

YOUR RESOURCE GUIDE TO

# Living a Fuller Life with ALS



## OUR MISSION

To lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.



# Table of contents

## Section 1: Understanding ALS

Receiving a diagnosis of ALS	3
<b>Lorri's Story</b>	4
What is ALS?	4
What Does the Name Mean?	5
Facts About ALS	5
Who Gets ALS? <i>Interview with Daniel S. Newman, M.D.</i>	6

## Section 2: Living with ALS

Diagnosing ALS	8
Should I Get a Second Opinion? <i>Interview with Rup Tandan, M.D., F.R.C.P.</i>	9
What Do I Say to People?	10
Telling Your Children... and Your Parents	12
<i>Interview with Andrea Thomas, M.A.</i>	

## Section 3: Getting Help

<b>Andrew's Story</b>	14
How Will ALS Affect Me?	14
My Thoughts and Suggestions	15
<i>Interview with Catherine Lomen-Hoerth, M.D., Ph.D.</i>	
What's the Treatment for ALS?	16
An Up-Close Look at Interdisciplinary Care	17
<i>Interview with Lisa Kronk, R.N.</i>	
Caring for the Caregiver	18
What Everyone Should Know About Caregiving	19
<i>Interview with Sharon Matland, R.N., MBA</i>	
What is Being Done to Treat and Cure ALS?	20
Where Do I Start?	21
<i>Interview with Mary Kelley, M.S.N., C.R.N.P.;</i>	
<i>Jennifer Klapper, R.N., C.N.S.-B.C. and</i>	
<i>Susan Schwartz, A.C.S.W., L.S.W.</i>	
The ALS Association Certified Centers <sup>SM</sup> of Excellence	22



## Receiving a diagnosis of ALS



**is challenging and overwhelming.** There is so much to know, a great deal to consider, and typically a host of questions. While no two people with ALS are alike or will experience the condition the same way, there is a great deal of collective knowledge and wisdom available from health care providers, people with ALS, family members and caregivers.

The ALS Association has been working with and supporting many thousands of people with ALS over the years and has developed a broad network of experts at the National Office, ALS Association Chapters, and ALS Association Certified Centers<sup>SM</sup>. People working in all of these areas offer their advice and perspective in this guide, and such expertise will be directly available to you when you need it, or want to talk.

Because everyone is indeed unique, we have organized this information so that you can read each section in any order you like, depending on what's on your mind and what is of particular interest to you. We hope it will be useful in answering questions clearly and straightforwardly and helping you find the resources you may need.

**You are not alone.** The ALS Association is dedicated to providing you and your family and friends the information, support and resources you need to effectively live with ALS. The ALS Association is the only national not-for-profit health organization dedicated solely to the fight against ALS. The ALS Association covers all the bases—research, patient services, advocacy, public education, and community services—in providing help and hope to those facing the disease. The mission of The ALS Association is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

---

*Please call our patient services staff at (800) 782-4747.  
We are here for you.*

# One Family's Story:

LORRI CAREY

Lorri Carey was 38 years old, married, with two teenage boys, and working full time in a job she loved when she learned she had ALS.

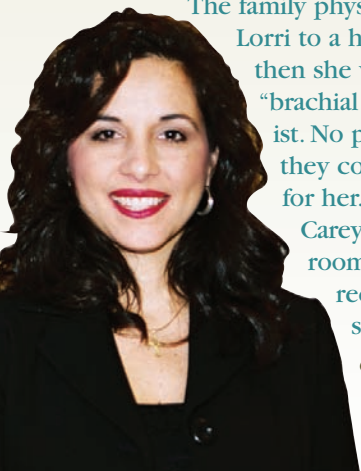
It was in February, 2004 – on Friday, the 13th, in fact – and she remembers the neurologist saying, “What do you know about what this could be?”

Lorri, who had done a great deal of Internet research on her symptoms, said she knew right away. “It’s ALS, isn’t it?” she quickly answered.

Lorri had been in a car accident in December and saw a doctor to get a general check-up soon afterward. She casually mentioned to her family physician that she may have arthritis since she had trouble opening jars and would occasionally get bad cramps in her legs. The doctor ordered tests to learn more. When the tests came back normal, the doctor was concerned that someone Lorri’s age was losing muscle mass on her right hand.

The family physician first sent Lorri to a hand doctor, and then she was referred to a “brachial plexus” specialist. No physician felt they could do anything for her. Then a friend of Carey’s, an emergency room physician, recommended she see a neurologist.

*Continued on pg. 6*



## What is ALS?

**Amyotrophic Lateral Sclerosis (ALS), also called Lou Gehrig’s Disease** or motor neuron disease, is a progressive, neuromuscular disease that attacks nerve cells and pathways in the brain and spinal cord. Motor neurons, among the largest of all nerve cells, reach from the brain to the spinal cord and from the spinal cord to muscles throughout the body. When these motor neurons die, the brain can no longer start and control muscle movement. At this time, there is no cure for the disease; however, over the past decade, we have made amazing strides in our understanding of the brain, the nervous system and genetics. Discoveries in each of these areas bring hope to people with ALS and their families that new treatments will be developed and a cure may be found.

Researchers know some of what happens in ALS, but they don’t completely understand why it happens. Somehow the nerves that control muscle movement become incapable of processing the critical messages they need to stimulate a muscle to contract and move, and the muscles weaken.

The disease affects only voluntary muscles, which are muscles you can mentally direct. It doesn’t affect muscles that move automatically, such as your heart or your digestive system, your bladder or bowel, or your senses, such as vision, hearing, taste and smell. But, depending on how ALS particularly affects you, muscles that you can signal – to take a walk, to pick up a pen, to hold your breath – may be eventually involved.

ALS affects people differently, and it is difficult to predict specifically what your experience will be. There are situations in which the disease stops progressing or progresses at a very slow rate. Others may find they experience a faster progression. Your healthcare team will meet with you regularly and will be able to give you information about how your disease is evolving and what can be done to help.

A progressive disorder, ALS typically moves gradually and steadily. The average lifespan after diagnosis is two to five years. But about 20 percent of people with ALS live five years or more, and up to 10 percent will survive more than 10 years, with five percent living 20 years or more.

## What does the name mean?

### What does “amyotrophic lateral sclerosis” stand for?

The term “amyotrophic” comes from Greek. “A” means no or none. “Myo” refers to muscle, and “trophic” means nourishment – “no muscle nourishment.” When a muscle has no nourishment, it shrinks. “Lateral” identifies the areas in a person’s spinal cord where portions of the nerve cells that signal and control the muscles are located. As this part of the spinal cord degenerates, it leads to scarring or hardening (“sclerosis”).

