ALS IS A FAMILY MATTER

A Communications Manual for Patients and Those Who Care for Them

by Joan Krash, Ph.D.
ALS is a Family Matter:

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Introduction

When ALS, also known as Lou Gehrig’s Disease, is diagnosed, it is a family matter. The avalanche of emotions — fear, anger, despair, guilt and confusion — that comes with the diagnosis, engulfs all members of the family. It affects the entire network of relationships and communication among family members and others close to them. It is important to be aware of the difficulties that tend to arise, because, without meaningful communication, both patients and those around them can become increasingly isolated and lonely, adding an additional burden to this already devastating disease.

Even those who have been intimate for many years may find themselves reluctant to share significant thoughts and feelings about their experience. As the widow of a PALS (person with ALS) said wistfully: “There were times I think that we missed each other. He shut down. He created a wall between us and also with other people. I wish he would have opened up — told me what he was thinking about. Maybe he was so tired he couldn’t think. I’ll never know.”

Shutting down is not only true for patients. Caregivers and family members, hoping to spare everyone pain, may keep their thoughts to themselves as well. Moreover, personality is a factor. To cope with a sense of profound vulnerability, most people, according to their personality type, will erect some form of armor, of which there are many kinds. Some grow silent. Some issue a barrage of words without meaningful communication. Others become so busy there is no time to think or converse. To further complicate matters, it is often true that individual members of the same family differ in the way they cope. Because their styles are different, they can get on each other’s nerves, creating additional roadblocks to sharing thoughts and feelings.

Nevertheless, when families are able to overcome the obstacles to good communication, they find that it relieves anxiety, facilitates decision-making, improves the quality of care and, in general, promotes a better environment for the whole family. How much to say, when to say it, and how to say it remain subtle and complex issues. There is no right answer for everybody. It is a challenge for families to discover and develop their own ways of communicating. Talking honestly and openly is not a panacea, but it can be of immense value when that is possible.

In researching this topic, we have consulted many patients and caregivers. Some have shared their experiences through answers to questionnaires or interviews and others through letters and memoirs. We are grateful to all of them. We have found many variations in the way people work out the issues presented by ALS. And, sadly, we have heard from too many who were unable to work out issues that were important to them. Because the observations, experiences and advice of our contributors are often personal, the quotations are authentic but no one is identified by name.

We hope that, even if you find yourself unable to speak openly about your own feelings as a patient, a caregiver or a family member, or are unable to elicit the thoughts and feelings from your family members, you will find value in reading about those of other people in similar circumstances. We hope they will help you to gain insight into your own responses and those of others in the family.

Issues of communication change over the course of the illness. Alongside the physical progression of the disease, there is a separate process of emotional change experienced by ALS families. We have divided this process, into three phases. The Early Phase, Middle Phase and Late Phase will be discussed separately. Each phase presents its own set of tasks for PALS, caregivers and family members.

* Amyotrophic lateral sclerosis
I. The Early Phase—a period of shock and confusion

For most people, the ALS diagnosis comes after a frustrating period of uncertainty and a number of referrals to specialists and clinics. Almost all are stunned to hear that they have a progressive illness with no known cure and only a few experimental treatments. The diagnosis comes to adults of all ethnicities and races, and over a wide age range—from people in their 20’s to those in their 80’s. It falls on people regardless of the quality of their relationships. Those with happy families may struggle as much with communication issues as those whose relationships have been more troubled.

If you are an ALS patient, you surely remember the moment when you were informed of the diagnosis. Possibly you were with a spouse or other close relative at the time. Probably you were unable to grasp its full meaning at once. ALS is a disease only vaguely known to most people. It takes time to absorb and digest information about the nature of the illness and the consequences for all involved. Yet, almost at once, questions arise about communication with others.

*Whom shall I tell?*
*How much should I say?*
*Do I want people at work to know?*
*How can I talk to my children about this? My parents? Sisters and brothers? Friends?*
*With whom, if anyone, do I dare share how frightened I am?*

Let’s look at some of the typical communications challenges that arise in the Early Phase of the illness.

**Communicating with your spouse or partner**

For those PALS who have spouses or partners, it may be hard, at first, to know how much of one’s feelings to share. While the initial reaction may be a state of turmoil, often partners try to pull themselves together in order to be brave for one another. That can be a blessing because so much needs to be done and cool heads can operate more efficiently. Also, if one partner is very frightened or depressed, the other may be able to hold things together for the time being. It often happens that partners take turns looking at the bright and the dark side. One ALS patient put it this way:

“I have many friends, my wife included, who get very blue when they realize what I am going through. It is strange, but at times I put on a big smile, a strong hug or handshake, a joke or two, to get them back on an even keel. While it seems to me that they should be cheering me, I end up cheering them.”

In trying to protect one another, the usual patterns of communication for a couple may be disrupted so that each of the partners slip into a state of isolation and loneliness. And, inevitably, much opportunity for misunderstanding may arise. Every couple has its own style of communicating. Some talk to each other about almost everything. Others are more reserved by nature or have a long history of non-sharing. Some couples can say a great deal to one another with a significant glance or gesture.

**Talking together about big decisions**

Most of those who spoke to us about their experience emphasized that major legal and life-and-death decisions should be made at an early point, while the events they anticipate are still remote. If wills and other directives have not yet been written, this becomes one of the early daunting tasks for the patient and family. Often PALS themselves or those closest to them are reluctant to raise these matters because they introduce a direct, and for many persons, a painful confrontation with questions related to the end of life. At first blush, it may seem cruel to address any of these questions at this point, when mainte-
nance of hope is a high priority. It also may bring to the surface many delicate family issues that previ-
ously had been kept under wraps. Nevertheless, once a pattern of avoiding these questions has been est-
established, as the illness progresses it becomes increasingly difficult to bring them up and deal with them
effectively. After these concerns have been addressed, however, they can be put aside so that attention
can be paid to other issues and decisions relevant to treatment and the concerns of daily life. Once they
have dealt with the legal issues, people report a sense of relief at clearing the air. In a world that is other-
wise filled with uncertainty, it is gratifying to know that an important concrete task has been accom-
plished.

