

LIVING WITH ALS

Coping with Change



Cover: *Nanny in a Box* by Elizabeth Walters.

The artwork on the covers of the *Living With ALS* manuals was created by individuals with ALS or their family members.

About the Artist

“Before my mother, Beverly Walters, was diagnosed with ALS, I was pretty sure of the diagnosis. I am a physician assistant and have had two patients in my career with this disease. When my mother started telling me about the “weird” things that were happening to her, I started to guess what it could be. From that time on, it became very hard for me to divide myself from the caring, grieving son and the realistic, educated health care provider.

My mother obtained your manuals and found comfort in them because they were the support group that we do not have in this rural area. She was a very giving and independent person. So, to the end, she hated us having to do things for her. She said this was the worst part of the disease, feeling trapped and having to depend on others.

That is when my daughter Elizabeth, age five at the time, painted this picture, which she called “Nanny in a Box.” She said that one box represents Nanny being at her house and us going down to help, and the other box is for Nanny feeling trapped. The most memorable moments Elizabeth had with her Nanny were when she would lay in bed with her grandmother and interpret her slurred speech for the rest of us. These simple, gentle moments, like the painting, are often taken for granted by the rest of us.

We feel it is an incredible honor that The ALS Association has chosen Elizabeth’s artwork, and we feel that this is just one more way my mother has touched people with her life and death.”

JOE WALTERS

*Loving son and caregiver of Beverly Walters
and father of the artist*

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Manual 2

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Written by

Marlene A. Ciechoski, MS, RN

A note to the reader: The ALS Association has developed the *Living With ALS* manuals for informational and educational purposes only. The information contained in these manuals is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.

LIVING WITH ALS
Coping with Change

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Contributors to the 2002 edition:

Jennifer Klapper, MSc, MSN, RN, CS

M. L. Del Bene, MS, RN, NP-P

Project Advisor:

Mary Lyon, RN, MN

Vice President, Patient Services

The ALS Association

Graphic Design:

Denton Design Associates

Illustration (text pages):

Neverne Covington

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Introduction

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PERSONAL MESSAGE FROM THE AUTHOR

When I was first asked to write a manual about the emotional impact of ALS on individuals and their families and friends, I thought I would relate my experiences working in this field for over 13 years. I understood that it would be appropriate and valuable to tell about my observations of the dynamics affecting people living with ALS. I knew there was an important story to tell.

Over several months, I reflected on what my experiences had been and came to comprehend and feel deeply that it was important to share my personal account of working with these individuals. However, it is not my story but that of all individuals with ALS and those who love them.

This manual is designed to provide a framework for you to consider thoughts, feelings, and responses to the diagnosis of ALS—in yourself or in a loved one. As such, it is written in an informal and personal manner. The manual consists of four sections. The first section, “Coping with the Diagnosis,” explores reactions people may have when they, a family member, or a friend is diagnosed with ALS. Understanding the broad spectrum of normal responses may assist you in knowing that you are not alone in this disease. Anxiety, depression, communication, and support will be discussed.

The second section, “Coping in Your Mind,” presents some possibilities for helping shape your thinking, as well as ways to live through the various transformations you will experience. Such issues as accommodation and acceptance, decision-making, and quality of life are discussed.

The third section, “Coping in Your Heart,” covers caregiving and how an individual living with ALS can come to terms with receiving help from others. In addition, issues surrounding intimacy and sexuality and how these personal concerns are affected by ALS are candidly discussed.

The last section, “Coping with Life,” focuses on living life to its fullest. This segment looks at both the possibilities and the difficulties of managing your life with ALS.

Ultimately, this manual is the story of the challenges faced by unique human beings who have been touched by ALS. I am but the storyteller, humbled yet privileged to be so, knowing that my hands and spirit are moved by the strength of the hundreds whom I have been fortunate to meet on their incredible journey. In part, in whole, in kind, or in contrast, this story also may be yours. My wish is that when you have read through to the last page, you will feel hope and peace.