### Why is ALS sometimes referred to as Lou Gehrig’s Disease?

Lou Gehrig played for the New York Yankees and was called the “iron horse” of baseball, playing the most consecutive games ever (until the record was broken in 1995). But in 1939, he began noticing physical problems and he quit for the good of the team. Soon he was diagnosed with ALS, and he died two years later. His popularity and experience with the disease has helped millions of Americans know more about ALS and support research and treatment.

### Who discovered it?

A French neurologist, Jean Martin Charcot, identified the disease in the late 1800’s in Paris, France. In Europe, the disease is sometimes referred to as Charcot’s disease or motor neuron disease.

## Facts about ALS

**Approximately 6,000 people in the U.S.** are diagnosed with ALS each year. It is estimated that as many as 30,000 Americans may have the disease at any given time.

**ALS occurs throughout the world** with no racial, ethnic or socioeconomic boundaries.

**ALS can strike anyone.**

**ALS is not contagious.**

## LORRI CAREY cont.

*Continued from page 4*

The whole process of getting to this point seemed like it took forever, Lorri says; each physician had a long waiting list for appointments. The neurologist diagnosed Lorri's condition as ALS.

Lorri got second and third opinions, which confirmed the initial diagnosis. She remembers very well the day she was told that the diagnosis was certain. She was standing outside her physician's office on the University of Cincinnati campus watching streams of cars going by in both directions for several minutes. "That's when it hit me; I realized then that the world goes on, no matter what was happening specifically to me," she says.

But from the very beginning of her new life with ALS, Lorri says she found ways to hold on to a sense of normalcy. "You know, the next day, I went to my nephew's basketball game and then right over to the nearby Target and bought our sons each an adorable brown stuffed dog for Valentine's Day," she said.

Lorri grew up in Fairfield, Ohio and graduated from the University of Ohio, Miami, majoring in mass communications. She had an internship at Channel 22 in Dayton as a reporter, and then worked in advertising, public relations and sales until just recently.

She met her husband Paul in 1985 after she and a couple of friends ran out of gas. Lorri and her buddies popped into a restaurant in Cincinnati, and ran into other friends there, several of whom introduced Lorri and Paul to each other. They were married three years later, and now have two sons, Paul, 16, and Christian, 15.

Lorri told her parents and sister about the diagnosis right away. But while her Mom and sister needed time to process the situation; her dad got right in the car and drove to Lorri's house.

*Continued on page 8*



**An interview with Daniel S. Newman, M.D.,** a neurologist and Medical Director of the Harry J. Hoenslaar ALS Clinic at the Henry Ford Hospital in Detroit, Michigan. The Clinic is an ALS Association Certified Center<sup>SM</sup> of Excellence

## Who gets ALS?

### What are the chances of getting ALS?

For 90 to 95% of people with ALS, the disease just seems to happen out of nowhere. These people have no known family members with ALS. Any given male has about a one in 1,000 chance of contracting ALS, and any given female has about a one in 1,200 chance.

### What if a parent had ALS? What would the chances be that a child would get it?

About five to 10% of patients get ALS due to what is called a familial autosomal dominant gene. In these cases, if a mother or father has ALS, the child would have a 50/50 chance of getting the gene, but still will not necessarily develop ALS. Sometimes it's hard to know if a case of ALS is related to a parent having had the disease; for example, a parent may have died at a young age of other causes, or an ALS patient may have been adopted.

### What if no parent had ALS, but rather a grandmother or a sister had ALS?

Those cases are considered familial; they are most likely genetically related.

### **Is there a specific gene involved in familial ALS cases?**

One gene has been associated with about 20% of the familial ALS cases. It's called SOD1, found on chromosome 21. There are more than 100 mutations in the SOD1 gene associated with ALS. Much still has to be learned about the genetics of ALS.

### **Are there risk factors?**

It's unclear. There may be some predisposing genetic factors that contribute to developing ALS. As for non-genetic factors, we are unsure. Research has suggested a variety of factors that could be related, but have not been proven to be, including: smoking, history of major trauma, occupational exposure to lead, history of extreme physical activity, and even a history of serving in the first Gulf War.

### **Is ALS related to anything one may have done in life?**

Not that we know of. I have had some patients tell me that they've "done some bad things in life" and that's obviously why they got ALS, and I tell them that's just not so. Besides, we've all done things we regret and if that was the cause of ALS, the incidence of ALS would be much, much higher.

### **What about age?**

The risk for ALS increases with age. The average age of developing ALS is between 58 and 62, but ALS can occur at any age.

### **As a physician, do you have a philosophy that you apply to caring for people with ALS?**

Yes, I do. I tell patients that our approach to caring for you is simple. We will have a long-term relationship, we'll see each other about every three months, and we will prepare you for whatever you will face. We'll walk the road together. Subcontract the worries to us. We're here, and we want you to live every day.

### **How can a patient know if he or she has a slower or faster progressing form of ALS?**

On day one, you don't know. As time progresses, the speed with which new symptoms develop can help us know. But ALS is a highly individualized disease and the situation has to be assessed as time goes on.

*Continued from page 6*

“Dad came over and we all sat down and drank a bottle of wine,” says Lorri. “With tears in his eyes, Dad said he’d go anywhere, do anything for me, and that he would absolutely find a way to fix this.”

Telling the kids wasn’t easy. Paul and Lorri waited about six weeks to talk with them about the diagnosis of ALS. Paul, who is now in 11th grade, said he remembers his Dad coming in his room and saying that everyone needed to gather together downstairs in the family room to have a talk. Everyone came together. “Then I remember Dad saying something like, ‘Your Mom has Lou Gehrig’s Disease, it’s fatal, and there’s no cure right now.’ Mom started to cry. Christian and I sat in silence for a long time.”

Christian, now in 10th grade, says he remembers feeling totally shocked. “My mom looked so healthy, it was hard to believe anything could hurt her.”

But as hard as it was to tell the children, Lorri said she actually felt relieved afterwards. “The day we told them, I had a burden taken off my shoulders. My focus shifted from me to them, and to helping them deal with the situation.”

The Careys say it took about a year for a sense of normalcy to creep back into the household. The boys are very active in school; Christian is especially interested in theater and Paul enjoys sports. Paul, 45, coaches hockey and has a new interest in photography.

The boys quickly got involved in organizing walks for a cure for ALS, raising significant funds for research and galvanizing the community for the cause. “We went to Advocacy Day in Washington, D.C., and we met all these great people with ALS. I realized then that while we initially went out there for my Mom, now we’re fighting for all our

*Continued on page 10*

## Diagnosing ALS



### **There is no single diagnostic test for ALS.**

The diagnosis is made by a neuromuscular specialist after observing a pattern based on symptoms, examination of findings, the development and progression of symptoms, and by ruling out other somewhat similar conditions. However, The ALS Association is funding research which may lead to a simple blood test for ALS.