One of the painful questions commonly broached in preparing the legal documents is whether,
or under what circumstances, the patient wishes the use of life-support systems and resuscitation. The
process of arriving at this decision varies greatly among families. In some instances, the PALS decides
independently. In others, the solution entails long and searching discussion.

One PALS, the father of two young children, made clear from the beginning that he would not
consider being put on a ventilator because the financial burden would erode the family’s savings. His
wife, meanwhile, had decided that his sense of well-being demanded that he feel in control of as many
aspects of their life together as possible. Although she had to overcome her personal conflict about
wanting him to be with them as long as possible, she understood that it was very important to him to feel
that, despite his condition, he still could be effective in providing for his family.

Another PALS took the opposite position. The Early Phase of his disease included a
weakened diaphragm. After his breathing failed on two occasions, resulting in unconsciousness, he chose
to be placed on a ventilator. His wife and adult children supported the decision. He had at the time no
leg movement and minimal arm movement and used an electric wheel chair. He taught himself to speak
and eat again after the tracheotomy required for the ventilator. Here are his observations about the ex-
perience:

“Probably the biggest decision for a PALS is whether or not to go on a ventilator. Most doctors have a skewed
opinion of what quality of life a person on a ventilator has. Doctors’ quality of life is probably better than most to begin with
and then they see many people suffering and dying throughout their careers; therefore they cannot give an unbiased opinion. I
know PALS who have been on a ventilator for 17 years. Some have had children, grandchildren, weddings, etc. The quality
of life on a ventilator depends on the disease’s progress after the tracheotomy has been performed and no one here on earth
can accurately predict that. Quality of life is also dependent on the PALS’ attitude and expectations. If life as usual is ex-
pected then be or she is going to be sadly disappointed. You make the best of what you have and be productive within your
limitations. You can always pull the plug later. I am not suggesting that a 90-year-old who is bedridden, has Alzheimers or
dementia, as well as ALS, should be put on a ventilator, but anyone who can communicate at all has value; if not to them-
selves they have value to others.”

Another PALS, whose onset was bulbar, waited to decide how he would approach the ventilator
question. At first, he proposed not to make the decision until his condition determined the need for it.
He told his wife that if, at that time, he was incapable of making the decision, she should make it. But she
was understandably uneasy with that responsibility. Eventually, this PALS did make a decision himself
that he would not be placed on a ventilator. The decision came at a time when his quality of life had de-
teriorated considerably.

Families find it easier to deal with end of life decisions when there has been a history of open
discussion about the patient’s and other family members’ wishes prior to a time of crisis. Not all deci-
sions have to be made early in the process and those that have been made can usually be modified if
one’s perspective changes. More important than the actual decision seems to be the fact that discussion
of a subject is not taboo and can be revisited at any time.
Telling your adult children

The issues involving adult children are different from those involving young children. Let’s first talk about conversing with adult children.

Many of those old enough to have adult children have found that it is harder to communicate with some of their children than others about what is happening and what will happen to them as a result of the illness. As one patient reported, “I seem to have the most difficulty talking to my son about this. He never asks questions or seems to want to hear what it’s like for me.” In another family, where a divorced older woman received the diagnosis, only one of her five grown children was able to cope with the realities of their mother’s situation. The mother, in her 60s, had long been accustomed to living self-sufficiently. She had always served as an emotional support for her children while she kept her own problems to herself. Now the roles were reversed. It was the mother who needed help while the children were called upon to take care of her. It proved to be impossible for most members of the family to adjust to the new situation. Fortunately, one daughter was able to take over the caregiving responsibilities. She left her job in another city and moved in with her mother, becoming the primary caregiver throughout the course of the illness. This family, however, never did resolve its conflicts, and after their mother died, there remained a legacy of hard feelings among the children. When there are deeply imbedded problems in a family preceding the onset of illness, there aren’t necessarily timely ways to resolve them. In these cases, family counseling undertaken as early as possible after the diagnosis can be very beneficial.

Telling teenagers and younger children about the illness

For teenage and younger, dependent, children there are other considerations. How does one introduce the potentially traumatizing information that a parent has a terminal illness? In one case, a father, in his 40s had to tell his teenage sons about their mother’s diagnosis. He put it this way: “Your mother is very sick and currently there is no cure.” By using the word “currently” he left room for hope while accurately describing the situation. There is a delicate balance between openness and honesty with children and telling them more than they can handle at one time. In this family, neither of the high-school-aged sons ever talked to their mother about her illness, nor did she want to talk directly to them about it. So all of the communication with both sons relating to her condition was conducted through their father, who did the best he could to maintain a sense of normalcy for them. Later, the father discovered that the older son had supplemented his knowledge of the disease through research on the internet.

When PALS do find that they are able to talk to their children about their illness, they reduce the sense of isolation both for themselves and their children. Having shared feelings of fear, anxiety and sadness, it becomes possible to share those of love and concern as well. And, perhaps most important, it clears the air for normal conversations about the matters of everyday life.

There are a number of factors to be considered in explaining the situation to children. As we have said before, all families are unique. Each has its own customs and patterns of communication. Yet, there are some basic principles that apply to all families with dependent children of all ages. First, and most important, parents should not lie to their children. Children should be told that their parent has a serious illness called ALS. The illness should be described using language and information appropriate for the children’s ages. Second, both younger and older children need to know that it is not a communicable disease, and, third, that it is no one’s fault that their parent has contracted ALS. (Young children are apt to blame themselves when someone close to them becomes ill or dies.) Fourth, they need to
know that no matter what happens, they will continue to be cared for and, specifically, by whom. Fifth, they should be encouraged to ask any questions whenever they occur to them. Keeping open a free-flowing dialogue will help both children and parents deal constructively with their emotions.

