What is ALS?

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. A-myotrophic comes from the Greek language. "A" means no. "Myo" refers to muscle, and "Trophic" means nourishment – "No muscle nourishment." When a muscle has no nourishment, it "atrophy"es or wastes away. "Lateral" identifies the areas in a person’s spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates, it leads to scarring or hardening ("sclerosis") in the region.

Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually leads to their demise. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, people may lose the ability to speak, eat, move and breathe. The motor nerves that are affected when you have ALS are the motor neurons that provide voluntary movements and muscle control. Examples of voluntary movements are making the effort to reach for a smart phone or step off a curb. These actions are controlled by the muscles in the arms and legs.

There are two different types of ALS, sporadic and familial. Sporadic, which is the most common form of the disease in the U.S., accounts for 90 to 95 percent of all cases. It may affect anyone, anywhere. Familial ALS (FALS) accounts for 5 to 10 percent of all cases in the U.S. Familial ALS means the disease is inherited. In those families, there is a 50% chance each offspring will inherit the gene mutation and may develop the disease. French neurologist Jean-Martin Charcot discovered the disease in 1869.
Recent years have brought a wealth of new scientific understanding regarding the physiology of this disease. There are currently four drugs approved by the U.S. FDA to treat ALS (Riluzole, Nuedexta, Radicava, and Tiglutik). Studies all over the world, many funded by The Association, are ongoing to develop more treatments and a cure for ALS. Scientists have made significant progress in learning more about this disease. In addition, people with ALS may experience a better quality of life in living with the disease by participating in support groups and attending an ALS Association Certified Treatment Center of Excellence or a Recognized Treatment Center. Such Centers provide a national standard of best-practice multidisciplinary care to help manage the symptoms of the disease and assist people living with ALS to maintain as much independence as possible for as long as possible. According to the American Academy of Neurology’s Practice Parameter Update, studies have shown that participation in a multidisciplinary ALS clinic may prolong survival and improve quality of life. To find a Center near you, visit http://www.alsa.org/community/centers-clinics/.

ALS usually strikes people between the ages of 40 and 70, and it is estimated there are at least 16,000 Americans who have the disease at any given time (although this number fluctuates). For unknown reasons, military veterans are approximately twice as likely to be diagnosed with
the disease as the general public. Notable individuals who have been diagnosed with ALS include baseball great Lou Gehrig, theoretical physicist, cosmologist and author Stephen Hawking, Hall of Fame pitcher Jim "Catfish" Hunter, Toto bassist Mike Porcaro, Senator Jacob Javits, actor David Niven, “Sesame Street” creator Jon Stone, boxing champion Ezzard Charles, NBA Hall of Fame basketball player George Yardley, golf caddie Bruce Edwards, musician Lead Belly (Huddie Ledbetter), photographer Eddie Adams, entertainer Dennis Day, jazz musician Charles Mingus, former vice president of the United States Henry A. Wallace, U.S. Army General Maxwell Taylor, and NFL football players Steve Gleason, O.J. Brigance and Tim Shaw.
Symptoms and Diagnosis

Symptoms

The initial symptoms of ALS can be quite varied in different people. One person may have trouble grasping a pen or lifting a coffee cup, while another person may experience a change in vocal pitch when speaking. ALS is typically a disease that involves a gradual onset.

The rate at which ALS progresses can be quite variable from one person to another. Although the mean survival time with ALS is three to five years, many people live five, 10 or more years. Symptoms can begin in the muscles that control speech and swallowing or in the hands, arms, legs or feet. Not all people with ALS experience the same symptoms or the same sequences or patterns of progression. However, progressive muscle weakness and paralysis are universally experienced.

Gradual onset, generally painless, progressive muscle weakness is the most common initial symptom in ALS. Other early symptoms vary but can include tripping, dropping things, abnormal fatigue of the arms and/or legs, slurred speech, muscle cramps and twitches, and/or uncontrollable periods of laughing or crying.

When the breathing muscles become affected, ultimately, people with the disease will need permanent ventilatory support to assist with breathing.

Since ALS attacks only motor neurons, the sense of sight, touch, hearing, taste and smell are not affected. For many people, muscles of the eyes and bladder are generally not affected.

Diagnosis

ALS is a difficult disease to diagnose. There is no one test or procedure to ultimately establish the diagnosis of ALS. It is through a clinical examination and series of diagnostic tests, often ruling out other diseases that mimic ALS, that a diagnosis can be established. A comprehensive diagnostic workup includes most, if not all, of the following procedures:

- Electrodiagnostic tests including electromyography (EMG) and nerve conduction velocity (NCV)
- Blood and urine studies including high resolution serum protein electrophoresis, thyroid and parathyroid hormone levels and 24-hour urine collection for heavy metals
- Spinal tap
- X-rays, including magnetic resonance imaging (MRI)
- Myelogram of cervical spine
- Muscle and/or nerve biopsy
- A thorough neurological examination
Who Gets ALS?

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord. There is currently no cure for the disease.

Based on U.S. population studies, a little over 5,000 people in the U.S. are diagnosed with ALS each year. (That's 15 new cases a day.) Every 90 minutes, someone is diagnosed with the disease and someone passes away from it.

It is estimated that at least 16,000 have the disease at any given time.

Most people who develop ALS are between the ages of 40 and 70, with an average age of 55 at the time of diagnosis. However, cases of the disease do occur in persons in their twenties and thirties.

ALS is 20 percent more common in men than in women. However, with increasing age, the incidence of ALS is more equal between men and women.

About 90 percent of ALS cases occur without family history. The remaining 10 percent of ALS cases are inherited through a mutated gene. On average, it takes about one year before a final ALS diagnosis is made.

There are several research studies – past and present – investigating possible risk factors that may be associated with ALS. More work is needed to conclusively determine what genetics and/or environment factors contribute to developing ALS. It is known, however, that military veterans are approximately twice as likely to develop ALS.

Half of all people affected with ALS live at least three or more years after diagnosis. Twenty percent live five years or more. Up to 10 percent will live more than 10 years.

Only four drugs are currently FDA-approved to treat ALS: Riluzole, Nuedexta, Radicava, and Tiglutik. Nuedexta is approved to treat pseudobulbar affect, difficulty with emotional control, including inappropriate laughing and crying, which impacts some people with ALS.

The estimated cost to develop a drug to slow or stop the progression of ALS from an idea to an approved drug is between $2 billion and $3 billion.