Coping with the Diagnosis

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he diagnosis of ALS is a life-changing event for an individual and his/her loved ones. Yet, for many, the journey began prior to the diagnosis, often with a twitchy finger or raspy voice; these “small problems” may have prompted visits to a variety of doctors and therapists in an attempt to find out what was wrong.

The pathway to diagnosis is often filled with inconclusive medical opinions accompanied by increasing anxieties that your symptoms are progressing without an actual name given to the entire process. For others whose symptoms allow them to be diagnosed in a shorter period of time or whose physicians are more familiar with ALS, the news comes more quickly. However long or short a time it takes, the final diagnosis is inevitably met by an overwhelming sense of fear, worry, and loss.

While many people at the time of diagnosis have heard about ALS, some may not know about it at all. Perhaps they are only familiar with its other name, **Lou Gehrig’s disease**, having either a vague or powerful memory of the famous New York Yankees’ baseball player and the disease that claimed his life.

Frequently, following diagnosis, people go to their local library or bookstore and study a medical book, or they check the Internet for information about ALS. What they find can be genuinely frightening, bleak, and grim. Eventually, they will discover the phone number of the National Office of The ALS Association (ALSA) or that of a local ALS Association chapter or ALSA Center. These resources can provide information that is positive, will answer your questions, ease concerns and direct you to national resources.

However, knowing these facts may increase your level of anxiety, which is why it is important to meet with an ALS specialist or ALS multidisciplinary team of healthcare professionals. A common initial response to the diagnosis is to be overwhelmed and concerned. You may feel extraordinarily compromised and fatalistic. The meaning of the diagnosis is very different to each person. To some, it is unthinkable, unbearable, and unacceptable. To others, it offers answers to their quest for some understanding of what has been happening to them.

The news of your diagnosis can take place on a solitary visit to the physician's office or in the presence of family and friends. Without a doubt, for the majority of people, the time of diagnosis is when the support of loved ones is most crucial.

Sometimes people want to receive the news alone, allowing them time to think about how to tell their family. Still others cope best when they have their loved ones at their side. Reactions to news about health problems vary widely—from shock and disbelief, to anger and despair. Most people are worried and distressed about the effect on their loved ones. They are anxious regarding the implications of ALS in terms of longevity, ability to continue working, and life roles.

Any emotional response to the diagnosis by you or your family members is absolutely normal; it is a period when everyone is stunned and concerned about its potential impact. There must be time to gather thoughts, before everyone involved can assess the circumstances and begin to address the multiple issues now confronting them.

You may want to discuss how you feel about your diagnosis with your closest family members and friends. However, certain loved ones may be unable to address these issues because they may feel that discussing the situation will only make it worse. They must realize that their need to discuss the newly-given diagnosis may not be in line with your needs and willingness to discuss your reactions. A period of time might have to pass until each person involved feels more collected, more sure of thoughts and feelings, before being able to reach out in communication with each other.

Your loved ones must be understanding while you begin to incorporate the meaning of this news on a very personal, emotional level. At the same time, family members and friends may find that talking with each other about their own reactions will help them achieve a sense of comfort when they interact with the person with ALS.

In some cases, an individual may decide not to return for follow-up medical care or may refuse any attempts to discuss these issues with his/her family and friends. It is critical that a close family member or friends try to help the person deal with the diagnosis by looking at communication obstacles. It could be helpful to acknowledge what is occurring, what lies ahead, and to encourage seeking support care offered through ALSA. An ALS clinic can do a great deal to help people cope with the diagnosis of ALS.

BEGINNING YOUR JOURNEY

When people receive news about a life-threatening health problem, it is not unusual to experience *any* feeling that is within the scope of human responses. Your ability to recognize and cope with your feelings is most often related to previous life experiences. How you have handled other life crises and difficult problems will influence how you will begin to face ALS. In particular, make sure that you recognize the resources available to you—your family and friends, health care professionals, and local and national ALS organizations—all of whom can be helpful in providing information, direction, and “tools” as you begin your journey.

