brace. Many kids need support in their positioning. Sometimes that means a brace for the ankle, or a knee-ankle-foot brace to keep joints in proper alignment.

A thoraco-lumbo-sacral orthosis is a specialized hard shell your child wears wrapped around their ribs and abdomen that helps with curvature of the spine. Standers are also beneficial for helping kids stay in an upright position for better circulation and breathing and can even roll for movement.

"One thing we watch for is pressure injury in kids who can't support themselves well," Hainlen says. "These devices can help prevent those complications."

HUNTSTOCK/VIA GETTY IMAGES