After talking with a patient in depth about how he or she began to notice something was wrong and how those symptoms have progressed or changed, the physician may order laboratory and urine tests, x-rays, an electromyogram (EMG), or other tests specific to the symptoms and problems.

About 90 to 95% of patients are given an EMG, considered the best test in the process of diagnosing ALS. About 80% of patients have Magnetic Resonance Imaging (MRI), and most have laboratory and urine tests.

Physicians have to rule out a wide range of diseases that can look like ALS, and the diseases they consider are related to the symptoms the patient is experiencing. For example, in about 25-33% of patients, early symptoms relate to the tongue and throat, involving problems with speaking, swallowing or drooling. Other patients develop early symptoms in the arms or legs, or have a particular weakness in a hand or foot. Some patients have symptoms that may end up related to previous conditions they have had, treatments for other diseases or conditions, infections, or may be related to rare conditions contracted while traveling.

Depending on the symptoms and problems the patient reports, physicians may have to rule out thyroid disease, particularly thyroidtoxicosis; cervical spondylosis; diseases of the nerve root; diabetes affecting the lumbar or brachial nerve plexus; carpal tunnel syndrome or an ulnar lesion in the elbow or knee; neuropathy, especially chronic inflammatory neuropathy or multi-focal neuropathy; myasthenia gravis; primary lateral sclerosis; hereditary spastic paraplegia, infections of the spinal cord, and other diseases.

The symptoms, laboratory findings and the results of other tests will suggest to the physician what conditions must be ruled out before a diagnosis of ALS can be made.

## Should I get a second opinion?

### Is a second opinion worth the trouble?

Yes. If a patient wants a second opinion, he or she should get it. I actually recommend getting a second opinion because the diagnosis of ALS is so life changing. The only way a person can begin to accept such a diagnosis is to be certain that the diagnosis is correct.

### How often is the first diagnosis of ALS wrong and the problem turns out to be something else?

In about 10 to 15% of the cases, patients get what we call a false positive. That means they are told they have ALS, but, in the end, another disease or condition is discovered to be the real problem.

### Are some patients told they don't have ALS and then it turns out that they do?

Yes, up to 40% of patients are initially told they have another disease, and then it turns out they have ALS. Many conditions can mimic ALS.

### What typically causes a delay in getting the right diagnosis and what is the impact of getting a delayed diagnosis of ALS?

An international study that surveyed physicians in the United States, Europe and Latin America showed that a delay in diagnosis typically occurs at three key times:

- At the onset of symptoms, some patients take up to six months to see a physician.
- Some patients do not see a neurologist right away, and it may take from three to six or seven months before they do so.

**An interview with Rup Tandan, M.D., F.R.C.P.**, Professor, Vice Chairman and Medical Director of The ALS Association Certified Center<sup>SM</sup> of Excellence at the University of Vermont, Burlington



- Sometimes the neurologist doesn't give a diagnosis of ALS because the patient doesn't fulfill all the criteria, is atypical, or hasn't shown any progression of symptoms, and in such cases a delay in diagnosis of 3 to 4 months can occur.

Depending on which of these factors combine, it can take nine to 12 months before a diagnosis of ALS is made.

There is an FDA-approved drug, Rilutek<sup>®</sup> which has been shown to produce a modest increase in survival. Research indicates that the drug is most beneficial if started early in the course of the disease.

### Why did you decide to focus your career on working with ALS patients?

Patients often ask me this. I was doing my residency in Neurology at the University of Michigan, and I heard Dr. Walter Bradley do a lecture on ALS. He was terrific. I decided to train with him and was exposed to a lot of people with ALS. I realized I wanted to devote the rest of my life to trying to have an impact on the disease. ALS patients are so involved in their care and so willing to be active participants in research, it is a very rewarding field.

*Continued from page 8*

PALS (people with ALS). And it really felt good that we were doing something.”

On a late afternoon in January, the Careys gathered around the table in a bright, cheerful kitchen, talking to visitors and discussing their experience with ALS. Lorri’s disease was progressing slowly, affecting the muscles in her right hand and just beginning to affect her left. She has recently left her full time job in sales and began disability insurance, and Paul, previously a stay-at-home dad, took a new job in sales for a packaging company. Talking about having ALS was now comfortable, although not always easy, and tears would surface when sensitive topics came up.

Not long after the diagnosis, the Careys did a few things that many people imagine they’d probably do in a similar situation. They took a second honeymoon trip to Mexico. They got a hot tub for the back yard. They bought a new four-poster bed for the master bedroom and matching furniture, and a flat screen TV. They bought Lorri a bright red sports car. Lorri and her Dad took Salsa lessons, something Lorri had always wanted to do.

But then, they say, the family settled back into life with a more day-to-day attitude. “Now,” said Lorri, “we’re pretty much living a normal life. We try, though, to notice more things to celebrate, like the end of exams for the kids, or Paul going back to work.”

The family takes a practical approach to coping. Paul loves his High School English class and finds writing about his thoughts and feelings helps. “I’d talk to Mom about it, but I’d be afraid that she’d cry. This way I can express myself,” he says. He also runs cross country, a great outlet for his energy, he adds.

Lorri gets exercise at a local gym that she joined with Paul, the boys, her sister and

*Continued on page 12*

## What do I say to people?

**Once you receive the diagnosis of ALS**, it can take some time before you’re ready to explain the situation to others. “Don’t feel you have to tell people immediately,” says Andrea Thomas, M.A., psychologist for the Harry Hoenslaar ALS Clinic at Henry Ford Hospital, an ALS Association Certified Center<sup>SM</sup> of Excellence in Detroit, Michigan. “Wait until you feel ready.”

Thomas says it’s best to come to terms with the news and the reality of the diagnosis before trying to tell friends, and sometimes it takes awhile to tell certain family members, too. Give yourself some time to consider how to tell your parents and children. Once you’ve come to accept the diagnosis, you’ll be better able to talk about it, experts say.

Yet, it’s a balancing act, because you will probably want to tell key people in your life as soon as possible. Waiting too long can confuse people who are close to you and who may sense there is something wrong, but don’t know what it is. The support you will get from friends and family is important every step of the way.

Telling co-workers and employers may take some thoughtful strategy setting, as there may be implications in terms of your role and status at work, depending on how people interpret the news of your diagnosis. You may want to discuss your approach to telling people at work with your physician and with others whose advice you trust.