There is some evidence that people with ALS are living longer, at least partially due to clinical management interventions and possibly other compounds and drugs under investigation.
Facts You Should Know

- ALS is not contagious.
- Currently, no cure for ALS exists.
- Although the life expectancy of a person with ALS averages about two to five years from the time of diagnosis, the disease is variable. Many people can live with the disease for five years or longer. In fact, more than half of all people with ALS live more than three years after diagnosis.
- Once ALS starts, it almost always progresses, eventually taking away the ability to walk, dress, write, speak, swallow, and breathe, and shortening the life span. How fast and in what order this occurs is very different from person to person. While the average survival time is three years, about 20 percent of people with ALS live five years, 10 percent will survive 10 years and 5 percent will live 20 years or longer.
- Progression is not always a straight line in an individual, either. It is not uncommon to have periods lasting weeks to months where there is very little or no loss of function. There are even very rare examples in which there is significant improvement and recovery of lost function. These ALS "arrests" and "reversals" are, unfortunately, usually transient. Less than 1 percent of people with ALS will have significant improvement in function lasting 12 months or longer.
- Approximately 5,000 people in the U.S. are diagnosed with ALS each year. The incidence of ALS is two per 100,000 people, and it is estimated that at least 16,000 Americans may be living with ALS at any given time.
- About 90 percent of ALS cases occur without family history. The remaining 10 percent of ALS cases are inherited through a mutated gene.
- On average, it takes about one year before a final ALS diagnosis is made.
- ALS occurs throughout the world with no racial, ethnic, or socioeconomic boundaries. The disease can affect anyone.
- Military veterans are approximately twice as likely to develop ALS.
- The onset of ALS often involves muscle weakness or stiffness as early symptoms. Progression of weakness, wasting, and paralysis of the muscles of the limbs and trunk, as well as those that control vital functions such as speech, swallowing, and breathing, generally follows.
- There can be significant costs for medical care, equipment, and home health care later in the disease. It is important to be knowledgeable about your health plan coverage and other programs for which you may be eligible, including Social Security Disability Insurance (SSDI), Medicare, Medicaid, and Veteran Affairs (VA) benefits. Only four drugs are currently FDA-approved to treat ALS: Riluzole, Nuedexta, Radicava, and Tigrutik. Nuedexta is approved to treat pseudobulbar affect, difficulty with emotional control, including inappropriate laughing and crying, which impacts some people with ALS.
- The estimated cost to develop a drug to slow or stop the progression of ALS is between $2 billion and $3 billion from an idea to an approved drug.

Last Revised May 2019
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.

Approaching End of Life in ALS 11-5
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.**

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

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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 becoming 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 breath 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)
Hospice chaplains see their share of death and dying. Even though the culture still seems to deny death, many dying individuals and their families request the presence of a chaplain at the end of life. In her 2010 book, *A Clergy Guide to End-of-Life Issues*, Martha Jacobs agrees with Ernest Becker who thought “that one of the most basic functions of culture is to help us avoid awareness of our mortality.”

We will all die...some day. Therefore, it comes as no surprise that dying individuals and their families have either connected with God or they seem to be searching for the “right moment” to be in God’s presence. Hospice chaplains are aware that an individual’s spiritual formation and development has many forms and shapes. Hospice chaplains serve individuals from a variety of religious and faith traditions, as well as atheists and agnostics, and therefore need to begin with the experience of the individual. Edwin DuBose in his study on the end of life encourages us to “meet me where I am.” Hospice chaplains meet individuals and families where they are.

From the beginning of life to the end of life “the Spirit blows where it will” (John 3:8). The emphasis on spiritual care at the end of life may generate significant interest in going deeper into one’s relationship with God/the Holy One. Therefore, hospice chaplains are able to benefit the dying individuals and their family members by providing them presence and listening. Hence, presence and listening are necessary foundations for all hospice chaplains.

**Hospice background**

The necessary foundations for all hospice chaplains are presence and listening. In order for the hospice chaplain to practice presence and listening, it is important to underscore some basics.

What is hospice? The Latin word “hospes” means host and guest, forming the root for the words hospitality, hostess, hospital, hotel, and hospice. They all include the ideas of kindness and generosity to strangers, or caring for our fellow human beings by offering them nourishment and refreshment. “Hospice” was first applied to the care of dying patients by Jeanne Garnier who founded the Dames de Calvaire in Lyon, France in 1842. The modern usage of the word “hospice” began in Britain in the mid-nineteenth century when “Sister Mary Aikenhead founded the Irish Sisters of Charity in Dublin in 1815 which ultimately led to the establishment of Our Lady’s Hospice in Dublin in 1879 and St. Joseph’s Hospice in Hackney, London in 1905.”

Florence Wald (April 19, 1917–November 8, 2008), who died at home in Branford, Connecticut, is the “mother of the American hospice.” She organized an interdisciplinary team of Yale University doctors, clergy, and nurses to study the needs of dying patients, which led to the first United States hospice in 1974 (www.hospice.com). Connecticut Hospice, as it was called, initially provided only in-home care. In 1980, an inpatient facility opened. By 2008, there were 4700 hospices in the United States.

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Connecticut Hospice was part of a demonstration project supported by the National Cancer Institute. In addition, the Connecticut Hospice served as a springboard for the formation of a National Hospice Organization (NHO) founded in 1978. Other hospice organizations are the National Hospice & Palliative Care Organization (NHPCO) and The Hospice Foundation of America (HFA). Both NHO and NHPCO are non-profit and incorporated with headquarters near Washington, D.C.

Originally, a hospice was a stopping place for weary travelers. During the Crusades, hospices were like Holiday Inns for devout and dedicated, but tired, pilgrims. Hospice today is a way of caring for the terminally ill, those weary travelers who are nearing the end of their earthly pilgrimage. Callanan and Kelley write that “the dying often use the metaphor of travel to alert those around them that it is time for them to die.” For example, by looking for his passport and papers, George reveals that he is dying and is beginning his final journey.

The pioneer institution in the care of the terminally ill is appropriately named for St. Christopher, the patron saint of travelers. On April 10, 1967, St. Christopher’s Hospice, located in the Sydenham section of London, opened its doors. The medical director was Cicely Saunders. She served St. Christopher’s until her death in July 2005. Dr. Saunders introduced the idea of pain relief on demand and used the phrase, “to live until you die.”

Hospice care is for comfort, including pain and symptom management. The usual place for hospice is in an individual’s own home, although hospice care has connections and contracts with skilled nursing facilities, hospital transitional and palliative care units, and board and care group homes. Hospice is interdisciplinary. The hospice team consists of physicians, nurses,

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12. See www.nhpco.org; also The Hospice Foundation of America (HFA), www.hospicefoundation.org.
16. Ibid., 75ff.
and family as they face end of life issues.26

The clinical training in Clinical Pastoral Education (CPE) informs hospice chaplains to be present and provide listening to the patients they meet. Another way to see presence is, as Jane Brody writes: “Your mere presence lets those who are dying know they are not alone.”27 Furthermore she adds: “people who are dying often face questions about the meaning of life. Your job is not necessarily to provide answers or solutions but to listen, to let them speak freely and openly without advice or contradiction.”28

The foundation of hospice is interdisciplinary, focusing on the physical, emotional, and spiritual needs of the individual and their families at the end of life.29 It should be noted that spiritual needs are more global and go beyond particular religious beliefs to the consideration of personal beliefs and meanings. Some patients say they are “more spiritual than religious.” As a hospice chaplain, my role is to provide spiritual care with families and individuals as they are dying and to be sensitive to religious and spiritual connections.30

Presence is “turning feelings into concrete, observable, practical expressions of love,” writes James Kok.31 These may be in form of prayer, an understanding word, a personal visit, a phone call, or a handwritten card. The hospice chaplain does all of these but most important for the dying person and their family is the personal visit.

Lani Leary in No One Has To Die Alone clearly indicates that “when we are truly present with the personal, spiritual experience of the dying…the transition from living to dying can become as sacred as being born into this world.”32 She also says that “practicing unconditional love is the most important work during our lifetime.”33

Elisabeth Kubler-Ross and Cicely Saunders were instrumental in the development of care for the dying and the early beginnings of hospice care, which included both presence with and listening to dying individuals. While at the University of Chicago, Kubler-Ross provided presence and listening to the dying patients she interviewed, as she researched and identified the so-called five stages of dying: denial, anger, bargaining, depression, and acceptance.34 Saunders laid the foundation for hospice care at St. Christopher’s by practicing her presence and listening skills with the patients she visited.

