

LIVING WITH ALS
RESOURCE GUIDE

11



Approaching End of Life in ALS



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.

Living with ALS
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INTRODUCTION

As ALS progresses you will have thoughts and conversations along the way about planning ahead for various treatments as well as planning for the latter 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 is geared to examining thoughts and feeling about dying and end of life and not about medical care decision making.** Advance care directives are covered in detail in the resource guide, *Living With ALS: Planning and Making Decisions*.

What we will cover in this resource guide:

- What to expect and what does death look like?
- Spiritual support
- Anticipatory grief and bereavement support for family
- Expectation and fears about the dying process and making 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 want to know in great detail what is going to happen. In some cases, caregivers want more or less information than the person with ALS. Be clear with your doctor and other healthcare team members about how much you want to know and when you are ready to learn more. They will take your lead.

Advance Directives

Another topic that must be discussed, and early on in disease progression, is advance directives. As one provider put it, "If you don't say what you want, something you don't want will happen." **Making early decisions regarding options for nutrition and hydration, or tracheostomy and ventilation (tube in the windpipe connected to a breathing machine) are essential and will direct your care if you are in an emergency situation and cannot speak for yourself.** Every ALS clinic can tell 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.

Noninvasive 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.

As your respiratory function declines, you will become eligible for hospice services. Many people fear hospice services as the final step. **Hospice requires a prognosis of six months for admission, but many patients live longer than six months.** Research has shown that controlling symptoms and promoting comfort and quality of life with hospice care 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 sleep more, sometimes up to 22 hours per day. **Most patients will, at this point, die very quietly and very peacefully while sleeping.**

With good monitoring and proactive control of symptoms, 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 a relationship with something greater than oneself. Many people find spiritual strength through a faith group (Christian, Jewish, Muslim, 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 a 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 relationship with God, nature, or a Higher Power. It answers the question, "Why am I here?"

Another potential spiritual need is transcendence, or a person's awareness and acknowledgment 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, imam, or other religious representative for guidance

Doing a life review—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 the loss of that person long before they die;** we grieve the loss of the person's "former self." Experiencing loss on a daily basis, 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.

Anticipatory grief can be a big part of the ALS process from diagnosis to approaching end-of-life decisions and loss. ALS is a disease of continually diminishing capacities. This continual change is a hardship on the person living with ALS as well as on caregivers and loved ones.

Jacqueline (Jackie) Tripi Pfadt, daughter of person with ALS
(Contributed by The ALS Association Northern Ohio Chapter)

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

- 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

Note that grief felt before death will not decrease the grief felt afterward or make it last a shorter time.

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, reconcile differences, and forgive. 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, 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/her to withdraw from others.**

The anticipatory grief did not necessarily alleviate our grief as we approached end of life, but I think it helped us open up communication channels to discuss changes in caregiving needs and plan for end-of-life wishes and decisions as well as allowed us to establish support networks (e.g., hospice team relationships). These preparations were invaluable to us as we traversed the end-of-life stages and the time immediately following the loss of my mom.

Jacqueline (Jackie) Tripi Pfadt, daughter of person with ALS
(Contributed by The ALS Association Northern Ohio Chapter)

Coping with Anticipatory Grief

When experiencing anticipatory grief, there are many ways to smooth the road you are traveling.

- 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** and 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 the fact that breathing has become more difficult, the feeling of “air hunger” occurs, and energy levels drop quickly. However, a peaceful death is very possible with proper planning.

Medications

While many people fear it, the use of **morphine in appropriate 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:

- Receptors in the main blood vessels of the body (aorta and carotid arteries) 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 can suppress this drive to breathe when oxygen levels are low** (hypoxic ventilator response).
- Morphine blunts the body’s perception of the mismatch between how much a person breathes (actual ventilation) and the brain’s response to the lack of oxygen (central drive). 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 appropriate doses**, and addiction does not occur when used properly. Also, when using the lowest effective doses, the “drugged” feeling rarely occurs.
- **Morphine is given using an eyedropper, 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, such as **atropine drops to control excess fluid in the throat and lungs, add to the comfort of the individual 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 and engage 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 for both the

person facing death and his/her caregivers is of the utmost importance to the hospice team, which includes:

A **nurse case manager**, who 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 individual.

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

A **social worker**, who can assist with coping with the changes that are happening, and any end-of-life planning left to be done, such as trusts and wills. 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 FOR 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 are or a loved one is approaching the end of life.

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—focusing on the positive, using humor, and 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 and encouraging expression of feelings. They can also assist with improving family relationships, logistics, problem solving, and working with your medical team to make sure 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, or sharing pictures or music are some of the ways to leave a legacy** and help loved ones to grieve.

SUMMARY STATEMENT

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

Living for the moment. I would rather have a good time for however long instead of living in a bubble for a long time. Either way, I would not know if I would live any longer if I did it a different way.

Janet Hein (Contributed by The ALS Association Northern Ohio Chapter)

RESOURCES

Books

Handbook for Mortals: Guidance for People Facing Serious Illness (2nd Edition)

By: Joanne Lynn, Janice Lynch
Schuster, and Joan Harrold

Publisher: Oxford University Press, 2011

The End-of-Life Handbook: A Compassionate Guide to Connecting with and Caring for a Dying Loved One

By: David B. Feldman and S. Andrew Lasher, Jr.

Publisher: New Harbinger Publications, 2007

Websites

Offering Spiritual Support for Family and Friends

http://www.caringinfo.org/files/public/brochures/faith_brochure.pdf

Marquette University College of Nursing: Institute for End-of-Life Care Spirituality

<http://www.marquette.edu/nursing/end-of-life-care/spirituality.shtml>

National Cancer Institute

<https://www.cancer.gov/about-cancer/advanced-cancer/caregivers/planning/bereavement-pdq>



The following is a list of topics covered in the *Living with ALS* resource guides:

Resource Guide 1

What is ALS? An Introductory Resource Guide for Living with ALS

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

Resource Guide 2

After the ALS Diagnosis: Coping with the “New Normal”

This resource guide 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.

Resource Guide 3

Changes in Thinking and Behavior in ALS

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

Resource Guide 4

Living with ALS: Planning and Making Decisions

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

Resource Guide 5

Understanding Insurance and Benefits When You Have ALS

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

Resource Guide 6

Managing Symptoms of ALS

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.



Resource Guide 7

Functioning When Mobility is Affected by ALS

This resource guide covers the range of mobility issues that occur with ALS. It 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.

Resource Guide 8

Adjusting to Swallowing Changes and Nutritional Management in ALS

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

Resource Guide 9

Changes in Speech and Communication Solutions

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

Resource Guide 10

Adapting to Changes in Breathing When You Have ALS

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

Resource Guide 11

Approaching End of Life in ALS

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.



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About The ALS Association

The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about The ALS Association, visit our website at www.alsa.org.