REACTIONS TO THE DIAGNOSIS—THE AUTHOR’S OBSERVATIONS

In 1984, I met the first person I ever knew who had a diagnosis of ALS. He was an outgoing, loving man with a repertoire of bad jokes and a great smile. He knew he had a difficult disease that was not clearly understood at that time. Whatever information was available, he sought out and learned. He certainly came to know a lot about ALS.

Over the years, I have observed many different reactions to being diagnosed with ALS. There may be a conflicting sense of *hopefulness* and *hopelessness*. Both of these feelings are likely to be experienced by everyone involved. Similar to the stages of dying and death, people experience anger, denial, bargaining, depression, and acceptance in varying order and degree (as described by Elisabeth Kubler-Ross in her well-known book on this topic). People are stunned by the news. Some, upon hearing their diagnosis, have bolted from the doctor’s office and sought other medical opinions. Still others are optimistic and want to live their life as fully as possible, in spite of knowing that they have this illness. They hope that research will find the answers.

People often ask me, “*How do I cope with ALS?*” My answer, borne out of contact with patients over the years, is “*You cope with it in your mind and in your heart.*” Although there is a human need to deny and diminish the impact of such a diagnosis, you need to be well-educated about ALS. You should make an effort to learn everything about this illness as you assemble your professional health care and support team. This includes information about good nutrition and eating tips; safe mobility; preventive care (flu shots, pneumonia vaccine); current treatments; equipment options; basic science and clinical research; advocacy programs; and the hope that comes with the giving and receiving of support, nurturing, and love. Successfully managing this disease will allow you to live the fullest life possible.

It is wise to become informed about the types of decisions that you might have to make. Most of all, find a way to live in this “new and different space.” ALS requires time, energy, resources, and determination. As a 46-year-old woman with the disease explained, “*ALS does not make its appearance when it is convenient. It does not necessarily affect you after the kids are raised, the house is paid for, work is secure, and you are emotionally prepared. Most problems in life, with health or otherwise, generally do not make appointments in advance.*”

I have always been impressed by the determination of people diagnosed with ALS. At a time when lives are shaken to the core, when progressing symptoms are responsible for physical challenges and fatigue, people rally their strength and spirit and take on this disease. They learn quickly that they must fight for the quality of their lives. A 42-year-old woman, full of grit and grace, was fond of saying that she would do “*whatever it takes to live and try to beat this.*”

At the same time, as a 50-year-old priest observed, “*ALS plays havoc with one’s emotions;*” indeed, it creates anxiety and depression which can be further disabling. Trying to tolerate and to understand these perfectly normal feelings can help you to deal with this devastating experience. One woman stated, “*I wanted to hide in a closet, cover my head with a blanket, and wait to die because I was so scared.*” A young man trying to deal with this disease said, “*I wanted to beat up on everything and anything because I was so angry and so scared.*” ALS can be scary; not only does it bring on physical changes, but it triggers a wide range of emotions and feelings as well.

Anxiety is an uncomfortable feeling resulting from something important being disrupted. In its milder form, anxiety usually makes you take action and as such is generally productive. At its worst, when it overwhelms, anxiety can be disabling. When you learn that you have ALS, you are uneasy and anxious, among other emotions. One man recalls, “*What I remember most of that moment is that I cannot remember it!*” He heard the news but felt as though he were no longer present nor participating. “*My anxiety level went through the roof. I was in shock for days.*” As recovery from the news occurs, anxiety generally diminishes.

Some people may respond to their diagnosis with a significant and profound sense of **depression**. Depression is an overall feeling of sadness, helplessness, and dejected emotions. It is normal and appropriate throughout life and especially during illness to feel depressed. At times however, if prolonged, depression can be debilitating. Actual comments I have heard include:

“Life felt as though it were over. Nothing at that time mattered.”

“I went home from the ALS Center, took to my bed for three days, and cried my heart out.”

“I did not want to talk with anybody or to see anyone.”

“I slept either too little or too much.”