28. Ibid.
31. James R. Kok, 90% of Helping is Just Showing Up (Grand Rapids: CRC, 1996) 7.
32. Leary, No One Has to Die Alone, 62.
33. Ibid., 60.
34. See Kubler-Ross, On Death and Dying.

**Most important for the dying person and their family is the personal visit.**

Henri Nouwen introduced the concept of the “ministry of absence” when in the presence of an individual.35 Nouwen realized that it is impossible to be with a person every second of the day. Hence, rather than building one’s anxiety level, Nouwen allows for one’s presence to be felt while absent. Of course, Nouwen was referring to God’s presence when the spiritual care provider was absent. God’s presence is always there, said Nouwen, it is, after all, “God’s work and not ours.”36 Nouwen realized that God’s Spirit is always there, and so should the hospice chaplain. The person is in the presence of the Spirit. We will turn now to the meaning of listening for the hospice chaplain.

**Listening**

As Thomas Hart indicates, “listening is not always easy. It takes time, and the time might be inconvenient besides. It demands really being for the other during that period, fully present and attentive, one’s own needs and concerns set aside.”37 “To listen attentively to another and to go with another in companionship are expressions of love.”38 The hospice chaplain listens for the hopes, joys, despairs, and other spiritual and emotional challenges with the individual and family members who are facing end of life issues. As the hospice chaplain listens, Dr. Ira Byock and Margaret Guenther offer some guidance to hear.

Ira Byock writes that the four things that matter most to the dying patient is for the dying patient to say: “please forgive me; I forgive you; thank you; and I love you.”39 Forgiveness, gratitude, and affection are foundational. Byock’s most recent book, The Best Care Possible, is also revealing and helpful for chaplains.40

The skill of listening by the hospice chaplain is demonstrated by two basic foundations: first, when the patient has demonstrated that they have a relationship with God, and, second, when the patient shares a willingness to go deeper in talking about their relationship in the Spirit.41 When a hospice chaplain listens and

36. Ibid., 51.
38. Ibid., 18.
40. Ira Byock, The Best Care Possible (New York: Avery, 2013) is also helpful for chaplains. In addition, see also www.dyingwell.org.
41. See William A. Barry, Paying Attention to God (Notre Dame Ave Maria, 1990), 15ff; William A. Barry, Letting God Come Close: An Approach to the Ignatian Spiritual Exercises (Chicago: Loyola, 2001), 91ff; William A. Barry and William J. Connolly, The Practice of Spirit-
hears that a person has a relationship with God and wants to go deeper, then that is the appropriate time to move together with the person to discover more about the spiritual connections.

While exploring my role as hospice chaplain with the dying, Margaret Guenther’s observations have been both instructive and insightful. She tells the story of the woman at the well (John 4:13–15), where Jesus helps the woman to look deeply into herself to discover her thirst for God. Guenther affirms that “in the ministry of spiritual direction, there are no right answers, only clearer visions and ever deeper questions.”

In addition, Guenther says that providing spiritual care… is about “holy listening,” waiting, attentiveness, and presence. As a hospice chaplain, the skill of listening is essential. One never knows when the Spirit will break in, so listening is vital and foundational for the hospice chaplain. During the second half of life, Guenther encourages chaplains “to sit with patients and listen to their stories… for they are rare parchment waiting to be read.”

The art of listening is essential for hospice chaplains. Do not get too far ahead of the individual… stay close and listen intently! “The true director is the Holy Spirit.” Guenther here reflects on the words of Thomas Merton who wrote, “spiritual direction is, in reality, nothing more than a way of leading us to see and obey the real director—the Holy Spirit hidden in the depths of our soul.”

Furthermore, hospice chaplains learn that spiritual growth can be gradual and often hidden at the end of life. Waiting can be burdensome. Guenther uses the image of midwifery as a way to encourage the individual to move ahead by giving birth to something that is new and not yet known. We recognize that even in birthing the world, God brought order out of chaos. As an individual passes from this world to the next, they too are experiencing a new birth. As Paul writes: “So if anyone is in Christ, there is a new creation: everything old has passed away; see, everything has become new” (2 Cor 5:17). The hospice chaplain provides the patient and family with presence, listening, patience, a limited time-frame, and a ministry of absence.

Presence and listening are vital

Brother Lawrence, writing in The Practice of the Presence of God, indicates that presence and listening would be important for the hospice chaplain. Brother Lawrence says that it is the art of “practicing the presence of God in one single act that does not end.” Furthermore, Brother Lawrence encourages “everyone to be aware of God’s constant presence, if for no other reason than because God’s presence is a delight to our souls and spirits.”

Henry Nouwen also recognized the importance of the presence of a spiritual care provider when accompanying the dying. Nouwen realized that a spiritual care provider/chaplain cannot be present with the dying person every minute. That’s why “…there is a ministry in which our leaving creates space for God’s spirit, and in which, by our absence, God can become present in a new way.”

What a great concept! The Spirit is present when we are absent! St. Paul said something similar: “we do not live to ourselves, and we do not die to ourselves. If we live, we live to the Lord, and if we die, we die to the Lord, so then, whether we live or whether we die, we are the Lord’s” (Rom 14:7–8).

To Nouwen a ministry of absence is important because it underscores who the real director is in spiritual care—the Spirit. In the absence there is a presence. As a hospice chaplain, I am aware of being ‘the symbolic presence of God’ with the dying person but also realize that God is with those dying, whether or not I am present. It is a grace-filled moment. The words of Jesus serve as a reminder: “…it is for your own good that I am going, because unless I go the Advocate [the Holy Spirit] will not come to you; but if I go, I will send him to you…When the Spirit of truth comes he will lead you to the complete truth” (John 16:7, 13). Nouwen says that the constant interplay between presence and absence is sustaining and allows for an “ever growing intimacy with God in prayer.”

Kenneth Doka writes that beyond the medical, social, and psychological needs of dying individuals, there are spiritual needs as well. Humans are aware of their finitude and yet have a sense of transcendence. It has been my experience as a hospice chaplain that both individuals and families know when a loved one is dying. Sometimes families forbid the hospice team from using the dreaded “D” word in front of the dying patient.

50. Ibid.
54. Ibid., 43–45.
55. Ibid., 53.

“there is a ministry in which our leaving creates space for God’s spirit, and in which, by our absence, God can become present in a new way.”
No one knows when a person will die. However, there are signs that serve as a trigger to indicate that the end may be near. Callanan and Kelley point to the following: "difficulty swallowing…rattling noise…breathing patterns may change…irregular body temperature…involuntary movements, and communication may be more subtle." Some of these signs may occur hours, weeks or months before the person dies. Each person is unique, hence these signs may not always be present.

Doka indicates that there are three spiritual needs for the dying person: 1) the search for meaning of life, 2) to die appropriately, and 3) to find hope that extends beyond the grave. As a hospice chaplain, I agree that a chaplain will "provide individuals with opportunities to explore their concerns in a non-threatening and non-judgmental atmosphere; that it is useful to explore faith stories with dying individuals; and that rituals such as confession or communion can provide a visible sign of forgiveness."  