By the time parents have told the children about the illness, the children usually already know that there is a problem. So, there will be a measure of relief just in bringing the facts into the open. Yet, while relieved to have an opportunity to discuss what has been going on, the children now have to take in the knowledge that one of their parents has a serious progressive illness.

Most likely, the parents will not really know at first what the impact of the news is upon their children. Children have their own ways of processing disturbing information. While some react with an open expression of their feelings, others may seem to be indifferent. Another group, who seem to be handling it well enough on the surface, make their anxiety known in less direct ways, such as troubled sleep, untypical school behavior or compromised academic performance. Maintaining a dialogue, even though it may seem unrewarding at the time, is important to help children better cope with the new realities in their life. Children need an opportunity to tell you what they are feeling. You may think you know what it is, but they may be feeling something quite different. Further, the process of telling you about their feelings, whatever they may be, is valuable to them. Even though you are having your own fears and grief to deal with, taking time to let the children talk about their fears and feelings will be well rewarded in the long run.

In addition to verbal communication, it is important to attend to the ways that children reveal their concerns through play and other nonverbal activities. Many families find it helpful to consult with a counselor who specializes in children’s grief and who is trained to translate children’s nonverbal communication for parents. Just as it can be beneficial for PALS and their caregivers to share their feelings in a support group or with a counselor, children can benefit greatly from consultations with a person outside the family who understands their feelings and concerns.

Speaking to children about their parent’s illness for the first time opens the door for further discussion as time and issues change. Children will need help periodically to deal with their feelings as new stages in the process reveal themselves. In fact, they will continue to try to make sense of this important event for the rest of their lives, and will need repeated invitations and permission to discuss their emerging feelings.

While we have limited space here to deal with the specifics of the different ways of speaking with children of different ages, there are a number of books that offer guidance in much greater detail. An excellent one is How to Help Children Through a Parent’s Serious Illness, by Kathleen McCue. It is published by St. Martins Press in New York.

**Telling other family members, employers, fellow workers, friends and neighbors**

While sharing information about the disease with members of the immediate household is itself a challenge, informing those outside the inner circle poses a different kind of trial. For some, there is the question of telling parents— who may be quite elderly— about the illness. Our suggestion about such decisions is that they be approached more or less with the same philosophy as telling children – each according to his or her own ability to grasp the situation. PALS and caregivers can enlist others whom they trust to pass along the word to more distant family members and friends in order to spare themselves this time-consuming and emotionally wearing task.

PALS also at times have good reasons to be reluctant let certain people know. A major reason may be to protect themselves from having to deal with the response. PALS may suspect that certain people will say things that will hurt them, implying, for example, that getting the disease was their own fault.
“I was always afraid something like this would happen if you didn’t stop smoking, (or exercising so much, eating so much fat, working so hard, etc.).” They also may feel reluctant to tell those who are likely to give unwelcome advice or whose own needs to be comforted will put an additional burden on the PALS.

Decisions about telling people at work can be more consequential. A great deal depends on how much job security exists in one’s workplace and how the initial symptoms relate to the type of work one is doing. Responses from our survey illustrate the dilemma. When PALS are self-employed or work under conditions in which their income is not guaranteed, the best approach may be different from an employment situation protected by government, company policy or a labor union. Those in the military, in particular, told us that they found their workplace very supportive when they disclosed the diagnosis, both in being allowed to work as long as possible and in receiving disability status later.

Since most people know little or nothing about ALS, or may be misinformed, it is important to reassure people in the workplace that the disease is not communicable and to explain the extent, if any, to which the PALS’ functioning on the job will be affected initially. Sometimes it is possible for the PALS to work at home or to be transferred to a job that can be accomplished effectively despite the current level of disability.

One PALS pointed out that she didn’t want people in her work situation to find out about the illness because, as an insurance agent, she felt that she would lose clients before it was necessary to stop working. On the other hand, another observed that “Since I did not explain my symptoms to people I work with, some jumped to the conclusion that I was drinking. Once I was able to convince myself that I (1) had the disease and (2) should tell others, it became easier. I found that it was OK to be handicapped.”

Some PALS have found it easier to talk of their feelings about life and death to friends who have no direct stake in their survival. As one man put it, “I have a close friend who lives day to day due to a serious heart condition. We can get deep into the subject.”

PALS and their caregivers have discovered that friends and neighbors can become highly supportive and an excellent resource when they know what is going on and have been given some guidance about the kind of help that is needed. In later phases of the illness, when it is difficult to get around, having visitors is an important diversion and reassurance that the PALS is not forgotten. Most PALS told us that they have found that talking to friends has been an important part of their support system. This doesn’t necessarily happen without taking initiatives. A PALS noted, as many others might, that “Since I have trouble speaking and getting around, I found it very easy to become a hermit. I have to force myself to interact with others.”

On the other hand, a number of people have pointed out that this illness can test one’s friendships. Some friends who have been important at various times and in various contexts find the illness too distressing, and drop out of the picture. PALS may feel the loss intensely. “You find out who your friends are very quickly,” one PALS said. “Some never spoke to me again. Or they will not touch you because they think it’s contagious.” Others faithfully visit and provide assistance in a variety of ways. And still others, who may not have been so close before, turn out to be good friends, indeed, in this situation.

In one community, a network was established where volunteers organized themselves to bring meals, shop, drive the patient to medical and other appointments, and do other errands in order to relieve the family of overwhelming burdens. Friends and neighbors also can help by reading to PALS when they no longer turn pages. One PALS, who both loved being surrounded by friends and relatives and was an avid sports fan, found that inviting people to watch televised sports events provided an unstressful way for him to have visitors in a manner that made it pleasurable for the visitors as well. It minimized the kind of awkward conversations common in making “sick calls”. Arrangements like this don’t usually just happen by chance. The PALS, the caregiver or someone in or close to the family has to be suffi-
ciently discerning to distinguish between those offers of help that are casual and those that are serious, and sufficiently enterprising to turn the serious offers of help into a useful support system. Other important elements of the support system include ALS support groups both for patients and their caregivers, which can be extremely valuable in providing information and sharing experiences; religious institutions and clergy; and individual and family counseling.

