Facts About ALS (amyotrophic lateral sclerosis)

Muscular Dystrophy Association • mda.org
**MDA and ALS**

MDA is leading the fight to free individuals — and the families who love them — from the harm of ALS (amyotrophic lateral sclerosis) and related muscle-debilitating diseases that take away physical strength, independence and life. If you’ve recently received an ALS diagnosis, this booklet will help you understand the disorder, while guiding you to the many support services MDA provides as well as research efforts aimed at finding treatments. You’re not alone in your journey. MDA is here for you every step of the way, ready to provide access to state-of-the-art medical care, resources and guidance, support groups and ways to connect with others who are living with ALS.

MDA’s involvement with ALS began in the early 1950s, when Eleanor Gehrig, widow of Yankees first baseman Lou Gehrig, was searching for a way to fight the disease that had taken her husband’s life. Mrs. Gehrig served more than a decade as MDA National Campaign Chairman.

Together with our supporters, we’re helping individuals with ALS live longer, stronger lives. Here’s how:

**Finding research breakthroughs across diseases**

MDA takes a big-picture perspective across ALS and related neuromuscular diseases to uncover breakthroughs that will accelerate treatments and cures. The power in this research approach is that knowledge and information from one disease can often yield progress in others to speed urgently needed answers for families.

**Caring for kids and adults from day one**

MDA provides early diagnosis, highly specialized care and access to promising clinical trials at MDA Care Centers and MDA ALS Care Centers in top hospitals and health care facilities across the United States and Puerto Rico.

- Approximately 12,000 individuals affected by ALS receive MDA services. They all have access to our nationwide network of more than 150 specialized MDA Care Centers — including more than 40 designated MDA ALS Care Centers — staffed by top health professionals skilled in the diagnosis and medical management of ALS.

- In addition, the MDA U.S. Neuromuscular Disease Registry seeks to gain a better understanding of the course of illness for ALS and other diseases; collect data about genotype-phenotype correlations (the relationship between genetic mutations and symptoms/disease course) to allow for better prediction of disease progression based on genetic information; identify long-term outcomes that highlight best clinical practices; provide data that can be used to develop a quality improvement program for MDA Care Centers; and expedite research by establishing a database of individuals eligible for consideration to participate in clinical trials for neuromuscular disorders.

**Empowering families with services and support**

From support groups and educational seminars to assistance with durable medical equipment, MDA empowers families in hometowns across America with help and support they need today.
In the United States, ALS also is called Lou Gehrig’s disease, named for the Yankees baseball player who died of it in 1941. In Britain and elsewhere in the world, ALS is often called motor neurone disease (MND) in reference to the nerve cells (motor neurons) that degenerate in this disorder.

What happens to someone with ALS?

In ALS, nerve cells that control muscle cells deteriorate. In most cases, the cause is unknown. As the number of healthy motor neurons declines, the muscles they control become weak and then nonfunctional. Eventually, the person with ALS may become paralyzed.

Without assistive technologies such as mechanical ventilation and feeding tubes, the average life expectancy is three to five years after an ALS diagnosis. However, about 4 to 10 percent of those with the disease live more than 10 years, and some survive for decades, such as British physicist Stephen Hawking, who has had ALS since the 1960s and is still able to practice his profession.

Modern technology has allowed people with ALS to compensate to some degree for almost every loss of function, making it possible even for those with almost no muscle function to continue to breathe, communicate, eat, travel and use a computer.

It’s important to note that the involuntary muscles, such as those of the heart, gastrointestinal tract, bowel and bladder, and those that regulate sexual functions are not directly affected in ALS. (However, prolonged inability to move and other effects of ALS can have some indirect impact.) Hearing, vision and touch generally remain normal.
The function of lower motor neurons is straightforward. They send “go” signals to muscles. When these cells lose function in ALS, muscles atrophy (shrink) and become progressively weaker and eventually unable to contract, resulting in paralysis.

The lower motor neurons that control most of the muscles in the body are in the spinal cord. Those that control the muscles involved in speaking, swallowing and facial expression are in the brainstem. They’re sometimes called bulbar motor neurons, because the part of the brainstem that houses them has a bulblike shape. The term bulbar involvement means that the muscles of the face, mouth and throat are affected by the disease.

The upper motor neurons have more complex functions, making them more difficult to study. Therefore, there is not as much information about them, although new technologies are being developed to change this.