As hospice chaplains we connect with local parishes, synagogues, temples, mosques, and various houses of worship for those individuals and families who request it. Edwin DuBose has referred to a Gallup survey reinforcing what dying patients seem to want most: “including death at home among close family and friends, recognition of and support for the deeper spiritual and meaning dimensions of dying and death, and assurance that their families will not be overburdened with their care or neglected in their loss.”

DuBose also discovered that among the qualities mentioned by patients as important in their spiritual care providers are: genuineness, humor, flexibility, attentiveness, empathy, and a listening presence. Patients rank empathy, warmth, sense of humor, and flexibility as central features of spiritual care.

As one who provides spiritual care at the end of life, I have assisted individuals and their families by reexamining their beliefs, exploring their beliefs about an afterlife, reconciling their life choices, exploring their lifetime contributions, examining their loving relationships, and discovering their personal meaning.

Discovering personal meaning is perhaps the most essential and valuable part of our individual humanness. Hospice chaplains are witnesses to these discoveries and experience the virtue of character in dying individuals.

As a hospice chaplain, it becomes apparent that some dying individuals want a deeper spiritual connection with God. Patients have said that God seems closer to them, especially in their prayer lives. They seem to pay closer attention to God. In Ignatian spirituality it is understood that “God can be found in all things” and especially in prayer. Thomas Merton, the contemplative Trappist monk, defined prayer as, “paying attention.” Merton is right, paying attention to the Spirit’s presence in our prayer life is vital.

Martin Marty writes: “Being a presence does not mean they will never have anything to say. But their narratives and their verbal counsel will more likely come in the context of urgings, as in wisdom attributed to Saint Francis: ‘Preach the Gospel. Use words if necessary.’ Being a presence may mean that silence rules. However, Pierre Teilhard de Chardin was also on to something when he reminded readers that “a presence is never mute.”

Two Cases: Lillie and Aaron

The following two cases, Lillie and Aaron (not their real names), highlight both presence and listening for the hospice chaplain.

Case One: Lillie is resident at a Board & Care. Her husband of sixty years died two years ago while they were living in Kansas. Lillie is an African-American woman in her 90s. Her niece brought Lillie to Los Angeles to live with her. Lillie’s diagnosis is chronic obstructive pulmonary disease, along with some dementia. She uses oxygen to ease her breathing. She is a strong Christian and loves the Lord. She has a Baptist background. Her niece said, “My aunt loves the Lord.”

Case Two: Aaron is a fifty-eight-year-old man diagnosed with lung cancer three years ago. He lives with his wife and two grown children. At times, he is in a lot of pain. He is very religious and values his faith.

61. Doka, *Death & Spirituality*, 149. See also DuBose, “A Special Report: Spiritual Care at the End of Life,” 43.
64. Ibid., 62.
Focus: Lopez Jr. Hospice Chaplains: Presence and Listening at the End of Life

Lillie is well-connected to the Spirit. Lillie sensed the presence of God in her life and during this visit. The hospice chaplain listened and provided openings for Lillie to stay close to her feelings of God’s presence. As a hospice chaplain, without Lillie’s willingness to want God in her life and to go deeper, this chaplain may not have been helpful. Practicing the skills of presence and listening have allowed Lillie to move forward.

Case Two: Aaron is a retired Los Angeles superior court judge. He and his wife, Carol, have been married for more than fifty years. They are both Jewish and in their 80s. Aaron has been the caregiver for Carol for the past five years. She has been on hospice and in a coma with a feeding tube for the past two years.

P1: I spoke with the Rabbi the other day…I’m not sure he was listening.
P2: Oh, he said something like ‘you need to slow down…’
P3: …and have you been able to slow down?
P4: Not really…I wish he would have said more about what Moses or the prophets have to say about my dilemma. Maybe something more religious…I mean after all he is a Rabbi.
P5: Sounds frustrating…
P6: Sure is…you know I’ve been wondering where God has been all these years. Now I’ve come to realize that God has been here all along.
P7: Sounds like God is walking with you right now.
P8: How has God been with you?
P9: Yes, God is with me, at least I think so…it’s just been very difficult for me. I sometimes have my doubts as to what I’m doing…I want to do the right thing for my wife.
P10: Yes, indeed, God is here…loving us…thank you, Jesus…thank you, Jesus…(tearful).

Key: P = Patient; C = Chaplain

P1: My niece said that you would be stopping by today. I am so glad to meet you.
P2: Yes, I keep the Lord close to me.
P3: You have a close connection to the Lord…this is very special to you?
P4: Yes it is. My parents were a strong influence with my faith. My father went to church and so did my mother. We loved the Lord and I even taught Sunday School for many years. Why there’s even a church building with my parents’ name on it in Kansas.
P5: You have some good roots and a strong Christian foundation.
P6: Yes I do…my husband also loved the Lord and together we would spread the Word to our neighbors.
P7: Do you still have that connection with Jesus?
P8: Yes, I do…I love Jesus and I’m thankful for what he has done in my life. I couldn’t make it without Jesus…
P9: You seem well-grounded in your faith journey.
P10: You are in a difficult spot and you are doing what you need to do. Have you felt God’s presence before as you have been caring for your wife?
P11: Yes, I suppose so…I know I have asked God for a sign.
P12: What sort of sign?
P13: A sign to know that I’m doing the right thing. I know during World War II when I was flying those bombing missions…the plane we were in got pretty shot up sometimes…but each time we were able to return to our base. That was a sign for me.
C7: Perhaps the sign that you are looking for is that you are providing good care for your wife and asking tough questions.

P8: Maybe so…

C8: Are you aware of God’s presence right now?

P9: Yes…

C9: God is with you in your struggles for understanding and peacefulness.

P10: Yes… God gives me what peace I have been feeling recently. Thanks for walking with me today…

Aaron realized that God was with him from the very beginning. By providing presence and listening, Aaron was able to move forward in his life even as his wife was dying.

Presence and listening are relevant in these two cases by opening each person to the presence and the listening they were seeking. The hospice chaplain provided the space for each person to go deeper into their own soul.

As a hospice chaplain, I, too, was able to witness these connections and affirm their search to go deeper. The Spirit was present in our visits. Both were comfortable and peaceful. They were thankful to be able to search for deeper spiritual connections and meanings in their lives. Both presence and listening were provided by the hospice chaplain.

Conclusion

Dying is a process involving the body, mind, and spirit.71 The primary discernment for a hospice chaplain with the dying is related to timing. Not everyone on hospice wants to meet the chaplain. The luxury of on-going visits are reduced to months, weeks, days, and sometimes hours. This means that an individual must be a willing participant in exploring their deeper connections with the Holy One.

Hospice chaplains have specific responsibilities like documentation, interdisciplinary collaboration, and endless hours of driving to and from appointments. As a hospice chaplain with the dying, chaplains must be willing to meet at the patient’s place of residence, be it at home, a skilled nursing facility, a hospital room, or even a board and care group home.

The hospice chaplain is “the symbolic presence of God” by providing listening and presence, which builds trust in order for patients to share their stories, dreams, and memories. Being a hospice chaplain with the dying is a work in progress. My sense is that a hospice chaplain stands on the banks getting ready to step into the flow of the river. The stories, dreams, and memories of the patients are always flowing. The chaplain must be grounded and open to the work of the Spirit in that person’s life as the stories, dreams, and memories come to the surface. Cicely Saunders was right that “we live until we die.”

The hospice chaplain is in the presence of the Holy as the individual slips from this world to the next. Just as the river continues to flow, so do the spiritual connections with the dying individual. Those connections continue until the last breath.

