

Approaching End of Life in ALS



LIVING WITH ALS
RESOURCE GUIDE



APPROACHING END OF LIFE IN ALS

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A NOTE TO THE READER: The ALS Association has developed the *Living with ALS* resource guides for informational and educational purposes only. The information contained in these guides 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.



Introduction



As ALS progresses, you will have thoughts and conversations about planning for various treatments as well as planning for the later stages and end of life. Your decisions about what you want at end of life may change over time, so it's a good idea to keep revisiting them with your loved ones and health professionals so your wishes are known and respected. **This resource guide will examine thoughts and feelings about dying and the end of life instead of medical care decision making.** Advance care directives are covered in detail in the resource guide, *Living with ALS: Planning and Making Decisions*.

The following topics will be covered:

- What to expect and what death looks like
- Spiritual support
- Anticipatory grief and bereavement support for family
- Expectations and fears about the dying process and preparing for a peaceful death
- Counseling support
- Leaving a legacy

Talking About It: What to Expect

How Much Information Do You Want to Know?

Some people may not want to know what the future holds for them; others will want to know in great detail what is going to happen. In some cases, caregivers will want more information. Be clear with your doctor and other healthcare team members how much you want to know and when you are ready to learn more. They will follow your lead.

Advance Directives

Another topic that must be discussed, and early on in disease progression, is advance directives. As one provider has put it, "If you don't say what you want, something you don't want will happen." **Making early decisions regarding artificial nutrition and hydration or tracheostomy and ventilation (tube in the throat and connected to a machine which breathes for you) are essential and will direct your care if you are in an emergency situation and cannot speak for yourself.** Every ALS clinic has stories of people without advance directives who ended up ventilated and didn't want to be.

What Death Looks Like in ALS

Most deaths in ALS occur very **peacefully**.

As the disease progresses, the diaphragm, the major muscle involved in breathing, becomes weaker. Therefore, it becomes more difficult to breathe. Non invasive ventilators assist breathing, and they can be effective for very long periods of time. As the diaphragm and other muscles used for breathing continue to weaken, breathing becomes more difficult and the assistive machine needs to be used for longer periods of time.

If you find you need to use noninvasive breath support 24 hours a day, you will meet criteria for a referral to hospice services. Many people fear hospice services as the final step. **Hospice requires a prognosis of six months for admission, but most of the patients we refer as early as possible live longer than the six months**

required. Research has shown that with hospice controlling symptoms and promoting comfort and quality of life, it has the potential of extending life. How this is done will be explored later in this resource guide.

As breathing weakens, it becomes harder for patients to exhale the complete volume of carbon dioxide. The carbon dioxide begins to accumulate causing a lowered level of consciousness. At this point patients will sleep more, sometimes up to 22 hours per day. **Most patients will, at this point, die very quietly and very peacefully while sleeping.**

People's fears about suffocation, dying gasping for breath or suffering greatly just before death are unfounded.

Spiritual Support When Approaching End Of Life



We are all spiritual. The definition of spirituality is a personal quest to find meaning and purpose in life and relationship with something greater than oneself.

Many people find spiritual strength through a faith group (Christianity, Judaism, Islam, etc.). However, spirituality is not limited to a church, synagogue or mosque.

Spirituality may be found in the connections, relationships and meanings that give life passion, commitment and hope, a poetry writing group, a 12 step program,

love of nature, meditation. It can come through a personal relationship with a higher power, but it can also be tapped via contemplation, art or music.

How we tap into our inner fire or spirituality differs for each person. The importance is giving purpose to one's life. Making those connections each day can bring about meaning. Doing so can offer comfort at the end of life: a sense of connectedness and that you are not alone.

Rituals and objects bring comfort. Anointing of the sick, prayers, touchstone, mantra, reading, pictures and singing are just some examples.

Many people find solace in their faith. Praying, talking with someone from one's religious community (such as a minister, priest, rabbi, or Muslim cleric), reading religious text or listening to religious music may bring comfort.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children can share how their father has influenced the course of their lives. Grandchildren can let their grandfather know how much he has meant to them. Friends can relate how they value years of support and companionship. Family and friends who can't be present could send a recording of what they would like to say or a letter to be read out loud.