These cells seem to exert complex control over the lower motor neurons. This control allows movements to be smooth, directed and varied in intensity. (For instance, they’re part of an elaborate system that allows a person to aim a hand at a glass of water, estimate its weight, pick it up, and use the right amount of force to lift it to his or her mouth, all while thinking about something else.) When upper motor neurons are lost and lower motor neurons remain, movements are still possible but can become tight (spastic) and less precise.

In ALS, a combination of these effects is usually seen because both upper and lower motor neurons are losing function. People with ALS can have weak and atrophied muscles with tightness (spasticity).

Muscle twitches (called “fasciculations”) and cramps are common; they occur because degenerating nerves become irritable.

ALS-associated pain can occur as a result of tightness (spasticity) of muscles, decreased range of motion of the joints, and abnormal stresses on the muscles, bones and skin that occur as a result of immobility. Pain and its management should always be discussed with your health care professionals.

Mild cognitive impairment is not uncommon, but severe cognitive impairment, known as “dementia,” occurs in only about 3 to 5 percent of cases. Some with ALS may experience involuntary laughing or crying spells that are unrelated to their emotional state. Called involuntary emotional expression disorder, or “pseudobulbar affect,” this symptom can be treated with medication. (For more on these cognitive and emotional symptoms, see “Emotions and intellect” on page 17.)

What happens to the nervous system in ALS?

Muscle-controlling nerve cells, or motor neurons, are divided into two types: upper and lower. The upper motor neurons are located on the surface of the brain and exert control over the lower motor neurons, which are in the brainstem and the spinal cord.

The lower motor neurons are directly attached to muscles through “wires” called axons. Bundles of these axons leave the spinal cord and extend out to the muscles. It’s these bundles that doctors are referring to when they talk about the “nerves.”

Upper motor neurons on the surface of the brain control lower motor neurons in the brainstem and spinal cord.
How is ALS diagnosed?

ALS usually announces itself with persistent weakness or tightness in an arm or leg, making it difficult to use the affected limb; or in the muscles controlling speech or swallowing, leading to difficulty with these functions. At this stage, it isn’t unusual for people to ignore these problems or to consult a physician who likely will find no cause for concern.

However, the disease — if it’s truly ALS — continues to progress. It generally spreads from one part of the body to another, almost always in parts adjacent to each other, so that eventually the problem can no longer be ignored or treated with exercise or a cane. It’s at this point that the patient is usually referred by a general practitioner to a neurologist, who will then consider ALS among many other possibilities.

A thorough medical and family history and physical examination are the starting points of a neurological work-up. The person will undergo simple, in-office tests of muscle and nerve function.

If ALS is still being considered at this point, the next step is usually an electromyogram, or EMG. This test measures the signals that run between nerves and muscles and the electrical activity inside muscles to see if there’s a pattern consistent with ALS. If there is, more tests likely will be ordered.

Additional tests may include imaging of the spinal cord and brain, usually by MRI.

Who gets ALS?

ALS usually strikes in late middle age (the average age of onset in the United States and Europe is between 56 and 63) or later, although ALS also affects younger adults and even children, as well as very elderly people. Some genetic forms of ALS have their onset in youth.

Men are somewhat more likely to develop ALS than are women. Studies suggest an overall ratio of about 1.5 men to every woman who develops the disorder in Western countries. In younger-onset patients, there seems to be a greater male predominance.

Genetic factors are involved in the cause of ALS, and the disease can run in families (see “Does ALS run in the family?” on page 24). ALS is “familial” (that is, there is more than one case in a family) about 5 to 10 percent of the time. The other 90 to 95 percent of the time, it is “sporadic” (that is, there is no family history of the disease).

For years, experts have tried to find factors common to people who develop ALS, such as environmental toxins, occupational hazards, places of work or residence, etc. So far, the evidence for such risk factors and triggers has been frustratingly unclear, although the finding of an association between developing ALS and having served in the Gulf War in the early 1990s has indicated one of the strongest of these proposed risk factors. In fact, military service in general, regardless of the branch or service during war time, is associated with an increased risk of developing ALS. (See “What causes ALS?” on page 19.)
In 2010, the FDA approved the drug Nuedexta for the treatment of uncontrolled expression of emotion related to brain changes in ALS. This condition, also known as pseudobulbar affect, involves laughing and crying spells unrelated to mood.