How you describe ALS and your situation will depend on your individual style of communicating. Essentially, you can tell people that you were experiencing certain symptoms, have been evaluated and have been told you have a disease called ALS. It’s a motor neuron disease that affects the voluntary muscles, such as those in the arms and legs, for example, and it will gradually affect your ability to do certain things. The course of progression and impact is individual and hard to know at this point. You may also want to tell them that while there is no known cure, there is much that can be done to maximize your quality of life and support you.

People may ask you questions that are tough to answer. You may have to explain to them that you don’t know the answers yet, emphasizing that situations are quite individual and yours cannot be predicted based on what has happened to other people they may have known. People may ask you how long you will have to live, and while you may choose to tell them information about the range and the

averages, you should probably also relate to them that it is impossible to know that now. You can always respond to questions by telling people you're just not ready to respond to that question now.

It may be quite helpful to refer people to The ALS Association's web site, [www.alsa.org](http://www.alsa.org), or to give them brochures and information like this. Everyone has a different way of processing new information, and sources like these allow people to find out answers as they're ready and interested.



You may find some people repeat the same question several times over a period of days or weeks. That can happen when they are having trouble hearing or contemplating the answers, especially at the beginning. You may find that you, too, need to ask what may seem like the same question several times or in different ways, and that is common. Over time, the answers will begin to make more sense.

One of the toughest questions people may often ask may strike you as a rather simple one: "What can I do for you now?" It can seem like a perplexing question because you probably won't know what you'll need or want at this point. You may even feel a little resistant about asking for or getting help from others. That's OK. You may want to tell people that you're still learning and adjusting to things, that at this time you don't know what they can do, but that you appreciate their support and will be sure to ask for help when you know better what you may need.

No matter what, the diagnosis of ALS doesn't change who you are, and your approach to dealing with the challenge of telling others about your situation will probably mirror your personal style and personality in dealing with other tough challenges. The bottom line: Be yourself, give yourself the time you need, and seek out resources when you feel you need them. Take it one day at a time and deal with how you feel *today*.

## LORRI CAREY cont.

*Continued from page 10*

niece. "It is another way to spend time together as a family," says Lorri. "There I am able to do a variety of cardio machines, range of motion exercises, and aqua fitness classes, which help me." She participates in support groups and is active in the local ALS Association chapter.

But Lorri says – despite the family's great support for each other – some days are still quite difficult. "I can see myself progressing every day. Just last week I was putting gas in the car, and couldn't get the gas cap off. I had to ask a man with a broken hand to help me," she says. "Every case is different but you do have a typical course of progression, and it can be very tough to accept."

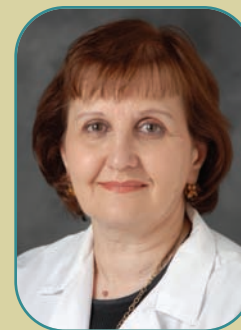
Lorri recommends connecting with experts and people with ALS through a local ALS Association chapter and an ALS Certified Center, if possible. "The Association put me in touch with a woman with ALS just a few months after I knew my diagnosis," says Lorri. "I met her and talked with her and she knew exactly what I was feeling."

Lorri says that in her experience, physicians can sometimes be difficult to talk with about the disease because they are typically unsure at first how any individual's particular situation will play out. She says they're also frequently unsure about how much you want to know, and when. "Tell your physician your information processing speed," she says, "and just how much you want to know."

Christian says he thinks it's important to be grateful for what you have. "Mom's still with us. We could have lost her in that car accident that she had before she went to the doctor, and we didn't. Now we know what's ahead and we're enjoying life as much as possible."

Christian's brother Paul has found a sense of purpose in fighting the disease. "I'll always be involved in this until we find a cure."

An interview with **Andrea Thomas M.A.**, psychologist for the Harry Hoenslaar ALS Clinic, Henry Ford Hospital, an ALS Association Certified Center<sup>SM</sup> of Excellence in Detroit, Michigan



## Telling Your Children... and Your Parents

### When should you tell your children?

The information you give and how you give it has to be tailored to the child's age, but you have to tell them something. To shut them out is to make them feel left out of everything, and they will sense being left out no matter how young they are. They're going to worry if they don't know or are left out of the process of supporting and caring for you. You may feel that by not telling them you are somehow protecting them, but in fact, they will see what you're going through anyway and they cannot really be fully protected.

### How does the approach differ depending on the children's ages?

With younger children, it's good to keep it simple, addressing what is happening but not going over their heads. You can say something like, "I have an illness now that is making my muscles weaker and I will need help with some things."

Realize that even young children want to play a role and can help. One 38-year-old man had his four-year-old daughter in charge of helping him put his leg braces on in the morning. If someone else in the room offered to help, his daughter would insist, "No, this is *my* job!"

Some children may want to help read the paper to you, or bring you your cell phone or help you up in your chair. Just making them a part of the process will help make them feel needed and involved.

### What is the downside of not telling them soon enough?

Children will quickly feel left out and will sense that there's a challenge in the family and they don't get to know about it. Kids sometimes tell psychologists that their one regret is that they wish they could have known more and done more.

### Do you have to tell them everything?

No. You don't have to tell them the ultimate situation. Gear what you say to their age, ability to process and to the kinds of questions they ask you.

### What about telling teenagers?

Tell them honestly and directly. They are likely to have all sorts of reactions over time, from anger and denial to being or feeling disconnected – which is actually typical of teenagers generally anyway. They may feel frustrated that having ALS in their family is making them stand out from their friends, or they may sometimes resent the added responsibilities they will be asked to assume. Through it all, having open communication and connecting them to ALS-related counseling resources, support groups and your network of friends and family will be important and valuable. The ALS Association offers many of these resources to patients and families.

### Will children and teenagers need or benefit from counseling?

They may. There are some signs to look for that will give you a heads up that a child or teenager is having some difficulty. In younger children, you may see some behavioral or adjustment problems or anger directed at their friends. With teenagers, it's important not to assume everything's OK if they're very busy, hardly at home, or extremely involved in activities. A teenager may not feel he or she can talk about their issues with you or with other people, and being busy may be an attempt at avoiding their feelings or could be an effort to deny the situation.

Depression is very common; children and teenagers who are depressed can benefit from counseling.

### What about telling my parents? They're seniors and dealing with their own challenges.

Just as it's hard to consider telling your children, it may be just as hard to tell your parents. After all, you're their child and hearing that your son or daughter is dealing with ALS is not easy. But they, too, should be told as soon as you feel you can. You may want to proceed step by step.

Start out by telling your parent or parents that something seems to be wrong, that you're having some symptoms that concern you and the doctor isn't sure what the problem is but is doing some tests. Then, a little later, let them know that you

have received the results of those tests and are getting a second opinion. Ultimately, you can tell them what you're facing.