Sadness is a normal response to a devastating illness, but it can take away your spirit and your energy. Both anxiety and depression can be treated effectively. You should not hesitate to seek professional help to cope and deal with the complex feelings that surround ALS. Support groups, counseling or psychotherapy with a mental health professional such as a clinical social worker, psychologist, therapist, psychiatric nurse or psychiatrist knowledgeable about ALS can be extremely helpful. In addition, your doctor or psychiatric consultant can prescribe medication to decrease the symptoms of anxiety and depression.

There can be an anguish to this disease that encompasses the soul. The diagnosis of ALS takes you down a path you would never choose. It forces you to face changes, challenges, choices, and more.

Coping in Your Mind

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or you to cope effectively with ALS, you must search within your mind and heart. Beginning with the mind, you are likely to ask the question, “*Why me?*” This question is frequently asked and revisited by anyone facing a life-threatening illness, and ALS is no exception. It is normal and understandable to ask, but if you remain focused on it, you will prohibit or delay learning to live with ALS. Other more positive ways of dealing with the diagnosis will include any or all of the following coping strategies.

Accommodation

This term refers to the process of adjusting and adapting to change. Accommodation is a means of reconciling the difference between what was and what is, and has to do with recognizing choices as well as changes. It implies being proactive and practicing self-advocacy, thus turning “*Why me?*” into “*What I can do.*” Yet, this process is not always immediate nor does it stop the necessary and nagging questioning. To incorporate the awareness of the disease and acknowledge that it is a real part of your life can take considerable time.

Being proactive and focusing on “what I *can* do” directs your energy to *living* with ALS.

Acceptance

Often, family and friends wonder how long it will take for you to “accept” the diagnosis. Acceptance takes however long you require. For some, it may be months, while for others, it may never happen. Acceptance and accommodation mean using a cane, walker, or wheelchair for easier and safer mobility, rather than continuing to experience anger, frustration, and grief when moving around becomes a problem. One woman repeatedly found herself in emergency rooms for treatment of injuries, because she insisted on walking without assistance when clearly it was not safe. Finally, after she sustained a fracture from a fall, she reasoned that now it was time to use a wheelchair. When asked why she let it get to this point, she answered, “*I had to keep fighting.*” An earlier accommodation and acceptance may have made things easier for both her and her family.

Acceptance and accommodation do not mean giving up or giving in. They mean taking charge of your well-being in order to gain a sense of control.

Self-survival

When your life is at stake, you will do everything you can to save it. Self-survival is the most powerful force in human beings. You want to “fight this thing,” but why not have a well-orchestrated battle plan rather than play Russian roulette? If you direct your efforts toward that goal, armed with knowledge, supported by caring people, and sustained by hope, you will have a much better quality of life with ALS.

DECISION MAKING

Most people agree that life is not predictable. Similarly, ALS varies dramatically from individual to individual. How slowly or rapidly it progresses and which areas of physical function it involves are but two examples of its fickle nature. ALS calls for a great deal of flexibility and creativity. As your symptoms and abilities change, ongoing decision making is required because it affects your activities of daily living (ADL). Making up your mind or reaching a conclusion is what almost everyone does automatically when confronted with a problem or question. In addition, due to changes brought on by ALS, decisions must be re-evaluated, and sometimes revised or even reversed.

All through life you've made decisions, and thinking back, it may have seemed so easy. Yet, decision making is a very sophisticated response based on your knowledge, skills, experience, observations, preferences, hopes and desires. It is a multi-step activity that is far more complicated than it appears, although it can range from a simple selection of liking blue over red to the complex choice of changing jobs. There may be no rhyme or reason for your decision—the blue tie just appealed to you more than the red one, whereas you may have spent weeks or months studying and weighing all the information available in order to decide whether or not to take a new job. The same process applies here.