Several other medications are now in clinical trials but it is still unclear whether these experimental therapies are effective at treating ALS.

MDA Care Centers use a team approach to patient care that mobilizes a variety of health care professionals, all of whom aim to alleviate symptoms, maintain function and independence, prolong life and offer guidance for those with ALS and their families.

In ALS, when it comes to technology, durable medical equipment and health-enhancing strategies like feeding tubes, the key is to stay ahead of the game. Investigate and obtain these important aids before you need them, to increase the chances that you will fully benefit from them.

Preserving hand function

Special grips for writing implements and eating utensils, devices that fit over keys to make them easier to turn, zipper pulls and button hooks can help make weakening hands more functional.

Eyegaze technology provides an alternative to using the hands to access the internet, write, use a communication device and even drive a power wheelchair.

A physical or occupational therapist associated with your MDA Care Center or MDA ALS Care Center can help you with these devices.
Preserving mobility

Today’s technology allows for mobility for almost everyone, no matter how few muscles remain functional. Physical and occupational therapists at your MDA Care Center or MDA ALS Care Center can help you identify the equipment that’s best for each stage of the disorder.

In the early stages, a cane or a supportive brace (“orthosis”) may be all that’s needed. An ankle-foot orthosis, or AFO, can keep the foot from dropping with each step and causing tripping while walking. Later, additional devices may be useful, such as walkers, manual wheelchairs and power wheelchairs.

As mobility becomes more difficult, a power wheelchair is usually highly desirable. A “tilt-in-space” type allows the seat to be positioned at a variety of angles, which relieves pressure and helps prevent skin breakdown. Some models allow the user to be brought into a standing position, which is generally good for circulation, bowel and bladder function, and bone preservation, as well as providing the psychological benefits of standing.

Careful planning for the type of wheelchair needed and desired, and a thorough knowledge of insurance matters in relation to wheelchairs, is important. Physical therapists and/or wheelchair specialists who can consult with you on these matters are often available in or near your MDA Care Center or MDA ALS Care Center.

Custom-fitted power wheelchairs can take many weeks or months to obtain, so plan ahead. Your physician or physical therapist may recommend a power wheelchair before you think you’re ready, but this is to avoid long delays between the time the chair is needed and the time it may arrive.

Preserving communication

For many with ALS, speaking ability may be lost as weakness increases in the muscles of the mouth and throat that control speech and in the muscles that help generate the pressure that moves air over the vocal cords. This happens earlier in the bulbar-onset form of the disease (when the disease begins with weakness of the speaking and swallowing muscles) than it does in the limb-onset form (when weakness begins in a limb).

For this reason, speech therapists, or speech-language pathologists, are vital members of the ALS care team.

Early in the disease process, while speech is still normal or nearly so, speech therapists may suggest that a person with ALS record his or her speech. A number of commonly used phrases can be programmed into a computer, or perhaps the person would like to talk about his or her life for future listening by friends and family.

Later, the therapist can teach the person with ALS special techniques for conserving energy and making speech understood as well as possible. In some cases, a dentist can make a device called a palatal lift that can help compensate for certain types of weakness in the roof of the mouth.

Later still, the therapist can help the person with ALS learn to use a communication...
who start out thinner or lose weight as ALS progresses.

Early solutions to swallowing problems involve changing the consistency of food and liquids — usually thickening the liquids and avoiding large pieces of food — as well as changing swallowing techniques.

Later, if swallowing becomes hazardous and eating takes a great deal of time and energy, the therapist and physician may recommend inserting a feeding tube (also called a “gastrostomy” tube) that allows food to be delivered directly into the stomach. The term “gastrostomy” refers to making a small incision in the stomach. You may hear a feeding tube referred to as a “PEG,” which stands for “percutaneous endoscopic gastrostomy,” or a “RIG” tube, which stands for “radiologically inserted gastrostomy.” These terms describe the procedures used when the tube is first inserted.

If still able to swallow some foods or liquids safely, people with ALS can continue to eat and drink by mouth after placement of a feeding tube. The tube can be used to supplement calories so that weight is not lost. This can be a relief to those who can’t take in enough calories by mouth because they get too tired or are afraid of choking, but who still want to enjoy the taste of food.