As the dying individual transitions from this world to the next, there are times when one foot remains in this realm and the other foot in the next realm. It has been my deepest experience to be in the presence of the Holy One and experience the mystery of the Holy as the individual is ushered into the arms of a loving God (1 John 4:7–21: “God is love.”).

Even though for the hospice chaplain the context of the dying person may be fuzzy or the water too deep, the clarity comes in what the Spirit gives. The dying individual is validated in their quest for a closer connection with God. There is an art to providing spiritual care with the dying. The hospice chaplain who provides spiritual care with the dying is seen as the connector, the messenger, the listener, the ‘presence of God’ for the dying individual and for the family.

Sogyal Rinpoche writes in The Tibetan Book of Living and Dying: “…don’t try to be too wise; don’t always try to search for something profound to say. You don’t have to do or say anything to make things better. Just be there as fully as you can.”72

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What Is Self-Care And Why Is Self-Care Important?

BY KATHERINE HURST

Self-care is a popular topic these days, but it is often poorly explained. Perhaps you keep seeing it mentioned in self-help books or magazine articles and yet don’t have a clear sense of how you’re supposed to add it to your life. It may seem wishy-washy or vague to you. Alternatively, maybe you aren’t convinced that you should practice regular self-care. Maybe you think your resources are better saved for working and for looking after others.

So, what is self-care, and why is it so important? As it turns out, there are many different self-care practices, and not all of them suit everyone. This guide will take you through the reasons why you need at least some sort of self-care in your routine, and will help you understand the specific changes you need to make.

What Is Self-Care? The Definition Of Self Care

Self-care is a broad term that encompasses just about anything you do to be good to yourself. In a nutshell, it’s about being as kind to yourself as you would be to others. It’s partly about knowing when your resources are running low, and stepping back to replenish them rather than letting them all drain away.

Meanwhile, it also involves integrating self-compassion into your life in a way that helps to prevent even the possibility of a burnout.

However, it’s important to note that not everything that feels good is self-care. We can all be tempted to use unhealthy coping mechanisms like drugs, alcohol, over-eating, and risk-taking. These self-destructive activities help us to regulate challenging emotions, but the relief is temporary.

The difference between unhealthy coping mechanisms and self-care activities is that the latter is uncontroversially good for you. When practiced correctly, self-care has long-term benefit for the mind, the body, or both.

Benefits Of Self Care

With a self-care definition on the table, we can now turn to look at what happens to us when we add it to our lives. So, why is self-care important?

As hinted above, there are many benefits of self-care. The most obvious relates to mood and energy levels. However, as it turns out, research shows wider ranging benefits as well.
Top 6 Benefits Of Self Care

- **Better productivity.** When you learn how to say “no” to things that over-extend you and start making time for things that matter more, you slow life down in a wonderful way. This brings your goals into sharper focus and helps you to concentrate on what you’re doing.

- **Improved resistance to disease.** There is evidence that most self-care activities activate your parasympathetic nervous system (PNS). What this means is that your body goes into a restful, rejuvenating mode, helping it to fortify its immune system.

- **Better physical health.** Similarly to the previous point, with better self-care often comes fewer colds, cases of flu and upset stomachs. Less stress and a better immune system can surely help you feel more physically able and strong inside and out.

- **Enhanced self-esteem.** When you regularly carve out time that’s only about being good to yourself and meeting your own needs, you send a positive message to your subconscious. Specifically, you treat yourself like you matter and have intrinsic value. This can go a long way toward discouraging negative self-talk and your critical inner voice.

- **Increased self-knowledge.** Practicing self-care requires thinking about what you really love to do. The exercise of figuring out what makes you feel passionate and inspired can help you understand yourself a lot better. Sometimes, this can even spark a change in career or a reprioritization of previously abandoned hobbies.

- **More to give.** When you’re good to yourself, you might think you’re being selfish. In truth, self-care gives you the resources you need to be compassionate to others as well. Giving compassion is a bit like filling a bucket; you can’t fill someone else’s if you don’t have enough of your own!

Types Of Self Care

One of the main excuses people make for ignoring articles about self-care is that they just don’t have time. The great news is that there are many different self-care practices, and none of them are especially difficult or require a lot of planning. The trick is to find some that you genuinely enjoy and that fit with your life and values. Once you start adding emotional self-care to your life, you’re likely to become fiercely protective of that time and wonder how you ever managed without it!

Here are the five main categories of self-care, along with explanations of how they help you. We’ll also look at specific self-care examples within categories, which should get you thinking about activities you’ll particularly like.
1. Sensory

Sensory self-care is all about helping to calm your mind.

When you are able to tune into the details of the sensations all around you, it’s easier to live in the present moment. And when you’re in the present, you can more effectively let go of resentments related to the past or anxieties about the future.

When you think about practicing sensory self-care, consider all of your senses: touch, smell, sound, and sight.

Most people are more responsive to one than the others, so ask yourself what that sense might be for you.

The following examples of sensory self-care involve at least one sense, but often more.

**Sensory Self-Care Ideas**

- Cuddling up under a soft blanket.
- Going to the countryside and focusing on the smell of the air.
- Watching the flames of a candle or a fire.
- Feeling the water on your skin during a hot bath or shower.
- Focusing on the movements of your own breathing.
- Lying down and listening to music with your eyes closed.
- Sitting in the heat of the afternoon sun.
- Having a small square of the most delicious chocolate.
- Walking barefoot in the grass.
- Having a massage with essential oils.
- Holding a pet in your arms.
2. Emotional

When it comes to your emotional health, one of the best self-care tips is to make sure you fully engage with your emotions. When you face them head-on, this actually helps with stress.

You may feel tempted to push down feelings like sadness or anger, but it’s healthy to feel them, accept them, and move on.

Remember that emotions are not “good” or “bad” in themselves. You are not blameworthy for the emotions you feel; only how you behave in response to them.

On this theme, consider any one or more of the following if you want to practice better emotional self-care...

Emotional Self-Care Ideas

- Keep a daily journal, and be totally honest about your feelings.
- See a therapist, even if it’s just for 8-10 sessions of general personal development.
- Write a list of “feeling words” to expand your emotional vocabulary.
- Make time to be with a friend or family member who truly understands you.
- Let yourself cry when you need to.
- Deliberately encourage yourself to laugh with old memories or funny videos.
- Sing along to the song that best expresses your current emotions.
3. Spiritual

If you’re not religious, you might be tempted to skim-read this section or skip it altogether. However, spiritual self-care isn’t just about believing in a deity. It’s applicable to atheists and agonistics as much as to religious people.

Spiritual self-care is about getting in touch with your values and what really matters to you. Self-care tips for depression often stress that developing a sense of purpose is vital to your recovery. Below are some versatile examples that can help you with this.

**Spiritual Self-Care Ideas**

- Keep up a daily meditation or mindfulness practice.
- Attend a service, whether it is religious or humanistic.
- Read poetry.
- Walk in nature and reflecting on the beauty around you.
- Make a daily list of 5-10 things that make you feel grateful.
- Be creative, whether through art, music, writing or something else entirely.
- Make a list of 5-10 things that make you feel alive, then ask yourself how you can better incorporate these things into your life.
- Say affirmations that ground your sense of self and purpose.
- Go on a trip with the sole purpose of photographing things that inspire you.
4. Physical

The importance of self-care definitely extends to purely physical aspects of your health. Physical activity is vital not only for your bodily well-being but also for helping you let off steam.