Stages of decision making

Clearly, decision making is increasingly more involved when the stakes are higher. As you perceive the magnitude of a decision, you become more aware of all the nuances that need to be considered. From this perspective, the myriad of choices available for how to live with ALS are remarkable. Certainly some choices, such as using a cane, are not especially difficult to make; however, deciding on ventilator support falls in a much different category of consideration, although the process contains similar steps. Seek support of ALS teams, other patients and families living with ALS. Keep in mind these two examples as you review the stages of decision making shown on the next page.

| <i>Process of decision making</i> | Example A <i>Walking Difficulties</i> | Example B <i>Breathing Difficulties</i> |
|-------------------------------------------|---------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <i>Difficulty is experienced.</i> | Walking is unsteady, and you experience tripping and near falls. | You experience changes in breathing. |
| <i>Problem is defined.</i> | Calf muscles are weak. | Breathing capacity changes. |
| <i>Possible approaches are suggested.</i> | Use a cane or walker for support when walking. | Non-invasive positive pressure ventilation (NIPPV)(nasal-mask assisted breathing), medications, comfort measures, tracheostomy, and ventilator support are considered. |
| <i>Consequences/outcomes are weighed.</i> | Think about walking around more safely versus risk of falls and injuries. | Among the positives are less discomfort in breathing, improved respiratory function, extended life, and helpful support as the later stages of the disease approach. |
| <i>Solution/strategy is accepted.</i> | Begin to walk with a cane or walker for assistance. | Use NIPPV, various medications, care and comfort measures, or hospice support, and/or make the transition to ventilator or tracheostomy. |

In example A, the choice to use or not to use a cane or walker centers on a relatively minor problem. The decision to accept various levels of support for breathing difficulties includes a variety of issues with profoundly different outcomes. These two examples show the different degrees of difficulty involved in decision making.

People living with ALS are continually faced with change and finding ways to cope with it. As decisions are required and reached, various coping strategies evolve – among them are action-oriented and information-seeking plans. Some people work at developing mastery over a situation to gain control; others employ avoidance and denial as an escape mechanism. Still others may have a sense of fatalism and feel stuck in their situation, while at the opposite extreme are people who are optimistic, positive thinkers who focus on the possibilities.

Other people make a decision to cope by just “being” and sitting with their feelings for a little while rather than taking immediate action. Many individuals choose to take the time to experience the range of feelings that occur when dealing with ALS. This approach helps a person process and understand their feelings before they make a decision.

Living with ALS forces you to make decisions about:

| | |
|--------------------|--------------------------------|
| Family life | Advance Directives/Living Will |
| Work | Feeding tube |
| Socializing | Tracheostomy/Ventilator |
| Intimacy/Sexuality | Living accommodations |
| Adaptive devices | Caregivers |

Some of these topics are addressed in detail in the other *Living With ALS* manuals. (See inside back cover.)

Decision making can be enhanced if you talk with family and friends. Remember that in considering your choices, you must weigh the consequences for your family and friends, since you are all affected by the outcome. However, *you* are the ultimate decision maker, not your family, friends, or your health care team.

The essence of every person lies in his/her individuality and uniqueness. Those traits are what humankind loves about one another. These similarities and contrasts are quite evident in how they feel, think, and make determinations. People with ALS approach decisions with different sets of values, ideas, experiences, and advice. Some can consider their options and make the best choices in a very timely manner, while others are slow, deliberate contemplators. Both are correct in their approach, but each style of decision making requires a different degree and quantity of information and support throughout the process.

FEELING DIFFERENT AND ISOLATED

Common to individuals with ALS is the need to feel as normal as everyone else. When a person becomes physically challenged, people may treat him/her differently than they did prior to the diagnosis. It's as if you do not have the same brain and personality that you did prior to the diagnosis. One patient proudly said, *"I am still me—even with ALS!"*

Changes in your body may significantly affect how you feel about yourself and the world around you. It is important for friends to know that in most cases the mind is not affected in people with ALS. We all need to feel that in the basic dimensions of life, we are similar to our peers.

ALS creates diminished functional abilities that cause you to define yourself differently in relation to others. This may lead to disconnecting from friends and activities. Yet many people suffer greatly because of this self-imposed separation.

The reality is that changes imposed on your body require you to do ordinary things differently. You must make an extraordinary effort everyday. With this labor-intensive disease, you can easily grow tired, working so hard to live like everyone else. These changes can make a person with ALS feel distant, removed, and separated from others. When activities of daily living (ADL) are decreased, you will need to adjust your pace to make up for the differences and not allow yourself to become isolated.