At some point during the Early Phase, PALS and those close to them inevitably will have the thought that a quick death might be preferable to the natural course of this disease. Some, perhaps many, PALS contemplate suicide at this time, though they may never mention it. A number of factors play a part in such thoughts – among them uncertainty about the quality of life that lies ahead, the fear of being helpless and dependent, and concerns about being a burden to others or of being abandoned. Early-Phase suicidal thoughts reflect a belief that life with ALS will be unbearable for themselves and others. Yet, those who negotiate these dark days often find that they can establish a high-quality existence for a long period of time. The relationships among family members, which previously were taken for granted, can be enriched in the shared struggle. When suicidal thoughts become a preoccupation, however, this represents a crisis and it is advisable then to seek mental health counseling with someone familiar with ALS. Many PALS -- and their caregivers as well -- find they are helped through this crisis with antidepressant medication.

“Words are, of course, the most powerful drug used by mankind.”
~Rudyard Kipling

ALS is a family matter
II. The Middle Phase—a period of adaptation

The “Middle Phase” is the longest period of the illness. It can range from a few months to decades. At the beginning of the Middle Phase, the physical condition of PALS may not be much changed from the period just after diagnosis. Emotionally, however, they have moved beyond their initial shock and confusion. They are winding up the tasks of the Early Phase. They have told those who need to know about their condition, considered the financial ramifications, applied for benefits and addressed the legal tasks. It is at this time that PALS find themselves coming to terms with the inevitable progression of the disease. They are dealing with such issues as:

How do I remain an independent person when I need so much help?
Who will take care of me when I can no longer take care of myself?
Will my caregivers come to hate me because I have so many needs?
Will people think less of my intelligence as I lose my ability to speak?
Will I be able to maintain my sexual performance? Will I want to?
Will I feel humiliated when I no longer can take care of my own physical needs? And how will my caregiver feel about that?
Will anyone still love me by the time this is over?

Caregivers are dealing with parallel issues:

Will I be able to do whatever I have to do to see this through?
How much of what I’m really feeling can I share with my PALS?
Where can I get support for myself?
Will friends and family abandon us before this is over?
What will my life be like afterward?

At the beginning of the Middle Phase, many of the issues of daily life are determined by the type of disease onset. Those whose symptoms began in their legs or arms are dealing with the ways in which those weaknesses interfere with their physical activity. Those with bulbar onset are concerned with impairment in speaking, breathing and swallowing. As the Middle Phase continues, people notice progressive weakness and paralysis in new areas, and, finally, in most parts of their bodies. Tiredness is experienced by everyone, including caregivers. Significant emotional pain and, sometimes, depression are experienced by many patients, caregivers and other members of the family.

Here is an excerpt from a letter written by an ALS patient to his wife that reflects on his experience toward the end of the Middle Phase:

“I have mentioned to you that a fatal illness brings much hurt. Of course there is the prospect of an untimely death, ruined plans, and a career cut short. There is the knowledge that one’s loved ones will also suffer, as you have. With PALS it’s also the paralysis, the awful dead muscles, the need for assistance to even wiggle a finger. With these there is no help. Nothing humanly possible could be done to prevent the hurt. ALS builds a wall, or at least the foundation for one, between lovers.”

Negotiating the tasks of the Middle Phase requires tremendous emotional flexibility and adaptation to an ever-changing situation. ALS families are caught in the quandary of wanting to preserve as much normalcy in their daily lives as possible and, at the same time, planning for a future that may be radically different. Household renovations to accommodate wheel chairs and lifts, one-floor living, and the like, frequently must be undertaken even though they are disruptive and a constant reminder of the
progression of the disease. PALS and their families must be mindful that they might become so absorbed in the practical difficulties of living that some basic human emotional needs may be neglected. An essential Middle Phase task is to achieve a balance between preserving independence and acknowledging and dealing with increasing dependency.

**Independence and Dependency**

Family tensions around dependency are inevitable. Couples, especially those who have been together a long time, have a relationship based on how they share and divide responsibilities. They take care of themselves and each other according to patterns already developed over the years. Now everything is topsy-turvy. Whether or not the partners want things to change, change is forced upon them. While they may agree on many things, each will have a different perspective on the situation. The patient usually wants to retain his or her functioning as long as possible. The partner, who is now becoming a caregiver, may be desperate to find a sense of order in the household. It is often easier and more expedient for the caregiver, who is now suffering fatigue and frustration, to take over physical tasks rather than watch as the PALS struggles. But, from the PALS’ perspective, it may be just as important to continue to perform some tasks, despite the struggle. As one PALS put it: “I fight each day to stay the same as the day before.” For the PALS each time a function given up, it may feel like a further step toward immobility, total dependency and, ultimately, death.

In the tension between independence and dependency, important issues may arise about such matters as who will manage the family finances, whether caregiving will be shared by various persons, whether and what kind of assistive devices will be used, and whether to make alterations to the home or move elsewhere. But no problem is more fraught with anxiety than the question of physical safety.

Often PALS are the last to acknowledge that it is no longer safe or possible to drive, walk unaided, or even to eat without the risk of choking.

Driving is the classic example of family conflict about safety. Giving up driving signifies a major loss of personal freedom and makes one dependent on others for a wide range of daily activities. Even though it will prove to be more inconvenient for themselves, other members of the family frequently want the patient to stop driving before he or she is willing to do so.

As falls increasingly become a risk, caregivers worry about the consequences of a serious one. But for PALS, a cane, walker or wheel chair, which would provide more stability, is another signifier of the progression of the disease.