You might think there’s nothing fun or self-compassionate about going to the gym, but that’s far too narrow a way of thinking about physical self-care. Instead, broaden the concept by thinking about the following lists.

**Physical Self-Care Ideas**

- Dance to your favorite songs
- Do yoga. Even if you’ve never tried it, there are poses that are perfect for beginners.
- Join a class and learn a new sport.
- Go running with your dog (or a friend’s)!
- Cycle through the countryside.
- Simply go for a walk.

In addition, remember that physical self-care is as much about the things you don’t do as the things you do! So:

1. Nap when you need to. Just 20 minutes can make you feel mentally and physically refreshed.
2. Say “no” to invitations when you’re simply too tired to enjoy them.
3. Don’t push yourself to do your exercise routine when you’re run down or unwell.
4. Commit to 7-9 hours of sleep per night, barring exceptional circumstances.
Finally, social self-care is another category that’s important for us all.

It might look different depending on whether you’re an introvert or extrovert. However, connecting with other people is necessary for happiness for a large diversity of people.

It helps you to understand that you’re not alone. Plus, it can also give us a sense of being fully “seen” by others. This can, in particular, help us combat loneliness and isolation.

Social self-care isn’t about just doing things with others for the sake of it, but about choosing to do things with people who really make you feel good.

*Social Self-Care Ideas*

- Make a date to have lunch or dinner with a great friend.
- Write an email to someone who lives far away, but who you miss.
- Reach out to someone you like but haven’t seen in a while.
- [Consider joining a group of people who share your interests.](https://www.example.com)
- Stop socializing with those who undermine or disempower you.
- Strike up a conversation with someone interesting.
- Join a support group for people who struggle with the same things you do.
- Sign up for a class to learn something and meet new people at the same time.
40 More Self-Care Ideas

1. Practice replacing ‘should’ in your vocabulary.
2. Take a different route to work or the shops.
3. Watch an episode of your favorite TV show. Then write 5 reasons why you like it.
4. Create a new, healthy, daily habit and schedule it into your life.
5. Unsubscribe from spammy emails.
6. Reflect on previous wins and achievements.
7. Take 15 minutes to soak up the sunshine.
8. Visit your local library.
9. Do a household chore you've been putting off.
10. Watch motivating videos and speeches.
11. Speak to a loved one about their own self-care ideas or routines.
12. Laugh!
13. Write a review for a business you have enjoyed lately (such as a restaurant or product you have purchased).
14. Make your bed.
15. Work on a puzzle you enjoy but challenges you. For example, a Sudoku puzzle, crossword or jigsaw.
16. Start a journal.
17. Write down a new affirmation.
18. Make sure you drink at least 8 glasses of water today.
19. Dance like no one is watching.
20. Learn how to give yourself a massage and do it.
21. Write a letter to your younger self.
22. Write a letter to your older self.
23. Do a 6-hour digital detox.
24. Go to the cinema on your own.
25. Do something for charity.
26. Clean out your car (if applicable), handbag, and jacket pockets.
27. Find a local therapist or counselor.
28. Do something fun you used to do as a kid.
29. Cook a meal you've never cooked before.
30. Research local history.
31. Set up daily reminders on your phone to remind you that you are awesome!
32. Clean your desk or workspace.
33. Watch a documentary.
34. When feeling particularly stressed, take a mental health day and call in sick to work.
35. Change your bedsheets and have an early night.
37. Consider joining a local support group.
38. Read inspiring quotes.
39. Make a self-care box filled with materials such as candles, essential oils, affirmation cards, self-care ideas, a book, etc.
40. Smile at yourself in the mirror!
CAREGIVING

Moving Forward After the One You Cared For Dies
Grieving caregivers typically face a challenging mix of emotions

By Julie Gorges
July 10, 2019

As anyone who has lost a loved one knows, grieving is a heartbreaking journey. When you’re a caregiver and the person you’ve been caring for dies, experts on grieving agree the psychological outcome and healing process are somewhat different. That’s especially true if your loved one had dementia.
I was the primary caregiver for my mother, who had Lewy body dementia during the last years of her life. I learned that grief takes many forms, and it isn’t just about mourning someone after they die. When your loved one has dementia, you lose that person in an excruciating way — a little bit at a time. As a result, some of the grieving process begins to take place while you’re still caregiving.

After my mother died, I not only lost her, but part of my identity as a caregiver. My life had changed drastically overnight.

Other complicated feelings often come into play. “After caregivers lose the person they cared for, there is often less grief alone, but a mixture of other emotions,” explains Dr. Marc Agronin, a geriatric psychiatrist and author of The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer’s Disease and Other Neurocognitive Disorders. “Those feelings may include sadness and uncertainty about the future, along with some degree of relief and a desire to move forward.”

**After a Death: A Mix of Emotions**

This was certainly true in my case. After my mother’s death, the emotions were overwhelming. I was relieved all of my heartbreaking duties as a caregiver were over. No more medical emergencies, constant worrying and sleepless nights. I also enjoyed my newfound freedom to take a vacation, go on a leisurely walk, spend quiet time with my husband or simply enjoy a book.

But there was a lot of guilt mixed in for feeling that way. I also felt remorse about the times I wasn’t the perfect caregiver and questioned whether I made the right decisions along the way.

On top of that, I felt lost. Caring for Mom had been my life for a few years. Most of my thoughts and feelings had revolved around her care. After my mother died, I not only lost her, but part of my identity as a caregiver. My life had changed drastically overnight.

**Accept Your Feelings and Move Forward**

So, how can you move forward will all the intense and contradictory feelings that come with the territory?
What I learned is that you have to accept all your emotions and be patient with yourself. Feel everything you need to feel. Lean on loved ones. Honestly discuss your thoughts and feelings with those close to you.

However, as time goes on, it’s important not to allow sorrow to become a way of life or dwell on all of the “should-haves” that interfere with recovery. In fact, you'll need to forgive yourself for mistakes you think were made while caregiving and stop feeling guilty that you’re relieved to have your life back.

The goal is to let go of negative feelings and enjoy a productive life once again.

How is that accomplished?

After my mother’s death, I took an important step that helped me pick up the scattered pieces of my soul and begin living again.

I deemed the year after my mother’s death, my “year of healing” and listed three non-negotiable things I had to do each day. There was nothing new or revolutionary on my list. Just a few simple things that provided an anchor, ensured that I took the time to care and focus on myself and helped me get through a bad day.

My list included:

- **Read something spiritual and inspirational each day.** If you’re a religious person, now is the time to embrace your spirituality and rely on your faith to help you move forward. It’s so easy to become sidetracked and allow time to slip by without any spiritual fortification. I realized daily reading, meditation and prayer were necessary every single day.

- **Exercise.** I’m not talking about running a marathon or doing 50 deep squats. But, **even if it was only for 15 minutes**, I did something for both my physical and emotional well-being. Maybe I’d take a stroll through the park listening to the birds sing, do some Pilates or walk the dog around the block listening to soothing music.

- **Do something you love.** I thought about what used to make me feel happy and brought fun and joy to my life. Then I made a point of putting those treasured activities back into my daily life. In other words, at the end of the day, I made sure that I did something just for me.
You know what? My list worked. Accomplishing these three things every day helped me feel calmer, more centered and, yes, happier.

I’d recommend making a list of your own. Maybe you’ll include laughing each day, spending time in nature, learning something new, being silly or enjoying time with loved ones.