Coping in Your Heart



CAREGIVING

As you cope with change, you face the reality of having others assist you in your ADL. Because of people's desire to maintain independence, an illness such as ALS is often difficult to accept and may cause feelings of defeat or despair.

Changes in independence may result in profound changes to your sense of self-worth and integrity, leading to anger, sadness, and grief for what one no longer has.

It is life-enhancing to explore any and all services and supportive therapies that could help you feel better. You can benefit from physical and occupational therapy, and also may feel more relaxed and comfortable after a massage or time spent in a warm pool. Be open to recommendations that are dedicated to your needs. The mind and body are intimately bound, one to the other. What feels good to the body generally comforts the mind and spirit. Likewise, music, guided imagery, meditation, and psychotherapy help you achieve mastery over those feelings that may interfere with your sense of peace and self-worth. As a male patient mentioned, *"I no longer felt whole and complete because of ALS. When I chose an opportunity to discuss my feelings in a supportive professional relationship, I developed insight and took on a new and better sense of who I am."* Another person stated, *"I may have ALS, but it does not have me."*

Coming to terms with the need for caregivers is generally something most people are very slow to accept. It is emotionally difficult to receive intimate care from spouses, children, or parents. Even the initiation of personal care by a professional nurse or aide requires time, patience, and understanding. However, the problems associated with caregiving are not limited to the person with ALS; the caregiver, whether a relative, friend, or professional, needs acknowledgment and support in the process of starting and maintaining the care-providing relationship.

You and your caregiver are a team. You share the process... and the benefits of a positive course. Through this journey, you have experienced a multitude of life-changing events. Now you continue your journey with hope.

INTIMACY AND SEXUALITY

People are born sexual beings who thrive on emotional and physical intimacy and the expression of both. We need to feel and be close to others in thought, spirit, and physical contact; the latter comes from hand-holding, stroking, hugging, kissing, and sexual intercourse. People shake hands or kiss a friend in a welcome greeting; they hold a grandchild in their arms to comfort and to communicate love. We express caring and intimacy differently in different circumstances. When two people are in love, they enjoy the physical expression of feelings. Imagine if none of these abilities were possible because of ALS and its limitations on moving, embracing, and/or consummating your love.

ALS does not affect the sex organs, but when mouth, hand, leg, and various other movements are affected, sexual expression may be difficult for either person. The need to express sexual feelings is not eliminated, even if the practice is. Some people find comfort and satisfaction in other forms of gratification. And others enjoy visual and auditory stimulation from videos and tapes with sexual content. A female patient explained, “*My husband and I don’t have coital intercourse anymore, but experience intimacy with oral sex or masturbation.*” A man remarked, “*I enjoy my partner holding me in her arms closely while in bed with our favorite music on.*”

Emotional and sexual intimacy, in the presence of ALS, often is new and different, but it can be fulfilling and desirable. You and your partner need to be open and up-front with each other about intimacy and intercourse. Consultation with health professionals, such as sex therapists, should be a welcome resource—not a source of embarrassment. Living life to its fullest with ALS makes it necessary to consider a variety of therapies that will promote your comfort, lessen anxiety and depression, sustain your self-esteem, and support personal dignity.

Coping with Life

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any people live their lives with hopeful expectations. They hope that they are physically healthy and independent, that they achieve a degree of happiness and success, and that their family is vital, supportive, and loving. In terms of actual living, they hope that they have many good years, that any illness is not painful or disabling for them or their loved ones, and that death comes peacefully.