With respect to eating, families may wait anxiously while they watch their loved one lose weight or suffer bouts of choking before they agree to have feeding tubes placed. Meanwhile, doctors recommend that the feeding tube be inserted before it is actually needed to avoid weight loss and post-operative complications. In fact, it is wise to anticipate the need for the whole range of assistive devices because PALS can then have time to learn the technology and to practice with them to avoid a gap between the time the device is needed and the PALS’ ability to use it. One can think of these devices as signs of dependency or, conversely, as attempts to preserve independence.

One PALS’ point of view about dependency was poignantly described in this communication: “As my weakness increased I needed more and more assistance. Though I was fortunate to have a wife who cared, children who came to be with me as often as possible and, later, health aides present most of the hours of the
day, it became very frustrating for all of us. One learns early to wash one’s face, comb one’s hair, and brush one’s teeth. Try sometime to have another person, no matter how well-meaning, perform these and other personal chores. They can’t know just where your face gets greasy, in which end of which drawer holds your favorite shirt, or how hard to squeeze which nostril to blow your nose. Multiply these examples by dozens with new ones added each day and you may get some idea.”

Speech problems

Losing comprehensible speech is, for most PALS, the hardest insult. One who relied on communication for her livelihood, declared to her husband: “I can live with any part of this disease and even accept that I will die from it, but the one part I can’t tolerate is the loss of my ability to speak.”

For some PALS, the disease begins with changes in the area of speech. For others, speech remains intact for a long time. At first, the loss in muscle strength may distort pronunciation. Later, it becomes very difficult for PALS to make themselves understood.

Just as with safety issues, it is often the PALS who are the last to know that their speech is incomprehensible to most people. Although the caregiver may understand what is being said, and, partly because of that, PALS believe others do as well. Because speech declines in small increments and because it is so terrible to think of being unable to speak at all, families tend to put off the acquisition of an assistive speaking device. As with the feeding tube, it is best to acquire a device long before it is actually needed for communication since the PALS will need time to learn how to use it. Also, there are different types of devices, according to the particular need and disability of the patient. The ALS Association can make referrals for an evaluation to determine the best device for a particular PALS.

Even with an assistive device, communication may become severely impaired. The frustration level for PALS, caregivers, other family members and visitors rises dramatically. One PALS reported that he finds it extremely annoying when people look over his shoulder to grasp what he is typing out before the machine speaks out the words. Another finds that he becomes irritable when people are impatient with the slow pace of his communications and finish sentences for him. He doesn’t mind repeating what he says, however, when others can’t understand. The irritation works both ways, of course. Caregivers can become irritable when they are trying to help and are unable to interpret what is being said. When these patterns can be identified and communicated, caregivers and PALS can reduce the level of friction between them.

One couple found that establishing routines and rituals provided reassurance to them throughout the course of the illness. It also served to simplify communication when the spoken word was no longer possible. Earlier in the course of the disease, they established a bedtime ritual. The husband, who was the PALS said, “Good night, my dear. I love you very much and thank you for what you do for me.” His wife told us that “later, he would say or indicate the same words in abbreviated ways, like grunting it out, so that I knew it was what he meant. Now that he’s gone, remembering that, as well as certain ways he looked me in the eyes, gives me so much comfort,” she said. “We communicated by eye contact. I could see that he had love and admiration for me. It was very beautiful.”

As the disease progresses, enormous effort required to speak or type out the words, and PALS’ communications become increasingly abbreviated. A caregiver advised others to “Communicate early. Discuss as much as you can as early as possible. The loss of speech is such a gradual thing that you don’t notice it and then all of a sudden it’s gone and the opportunity is lost.”

Sometimes the messages are simply brief, but sometimes they are brief and witty as well. It is difficult to know where, amidst all this tragedy, a sense of humor can emerge, but blessedly, it often does.
Questions of intimacy and isolation

As time passes, couples may find it difficult to maintain loving physical contact, including their sexuality. And, often, this happens for reasons other than the very real physical limitations that have developed. Both members of the couple are anxious, tired, fearful, and become so preoccupied with physical care that loving touch gets lost.

Loving touch, which can be sexual or nonsexual, grows in importance for PALS as physical mobility declines. As distinguished from general physical care, like bathing or dressing, the focus of loving touch is on providing comfort and pleasure rather than accomplishing a task. It is especially meaningful to PALS who, while they become increasingly deprived of movement, have no reduction in sensation. The ordinary ways in which we are touched by others -- as in a simple handshake or just brushing against someone -- and the ways we routinely touch ourselves in the course of daily activities -- as in washing our hands or scratching our heads -- occur less and less often as mobility declines. Therefore, PALS often become increasingly deprived of all tactile stimulation. But loving touch, especially, tends to be sacrificed because there are so many practical tasks that have to be done every day.

Loving touch can take many forms – from a hug, stroking, or giving a hand massage to a full-body massage. Caregivers and family members can do much to reduce the deprivation of sensory pleasure by taking time to provide physical contact that the PALS finds enjoyable or comforting. Since each of us has different reactions to being touched, it is important to find out from each PALS what his or her preferences are. Some PALS dislike being touched or stroked by people other than those they know and trust, while others may derive additional comfort from the services of a professional massage therapist who understands the needs of ALS patients.

We cannot leave this subject without noting the parallel effects of the loss of loving touch on a spouse or partner of a PALS. In the words of one spouse: “I can put my arms around him, and be close in that way, but I greatly miss the pleasure and comfort I used to get when he could do the same for me, and I have much need to be held and comforted these days.”

Sexuality

It is useful to make a distinction between loving touch and sexuality. Both are important in an emotionally healthy life, and, indeed they are often intertwined. While ALS, as it progresses, may interfere with the usual forms of sexual activity, couples can develop their own ways of enjoying sexual contact. Sexual contact can continue until the end of life although its form, by necessity, may undergo much change.