Spirituality is the deep inner essence of who we are. Related to our soul, spirituality comes from the unique qualities of each individual. It is based on personal experiences and our relationship with God, nature or a Higher Power. It answers the question, "Why am I here?"

Another spiritual need is transcendence, or a person's awareness and acknowledgement of issues that transcend, or go beyond, earthly concerns. Each person may want assurance that, in some way, life will continue after death occurs. Some people may turn to God for guidance and comfort, while others may focus on the legacy they leave behind.

Methods to connect with spirituality may include:

- Meditation
- Relaxation techniques
- Creating a legacy
- Enhancing relationships
- Turning to your priest, rabbi, minister, chaplain or religious representative for guidance

Doing a life review, such as looking at photographs, watching movies or listening to music from particular periods, will allow you to reminisce about events and relationships throughout your life. It can let you rediscover legacies, meaning and spiritual strengths.

Anticipatory Grief and Bereavement Support for Family

Anticipatory grief may occur when a death is expected. When caring for someone over time, you may start to grieve that person long before they die; we grieve the loss of the person's "former self." Experiencing loss daily, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death.

Caregivers may experience guilt or shame for "wishing it were over" or thinking of their loved one as already "gone." It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Anticipatory grief helps family members get ready emotionally for the loss. It can be a time to take care of unfinished business with the dying person, such as saying, "I love you" or "I forgive you."

Like grief that occurs after the death of a loved one, anticipatory grief involves mental, emotional, cultural and social responses. However, anticipatory grief is

different from grief that occurs after death. Symptoms of anticipatory grief include the following:

- Depression
- Feeling a greater than usual concern for the dying person
- Imagining what the loved one's death will be like
- Getting ready emotionally for what will happen after the death

Anticipatory grief may help the family, but not the dying person. Anticipatory grief helps family members cope with what is to come. For families, this period is also an opportunity to find closure. To reconcile differences. To give and grant forgiveness. For both, it is a chance to say goodbye. Though anticipatory grief doesn't necessarily make the grieving process easier, in some cases it can make death seem more natural. It's hard to let our loved ones go. Seeing them when they are weak, and failing and tired makes it maybe just a tiny bit easier to say, "It's okay for you to move on to the next place." **For the person who is dying, anticipatory grief may be too much to handle and may cause him or her to withdraw from others.**

Also, grief felt before the death will not decrease the grief felt afterwards or make it last a shorter time.

Coping with Anticipatory Grief

When experiencing anticipatory grief, there are many ways to smooth the road you are traveling. Try some of the techniques below:

- Go for short **walks** whenever possible.
- Keep a **journal**.
- **Plan** for the future.
- Seek **spiritual assistance**, if needed.
- **Talk to someone**, such as a friend, family member, clergy or Community Hospice psychosocial specialist or chaplain.
- **Make changes only as needed**, and put off major decisions when possible.

- **Do the things you want to do now.** Postpone chores that you can do later.
- **Spend time with loved ones,** friends and family.
- **Seek help** from your family, friends or a Community Hospice volunteer to arrange some time to spend doing things you enjoy.
- **Call your physician if the physical symptoms of grief become overwhelming.**
- **Join a caregiver support group** to assist you with overwhelming emotional needs.

Expectations, Fears And Requirements For The Best Possible Peaceful Death

As explained earlier, many people with ALS may fear dying because of the belief there will be suffocation, gasping for breath or major suffering throughout the dying process. These fears are most likely based on breathing becoming more difficult, the feeling of “air hunger” occurring and energy levels dropping quickly. However, a peaceful death is very possible with proper planning.

Medications

While many people fear it, the use of **morphine in low doses is very effective** in relieving most of the symptoms of shortness of breath and air hunger. There is a physical reason why morphine works so well for these symptoms. Without becoming too technical, the mechanism is this:

- In the heart are receptors for the body to determine levels of oxygen reaching the heart muscles. If the levels are too low, the body is signaled to breathe more and harder to increase the levels of oxygen.