ALS has a profound impact on these hopes. It interrupts plans, and puts the future on hold. ALS is not considerate of where you are in your life, what you are about, or what is important to you. It has no respect for what you have accomplished or what you are working towards. It does not matter if you are planning to marry, have children, care for a parent, change careers, divorce, move, or various other options—no special circumstance will exempt you. The diagnosis of ALS sends your hope on a collision course with fear; however, eventually you realize that you are not likely to die suddenly. At this point, the most prevalent question is, “*How do I live with ALS; how do I cope with life now?*”

Discussions with many people living with ALS have revealed one answer: *The sustaining factor in living with this disease is the continual harvesting of hope and finding new meanings in your life in the present.*

When you learn that you have ALS, you quickly realize that at this point it still remains a deadly illness. Though eventually something is going to cause the demise of every person, patients and families alike wonder why ALS is so different from other very serious diseases. For the longest time, people have been told that nothing can be done for ALS, whereas there have been

options for people with other diseases. The outcome may not always be successful for these other diseases, but there are treatments. However, much has changed in the care and treatment of ALS.

Hope must remain the guiding force throughout your life and your ALS experience. We grow in understanding, spirit, and wisdom as we live, and hope enhances our journey. ALS tests our understanding, especially as physical changes occur and life is made more difficult. It is important to deal with this disease one day at a time and try to find new ways to experience meaning in your life. Hope comforts and strengthens; it is what allows you and your loved ones to endure.

ALS is a challenging illness to manage. Every person, when faced with a serious illness, does not come to it totally unprepared. Other life experiences have provided you with intellectual and emotional skills to help you deal with ALS.

Some practical considerations to support you on your ALS journey are your own sense of spirituality and faith which you may express through religious observances. You may achieve great comfort in talking with friends, family, clergy or counselors. Many people with ALS and their families become closely involved with support groups. Meaningful information and resources, along with interest and concern, are shared. Making a commitment to yourself to live every day to its fullest lends itself to your involvement in your own life and the lives of those you love.

Every person has a unique blend of ideas, dreams, likes, quirks, humor and wit. Use each of your unique ways to continue on. Express your hopes, name your fears, tell your jokes, do your tricks, be everything you are and always have been. All of this is coping.

Another method of coping is taking charge of your life. This means remaining actively involved in the world around you, especially in your own health care. A key part of this is to choose a doctor and health care team you like and trust.

Maintaining a sense of humor is very health enhancing. It is a state of mind with which you approach a situation. Do not fill your path with regrets, since they will only burden you. Instead, focus on your strength and conviction to live life to the fullest.

JUST BETWEEN YOU AND ME

People with ALS face some of the most complex of life circumstances. I marvel at the conviction, courage, and fortitude that I have observed as people cope with these challenges. No one can or should face ALS alone. You, your family, friends, and health professionals can participate in helping to identify options and consider decisions together. Ultimately though, *you* must decide what is best for you. One gentleman with ALS was ambivalent about a decision until he finally made it, and then he felt it was “*right*” for him.

ALS is unique in that you can choose extraordinary measures, in the form of a ventilator and/or tracheostomy (a surgical opening in the windpipe), when noninvasive support will not sustain life. As ALS progresses and respiratory function is affected, you may use various medications and noninvasive ventilator (NIPPV) support to assist you in breathing (See Manual 6). Such problems do not occur suddenly with ALS; they may develop over many months or years. Likewise, energy conservation, medication, and respiratory support, such as non-life-support ventilation, can be helpful for a long period of time.

However, these decisions are the most complicated. You are literally electing either to stay alive by way of mechanical support or to die through the natural progression of the disease. The physical, emotional, and spiritual dimensions of this choice are of the greatest magnitude. People with ALS are faced with a very complex set of circumstances.

Remember that although the subjects discussed in this manual are difficult, they elicit fear only when left unexamined and unexpressed. Fortunately, you are not alone on this journey. You have courage and support on your side. Now is the time to live your life as you receive all of the care and comfort that is available to you.

Just as you plan and accommodate for living with ALS, you may find yourself thinking about dying. In open and frank discussions with patients and families, I have learned how critically important it is to prepare for life's closure. ALS gives you an unusual opportunity to do just that. Generally, you have resources for professional assistance and written information as well as time, insight, and all your intellectual capacities to "design" your remaining years. Taking leave of the world can involve as much or as little preparation as you desire. Many people plan ahead with Wills, Advance Directives, funeral arrangements, and an assortment of "tools and treasures" they have accumulated.