When ALS occurs early in adult life, sexuality is not only an issue of desire and pleasure, but also one of parenthood. Couples have to consider the consequences of pregnancy. For many, it would be yet another burden. But there are those who make the opposite decision. One couple, for example, were in their 30’s and only recently married when the husband’s first symptoms appeared. They were sexually active for a long time over the five-year course of his illness and produced two children. In an interview after his death, his wife said:

“We decided not to let the disease take over. This was especially true about having children. We decided not to use contraception and let whatever happened happen. When people were surprised about my pregnancies, he used to joke that the illness doesn’t affect the penis.”
Later in the course of the disease, when he had less energy, they established a routine of cuddling in bed after she prepared him for the night. This couple and others have found that an investment in a large-sized bed with separate motor controls, though expensive, greatly improved their ability to remain intimate until his death.

Others in our survey have reported a loss of interest in sex, which may be a result of physical discomfort, tiredness and depression, or it may occur as a side effect of medication taken for depression. Many PALS and their partners have found that antidepressant medications help them to cope with the emotional impact of ALS even though a side effect of antidepressants can be a reduced sexual interest and response. When couples can communicate candidly about what is happening in their sexual relationship, it may relieve much misunderstanding about the reasons for changes that have occurred. With imagination and creativity, they may then be able to find new ways to share intimacy.

**Personal care and toileting**

Another area that PALS and their partners find difficult to discuss is personal care. Perhaps the most delicate subject of all is the need to have someone else perform our usually-private toileting functions. At some stage in the course of the illness, patients will be unable to get to the bathroom themselves and, once there, unable to wipe themselves. One widower of a PALS pointed out that as his wife became unable to do so, he learned to put on her makeup and dress her. She accepted his help in these activities without much problem, but it was much harder for her to allow him to take care of her toileting needs. He said that as much as she wanted to live, she found this aspect of her life humiliating and unbearable. A widow of another PALS said that her husband had taught her a special way to fold the paper so that he could use it himself. Often caregivers are less upset about giving this kind of care than PALS are about receiving it. One caregiver told us that she never minded bathing or toileting, but hated feeding. She asked other members of the family to do as much feeding as possible.

**The emotional states of PALS and their caregivers**

Neurological damage contributes to the moods and emotional states of PALS. They may surprise themselves and others by bursting into uncontrollable tears or laughter without warning. These episodes, which have a neurological origin, however, are only a small part of the emotional side of the disease. PALS find themselves anxious, depressed, irritable, fearful about helplessness, fearful about the future, fearful of suffering and of dying, and concerned about wearing out their helpers. As the Middle Phase progresses, and they become more immobilized, PALS also may begin to suffer from a psychological regression. Because the disease causes them to be as physically helpless as they were in infancy, and because they are being handled in the ways they were handled as infants, their emotional state and behavior may at times seem to be similar to those of that early stage of life. One caregiver described this as an “illness mentality” in which her husband thought that he only would have to ask for something and his need would be met. “He lost track,” she said, “of the fact that other family members were suffering too.”

Caregivers, although not susceptible to the neurological symptoms or the regression, are subject to many of the same emotions as PALS. Yet they are expected to be managers and nurturers regardless of their feelings. As one caregiver reported when members of a support group praised her competence and composure, “What you don’t see is that I’ve cried every day for six months.”

When relationships have been less than ideal, other kinds of thoughts may prevail. For PALS it may be frightening to be dependent on a person who has been undependable or indifferent or insensitive in the past. On the other hand, when the caregiver perceives the PALS as having been indifferent or hurtful, it becomes most difficult to be a generous caregiver. Caregiving may then become a hateful task.

Most relationships lie somewhere between the ideal -- where communication is free-flowing and everyone has good will toward one another -- and the dysfunctional, where there is little ability, desire or
attempt to understand one another. For most families, there are topics that are never discussed. There are thoughts and emotions that are suppressed in various ways, consciously and unconsciously. Sometimes they erupt unexpectedly and sometimes they appear in disguise, so that the real issue remains hidden. Sometimes the complex emotions among those living with illness can present more problems than dealing with the physical aspects of the illness itself.

In the face of emotional pain, we have been blessed with an armory of defenses that can keep us going. One of the most valuable—and sometimes also one of the most destructive—is denial. Because of the ability to deny the reality of a situation, we can do the things we have to do without collapsing. Here is an excerpt from a letter sent by a wife to her PALS husband late in the course of the illness:

“Since you came down with ALS I have practiced a couple of rituals of denial. One, I refused to buy clothes for funeral services. Two, I refused to look at the financial picture when your salary was no longer there. I know I was/am being an ostrich, but by not doing those things, I feel like I am putting off the inevitable.”

Valuable as it is for day-to-day coping, there is both an emotional and physical price to pay for denial. The thought or feeling that is denied often remains unconsciously buried within us. Sometimes it affects our moods or even our physical health. We may get sick or have accidents. Other times the denied feeling emerges in a disguised form. There may be lapses in caregiving, anger or blame directed at innocent others, impulsive decision-making, unnecessary worrying about the health or safety of others, and the like.

Another subtle manifestation of buried pain, guilt or anger is emotional withdrawal. Either the patient or the caregiver can initiate a process of withdrawal. It happens little by little. One PALS has referred to it as putting bricks, one by one, into a wall. Sometimes it occurs because the thoughts either party is having seem to be too cruel to verbalize. “I’m so tired of having to meet your every need that I’m beginning to hate you!” Or “I’m the one who is helpless and you can’t take the time to see that my body is in a comfortable position!” Or “I’m sick of everyone thinking you’re a saint while I’ve given up my life to take care of you!” And, ultimately, “I wish this were over.”

What can be done to alleviate the damage done by buried emotions?

Sometimes, it is possible, in a moment of calm—not in the heat of the moment—to have a conversation about the deepest of these feelings, many of which, surprisingly, are shared by patient and caregiver. Often unspoken is the fear of death—PALS aren’t the only ones who fear death; everyone in contact with them is reminded that we all must die sooner or later. Another is the fear of abandonment—both on the part of PALS and those who will survive them; PALS can be terrified that those whom they need most will cease to care for them, leaving them helpless and dependent on strangers; caregivers and others who may have been dependent on the patient may feel abandoned as the PALS lose their capacity to function, and, of course, fear the ultimate abandonment that their death will bring. Another is the fear of physical suffering. Both PALS and family members dread the possibility that the PALS will suffer during the end phase.