The most serious problems are outright choking — obstruction of the windpipe by a piece of food — and aspiration, which means inhaling food or liquid into the lungs instead of routing it down the esophagus into the stomach. Normally, the throat muscles protect us from aspirating food or drink, but they may lose their ability to do so as ALS advances.

Speech-language pathologists or therapists are also specialists in swallowing, since these functions involve the same muscles as speech. Some therapists specialize more in speech and others more in swallowing. Your MDA Care Center or MDA ALS Care Center can refer you to a therapist who can help you address swallowing problems as they arise.

Swallowing problems can cause weight loss, and that’s not a good thing. In ALS, there is a clear link between weight and survival. Studies show that people who are slightly overweight at the time of diagnosis, and people who maintain their weight through the course of the disease, live longer than those baseline.
Another form of breathing support, known as invasive ventilation, delivers air from a device (ventilator) through a hole in the trachea, or windpipe. The surgical creation of this hole is called a tracheostomy, and the tube through which the air is delivered is called a tracheostomy (“trach”) tube.

Invasive ventilation is thought by most doctors to be a more reliable means of delivering air to the lungs when ALS is advanced and the respiratory and throat muscles are almost entirely nonfunctional.

Decisions about invasive ventilation aren’t easy to make. Professionals at the MDA Care Center are there to help you.

Another aspect of respiratory care that’s important in ALS is assisted coughing. As the coughing muscles weaken, it becomes increasingly difficult to clear mucus from the airways. An assisted coughing device, which pushes air into the airway through a mask and then quickly reverses air flow, can help clear the airways and prevent infection. Your doctor also may recommend other methods to assist with coughing and clearance of secretions from the airways.

Emotions and intellect

Once the shock of the early stages of the disease has passed, many people with ALS report that they have rich emotional lives with family and friends, careers and interests, and a healthy sense of perspective and humor.

However, one “emotional” symptom of ALS that some people experience may be related purely to the physiology of the disease. Known as “pseudobulbar affect,” or “involuntary emotional expression disorder,” it involves prolonged laughing or crying spells.
ALS can be tough to handle alone — that’s why MDA is here for you from day one to provide state-of-the-art medical care, information and support. Many people with ALS and their families find support groups or Internet chat groups useful. MDA’s support groups provide important help for spouses and other caregivers, whose job can be very demanding; ask at your MDA Care Center or local MDA office about one in your area.

Relief of symptoms

While researchers continue efforts to identify compounds that slow or stop motor neuron degeneration in ALS, physicians can prescribe medications to treat troublesome symptoms during the course of the disease. These include drugs to ease cramps and muscle twitches, help in handling saliva, reduce anxiety and depression, treat constipation, help with sleep problems, and alleviate pain associated with prolonged immobility and joint displacements.

What causes ALS?

Years ago, it was widely believed that there might be one cause to explain all ALS. Today, doctors and scientists believe this might not be the case. Together, they’re working to identify potentially multiple causes of the disorder.

The findings in the 1990s showing that mutations in the SOD1 gene can cause ALS (see “Does ALS run in the family?” on page 24) opened a window into ALS.
Even though very few people with ALS have flawed SOD1 genes, their disease looks similar to ALS not caused by SOD1 gene mutations. This means there may be common biochemical and physical changes that occur in the motor neurons in ALS cases initiated by divergent genetic causes.

Additional clues, including several other genetic mutations that can cause ALS, have emerged since the 1990s.

The following possible causes are being studied by ALS specialists, many of whom have received MDA support.

**Genetic factors**

Although ALS is clearly “familial,” or “inherited,” only 5 to 10 percent of the time, genetic factors probably play a role in ALS in many people in whom the disorder does not appear to be inherited. It may be that genes that aren’t directly involved in causing ALS can contain variations that increase or decrease the likelihood of developing the disease in the presence of as-yet-uncertain environmental factors. (See “Does ALS run in the family” section on page 24.)

**Protein misfolding**

A common feature in ALS is the presence in nerve cells of improperly folded proteins that clump together, forming “aggregates.” Research is ongoing to determine what role protein aggregates may play in the disease.

**Free radicals**

Free radicals are molecules that carry electrical charges that make them unstable and liable to damage cellular structures. They’re a normal part of cellular life, and cells are usually able to neutralize most of them and keep their numbers in check. But in ALS, free radicals may build to toxic levels and damage cells, through an attack process called “oxidative stress.”