One man I worked with was concerned about telling his mother, a woman in her 80's with a heart condition. I told him that he still had to tell her about his situation, but could do so gradually, making sure she was able to take in the information and process it before he proceeded to tell her more.

If your parents are able, you can bring them to an ALS Association Clinic with you so they can see the team of people working with you; they may be reassured to see the high level of support you're getting. They also may want to ask questions and talk with some of the staff.

### Once you've told these important people about the diagnosis, does it get easier?

It's always easier to have everyone on the same page and dealing with the truth. As things change, however, you will have to update them on new aspects of the disease that you're dealing with and people will continue to need to hear the news and readjust. Each change can cause frustration, anger and grief – and everyone reacts a little differently. But one of the greatest stresses of all is having people in the family who are not communicating, feeling left out or confused.

Remember, too, that some family members could experience emotional challenges that they may not want to discuss with you because they will be afraid of over-burdening you. You can choose to try to open up discussion with them. Also, you can always refer them to The ALS Association's closest chapter. The staff there has support groups and can help you and your family meet others who are dealing with similar issues and challenges. You can also call the National Office for a referral, (800) 782-4747, or email [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org).

Remember that everyone needs some latitude to adjust to especially challenging situations in his or her own way. Also know that if there were any interpersonal problems you may have been facing before you received the diagnosis of ALS – tensions, marital problems, people with addictive behaviors – those problems could demand fresh attention because the stress of ALS may complicate them.



# One Person's Story:

ANDREW FLEESON

**Andrew Fleeson says he knew** something was definitely wrong but didn't have any idea what it was. He was living in the United Kingdom, working as a director of Information Technology Ltd., a computer systems company, responsible for sales and marketing. He was married with two young teenagers, a boy and a girl.

"I kept falling off my ice skates; occasionally an ankle would fold," says Andrew. "So I saw a neurologist. After the examination and tests, he sat me down and he told me he was terribly sorry, but I had a motor neuron disease and it was ALS."

Later, over dinner, the doctor, who was a good friend, put his impression bluntly, Andrew recalls. "He said, 'There is no treatment. You'll be dead in two years if you're lucky and three years if you're not. And I'll do anything I can to help you.'" It was March 26, 1983, and Andrew was 37.

Fast forward to today. Andrew is sitting in an electric wheelchair by the side of a hotel pool in Newport Beach, California, attending an ALS symposium, 23 years later. He's a National Trustee of The ALS Association, divorced, living in Arizona, and a young-looking 62. He's now a grandfather of four. "I'm a total believer in serendipity," says Andrew.

*Continued on page 16*



## How will ALS affect me?

**Every person's case develops in its own way**, so it is difficult to predict how your situation will evolve. Typically, the early symptoms of the disease are at first overlooked. You may have noticed that you would occasionally trip when walking, or had muscles in a hand or arm that seemed weak. The major signs and symptoms of ALS involve the voluntary muscles becoming smaller and steadily weaker over months and years. Muscle weakness is a hallmark initial sign in ALS, occurring in approximately 60% of patients.

Over time, you may notice: muscle weakness in one or both hands; arms, legs; shortness of breath; muscle twitching and/or cramping, especially in the hands and feet; weakness in the arms and legs; thickened or slurred speech and difficulty projecting your voice; and, later, difficulty breathing, and swallowing.

Symptoms can begin in the muscles of speech, swallowing, or in the hands, arms, legs or feet. While not all people with ALS experience similar symptoms or patterns of progression, nearly everyone with ALS experiences progressive muscle weakness and, eventually, paralysis.

You may experience difficulty in lifting, walking or dressing, washing and buttoning clothes. As the weakening and paralysis continue to spread, the disease typically will eventually affect speech, swallowing, chewing and breathing. When the breathing muscles become affected, you may need a machine to help you breathe.



## My thoughts and suggestions

### Just hearing the diagnosis is so hard. Is this what it's going to be like to be an ALS patient?

Actually, the time of receiving the diagnosis is the worst part. It changes your whole life. Once you adjust to the diagnosis and understand ALS better, it gets more manageable.

### How often will I need to see the doctor?

If you go to an ALS Association Certified Center of Excellence, you'll benefit from the team approach to managing your care. Depending on the progression of ALS for you, you'll visit about every three to six months. Evaluations are done to help determine how you're progressing and what adaptive approaches would be helpful to you. Visiting with the various members of the ALS Center team and discussing your questions generally takes about three to four hours. The team includes a neurologist, a registered nurse, a speech pathologist, a respiratory therapist, a physical therapist, an occupational therapist, a dietician, a rehabilitation technologist and a social worker. As you can see, you will not be facing ALS alone.

### Should I read everything I can get my hands on?

Everyone has a different approach to understanding the disease. I suggest you learn about the disease at your own pace, as you develop questions or want to know more.

### I think I'm still in shock. Is that normal?

The reaction to hearing and adjusting to the diagnosis varies. Some people feel they're in shock and have trouble absorbing information or processing the situation. Others feel sad or angry. Some experience denial, continuing to insist their diagnosis must be something else. As you have time to adjust, those feelings usually gradually dissipate.

### Should I tell my boss and others with whom I work?

It's of course ultimately up to you in terms of how long you feel comfortable waiting. I discourage people from telling their diagnosis at work. Typically, it's a good idea to not tell

An interview with  
**Catherine Lomen-Hoerth, M.D., Ph.D.**,  
a neurologist and Medical Director at  
The ALS Association Certified Center<sup>SM</sup> of  
Excellence at the University  
of California, San Francisco



your employer or coworkers until you're somewhat close to going out on disability. That's because it's hard early on to know when you'll want to leave work.

### Will I be able to pay for everything I'm going to need in terms of care and related support?

Most needs are covered. Caregiving is typically not, but there are strategies for maximizing your options and strengthening your "care network."

### I can't help but worry about what I'll do if my legs are paralyzed or I have trouble talking.

We'll take it one step at a time. There are a wide range of ways to help you depending on what issues develop. There are systems to help you get around if you can't walk, eat, speak, work on the computer, or breathe well when you're lying down. Some you may need, and others you may not need. The regular appointments with your team to evaluate your situation will help them anticipate your needs before a problem develops.

### What about my spouse?

It's without question a very challenging role. But there are resources and support groups that will be helpful.

### What if I'm single?

Many people who are single move closer to family or very close friends. Sometimes a family member will move closer to the person with ALS. It's important to have either someone who will provide support and care or a network of friends and family who are near and committed to helping you.

*Continued from page 14*

“Things happen for a reason.”