Expect to reminisce—by yourself and/or in the company of others. It is a time when your loved ones, for their sake and yours, need to be connected to one another. Often the young and the old are shielded from this experience, when, in fact, they need and want to contribute to your life's closure. Each has something of great importance to share with you; it may be a child with a drawing, a parent serving a special meal, or a friend listening to music with you. These times are so dear.

You probably will search for meaning in your life and wonder what your legacy will be. Of course, your life speaks for itself in what you have done and said, and how you have lived it. Before it is complete, you may want to initiate some lasting memories.

- A woman with ALS made a trip to her homeland and attended her nephew's graduation.
- A young musician spent his time composing music which would live on.
- A college professor wrote, with his computer, his life story to share with his children and future grandchildren.
- A friend assisted a man in writing letters to loved ones, especially those with whom he needed to mend relationships.

Have reunions with people who have been a part of your life and have helped to define your life history. Gather them together and reflect on the memories—of such “things” life is made.

The Last Word

You and I have shared a special place during the time which you spent reading this manual. I hope you have felt your strength and have been able to ease your fears. I have observed so many exceptional people with ALS, like you, embrace life in the face of this difficult disease. Your journey may be longer or shorter than theirs, but it is *yours*. Travel well on your path, and fear not the shadows, for your courage will illuminate them. All around you is love, and always hope.

Some special readings that you may find helpful are listed below:

Bolen, J.S. (1996) *Close to the Bone: Life Threatening Illness and the Search for Meaning*. New York: Scribner

Doka, Kenneth (1993) *Living With A Life Threatening Illness*. San Francisco: Jossey-Bass, Inc.

Levine, S. (1997) *A Year To Live*. New York: Random House

Remen, Rachel Naomi, M.D. (1996) *Kitchen Table Wisdom*. New York: Riverhead Books

Shuman, Robert (1996) *The Psychology of Chronic Illness*. New York: Basic Books

Siegel, B.S. (1986) *Love, Medicine and Miracles*. New York: Harper and Row

Topf, L.N. (1995) *You Are Not Your Illness: Seven Principles for Meeting the Challenge*. New York: Simon and Schuster

The following is a list of the topics covered in the *Living With ALS* manuals:

Manual 1

What's It All About?

This manual provides an overview of ALS, what it is, and how it affects your body. It also provides information on what kinds of resources are available to help you deal with ALS more effectively.

Manual 2

Coping with Change

This manual addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

Manual 3

Managing Your Symptoms and Treatment

This manual discusses the symptoms that affect you when you have ALS and how to treat them. It also covers the most recent breakthroughs in medications and how these treatments can improve the quality and duration of your life.

Manual 4

Functioning When Your Mobility Is Affected

This manual covers the full range of mobility issues that occur with ALS. It specifically discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Manual 5

Adjusting to Swallowing and Speaking Difficulties

This manual addresses swallowing difficulties and how to maintain a balanced diet with ALS. It also covers how speech can be affected by ALS and the specific techniques and devices available for improving communication.

Manual 6

Adapting to Breathing Changes

This manual explains how normal breathing is affected by ALS. Specifically, it explains how to determine if you have breathing problems and what options are available to assist you as your breathing capacity changes.

The information contained in this manual can be very valuable to people living and dealing with ALS. Please donate this manual to your local library if you no longer need it.

A Reason for Hope



The Amyotrophic Lateral
Sclerosis Association

DC/MD/VA Chapter
615 S. Frederick Ave., Suite 308
Gaithersburg, MD 20877
TEL: 301/978-9855 (Outside DC Metro area: 1-866-348-3257)

Fax: 301/978-9854
www.ALSinfo.org

The ALS Association is the only national not-for-profit voluntary health organization dedicated solely to the fight against amyotrophic lateral sclerosis (often called Lou Gehrig's disease) through research, patient and community services, advocacy, professional education and public awareness.

Member of the National Health Council and Community Health Charities (CHC)