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A NATURAL DEATH IN GOD'S TIME

*A Caregiver's
Life-affirming Guide*

HALO MISSION STATEMENT

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The mission of the Healthcare Advocacy and Leadership Organization is to promote, protect, and advocate for the rights of the medically vulnerable through direct patient and family interactions; through community education and awareness programs; and through promotion and development of concrete “life-affirming healthcare”* alternatives for those facing the grave consequences of healthcare rationing and unethical practices, especially those at risk of euthanasia and assisted suicide.

**“Life-affirming healthcare” is defined as medical care in which the paramount principle is the sanctity of life, which means that the life and safety of each person come first and each person receives medical care across their lifespan based on their need for care and never with an intention to hasten death, regardless of their abilities or perceived “quality of life.”*

INTRODUCTION

“A Natural Death in God’s Time: A Caregiver’s Life-affirming Guide” has received great reviews from those who’ve read it. Many of us are not prepared to care for a loved one who is in the last stages of life and do not know what to expect or how to be helpful. This beautiful little booklet, written by Dr. Cristen Krebs, a nurse practitioner who founded and operated a life-affirming Christian hospice for 23 years, prepares family members and other caregivers to embrace the journey with a loved one who is dying.

One Word of Caution:

Some of the symptoms indicating that a person is near death are similar to symptoms caused by unintentional or intentional overdosing with pain medications and antipsychotic drugs, as well as denial of food and fluids. These are all too frequent occurrences in hospice and palliative care settings. Therefore, HALO has prepared fact sheets, “Drugs Commonly Used in Hospice and Palliative Care” and “Principles for Medical Decision-Making that Respect the Dignity of Human Life,” to help guide you in protecting and caring for your loved one. These are available on our website (www.halovoice.org) under “Resources.”

Human life is a precious gift. The uncertainty of life compels us to appreciate its fragility.

Just as the onset of labor and date of birth are mysteries, no one can predict the exact day, hour or moment of death. When a loved one is living the last stages of a terminal illness, family and friends often question when death will occur. Because the process of dying is a personal journey, the time of death is difficult to predict, even for doctors and nurses who specialize in care of the dying.

While certain symptoms are usually associated with the natural dying process, these symptoms of approaching death may vary depending on the unique end stage illness a person is experiencing. Not all the symptoms will be present in every case, and most individuals demonstrate a combination of the symptoms in their final days or hours of life. Additionally, some individuals never display any of the common symptoms as death approaches.

The dying process usually begins several weeks before death occurs. As the physical body begins to decline, an individual's emotions and sense of spirituality also begin to change as the mind strives to embrace one's own mortality.

The following list accounts for the most common changes that occur in the last months, weeks and days of life.

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Withdrawal from Family and Friends

In the process of accepting their own mortality and approaching death, patients often begin to withdraw from their immediate surroundings and family members and friends closest to them. Even activities previously pleasurable to the patient may be abandoned as death nears. This process of separating from their earthly world while contemplating life and memories is a necessary part of the dying process for many patients. Patients experiencing the final stages of a terminal illness frequently decline visits from family and friends. Visitors can easily exhaust a patient and leave the patient feeling as if they are responsible to entertain them. When visitors are permitted, patients often act reserved and introverted. Additionally, patients who have had a long day of visitors often display increased fatigue and exhaustion the following day. This may result in the patient sleeping much of the day, being unable to awaken easily, or not communicating verbally.

During this time, patients require privacy. It is necessary to respect a patient's wishes for solitude and quietly express love to the patient during this period of withdrawal. Patients nearing the final phase of terminal illness are very sensitive to what is communicated by those around them—both verbally and non-verbally. Calmly sitting nearby, holding hands, or offering silent prayers are ways to remain engaged with a loved one who is withdrawing. Providing safe, peaceful and comforting surroundings allows the patient the time needed to reflect on life closure.

Loss of Appetite and Weight Loss

As the body begins a natural decline, an individual's energy needs also decline. The energy required by the body to process food becomes greater than the energy the body can derive from it. As a result, patients often experience a loss of appetite and routine eating habits change. Patients frequently refuse full meals and large amount of liquids and request smaller quantities of food items that are soft and bland, such as puddings, scrambled eggs, or hot cereals. Favorite foods are also of little interest as the body declines.