- Morphine has the property of dilating the coronary arteries, so that more blood reaches the receptors. More blood gives more oxygen, so the body signals that it's okay to relax now since the oxygen levels are better.
- The heavy breathing and shortness of breath are relieved, as well as the anxiety caused by feeling breathless.
- Morphine is perfectly safe when used in these low doses, and addiction does not occur when used properly. Also, in such low doses, the "drugged" feeling rarely occurs.
- Morphine is given using an eyedropper and placing several drops under the tongue. No injection or IV is necessary. In the process of actively dying, more frequent doses may be necessary to maintain comfort.

Other medications for symptom control, like **atropine drops to control excess fluid in the throat and lungs, add to the comfort of the patient and caregivers** during the dying process.

Lorazepam (Ativan®), also in low doses, is most effective in **relieving anxiety and fear** during this process.

Hospice Services

It is highly recommended that you and your family accept hospice services when offered by your ALS clinical care providers. The disease is allowed to take its natural course and various medications are used for symptom management to promote the greatest level of quality of life. Comfort of both the person facing death and their caregivers is of the utmost importance to the hospice team.

A **nurse case manager** will visit at least once a week, more if needed, to check on the effectiveness of medications, add or subtract medications, adjust dosages as needed and check on the overall condition of the patient.

A **home health aide** will be available to assist with bathing, showering and the basic physical needs of the patient. This also gives caregivers a break.

A **social worker** will be available to assist with coping with the changes that are happening and any end of life planning left to be done (i.e., trusts, wills, etc.). Additionally, a **counselor** is available to help with issues relating to the human spirit, anticipatory grieving and grieving the loss of self. Bereavement services will follow the family and extended family for a year following the death. **The earlier the involvement of hospice, the more beneficial the services become.**

Counseling/Psychotherapy Approaching End Of Life

When you or a loved one must face the end of life, the world is turned upside down. Even though we know that all humans eventually die, we're never ready to find out that we or a loved one is approaching the end of life.

For some, starting a journal and writing down thoughts and stories for family and friends gives them a purpose and an opportunity to reflect on their lives and share their values with those left behind.

Numbness, disbelief, fear or anger may shake up your life. "What a shock." "Why me?" "Why now?" "Why would God do this?"

Even the most mentally healthy, fiercely independent and spiritually confident people feel some fear and disorientation when facing death.

The coping mechanisms you've counted on in the past, such as focusing on the positive, using humor, finding comfort in family, suddenly don't work as well.

A therapist/counselor can offer ideas and strategies to assist in coping with the vast amount of emotions, encourage expression

of feelings and assist with improving family relationships, logistics and problem solving. They can also work with your medical team to make sure that you are as comfortable as possible.

Leaving a Legacy

Many people take comfort at the end of life engaging in the process of leaving a legacy.

For many people, their personal effects are an important part of their lives and are expressions of who they are. Sentimental objects, pictures, books and other things that people own can create a sense of comfort and connection that can help them during a difficult time. This is especially important for those in nursing homes or hospice facilities.

Giving away possessions can also be a meaningful way to come to peace with death and connect with family and friends. If you are a loved one of the person dying, ask them if this is something they want and help them facilitate it if they do.

For some, **starting a journal** and writing down thoughts and stories for family and friends gives them a purpose and an opportunity to reflect on their lives and share their values with those left behind. **Writing cards, posting messages on social media and sharing pictures or music are some of the ways to leave a legacy** and help loved ones grieve.

Summary Statement

Approaching end of life is difficult and support is critical to help sort out feelings, expectations and plans. The goal is to feel peace in the end. Through talking with friends, family and professionals, planning and communicating your wishes and leaving a legacy can help you prepare for the best possible end of life phase and death. For those who must say good-bye and carry on, knowing their loved one experienced a comfortable, peaceful death will help them cope with their loss afterward. While end of life can be a sad time, it is also a time for strengthening relationships and bonds with those who matter most.

Resources

Websites

[Institute for Palliative and End-of-Life Care // College of Nursing // Marquette University](#)

[Coping with Grief and Understanding Grief - CaringInfo](#)

[How to Start Talking About End-of-Life Care \(aarp.org\)](#)

Books

Nolan, Steve. (2012). *Spiritual Care at the End of Life: The Chaplain as a 'Hopeful Presence'*. David B Feldman (2008) *The End of Life Handbook: A Compassionate Guide to Connecting with and Caring for a Dying Loved One.*



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About The ALS Association

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.