Support groups and individual or family counseling may provide safe places to explore these fears before they become too destructive. When they can be discussed, a way can be opened for families to acknowledge other deep feelings that have gone underground along with the dreaded topics. Each fear implies its opposite—appreciation of how much the PALS have meant and still mean to their families and the appreciation of how much the continued love and support mean to everyone.
It may help to have a discussion of the extent to which the primary caregiver can do without assistance or respite. As the Middle Phase progresses, caregivers are called upon to do more and more and to give up more and more of the activities that they previously enjoyed. Sometimes it is possible to improve the quality of the relationship and of the care as well by finding others to share in caregiving.

**Considering One’s Life, Death and Survivors**

Although the deepest thoughts in the minds of many PALS and their families remain unspoken, some do manage to communicate to loved ones what they are thinking and some have shared those thoughts with us. One PALS in Middle Phase put it this way:

“At my age of 65, I could have expected to live 15 or 20 years longer, and I was looking forward to (1) enjoying travel with my wife to the places on our life list of locations we wanted to visit and experiences we hoped to share; (2) spending time with our friends and siblings; (3) watching our children and grandchildren advance and grow up; (4) developing businesses out of some of the hobbies I have pursued over the years (collecting rare books and prints and stamps and coins). ALS threatens to cheat me and my wife out of what would have been many pleasant and enriching retirement years. On the other hand I have had many rewarding experiences — ‘a good ride’ if you will. My heart goes out to those who contract this disease at a young age and are cheated out of much more than I.

“The hardest thing for me”, he continued, “has been convincing my wife of 25 years (age 59) that she will have a good life and hopefully find another life partner after I am gone. She is a sensitive and loving partner and a wonderful caregiver. She is very depressed about my situation and is neglecting her own health.”

Whether able or not to communicate with family members about such things, a great many PALS and family members seek comfort and guidance from clergy and get support from their religious institutions. Often, PALS, whether or not they were previously observant, have asked to confer with the clergy about their spiritual concerns.

**Having Fun, Participating in Community Life, and Virtual Reality**

Remembering that the point of the struggle with all these issues is to maintain an acceptable quality of life, PALS and their families find many ways to enjoy this time. One PALS, an avid sports fan and bridge player was able to do both until the last days of his life. Other families have fitted out vans for the PALS’ motorized wheel chairs and obtained portable lifts and other mechanical aids so that they could do some traveling. This, of course, takes a lot of planning, but those who have undertaken such trips speak highly of the adventure.

On a simpler level, getting out to movies, plays, concerts and sports events, and engaging in community activities, can play an important role in keeping family members’ spirits high. One couple who couldn’t afford to buy a handicapped-equipped van rented one on special occasions for family outings.

We have talked about family time a good deal, but personal time for both PALS and their caregivers is an important aspect of maintaining morale during the Middle Phase. Retired PALS have developed activities that they enjoyed as hobbies during their working years into business enterprises or have taken up political advocacy. One, for example, has converted his interest in rare books and prints, stamps and coins into an online business. Another has become an online authority on the politics of stem-cell research. Quite a few have engaged in ALS advocacy.

The internet has provided a valuable medium for contact with the world for many PALS who are otherwise isolated by their physical disabilities. They acquire a new set of on-line friendships -- many of them with other PALS. They are in touch with current events and with much information that would
otherwise be difficult to acquire. On-line shopping takes the place of going to the mall.

Caregivers find themselves giving up more and more of their own personal activities as the Middle Phase progresses. This is particularly true for activities outside the home. However, when they succeed in getting enough help to preserve some of their own activities on a regular basis, they find themselves less stressed, irritable and resentful. They, of course, may have to put up with the PALS’ resentment when they go off on their own for a while.

“COMMUNICATION
LEADS TO
COMMUNITY, THAT
IS, TO
UNDERSTANDING,
INTIMACY AND
MUTUAL VALUING.”
~ROLLO MAY
III. The Late Phase

Sometimes the transition from the Middle Phase to the Late Phase is seamless. The changes each day may be imperceptible and the preoccupations with daily care so absorbing that it is not noticed that there has been a transition in which the PALS has lost most functioning and is now having trouble simply staying alive.

In the Late Phase, caregivers feel they can no longer be apart from PALS for more than a few minutes due to their increasing care needs. At this stage, depending on the circumstances, choices have to be made about how to render the best care while maintaining the health and well-being of caregivers. An important service of which many people are unaware is that provided by hospice. Hospice workers can bring various health care professionals into the home to administer a variety of treatments designed to make the PALS more comfortable. This is called palliative care. The usual requirement for hospice service is certification that a patient has a life expectancy of six months or less and that aggressive treatment of all kinds will be terminated. This requirement is not usually observed rigidly, however, since life expectancy is so hard to predict. Home visits are made by doctors, nurses, social workers, home health aides and, often, other special service professionals like physical therapists, speech therapists, dieticians and chaplains. Some hospices also provide help with financial paperwork and other practical concerns. Hospice costs are covered by Medicare, for which all ALS patients are eligible.

At times, even with such help, caregivers can no longer provide what PALS need at home. They may then have to consider a nursing home or residential hospice, where the burden of caring is shared by many, and medications and equipment are readily available. This move is often a painful choice for PALS and caregivers and one on which they may disagree.