Andrew says his first reaction after hearing the diagnosis from his doctor more than 20 years ago was to think of his dad, who died at 47. “So I knew people died before the natural allotted three score and ten,” he says.

Andrew made the decision to defer telling his teenage children for about a year. He says he wishes he had told them right away. “It was a big mistake to hide it from my kids; they would have accepted it.”

Andrew decided he wouldn't initially tell anyone at work. “I didn't want people asking about me.” He says he grew up in a family with two much-adored sisters and learned to fend for himself. “I accept help very ungraciously,” he says.

He waited about six months before sharing his situation with his colleagues. It was an exciting time in the computer industry, and the firm was doubling in size every six months and doing quite well. Andrew said he was beginning to show some obvious changes in his gait and had weakness in his right arm. He was an equity director in charge of sales and marketing. “I told my fellow partners that my situation would affect my ability to lead and motivate others.” His colleagues encouraged him to carry on for as long as he could and wanted to work.

Andrew continued to work, but about 1990 (seven years after being diagnosed with ALS), he felt it was time he left. A potential partner who was at first interested simply in buying out Andrew's portion of the company ended up making an offer to all the directors, and the firm was acquired. It was the perfect time for him to retire, he said.

About eight years ago, Andrew decided it was time to use a wheelchair. “I should have taken to the wheelchair sooner, because I

*Continued on page 18*

## What's the treatment for ALS?

There are a broad range of treatments designed to address symptoms and problems associated with the disease, even though there is no known cure for ALS.

There is an FDA-approved drug, Rilutek® (riluzole) that has been shown to very modestly extend survival time in patients who start taking the drug fairly early after the diagnosis of ALS is made.

There are also typically many research studies underway at many sites across the nation and you may choose and qualify to participate. Each study will be looking for people with different qualities which vary depending on the study itself. The Association web site is an excellent source for up-to-date research and drug information ([www.alsa.org](http://www.alsa.org)).

It's important to find an ALS clinic or Certified Center that uses the multi-disciplinary team approach, involving many disciplines to give information and advice, provide treatment, and help manage the particular symptoms and challenges that occur.

To find the closest clinic, refer to the inside back cover of this publication. The staff at the National Office of The ALS Association can help you with your selection of a multi-disciplinary clinic and can also help you connect with your nearest ALS Association Chapter.

Chapters are wonderful sources of information, and can provide you with help, answers, support groups, home visits, equipment, and assistance with finding other important resources.





**An interview with Lisa Kronk, R.N., Patient Service Coordinator for the Minnesota Chapter of The ALS Association.** She also participates weekly with the team at the Hennepin Faculty Associates (HFA) ALS Association Certified Center<sup>SM</sup> of Excellence in Minneapolis

## An Up-Close Look at Interdisciplinary Care

### What will happen when I go to an ALS Association Certified Center<sup>SM</sup> of Excellence?

You'll be welcomed into an exam room and will be seen by a neurologist, who will make certain recommendations and suggest you return, probably in about three months. He or she will then introduce you to other members of the team, depending on what you may need at the time. For example, if you're having some trouble buttoning your buttons, you may meet the occupational therapist. Or if you're having some trouble walking, a physical

therapist may talk with you about using a cane, orthotics or a walker. A respiratory therapist may give you a simple breathing test, and you may meet a chapter representative, like me, and a social worker, to offer you additional ideas about resources and problem solving.

The team will discuss your situation and the clinic nurse will then summarize everything for you before you leave. He or she might say to you and a family member, for example, "Your breathing test showed that nothing has changed, but your neurologist has prescribed this drug, which you'll take twice a day, and we want you to try this loaner walker to see how it works for you. And we'd like to see you again in three months." Over time, you'll find you're really building relationships with all these people and feeling more and more comfortable.

### Can I call or email the clinic staff if I have a problem between visits?

Yes. Call the nurse or clinic coordinator.

### What if I live far from any ALS Association Center?

You may want to arrange to visit an ALS Association Center twice a year, and then have your local neurologist collaborate with the clinic team in between.

### What does your chapter offer and how is that different from what an ALS clinic provides?

The ALS clinic is completely oriented around assessing your

situation and having people from many disciplines prescribe and suggest ways to deal with any issues or problems. The chapter offers support groups, resources, ideas, and provides a large group of people who have lived with ALS as either a patient, a family member, a friend, or a health-care provider. We have medical equipment and voice synthesizing devices, home health aid support, an occupational therapist on staff for equipment recommendations, and we offer care conferences to help groups of people learn about the disease together.

### How does the staff cope with such demanding work?

I know I am not alone in feeling that it's an incredible privilege to be allowed to help a patient and family through this journey. It continually inspires me and has helped me learn what is important in life – being together and helping one another.

### What can I do to be in the best possible shape?

It's important to take care of yourself in every way possible:

- Eat a nutritious diet
- Get regular exercise as recommended
- Continue to enrich yourself intellectually and pursue activities you enjoy
- Spend time with people you like and love



Talk with your physician and team if you need help in managing changes so that you can still enjoy a good diet, get exercise, and participate in activities you enjoy. If there are things you want to do but they seem more difficult due to your disease, talk with the ALS clinic team about how you could still integrate them into your life.

One way to continue to stay in the best possible shape is to make the necessary preparations in your home or workplace should you need them. Talk with your physician and team about how any changes you're experiencing may affect what you'll need at home and work. It's also a good idea to begin to ensure that your legal and financial affairs are in good shape and will give you the support and "fiscal fitness" you and your family may need.

*Continued from page 16*

was falling a lot, but I resisted it,” he says. Now he directs the fast-moving chair with the palm of his right hand.

In 2000, after considering Australia and South Africa, Andrew decided to move to Phoenix. He knew the city because he had traveled there frequently on business, liked the climate and appreciated the area’s quality of healthcare services. He rented an apartment for the first year while he looked for what he had in mind, and then found a home he liked. He loves the desert. “I grew up – until I was 11 – in the Middle East, in the British Palestine Protectorate, Egypt and Kenya. The desert is beautiful and feels like home.”

Andrew credits his grandmother with instilling in him a can-do philosophy that he has found especially useful over the last 23 years. He says he remembers her saying, for example, “Each and every day is a one-time experience, so make the most of it”; and “Learn something new every day that will broaden your view”; and “You worry, you die; but if you don’t worry, you still die. So don’t worry.”

He says he tries to live every day with that sort of approach to things. Each morning, an assistant arrives to help him start the day and have breakfast. And each late afternoon, another assistant makes him dinner and assists him with the end-of-the-day activities. His two assistants are sisters. Andrew skips lunch, preferring two meals a day.

