SPINAL MUSCULAR ATROPHY

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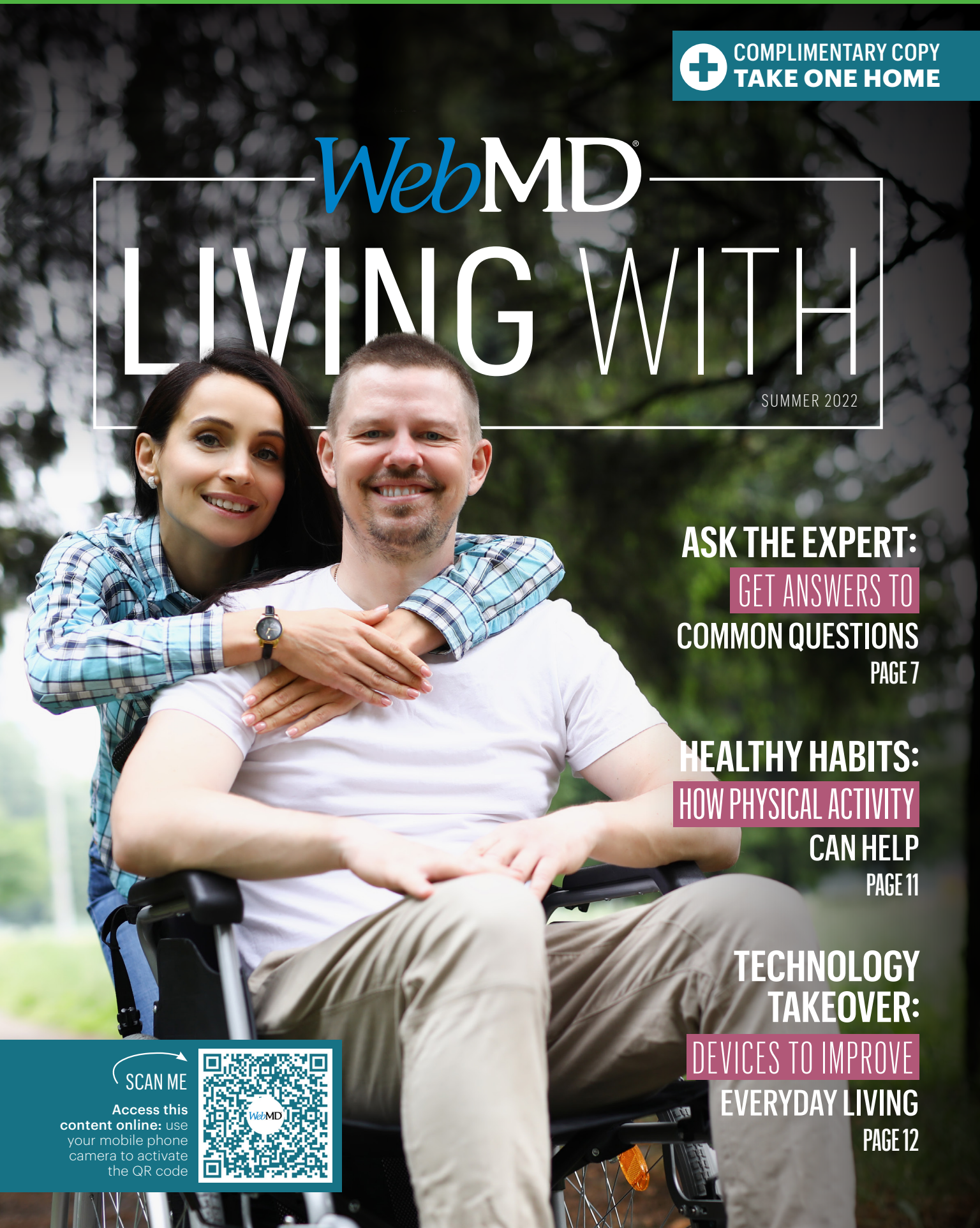

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SCAN ME

Access this content online: use your mobile phone camera to activate the QR code

SPECIALISTS TO SEE

Nicholas E. Johnson, MD, shares the types of health care professionals who can help your SMA issues.

+ **Neuromuscular neurologist.** This is typically the leader of your team at a multidisciplinary clinic.
+ **Pulmonologist** to manage lung problems.
+ **Orthopedic surgeon** to evaluate and manage scoliosis (spine curvature).
+ **Physical therapist** to deal with strength issues.
+ **Genetic counselor** to help you understand your diagnosis.
+ **Speech therapist** to monitor sleep and feeding.
+ **Dietitian** to help you get good nutrition.