We are taught at a young age that food is a fuel that gives the body energy and helps sustain life. Family and friends want to nourish their loved one with plenty of good food in the hopes that the patient will begin to feel stronger and possibly recover or live longer. While caregivers are often troubled by the patient's loss of appetite and subsequent weight loss, it is important they understand the patient's refusal of food to be a signal that nourishment must be derived in other ways—through the mind, soul and spirit. Additionally, they should be aware that the body naturally requires less food and drink as it declines. Caregivers can offer frequent sips of liquids and ice chips, or small bites of ice cream, pudding or other soft foods.

Refraining from force feeding and following the patient's food requests will enhance comfort. Forcing a patient to eat or making them feel guilty if they refuse food strains the patient-caregiver relationship and may lead to patient isolation. Patients who are declining require reassurance that loss of appetite is accepted. This respect and acceptance ultimately enhance patient comfort.

In the last 2-3 days of life, the patient may be unable to swallow, resulting in the inability to take medications by mouth. At this time, caregivers can apply balm or petroleum jelly to the lips to keep them moist and use mouth swabs dipped in cool water to keep oral membranes hydrated. These measures further ensure comfort.

Declining Metabolism and Excessive Weakness, Fatigue and Sleep

As the patient's food/fluid intake and metabolism decline, the body begins to display other changes. Body temperature lowers by a degree or more, blood pressure slowly lowers, and the pulse becomes irregular and may slow down or speed up.

As these changes occur, less oxygen is available to the muscles, resulting in increased weakness. It requires more effort to complete everyday tasks that were previously easy to accomplish. Patients often display discouragement or depression as they resolve to ask for assistance with bathing, walking, and eating. Caregivers assisting with daily physical tasks must remain sensitive to the patient's feelings.

Patients may begin to sleep 12-20 hours each day and may be difficult to awaken. Even simple activities become difficult, such as changing position, holding a cup, or sipping from a straw. As the fatigue and amount of sleep per day intensifies, the patient's awareness of immediate and even familiar surroundings begins to fade.

Allowing the patient to sleep without interruption is essential as the body and mind decline. However, keep in mind that a patient's sense of hearing is believed to remain intact up until the time of death. Therefore, even if the patient appears unresponsive, presume all verbal communications can be heard.

Mental Confusion or Disorientation

During the progression of terminal illness, a patient's level of awareness often changes frequently and unexpectedly. As the body adjusts to a slower metabolism, vital internal organs also slow down, including the brain. When a patient becomes confused, it can be due to decrease of oxygen to the brain resulting in the inability to recognize familiar people or places, or the current time of day or year. Also, patients may hear voices or see visions. This type of disorientation is common.

As mental capacity declines, the patient may no longer speak or answer questions, and their responses may be slow and difficult to comprehend. Responding to or openly conversing with people who can't be seen in the room by others is common. Often these people are ones who have already died. Hallucinations and visions, especially if they are of deceased loved ones, can be comforting to the patient and the caregiver.

Caregivers and visitors are encouraged to always identify themselves and speak softly and calmly to the patient, while not placing expectations on the patient. A reassuring voice and gentle physical presence provide much comfort. Caregivers should never negate what a patient is saying or seeing, or debate with them. This confused state becomes the patient's reality. It is often a pleasant and comforting experience and may be a sign that the patient's mind is at peace with joyful and happy thoughts. Attempting to convince a pleasantly confused patient that a loved one isn't there can make that person agitated or combative.

If the patient begins to express, verbally or non-verbally, upsetting or disturbing experiences, caregivers are encouraged to gently stroke their arm or hold their hand, while speaking calmly in a soft reassuring voice and reminding them of who you are, where they are, and what day it is.

During periods of confusion, a patient's favorite music or prayer may help to provide familiarity and comfort.

Restlessness

It is common for patients to become restless or agitated and make repetitive motions. For example, they may pick at the air, bed sheets or clothing. While these movements and actions may seem pointless and do not make sense to caregivers and visitors, they can be a sign of decreased oxygen to the brain or of physical stress such as pain, nausea, distended bladder or constipation.

During periods of restlessness, caregivers must remain calm and stationary as they assess the needs of the patient. Caregivers must refrain from the desire to interfere or restrict a patient's restless motions, but instead strive to protect the patient from physical injury. Proper pain and symptom management is crucial to soothe a restless patient.

Restlessness can also be a sign that the patient is experiencing emotional stressors such as anxiety or spiritual distress. Praying with the patient or calling clergy to the bedside to meet one on one with the patient may help to alleviate patient fears and instill a sense of peace and confidence. Caregivers may also need to give the patient permission to 'let go' so that rest may follow.