During the bulk of each day, he’s on his own, reading, sending email, making phone calls, or planning his next trip. He serves as an ALS National Trustee and he has a wide circle of friends. About one night a week he goes out for dinner and movie with a friend, and Saturdays, he uses his wheelchair-

*Continued on page 20*

## Caring for the Caregiver



**Of all those who care about a person with ALS,** one of the absolutely most challenging roles is that of the main caregiver. There is increased responsibility and time commitment; a need for high energy and patience; new educational needs about ALS treatment, support, and resources; and then a big dose of worry and concern. Most caregivers say they wouldn’t want to be anywhere else, but it’s still typically very, very challenging.

If you’ve just been diagnosed with ALS, it may be helpful to know that the person who will most consistently be by your side will be having great challenges in his or her life, too. They are facing shock and grief not too different from what you face, and they will assume greater responsibility as time goes on. Knowing that and helping to communicate back and forth with the caregiver or caregivers in your life will be important.

If you’re going to be a caregiver for someone with ALS, know that you will have challenges and needs you can’t fully imagine now. Learn to communicate your thoughts and feelings not just with the person you’re caring for, but with friends and others with whom you can openly talk.

### Here are some things to consider:

- Caregivers often do not get enough free time. Take care of yourself physically and emotionally. Taking time for yourself is not selfish and will improve your capacity to care for your loved one. Make your needs known and create time to do the things that are important to you personally. Continue relationships and activities that are important to you.
- Caregivers may not ask for the help they need to provide care for their loved one and to take care of themselves. Have a “wish list” available when people ask what they can do to help you. Have friends and relatives help you with specific caregiving or household tasks. Most people want to help, but do not know what to do.
- Depression can strike anyone and caregivers are especially vulnerable - it is the most common healthcare condition reported by family caregivers. Be aware of the early signs of depression and see your healthcare professional if you think you are becoming depressed. You do not have to live with depression.
- Caregivers do amazing work in caring for their loved ones. Recognize the important and good job you are doing and realize how valuable you are.
- Knowledge is empowering. Get as much information about ALS and caregiving as you can. The more you know, the better prepared you will be in providing care and support. Ask friends and relatives to help gather information and resources. Become an advocate for your loved one and for yourself.

- In becoming a caregiver, some people experience a loss of the roles and relationships they had with their loved one before the illness. It is easy to see yourself as more a caregiver than a family member or close friend. Identify ways to keep your personal and family roles and relationships alive. Talk about family events and news about children and grandchildren. Look at family photos together. Change the daily routines periodically like adding candles to the dinner table or putting on your favorite music. Making the effort to retain the relationship you have had with your loved one - aside from your role as caregiver will help you in coping with the multitude of changes family caregiving poses.
- Establish networks and support systems with other caregivers to share solutions to common problems and to talk with people who can understand first-hand what you are experiencing.
- Take advantage of local, state and federal programs that support and assist caregivers. Some states and local agencies provide financial support in the form of vouchers or cash for services and equipment. Many state and community agencies and non-profit organizations - such as The ALS Association and religious groups - offer respite services and caregiver-specific support groups.

## What Everyone Should Know About Caregiving

### How involved should the family be in caregiving?

ALS is actually a family disease; it affects many others beyond the person who has been diagnosed. The goal is to have everyone involved, knowledgeable about ALS, coming to the ALS clinic appointments, participating in The ALS Association Chapter events, and helping in whatever way they decide.

When The ALS Association chapter representative makes a home visit, they're there to talk with the person who has ALS and with the caregivers in the family. ALS chapter Support Groups often break out into separate sessions so caregivers can have time together to compare notes and learn from each other. Some groups are designed only for caregivers.

### What if you have a very small family and few people who can help?

Whether your family is large or small, it's wise to set up a network of caregivers and incorporate as many people as possible in the process. Consider involving people from your faith-based organization; neighbors; friends and extended family. Remember that some tasks are not as personal as

you might think: grocery shopping, errands, helping to fix something around the house, walking your dog. You can start small, but just having an extended network will really help.

### How can you keep from feeling isolated and depressed?

Stay connected with what you like to do, continue to meet with friends outside the house, and be sure to take care of yourself. Schedule doctor and dentist and personal appointments. Run some errands. Get some fresh air. Keep up your exercise regimen. This isn't selfish; it's essential to help you re-energize for your role as caregiver. It's safe to ask for help. You don't have to do it all yourself. Reach out to The ALS Association and to other resources in your community.



An interview with  
**Sharon Matland, R.N., MBA,**  
 Vice President of Patient Services  
 for The ALS Association

*Continued from page 18*

friendly van to go with one of his assistants to the grocery store so he can help pick out the next week's most interesting menu items.

Andrew says he needs three “gadgets” to get through the day: his electric “power chair,” his computer with speech detect software, and his TV and recorder (to watch CNBC, Fox, and the History and Discovery channels, and as much good comedy as he can find). He also uses a speaker phone which he manipulates with his toes, but he's having telephone software installed on his computer that will be far easier to use.

It's not that every minute of every day is terrific, not by any means, Andrew says. “Anger comes,” he says. “I shout at the wall; it's an emotional release.”

Andrew says he tries to take a practical approach to daily life. “I tell myself: this is life. ALS has happened. I have to deal with it.”

Over lunch, sipping a martini through a straw, and munching on crab cakes, fruit and half a club sandwich, Andrew explains part of the impact of ALS on his life. “Dealing with your mortality is a big issue. It enlarges you as a human being. It made me look at what I was doing with my life in an entirely different way. I learned to stop looking at what I couldn't do and start focusing on what I *could* do,” he says.

Andrew says people often ask him, “How long have you suffered from ALS?”

His answer? “Never; but I've been *inconvenienced* by ALS for 23 years.”

### ADVICE FROM ANDREW

- Don't try to take it all in at once. Avoid the temptation of reading too much, too fast. Don't succumb to information over load.

*Continued on page 22*

# What is being done to treat and cure ALS?

**The ALS Association supports researchers** worldwide who are working to understand the causes of ALS, the dynamics of the disease process, the variety of ways it is manifested and why it often progresses at different rates.

A broad range of programs are bringing ideas from the research arena to people with ALS:

## 1. Studying the impact of cell processes

Research suggests there is probably not a single cause for ALS, but rather a complex combination of genetic and environmental influences.

## 2. Researching the dynamics of the disease process

Much needs to be learned about how ALS starts and develops, and how motor neurons and surrounding cells interact.

## 3. Understanding the manifestations and the progression of disease

Not everyone with ALS has the same set of symptoms and the disease can progress at different rates. Researchers are studying why this occurs and what the implications may be to the development of treatments.