"JUST AS IT'S IMPORTANT TO CARE FOR YOUR CHILD'S PHYSICAL WELL-BEING, CARING FOR YOUR PSYCHOLOGICAL WELL-BEING IS ALSO VERY IMPORTANT. DON'T FORGET TO TAKE CARE OF YOURSELF, TOO."

—MATTHEW M. HARMELINK, MD, DIRECTOR, PEDIATRIC NEUROMUSCULAR PROGRAM, CHILDREN'S WISCONSIN IN MILWAUKEE

Watch a video on **How Targeting One Gene Treats SMA** at WebMD.com/treatsma.

MANAGING YOUR SPINAL MUSCULAR ATROPHY

TIPS AND TREATMENTS FOR EVERYDAY LIVING WITH YOUR SYMPTOMS

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Although spinal muscular atrophy (SMA) doesn't yet have a cure, there are many treatments to help manage it. SMA treatments focus on easing your symptoms, preventing complications, and helping you live more comfortably. And these therapies are improving constantly.

"With new disease-modifying therapies available, the goal of treatment should be to slow the progression of the disease and therefore improve quality of life," says Nicholas E. Johnson, MD, associate professor and division chief of neuromuscular medicine and vice chair of research in the Department of Neurology at Virginia Commonwealth University in Richmond.

Here are some of the ways to do that:

IMPROVE YOUR MOVEMENT

Several FDA-approved medications are now available for SMA. Typically, you get these in one infusion dose. They work directly on cells in the spinal cord and can improve motor function.

"The natural progression of SMA across all ages is slow loss of the ability to use arms, legs, and even the trunk," Johnson says. "It's critical to be on a therapy to help prevent this, whether it's gene therapy, antisense oligonucleotides, or splicing inhibitors."

In addition, orthopedic braces, wheelchairs, and physical and occupational therapies can help improve your movement and help you function better throughout the day.

CHECK YOUR SPINE

Nearly all children with SMA develop scoliosis (curvature of the spine) at some point. This can cause problems such as hip dislocation, balance issues, and even trouble with breathing.

You may need a brace or even surgery to help correct the curve in your spine. This can help lessen pain, ease your breathing, and allow you to use your arms better.

SUPPORT BREATHING

The level of breathing help you need will depend on how severe your SMA is. "For patients with milder symptoms, they may not need any respiratory treatments," says Matthew M. Harmelink, MD, director of the pediatric neuromuscular program at Children's Wisconsin in Milwaukee.

For those who do, he says, the options range from a mask and machine that provides air pressure (BiPAP) to a permanent tube in the throat connected to a machine that breathes for you (tracheostomy and ventilator). There are also medications that can help with breathing.

Additionally, there are devices that can help you cough up mucus to help prevent infection in your lungs and airways and to keep oxygen flowing to your tissues. "As the disease progresses, the ability to cough up bad bacteria or viruses worsens," Johnson says. You can treat this by supporting the pressure in your lungs, particularly at night.

EAT WELL

A proper diet can help you grow, maintain a healthy weight, breathe better, prevent illness, and even improve your motor function.

If weak swallowing muscles get in the way of your eating, you may need a feeding tube that goes through your nose into your stomach (called an NG tube) or directly into your stomach (called a gastrostomy tube, or G-tube). See a specialist if you're having trouble getting the nutrition you need.

"A dietitian can work with you to modify which foods you eat if you have increasing difficulty swallowing," Johnson says. You can also see a speech therapist for help strengthening the muscles used for swallowing.

CONSERVE ENERGY

The muscle weakness of SMA can often make it feel like you're walking around with full medieval chain mail on your body. Fatigue is a common issue. Harmelink says it's helpful to budget your energy like you would your money.

"Think about how and when you'll need your energy during the day," he says. "If you have a big event or meeting in the afternoon, for example, take it easy in the morning."

Exercise done right can also help boost your mood and energy levels. Talk to your doctor about what type of movement could work for you to get your heart pumping and muscles moving in a positive way.

CATHERINE FALLS COMMERCIAL/VIA GETTY IMAGES

Evrysdi **in action**

Proven to make a difference in infants, children, and adults 2 months and older with spinal muscular atrophy (SMA)

1,400+

people in the US with SMA are taking Evrysdi, including people up to 83 years old*†

* Number of people taking Evrysdi since August 2020 (approval) through June 2021.