We spoke earlier of a family in which the mother of two teenage boys was the patient. After several years with the disease, the family reached a point at which the demands of the illness became overwhelming. The husband, who had diabetes, knew that stress could put him into a diabetic coma. This would prevent him from caring for either his wife or children as well as himself. He, his wife and his sons also were becoming increasingly upset about choking episodes. More and more often, the family and a part-time home health aide were having to suction her and were finding the procedure frightening. They talked about moving her to a residential hospice nearby, but she was reluctant to go because she imagined it would resemble the state mental hospital in which her mother had been confined years before. Since she could not easily visit the hospice to inspect it herself, her husband and one son made the visit, using a video camera to film the facility and interviews of members of the staff. After seeing the film, she agreed to a trial period in the hospice. She lived her final seven weeks there, attended by her family, the hospice staff and, by special arrangement, the home health care aide who had previously tended her. Both she and her family felt grateful to be able to spend much of these final weeks together in a setting where they were relieved of constant anxiety that the suctioning would not be done properly. Although the members of this family found many issues difficult to handle, they were able to communicate well enough and creatively enough so that they could find solutions that benefited everyone.

For some, death comes unexpectedly. The family is surprised that it happened so soon. For others there is a long period of anticipation. The focus on death in the Late Phase has a different quality from that of the Early Phase. In the Late Phase, both PALS and caregivers may find themselves in a state of conflict between the wish for life to continue and for the struggle to be over — or between the fear of death and the fear of suffering. Decisions made earlier about life support devices and “do-not-resuscitate” orders take on new meaning and might be revisited.
Questions of discontinuing the use of ventilators, feeding tubes and assistive breathing devices, like bi-paps, have a moral or religious dimension for many people. PALS and their families, even those who are not particularly observant, have found it helpful to consult clergy to discuss these concerns. A husband told us that his wife, who had not previously been active in any religion, met with chaplains from several different faiths to enhance her own understanding of the moral issues as she approached her final weeks.

Since most PALS in the last days of their lives are quite helpless and many are unable to communicate without extraordinary effort, the burden of implementing these decisions lies with the survivors. Although any death has a tendency to induce guilt feelings about whatever decisions are made, that burden is lightened when the PALS’ wishes have been discussed and the family is in agreement with them. This, of course, is not always the case. When family members have not discussed the PALS’ wishes and there are disagreements, emotional wounds can be created that may be difficult to heal.

On another level, PALS sometimes forget that the choice to go on living or to allow themselves to die is not an issue for themselves alone. For those who love them, how and when they die may be extremely meaningful. Here are excerpts from one PALS letter to his wife and one that she wrote, later, to a counselor who was helping them navigate the course of ALS. The PALS was on a ventilator which he periodically considered having turned off.

“I think that it is time for me to go. The physical problems continue to grow and I see others looming in the future....A life should, I wish to think, be made of dignity. One should feel selfworth, not selfworthless. I have had all of my feelings of worth taken away. From spending three hours hanging from the sling this morning, legs and feet asleep, having four enemas while waiting unsuccessfully for some response, to being unable to complete sentences in conversation without someone trying to finish it for me, I am in a situation that asks for discontinuance.”

And his wife’s response: “I was devastated to learn that he is thinking about ending his life this month. It is true that his quality of life is declining, partly because of pain and the indignity of having nurses care for him and partly because his mental attitude has shifted to perceiving the glass as half-empty rather than half full. Yet there are still lots of times when he seems to be enjoying life. He still laughs, makes jokes, smiles when friends visit, enjoys a pretty day, works, writes to email friends, has a full range of emotions, and generally doesn’t look like someone who has had enough.

I want to support him if this is what he really wants even though I crumble inside at the thought of life without him. I know that I once thought that I was ready for him to die, but as the reality comes closer, I’m not so sure that it is possible to be ready....I have asked him to put ‘the end’ off until next year. All the children and their spouses and possibly some grandchildren are planning to come here for his 65th birthday in early November. Most will be here for a long weekend and his daughter will be here for a couple of weeks. We haven’t had all the kids together for years and I thought it would be enjoyable for him as well as giving everybody closure. I have also asked him to honor my request to celebrate our 25th anniversary in December and to have one last Christmas together. If he still feels the same after that, I promised him that I would not ask him to delay again.”

Although this PALS continued to suffer bouts of despair, he did not die for another year.

During the Middle or Late Phases, some PALS find it meaningful to plan their own funerals or memorial services. Like writing a memoir, it is a way of bringing together the many dimensions of one’s life. Envisioning the setting, choosing the speakers, planning whether selections of music and poetry will be included and what they will be, are ways that a PALS can transcend, in a way, his or her own death.
Saying goodbye

Several couples in an ALS support group were talking about how important it was to be able to discuss their beliefs about death and their wishes about their own deaths with their partners. One couple related a story of the regret felt by the children of a friend because their father had died without ever having talked to them about his feelings about death because the topic of his death was thought to be off limits. They especially regretted that they were unable to say goodbye or tell him how much they loved him. With ALS, such a discussion may have to come at an earlier time than with other illnesses, when PALS can communicate with less effort. But when it is too late for a mutual discussion because speech is lost, families can remember that their PALS can still understand expressions of caring from them in words, gesture and touch. And perhaps, if they have laid the groundwork with previous routines and rituals, their PALS can respond with a meaningful look.

“We are healed of a suffering only by expressing it to the full.”

~Marcel Proust

In the end, when thinking about emotions, it is difficult to know who is the giver and who is the receiver of care. Those who serve officially as caregivers need as much emotional nurturance and support as their patients. And PALS often are just as concerned about protecting their caregivers and family members from the inevitable emotional damage that the disease has inflicted on them. We hope that we have been able to illuminate the feelings and thoughts of all those involved and make it easier in some measure to cope with the tragedy that is ALS.
Suggestions for further reading

Ciechoski, Marlene A. *Living with ALS: Coping with Change*. 2005. ALS Association


National Institutes of Health. *When Someone You Love Has Advanced Cancer*. An excellent free booklet which, although about cancer, has much advice that can be applied to ALS. Available through the National Cancer Institute, call 1-800-422-6237.


The mission of the ALS Association— DC/MD/VA Chapter is to improve the quality of life for people living with ALS (PALS) in the District of Columbia, Maryland, and Virginia while raising public awareness and support for finding a cure.

www.ALSinfo.org