## 4. Gaining insight into ALS through stem cell biology

The research is showing how cells differentiate – or take on different roles – and what procedures might facilitate stem cell transplantation in humans.

Developing new therapies is also a primary goal of The ALS Association.

By better understanding the mechanics of the disease – how it occurs and progresses – we hope to discover drugs for treatment.

**1. Drug therapy:** Rilutek® (riluzole) has been on the market for ALS since the mid-1990s. It works on one mechanism that is thought to be involved in the disease.

**2. Clinical trials** continue to be performed in the hope of finding effective new therapies.

Because drug development is a lengthy process, many drugs for ALS that have already taken a decade of research are just now being evaluated in clinical trials.

## Where do I start?

### Guidance for moving on from here.

#### Where should someone who has been newly diagnosed with ALS start?

**Jennifer:** I think it's important to join a support group as soon as possible. That often sounds a little uncomfortable to some people because they are still coming to terms with the diagnosis. But starting early with such a group helps you begin to deal with the nuts and bolts of how you keep moving forward and offers lots of practical information. It's not group therapy. It's an exchange of information and a way to learn useful hints and get help.

**Susan:** You'll learn about resources, about your own coping skills, The ALS Association's support services, and get lots of practical information. We help explain some of the lingo of health care that you'll hear, such as what PT means (physical therapist) or DME (durable medical equipment, such as a walker). We also provide helpful organization hints. I, for example, suggest you begin to develop a notebook with sections for clinic names and resources, community support organizations, social security, business cards you get from people, and more. Such a notebook makes it easier to get information when you need it and helps make it easier for a clinic team member to follow up on any problems.

#### What do you suggest to people who feel they would benefit from getting some help from extended family and friends?

**Jennifer:** We do an exercise with the group called "Caring Circles." We help people consider three levels of potential helpers in the community: immediate family, people from their faith-based organizations, neighbors and others who might want to help. We also discuss the fact that some people with whom you may not be close can help in all sorts of ways – returning library books, walking the dog, or picking up the kids at school.

#### Are there specific steps you suggest people take?

**Mary:** Yes; you should first contact your closest ALS Association Chapter to find out what they offer and what they recommend.



**Mary Kelley** M.S.N., C.R.N.P., (left) Clinic Coordinator of The ALS Association Certified Center<sup>SM</sup> of Excellence at the Pennsylvania Neurological Institute, **Jennifer Klapper**, R.N., C.N.S.-B.C. Mental Health Nurse at the Center (center), and **Susan Schwartz**, A.C.S.W., L.S.W. (right), of the ALS Greater Philadelphia Chapter at the Center offer these concrete suggestions for starting the journey with ALS

You should also call family members and close friends as you feel ready. Keep in mind that all the resources are a smorgasbord from which you, and your spouse and family members can pick and choose over time.

**Jennifer:** There are really five categories to focus on soon after being diagnosed with ALS, and these are not in any specific order: Financial and health insurance issues; Family (telling them about the diagnosis and supporting your children and parents); Health, such as following-up on any tests your physician has asked you to have or starting a new medication; Coping, which means beginning to integrate all the information you've gotten and applying the coping skills you've used in the past; and Support, which involves developing your relationship with your closest ALS Association Chapter and beginning to identify your network of supportive friends and neighbors.

#### What if I would like to wait awhile before getting involved with my closest ALS Association Chapter?

**Mary:** I encourage people to make contact with the chapter even if you want to stay under the radar for awhile. It's a great resource to have in your back pocket. It's very helpful to have the name and phone number of a person you can talk with if and when you need to.

#### What if I have some unusual or atypical questions?

**Susan:** If there's something you're worried about, I guarantee you someone else has thought about it before.

*Continued on page 22*

## ADVICE FROM ANDREW cont.

*Continued from page 20*

- You'll know when you've accepted your diagnosis in much the same way that you knew when you had learned to drive. At some point, you realized you changed lanes without thinking about it much. And at some point, you'll live your day without thinking about ALS as the center of things.
- Remember that no two cases are the same.
- Be a nuisance to the neurologist: ask him or her to explain things to you.
- Learn to take things as they come. Don't go looking for trouble.
- Find a support group and talk to people who have worked out solutions to problems.
- Remember the old adage, "Laugh and the world laughs with you."
- Some days you may feel like you're the only one who's got ALS. You're not. You're in good company.
- Avoid the temptation to go out and do things you haven't yet had a chance to do. If you haven't found the time to do it up to now, those things might not be as important to you as you might at first think.
- Remember that you may have issues with your limbs, with swallowing and with breathing, but one thing hasn't changed and isn't going to change in most cases: what's between your ears is the same as it was. You're the same person you were.

# ALS Association Certified Centers<sup>SM</sup> of Excellence

The ALS Association Certified Center<sup>SM</sup> program defines, establishes and supports a national standard of care in the management of ALS, sponsored by The ALS Association.

The ALS Center Program encourages and provides state-of-the-art care and clinical management of ALS through:

- Multi-disciplinary care of the person with ALS and his or her family
- Specially-trained clinical staff knowledgeable about the the needs of those living with ALS
- Collaborative work among Centers to enhance ALS patient care and conduct research studies

The ALS Association selects, certifies and supports distinguished regional institutions that are recognized as the best in the field, and have neurological diagnostics and imaging, and available on-site licensed and certified ancillary services on clinic days. Staff includes:

- Neuromuscular physician
- Nurse
- Physical therapist
- Occupational therapist
- Respiratory therapist
- Registered dietician
- Psychologists/Psychiatrists
- Speech and language pathologist
- Social worker
- Assistive technology specialist

## Where do I start? *Continued from page 21*

### Are there any books you might recommend?

**Jennifer:** Yes, here are some excellent resources. Some may apply to your situation and others may not:

- *Handbook for Mortals: Guidance for People Facing Serious Illness*, by Joanne Lynn and Joan Harrold.
- *Taking Charge: How to Master the Eight Most Common Fears of Long-Term Illness*, by Irene Pollin with Susan Golant. (This book is out of print but may be available on online booksellers such as amazon.com).
- *You Are Not Your Illness: Seven Principles for Meeting the Challenge*, by Linda Noble.
- *How to Help Children Through a Parents' Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist*, by Kathleen McCue.
- *Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill*, by Cappy Capossela and Sheila Warnock
- *Mainstay: for the Well Spouse of the Chronically Ill*, by Maggie Strong.

## OUR VISION

In the quest to create a world without ALS, our vision is to care for and support all people living with Lou Gehrig's Disease as we leave no stone unturned in our relentless search for a cure.



**The ALS Association**

27001 Agoura Road  
Calabasas Hills, CA 91301  
Phone: 818.880.9007  
Fax: 818.880.9006