† 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 adults and children 2 months of age and older.

It is not known if Evrysdi is safe and effective in children under 2 months of age.

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. 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, 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
  - 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 and pharmacist when you get a new medicine

- **Evrysdi helped infants with Type 1 SMA achieve a key motor milestone and delayed disease progression‡**

  41% of infants (7/17) sat without support for at least 5 seconds after 12 months, as measured by the BSID-III gross motor scale

  90% of infants (19/21) at 12 months and 81% of infants (17/21) at 23 months were alive and able to breathe without permanent support§

- **Evrysdi significantly improved or maintained motor skills in adults and children with Type 2 and 3 SMA***

  Motor function improved after 12 months (average 1.36-point increase on the MFM-32 scale with Evrysdi vs average 0.19-point decrease without Evrysdi)

  - 1.55-point estimated improvement versus placebo on the MFM-32 scale at 12 months (95% CI: 0.30, 2.81; *P*=0.0156)‖

- **Evrysdi is designed to help make and maintain more SMN protein**

- **The safety of Evrysdi is being studied in more than 450 people, from 2 months to 60 years old, with Type 1, 2, or 3 SMA‡**

- **The first and only medication to treat SMA with at-home dosing**

‡ The efficacy and safety of Evrysdi was established in 2 main studies. FIREFISH is a 2-part, open-label study of Evrysdi in 62 infants aged 2-7 months with Type 1 SMA. SUNFISH is a 2-part study of Evrysdi in 231 children and adults aged 2-25 years with Type 2 and 3 SMA. A third study, JEWELFISH, is an ongoing safety study of Evrysdi in 174 infants, children, and adults aged 1-60 years with Type 1, 2, and 3 SMA previously treated with approved and investigational SMA medications.

§ Permanent support was defined as having a tracheostomy (a surgery where a tube is inserted in the front of the throat into the windpipe) or more than 21 days of either noninvasive ventilation support (16 or more hours a day) or being intubated (a procedure where a breathing tube is inserted down the throat and into the windpipe) to help with breathing, in the absence of an acute reversible event.

‖ This 95% CI (confidence interval) means that we are 95% confident that the actual average change in MFM-32 with Evrysdi will be between 0.30 and 2.81 points higher than with placebo.

BSID-III stands for the Bayley Scales of Infant and Toddler Development–Third Edition.
MFM-32 stands for the Motor Function Measure-32 Items.
SMN stands for survival motor neuron.

Important Safety Information (continued)

- 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. 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, sore throat, and cough (upper respiratory infection), lung infection, constipation, vomiting

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.

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

Evrysdi® risdiplam 60 mg powder for 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 adults and children 2 months of age and older.
- It is not known if EVRYSDI is safe and effective in children under 2 months of age.

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.
- 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 and 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. 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 syringes 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 syringes provided by your pharmacist (you should receive 2 identical oral syringes) 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 syringes are lost or damaged.
- Once 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, sore throat, and cough (upper respiratory infection)
  - constipation
  - diarrhea
  - lung infection
  - vomiting
  - rash

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.
- 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). Please see the Discard After date written on the bottle label. (See the **Instructions for Use** that comes with EVRYSDI).

Keep EVRYSDI and all medicines 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.

Genentech
A Member of the Roche Group

EVRYSDI® (risdiplam)

Distributed by:
Genentech, Inc.
A Member of the Roche Group
1 DNA Way
South San Francisco, CA
94080-4990

M-US-00007143(v2.0)

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: 4/2021

For more on **What You Should Know About SMA type 3**, visit WebMD.com/sma.

PROFESSIONAL POINT OF VIEW

GET ANSWERS TO YOUR COMMONLY ASKED QUESTIONS ABOUT SMA TYPE 3

By Rachel Reiff Ellis
Reviewed by Neha Pathak, MD, Lead Medical Editor

Lindsay A. Zilliox, MD, neurologist at the University of Maryland Medical Center and assistant professor of neurology at the University of Maryland School of Medicine in Baltimore, shares some basic facts about SMA type 3.

Q. HOW DO YOU GET SMA TYPE 3?

SMA is an inherited disorder that is passed down from your parents. It is inherited in a "recessive pattern," which means you get one copy of the genetic change from each of your parents and have two abnormal copies of the gene. If both of your parents are carriers (each has one copy) of the mutation, your chance of inheriting the disease is 25%.