**Excess glutamate**

Glutamate, a common chemical in the nervous system, is used by neurons to send signals to other neurons. But, like many things, glutamate has to be present in the right amount to work: Too little leads to a lack of signaling and too much to the death of nearby nerve cells.

Evidence from studies of people with ALS points to an overabundance of glutamate in the nervous system. This may result from inadequate transport of glutamate away from nerve cells after it has finished its signaling work.

**Defects in mitochondria**

Of all the working parts of a cell, the energy-producing mitochondria are arguably the most crucial — especially for high-energy cells like motor neurons. They’re also among the most complex and most studied parts of the cell.

Since processes inside the mitochondria produce potentially dangerous chemicals, mitochondria are always in danger of being damaged. Some amount of damage occurs naturally as part of the aging process, but in ALS there may be more damage to mitochondria than the average aging cell sustains.

Abnormalities in the structure of the mitochondria have been observed in ALS patients and laboratory models of ALS. It’s still unclear whether these abnormalities
this retrovirus could be a cause of sporadic ALS or whether elevated levels of the virus are a consequence of the disease.

**Toxins**

The heavy metals lead, mercury and arsenic, although they can be toxic to the nervous system, haven’t been shown to be causative agents in ALS.

Lead can damage upper and lower motor neurons, but, in the United States, exposure to lead has been monitored and limited for most people for several decades. In some circumstances, it may be worth testing for these exposures.

Prolonged contact with agricultural chemicals, such as pesticides, may be an ALS trigger in some cases. Other possible environmental risk factors include smoking and exposure to formaldehyde.

The association of ALS with service in the Gulf War of 1990-1991 may yield some clues. Some studies suggest that service in the military in general is a risk factor, in which case a broad range of factors will need to be investigated.

A high incidence of ALS on the island of Guam following World War II has led to the idea that the cycad seed, ingested by people on the island, could be an ALS trigger.

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**Cell suicide**

Most cells have a built-in “suicide” program known as “programmed cell death,” or “apoptosis.” Under some circumstances, programmed cell death is normal. But in ALS and other degenerative diseases, it’s possible that the cell death program is activated inappropriately.

**Immune system abnormalities**

Many disorders that affect the nervous system are “autoimmune” in nature, meaning they occur when the body’s immune system mistakenly attacks its own tissues. Microglia, immune system cells found in the nervous system, appear to play a role in ALS. None of the medications that are helpful for other autoimmune diseases has been effective against ALS so far, but some are being tested now, and new ones are in development.

**Viruses and other infectious agents**

For decades, scientists have guessed that viruses may play a role in ALS and other disorders that involve degeneration of nerve cells. In 2015, scientists identified an ancient type of retrovirus that seems to become reactivated in ALS patients. Current research is ongoing to determine whether
Does ALS run in the family?

ALS is “familial” — that is, there is a family history of the disease — about 5 to 10 percent of the time. For this reason, people who have close relatives with ALS are more likely to develop the disease than those who don’t.

Since the early 1990s, more than 20 genes that, when flawed, cause ALS, have been identified, many by MDA-supported researchers. The most studied of these genes, SOD1, was identified in the 1990s. In 2011, expansions in a gene called C9ORF72 were identified as the most common known cause to date of inherited ALS.

Familial ALS is usually inherited in an “autosomal dominant” pattern, meaning only one gene flaw (mutation) from one parent is needed to cause the disease. In this scenario, a parent with ALS has about a 50 percent chance of passing on the altered gene to his or her children. However, some rare genes are inherited in different fashions and not all genes altered in ALS cause the disease 100 percent of the time.

The familial nature of ALS can be complicated. For one thing, there may be genetic variants (not exactly flaws, just normal variations) that predispose people to develop or not develop ALS, perhaps in the presence of certain toxic exposures, such as those that may have been present during the Gulf War in the 1990s.

Also, since ALS usually occurs in middle age or later, family histories can be misleading. If a parent died from other causes (for instance, an accident, heart attack or cancer) at an age younger than that at which ALS usually develops, the genetic component in the family may go unnoticed. Additionally, it has been found that even in the same family, certain genetic alterations (C9ORF72 expansions) can cause ALS or a form of dementia called frontotemporal dementia (FTD) or both. Therefore, a family history of dementia may also increase one’s risk of developing ALS and may serve as a reason to initiate genetic testing.