**Helping Others Helps Yourself**

Perhaps one of the most important items to put on your list is to perform one simple act of kindness for someone else each day. Compassionate deeds and [volunteer work can help you find meaning](https://www.nextavenue.org/moving-forward-after-caregiving/) and purpose again.

“I think focusing on others helps a person to move forward,” says Vicki Tapia, author of *Somebody Stole My Iron: A Family Memoir of Dementia* and co-founder of [AlzAuthors](https://www.nextavenue.org/moving-forward-after-caregiving/), a website featuring authors who write about their experiences related to Alzheimer’s and other dementias.

Tapia cared for both her parents with dementia before their deaths. “Doing something helpful outside of yourself can often be a balm to the soul, whether it’s lending a listening ear or volunteering to help with a support group for other caregivers,” she says.

**Finding a New Perspective on Life**

Losing someone you love changes how you look at the world and forces you to acknowledge that life doesn’t last forever. The experience can clarify your priorities and redefine your path. So, embrace the new you and your new life.

“Find a new role that provides meaning and purpose,” suggests Agronin. “This might involve renewed relationships with others, volunteer work, travel or some other pursuit that provides a sense of personal direction.”

Several months after Mom died, my husband and I took an anniversary trip to Chicago. Even though I have a fear of heights, I was determined to sit on one of those scary glass enclosures that jut from the Willis Tower Skydeck, a whopping 103 floors above the city. I had this overwhelming feeling that I had to start living again and this was the first step. So, I bravely forged forward onto the glass and I felt alive, empowered and revitalized.

I have faith that you’ll take that first step too. You will heal, move forward, and rediscover yourself. You will feel happy again. As Martin Luther King Jr. famously said: “Take the first
step in faith. You don’t have to see the whole staircase, just take the first step.”

By Julie Gorges

Julie Gorges is an award-winning journalist and author of four books, including her latest, *I’m Your Daughter, Julie: Caring for a Parent with Dementia*. Hundreds of her articles and short stories have been published in national and regional magazines and her blog, *Baby Boomer Bliss*, was recently selected by FeedSpot as one of the top 75 baby boomer blogs on the web. To learn more about Julie, visit her author’s website.

Next Avenue Editors Also Recommend:

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The Comfort of the Ordinary — On Dying as We’ve Lived

Caroline Wellbery, M.D., Ph.D.

Years ago, I heard about the death of an old family friend whom I’d loved as a child for her eccentric cooking habits, feeding her parakeets saliva-soaked crumbs from her lips, and letting me rap my knuckles on her wooden leg. Although I wasn’t with her at the end of her colorful life, I can almost hear her Polish accent as she uttered the kind of wry, unflinching assessment I’d found so pleasantly shocking as an adolescent: “If this is dying, it’s not so bad.”

My friend’s last words made the rounds. They struck a chord. Death isn’t, after all, just about the dying. It’s about us survivors, who want some sort of reassurance that our loved one died in peace. More generally, we look for guidance on navigating mortality, including our own.

I’ve been a part of many deaths, as a doctor, family member, or friend. In recent years especially, many people I’ve known have died, mostly of the generation ahead of mine. Our parents, our friends’ parents, our last relatives are vanishing one after the other, fast enough to make the U.S. death rate of 7452 per day suddenly seem plausible. One death every 12 seconds makes for a lot of grief among the ranks of the survivors.

That’s why I’ve started noticing ways in which people die, how what they say and do can be a source of comfort, humor, and collective acceptance. Take, for example, my friend Herbie, who first held me in his arms when I was a day old and remained an important part of my life for the next 65 years. I called his hospice room a few days before his death to tell him how much I loved
him. “I’m watching Rachel Maddow,” he said. He wouldn’t let anyone interrupt him while he listened to the televised hearings over Brett Kavanaugh’s Supreme Court nomination, but in between he did find time to instruct his family on the wording of his obituary. “They better not use the phrase ‘passed away,’” he growled. “They should say ‘died’!” We all understood, because Herbie hated euphemisms, and especially those intimating that there was an afterlife.

I’ve seen this sort of thing again and again: people die as they’ve lived. On one of the days when my father lay dying from a stroke that garbled his speech, he wanted urgently to tell us something. We crowded around, trying to make out his words. Was it a family secret? A declaration of love? Was there a document we didn’t know about hidden in some cubbyhole? Finally, we managed to encode his message by repeating the alphabet, watching him nod each time we got to the right letter. “Have you found a house yet?” we spelled out. That was it? That’s what we’d been working so hard to decipher — just ordinary conversation? My sister and her husband had been house hunting in the days before my dad’s stroke. How was the search going, he wanted to know. I realized that he’d always handled a crisis that way; when people around him were arguing or upset, he rarely let himself be drawn into the fray. Instead, he’d think of ways to steer the conversation in another direction. On his deathbed, he did what he had always done.

How can the dying be so habitually themselves, expressing mundane thoughts? Shouldn’t death be a time of truth telling and atonement, of reconciliation and expressions of love? In fact, yes, death might offer an opportunity for all these things, but maybe more reliably, it allows a space for life to go on just as it was.

Many families laugh, sing, and tell stories at the bedside of a dying relative. Many find it oppressive to dwell strictly on meaning making, intense emotions, and life review. And that’s probably even more true for dying people themselves. The mundane may be the greatest comfort there is, a reminder that life simply goes on.

In this light, we can learn from patients with a terminal illness who don’t want to discuss their prognosis. It’s as though the death clock starts ticking at that moment of discussion: suddenly, life as the patient knows it is over. Though the fear of irrevocability is justified, it’s also not
entirely valid. Life may never again be the same, but in many ways it remains deliciously familiar. No wonder patients with a life-threatening illness exhibit what seems to be contradictory behavior: they will buy a house in the country while writing letters of farewell; they will put their papers in order while pursuing experimental cures.

This observation has led some palliative care experts to formulate what they call a “dual framework.” Patients might not want to talk about dying, and many cling to the hope that they will somehow survive the odds. At the same time, they can’t completely ignore their condition. They may swing wildly between hope and despair. The balance changes over time, though, as the illness progresses: “As patients develop a greater awareness of the likely outcome of the illness, they cope less by swinging back and forth between optimistic hopes and realism and more by holding these ideas simultaneously.”

Could it be that the everyday ordinariness I’ve seen in Herbie, my father, and so many others simply reflects the habit of living until living is no longer an option? Even if the dying person has reached the point at which she completely accepts the inevitable, she still dwells in the here and now. She is still alive.

When I was in medical training, I was told to help patients strive for a “good death.” Deaths were “good” when patients retained a sense of control over dying, were free from pain, and had a sense of life completion. I never heard anyone talk about “ordinary death” — understandably, since what death is ordinary? No death is just ordinary. But maybe it’s helpful, maybe it’s especially comforting, when death is ordinary too, in the sense that we can continue to find room for our everyday selves until we die.

My uncle died not long ago. He lived for 3 weeks in hospice — plenty of time for him to express joy and gratitude to those he loved. He had little pain, but on the occasions when he was given morphine, he’d exuberantly launch into recollections of the past. He even revealed some conciliatory thoughts about our family’s complicated history that he’d not spoken of before. It was a good death.