Q. WHAT'S THE TYPICAL PROGRESSION FOR SMA TYPE 3?

SMA type 3 usually affects people between 18 months of age up until adulthood. It presents with weakness in the legs more than the arms, which can impact activities like walking or climbing. Over time, the weakness slowly gets worse and you may need assistance to stand or walk. Your muscles that control breathing and swallowing might also be affected, but not always. This can lead to difficulty taking deep breaths and more frequent respiratory infections. There are new therapies that have been developed that may slow down the progression of the disease.

Q. HOW DO YOU DECIDE THE BEST TREATMENT FOR SOMEONE WITH SMA TYPE 3?

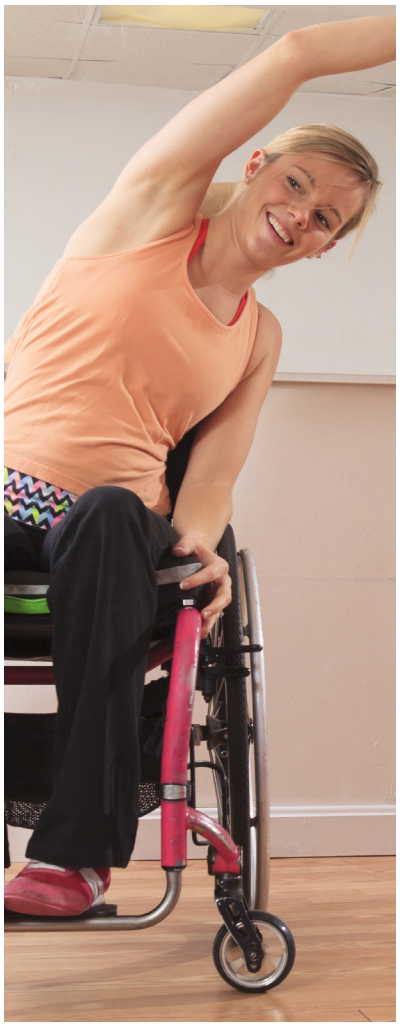
SMA treatment is mainly supportive with the goal of managing symptoms and preventing complications. This typically involves different specialists including neurology, pulmonology, genetics, physical and occupational therapy, and nutrition. In addition, there are disease-modifying treatments that may slow the progression of weakness. The best treatment is individualized and tailored to each person with the disorder. We recommend education about SMA, including genetic counseling, for people with SMA and their families.

Q. WHAT KINDS OF COMPLICATIONS CAN SMA TYPE 3 CAUSE?

As your weakness progresses, you may need assistance with walking or you may become wheelchair dependent. Muscle weakness can also result in changes to your spine (scoliosis) or other joints, especially those in your feet. While other forms of SMA are associated with breathing problems, SMA type 3 usually is not. SMA type 3 is typically associated with a normal life span.

Q. WHAT KIND OF EVERYDAY LIFESTYLE CHANGES MIGHT HELP WITH THE SYMPTOMS OF SMA TYPE 3?

Maintaining a healthy weight is important for mobility. Although we don't generally recommend intense exercise, a stretching program can help prevent shortening of muscles and joint changes that occur over time. Breathing exercises can reduce the effects of respiratory infections.



HUNTSTOCK/VIA GETTY IMAGES

THE IMPORTANCE OF MENTAL HEALTH CARE

TENDING TO YOUR EMOTIONAL NEEDS WHEN YOU HAVE—OR CARE FOR SOMEONE WITH—SMA

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Because spinal muscular atrophy (SMA) takes such a physical toll on those who have it, it can be easy to ignore mental and emotional well-being. But your mental and physical health are very much tied together.

Anxiety, depression, grief, body image issues, and even substance abuse are common for people with SMA. Noticing and dealing with them is an important part of whole-body wellness.

EMOTIONAL TOLL

Typical issues that can impact your mental well-being when you have SMA include:

- Making difficult treatment choices
- Worry about future loss of function
- Lack of sleep
- Stress
- Thoughts about death
- Limitations on social activities
- Finances

Kids with SMA may especially grieve their loss of independence once they reach the age where separation from family would typically happen.

"Just when you're aching to get free, you can't," says Thomas O. Crawford, MD, professor of neurology and co-director of the Muscular Dystrophy Association Clinic at Johns Hopkins Medicine in Baltimore. "It's a distortion of normal development."

SOURCES OF SUPPORT

Connecting with others who understand SMA and its impact on daily life can bring you comfort and help you feel less alone. Online communities are invaluable for rare conditions like SMA, since you may not live close to others with the condition.