Many laboratories now test for ALS-causing genetic mutations, generally requiring only a blood sample. Genetic testing is typically offered to patients with a family history of ALS; however, some MDA Care Centers and MDA ALS Care Centers now offer certain types of genetic testing to people without a family history.

Genetic testing for ALS is a personal and complex choice. Ask your physician or genetic counselor for guidance on genetic testing. Laboratories providing genetic testing for ALS can be found on genetests.org.
In addition to clinical trials, which test experimental drugs, there are a number of ongoing clinical research studies that people may also choose to participate in. Although these studies often do not include testing of a drug, individuals with ALS for example can donate specimens such as blood, cerebrospinal fluid and skin cells to allow laboratory scientists to study what causes ALS. Additionally, patients may be asked to fill out questionnaires to help in identifying what type of environmental exposures may have led to the development of their ALS.

These clinical research studies are important in helping scientists better understand what triggers ALS and what changes occur in cells during ALS. Information gained from such studies may be helpful to scientists working to develop effective therapies for ALS.

MDA’s search for treatments and cures

MDA is leading the fight to end ALS. We take a big-picture perspective across ALS and related neuromuscular diseases to uncover breakthroughs that will accelerate treatments and cures. MDA covers more than 40 neuromuscular disorders, leveraging the advances in research and best practices for clinical care from one disease to inform progress in others. The power in this research approach is that knowledge and information from one disease can often yield progress in others to speed urgently needed answers for families.

We support ALS research projects around the world, and many drugs in development through industry sponsors had their early development in MDA-funded basic science research.

While there is no cure for ALS, the number of clinical trials testing experimental drugs for the disease has risen significantly in recent years with many novel approaches currently under investigation. Some general approaches being tested for ALS include:

- Combating misfolded proteins
- Modulation of the immune system
- Protection of nerve cells (neuroprotection)
- Improving mitochondrial function
- Stem cell therapy
- Gene therapy
- Improving muscle function
Registries increase knowledge about ALS and improve care

The MDA U.S. Neuromuscular Disease Registry is the first comprehensive registry for ALS that collects information from health care professionals operating through MDA’s Care Center network. Information about medical care provided to patients in participating MDA Care Centers is recorded.

The National ALS Registry (cdc.gov/als) is the only congressionally mandated ALS registry in the United States, and is one of the largest ALS registries in the world. To date, thousands of people with ALS from all 50 states have registered and more individuals enroll each week. The ALS Registry uses data from national administrative databases such as Medicare and the Veterans Health Administration as well as an online portal where people with ALS can self-register.

Enrollment in the National ALS Registry is important for a number of reasons. Researchers are using data collected through the Registry to identify certain geographical regions where ALS may be more prevalent, discover whether specific environmental or occupational hazards cause ALS, and better track whether the number of ALS cases in the U.S. is rising. In 2013, almost 16,000 ALS cases were identified in the U.S. Additionally, enrollment in the National ALS Registry connects people who enroll with the community so that they can receive alerts about ongoing research and clinical trials that they may be eligible to participate in.

A new component of the ALS Registry, the National ALS Biorepository, allows people with ALS to donate blood and postmortem tissue for research. These samples will be sent to researchers working to better understand ALS genetics and possible risk factors. There is no charge to enroll in the Biorepository. Additional information can be found at cdc.gov/als.

MDA is here to help you

The Muscular Dystrophy Association is here to provide an array of services to support you and your family every step of the way on your journey with ALS. Your local MDA team is prepared to provide assistance and information about resources that include:

- MDA’s nationwide network of Care Centers, some of which are designated MDA ALS Care Centers, staffed by top neuromuscular disease specialists
- assistance with medical equipment through MDA’s national equipment inventory program
- information on community-based resources
- support groups and educational opportunities for people with ALS and their families

MDA helps you stay informed and up to date on research news, medical findings and disability information at mda.org — which features an ALS-specific disease center at mda.org/ALS — as well as through its quarterly magazine, Quest (mda.org/quest) and other educational materials.

If you have any questions about ALS, someone at MDA will help you find the answers. You can reach out to your local MDA team (go to mda.org and enter your ZIP code in the “Find MDA in Your Community” box), or connect with information specialists at the MDA National Resource Center. Call (800) 572-1717.