It was also a death infused with everyday life. My cousins sent me a video. In it, my uncle was lying on his deathbed, his hands folded across his chest. His mouth hung open; his nose had that
sharp prominence so often seen in the dying. “Greensleeves” played quietly in the background. Suddenly, he unclasped his hands and plucked at the bedclothes with his right thumb and first fingers. “Pizzicato,” he announced instructively. The utterance contained so much — it spoke not only of my uncle’s love of music, but of his willingness even in extremis to engage without sentimentality, and maybe as well of his past as a schoolteacher, always ready to call out a salient fact.

What I’ve extracted from these stories is that if we’re lucky, we’ll continue to live as we always did until the very end. We’ll be allowed to seek refuge in the ordinary, thus building a bridge between the lived life of our loved ones and the future of those who must carry on. In the end, there may be no better bridge than the poet Jane Kenyon’s dying word: “OK.” Perhaps Kenyon was accepting death, or comforting her grief-stricken husband, the poet Donald Hall. But as Hall recorded it in his poem “Last Days,” it seemed merely a response to his ordinary comment, “I’ll put these letters in the box.” So perhaps, after all, “OK” was just “OK.” And sometimes OK is the best affirmation we can pluck from the wreckage of death.

From the Department of Family Medicine, Georgetown University Medical Center, Washington, DC.
I sat listening to the case presentation about a woman who waited far too long to seek care for advanced breast cancer. By the time she presented for medical evaluation, her right breast was twice the size of her left and hung like a misshapen butternut squash hidden under her blouse. The physical exam revealed that the tumor was breaking down her skin, which was ulcerated and excoriated, with the orange-peel texture common in advanced breast cancer. I listened quietly to the familiar conversation among the surgeons, oncologists, radiation oncologists, and presenting medical student. The “wonder why she waited so long” commentary was inevitable. The “what a shame” discussion followed. “She had health insurance,” the well-meaning student added, as evidence that funding was not a barrier to care in her case. The tenor of the conference was familiar to me after 14 years in clinical practice. I am well versed in the concept of patients’ denial in the face of a devastating diagnosis.

My mind drifted back to a lecture during my first year of medical school that had included a detailed discussion of the progressive symptoms and hopeless prognosis for patients with amyotrophic lateral sclerosis (ALS). Outlining the way in which function would decline until the patient was left with no ability to move even a single muscle, the professor described the disease as “a front-row seat to one’s own death.” “What a horrible fate,” I thought, mentally cataloguing ALS as one of the worst diagnoses imaginable.

Then, during my second year of medical school, my father was diagnosed with ALS. To be honest, he wouldn’t be formally diagnosed until my third year — a delay caused by my own denial. During a hurried call I made from a pay phone at the library, my dad mentioned that he was becoming slow to get to the ball on the tennis court. I laughed it off as his excuse for having lost a match to his cousin over the weekend. My dad was notoriously hypercompetitive in recreational sports — with his friends, his relatives, and especially his children. But despite my attempt to minimize his complaint, he insisted that his muscles felt weak. Odd — my dad rarely complained.
I don’t know what prompted my next question. Perhaps it was the physiology test on motor neurons for which I was studying, but when I asked, “You don’t have fasciculations, do you? You know — muscle twitching?” his affirmative answer stopped me cold. I had just heard another lecture on ALS, in which my neurophysiology professor had described lower motor neuron disease with dry, clinical detachment and opined that ALS is perhaps the worst of all diseases, because cognition remains intact while the body fails. A patient ultimately becomes “locked in” — fully aware but unable to communicate.

My father saw a neurologist within the next few weeks, and a full laboratory and imaging workup ensued, complete with a brain MRI, a lumbar puncture, electromyography, and a sural nerve biopsy. Meanwhile, I vigorously researched alternative diagnoses in the medical school library. In those days of photocopying of printed articles, before computer use became widespread, I pulled journal after journal from the bookshelves in a quest to find a better diagnosis to explain my father’s symptoms. He had so much faith in me. I was determined to change his fate by doing an exhaustive search of the medical literature. This could not possibly be ALS. Dad was only 50 years old.

When I prodded him for more information, he told me he might have been bitten by a tick on a recent trip to the northeast. He said he’d developed a bull’s-eye–shaped rash on his elbow less than a month ago. “Perfect,” I thought. “It’s Lyme disease.” Everything seemed to fit.

I made a case to my father’s neurologist that his weakness was not a symptom of ALS, but a rare neurologic manifestation of Lyme disease. I’m not sure whether I was truly convincing or whether the neurologist was merely allowing my family time to adjust to a diagnosis that he knew was a death sentence, with no effective treatment or cure. If he was indulging my denial, he was extra-indulgent in encouraging us to take a trip to New York to pursue exhaustive testing by experts in Lyme disease and starting my dad on empirical treatment for that condition. My father continued to decline clinically.

I got married that summer. My dad received his second daily dose of IV antibiotics for Lyme disease just before the ceremony began and then tucked the PICC catheter into his tuxedo shirt. He was determined to walk me down the aisle and to do the traditional father–daughter dance.
He picked out the song for that dance, Whitney Houston’s “Wind beneath My Wings.” He’d always been the wind beneath my wings, supporting all my dreams, from college tennis through medical school, but on this occasion I was more literally the wind beneath his, as I physically held him up. I could feel the strain of his shaking muscles from the sheer exertion of dancing and the perspiration on his shoulders during what would be our last dance together. He was determined to defy the odds and prove the diagnosis wrong. This dance was one of his many self-tests, designed to convince himself that he could not possibly have something as devastating as ALS.

I was sitting with him on the wicker love seat on my parents’ back patio early one evening, when he handed me the phone. His neurologist was on the line and had asked to speak to me. With no greeting or pleasantries, he said, “Heather, I’m afraid this diagnosis of Lyme disease is a red herring. It is time to come to terms with it. Please talk to your family.”

I was not ready for this. I was 23 years old and didn’t feel qualified or up to the task of relaying such terrible news to my parents. I hung up the phone and watched my parents’ concerned faces as I conveyed the information. If I close my eyes, I can relive that moment as vividly as if I were there right now.

Over the course of the next year, my father went from a jovial, athletic man, the bedrock of our extended family, to a quadriplegic. He continued to decline. By the time he died, he had been quadriplegic for 10 years. He was on a ventilator. He was fed through a tube. And that all would have been tolerable, acceptable — if only he could talk. The inability to communicate is the most tragic part of ALS. My father could not smile or gesture with his face. He could not voluntarily blink. He could not wave a hand or move a finger. He could not express himself in any way to those who loved him. He suffered the living hell that my physiology professor had so accurately described in the lecture hall that day. But my dad never threw in the towel. He always had a will to live — for himself and for us.

So yes, I am familiar with denial. When I see patients who cannot face the prospect of a terrible diagnosis, I understand their delay, their reluctance, their trepidation on a deep level — a level that perhaps only someone who has witnessed a loved one’s slow demise from a terminal illness
can appreciate. In the face of a diagnosis for which there is no effective treatment and no cure, our denial allowed my family 6 months of relative peace before things became unbearable. We had a few extra months with my father without the constant awareness that his death was imminent. My medical inexperience, clouded clinical judgment, and desperate desire for more time with my dad extended our denial of medical reality for longer than is typical.

Today, when I hear detached descriptions of patients who’ve waited too long to address a devastating illness, I understand. “Denial helps us to pace our feelings of grief,” Elisabeth Kübler-Ross explained. “There is a grace in denial. It is nature’s way of letting in only as much as we can handle.”

From North Broward Radiologists, Fort Lauderdale, FL.