"It's hard to get people physically together, so we now have these strong virtual communities coming together and forming groups," Crawford says.

MINISERIES/VIA GETTY IMAGES

SCAN ME

Want to read this guide on the go? Use your mobile phone camera to activate the QR code.

FATCAMERA/VIA GETTY IMAGES

SIGNS OF MENTAL DISTRESS

Anxiety and depression can be hard to spot when you're experiencing them. Here are some symptoms you might have:

- **Bouts of nervousness or feeling tense**
- **Concerns that something "bad" will happen**
- **Trouble concentrating**
- **Fast breathing or rapid heart rate**
- **Problems sleeping or sleeping more than usual**
- **Feeling sad or hopeless**
- **No interest in things you used to enjoy**
- **Irritability or unexplained anger**
- **Low energy levels**

A big benefit of SMA support groups, especially for kids, is seeing others who are thriving with the condition. "One of my 14-year-old patients who had decided she'd never be able to do much met a young lady through an SMA group who had a baby, and it changed her whole life outlook," Crawford says. Positive representations of others with SMA can foster hope and encouragement.

Professional therapy is another avenue to help you cope with mental struggles. There are many different therapy methods, including interpersonal therapy and cognitive behavioral therapy. You'll get the most out of this kind of help if you find a therapist you connect with who understands your issues.

"Remember, the purpose of life is not to do therapy. The purpose of therapy is to do more life," Crawford says.

CAREGIVER STRESS

If you're a loved one caring for someone with SMA, you also bear an emotional and mental stress load. A study of parents of kids with SMA found that not only was stress high for them, but also that stress went up with the severity of their child's disease.

"Caregiver burnout" is a state of emotional, physical, and mental exhaustion that often happens when you're the primary support person for someone with SMA. You care for yourself when you:

- Find your own "support person" to talk to
- Tap into respite care resources such as home health
- Join a caregiver support group
- Know and name your limits

It's common to feel guilty about taking time for yourself when your loved one depends on you, but by investing in your mental well-being, you're better prepared to take care of them.

FACTS & STATS

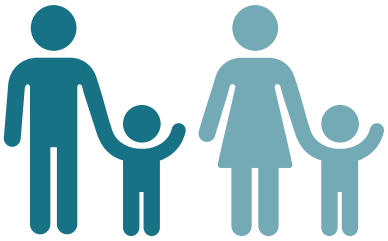
By Sonya Collins

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

up to 25,000

Estimated number of children in the U.S. who have spinal muscular atrophy (SMA).

1 **Number of copies** of a mutated VAPB gene that a child must inherit from their parents in order to have adult-onset Finkel type spinal muscular atrophy.



1 in 6,000 to 1 in 10,000

Number of people who are born with spinal muscular atrophy.

1 in 2

Chance that a person with Finkel type spinal muscular atrophy will pass the condition on to a child.

2

Number of copies of a mutated SMN1 gene a person must inherit from their parents in order to have spinal muscular atrophy. (A child must inherit a mutated gene from both the mother and the father.)

Up to $196,429

Average annual cost of SMA type 1—the most common and severe type of SMA. Cost depends on severity of symptoms and the age at which they start.

1 in 4

Chance that a child will be born with spinal muscular atrophy when both parents carry the gene.

Up to $82,474

Average annual cost of SMA types 2, 3, and 4—less severe forms of the condition that develop later than type 1.

1 in 40 to 1 in 50

Number of people in the U.S. (about 6 million) who carry the gene for spinal muscular atrophy.

SOURCES: National Human Genome Research Institute, SMA Foundation, MalaCards Human Disease Database, National Cancer Institute, National Organization for Rare Diseases, *Orphanet Journal of Rare Diseases*

GETTY IMAGES

TYPE 3 AND EXERCISE

HOW PHYSICAL ACTIVITY CAN HELP YOUR SMA SYMPTOMS

By Rachel Reiff Ellis

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

Exercise is good for all bodies. It lowers stress levels, helps heart health, and boosts your mood. When you have spinal muscular atrophy (SMA), regular intentional movement is a key part of symptom management.

Putting a priority on consistent physical activity helps you move from "reactive" care of your SMA to "proactive" care, says Bakri Elsheikh, MD, associate clinical professor of neurology at The Ohio State University Wexner Medical Center in Columbus, OH.

"Exercise halts muscle deterioration and helps prevent harmful and costly secondary conditions of SMA," he says. "And it improves your quality of life. It allows for more independent living and greater participation in the community."

BENEFITS OF BODY MOVEMENT

With steady workouts or sessions with a physical or occupational therapist, you can:

- Increase your range of motion
- Boost circulation
- Reduce or prevent joint stiffening
- Strengthen your muscles, including the ones that help you breathe
- Help maintain your posture

Healthy movement helps teach your body good habits, too. "You're promoting good neuromuscular education when you exercise," Elsheikh says.

WHAT TO TRY

Elsheikh says it's good to aim for at least 30 minutes of exercise at least 3 days a week, but 5 days is better. He recommends:

Swimming. Swimming laps or doing water aerobics in a warm pool gives your joints a relief from gravity while working them with gentle resistance at the same time.

Walking. Daily walking is a good weight-bearing exercise that can help prevent joint stiffening and promote bone health.

Biking. Recumbent or stationary bikes are great options for aerobic workouts that don't require balancing on two wheels.

Game-based activities. Video games or other kinds of games that promote movement, such as virtual sports or badminton in the yard will get your heart pumping and help you get moving.

Yoga. The slow and gentle stretching of yoga helps regulate mood, encourages better, deeper breathing, and increases flexibility.

Elsheikh says no matter what you choose, don't let physical limitations keep you sidelined. "Adapt your workouts so they work for you, and so you can enjoy life."

DOS AND DON'TS

Bakri Elsheikh, MD, offers these tips to help exercise become a habit.

+ **Don't go rogue.** Always talk to your doctor before taking on a new workout routine.
+ **Do schedule smart.** Optimize your energy and strength by working out when you have the most energy.
+ **Don't overdo it.** Watch for pain or increased weakness and take breaks when you need them.
+ **Do have fun.** You're more likely to stick with movement you enjoy.

CAMARALENTA/VIA GETTY IMAGES

ASSISTIVE AIDS

THESE DEVICES HELP IMPROVE EVERYDAY LIVING WITH SPINAL MUSCULAR ATROPHY

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

Assistive devices are pieces of equipment you or your child can use to stay as functional as possible while dealing with the symptoms of spinal muscular atrophy (SMA). These devices can help you do things like shower, get dressed, walk, speak, breathe, swallow, and cough.

You may wonder if using an assistive device will hold you back in some way, but Nassim Rad, MD, physical medicine and rehabilitation specialist and co-director of the UW Medicine MDA-ALS Center in Seattle, says the opposite is true.

"Many people are resistant to assistive devices because they fear they're 'giving up' or they believe in the 'use it or lose it' mentality," she says. "But using assistive devices helps you save energy to engage in *more* activities while also keeping you safe and reducing your risk of falls or infection."

Some of the tools you can use include:

DEVICES TO HELP YOU MOVE

Because muscle weakness is a hallmark symptom of SMA, there's a wide range of mobility devices. These aids help with sitting, standing, walking, or generally moving around. Aids you might use:

- Cane
- Walker
- Manual or power wheelchair
- Adaptive strollers (for a child with SMA)
- Bath chairs

"Many people will start with one device and over time need to transition to another form as their disease progresses," Rad says.

A few accessibility changes around your house can help with mobility issues, too. "You might need to alter bathrooms and showers to accommodate raised toilet seats, grab bars, and shower/bath chairs," Rad says.

DEVICES TO HELP YOU BREATHE AND EAT

Respiratory (breathing) problems are the leading cause of illness in people with SMA. These devices can help prevent infection as well as make you or your child more comfortable. You may use these devices for help coughing, swallowing, and breathing:

- **Bilevel positive airway pressure (BiPAP) machine**—a ventilator that helps get more air in as you breathe, especially when you're sleeping.
- **Cough assist machines**—face masks hooked to a tube and machine that pushes air in and out of lungs.
- **Standers**—devices that hold you in a standing position to help with digestion, circulation, and breathing.
- **Feeding seat**—a special foam seat to position a child for eating.

The level of breathing or eating help you or your child needs will depend on how severe the SMA symptoms are.

ASK THOSE IN THE KNOW

Many other incredible tools are available for everyday functioning such as robotic arms, eye gaze computers, and wheelchairs you can power with head movements. Talk with your doctor so you can figure out what you need when.

"Technology is constantly advancing, so it's important to check in with your provider and discuss functions that are becoming harder for you," Rad says. "They can refer you to physical therapy, occupational therapy, and speech therapy to evaluate for assistive devices you might not even know exist."

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