In some cases, a patient may experience ‘terminal delirium’ during the last days or hours of life. Terminal delirium is defined by heightened restless activity and intense confusion that is often accompanied by hallucinations and aggressive behavior such as striking out or screaming at caregivers or attempting to climb out of bed or leave the room. Keeping the patient safe and protecting from injury is the top priority. Utilizing medications prescribed by the patient’s physician specifically to treat terminal delirium also assists in alleviating these distressing symptoms. Non-medical interventions include keeping the room safely, but not brightly, lit (bright light can increase restlessness) and maintaining a quiet room by avoiding loud noises and multiple visitors.

Difficulty Swallowing

As the body declines, the reflex that controls swallowing becomes weaker. Patients often experience difficulty swallowing and may even develop fears when taking food or fluids by mouth.

Caregivers are encouraged to offer small amounts (half a teaspoon) of food or fluid and observe the mouth and throat to see if swallowing has taken place. Also, to enhance patient safety, caregivers should feed a patient only after the patient is placed in an upright position, with head elevated, straight and not turned to the side. Caregivers must never orally feed or hydrate a patient who is unable to awaken fully to swallow, is unconscious, can no longer hold their head up, or remain upright, as the risk of aspiration of food/fluid into the lungs is increased.

A patient’s food tolerance most often progresses from solid foods to soft foods, and then from liquids (soups and dietary supplements) to ice chips and water/juice spooned or sucked from a straw. The sucking reflex often remains intact until the last days/hours before death.

Difficulty swallowing can hinder the patient’s ability to swallow oral medications. When this occurs, alternative medications or modes of delivery are available. For example, some medications can be crushed, and capsules opened and mixed with pudding, yogurt or like foods, and many pharmacies can manufacture medications to be given as drops under the tongue, patches for the skin, or topical creams and gels applied directly to the skin.

Elimination

As weakness increases and circulation of blood and oxygen diminish, the muscles that control the bowel and bladder are also affected. These muscles often begin to relax and “incontinence” (involuntary loss of urine or feces) may occur. The patient may experience embarrassment as a result of incontinence. Caregivers must offer dignified and respectful care.

Additionally, as the patient's oral fluid intake diminishes the amount of urine produced decreases. Urine becomes dark in color, indicating that the kidneys are shutting down. At times, a urinary catheter is necessary to drain the bladder and keep urine away from the patient's skin.

As the kidneys shut down, body fluids often accumulate in areas of the body that are away from the heart, such as the patient's feet and ankles. However, the fluid may also accumulate in the patient's face, hands, or torso. The skin begins to work to eliminate toxins from the body. As a result, the patient may complain of itching over different parts of the body and may experience increased sweating. Offering the patient warm baths, frequent linen changes, frequent repositioning, or cool cloths for the face, armpits or groin may provide relief from skin irritations.

Keeping the skin clean and dry is essential to comfort. Incontinence and sweat can lead to skin rashes or open sores that lead to further discomfort.

While daily bowel movements are not expected as a patient declines, too many days between bowel eliminations can result in problems and increased discomfort. Therefore, caregivers are encouraged to keep track of each bowel movement. As food intake decreases, smaller less frequent bowel movements can be expected.

Cooling Body Temperature and Skin Color Changes

In the days and hours before death, blood circulation draws back from the body's arms and legs as vital organs work hard to retain circulation. Mechanisms that control the body's ability to control its temperature will start failing. Hands, feet, fingers, and toes become cool to the touch. Lips and nail beds may also look more pale or bluish. At times, the patient may complain of feeling cold as circulation declines. Warm blankets provide comfort if needed. Also, it is important to avoid drafts that may cause the body's temperature to fall too fast and cause shivering.

The patient's skin may develop a distinctive pattern of blotchy pale purplish/reddish/bluish coloring called mottling. This is one of the later signs of approaching death that results from a reduction in blood circulation. Mottling is often first detected on the soles of the feet, toes and knees, and may slowly work its way up the legs, torso, and arms.

Labored Breathing

Changes in breathing patterns are common as patients decline.

Intermittent use of oxygen is often beneficial if breathing becomes difficult, or irregular due to anxiety. Also, a ceiling or floor fan blown over the patient's body may give the sensation of being in fresh air, providing comfort and relief. Furthermore, keeping the head of the bed elevated can enhance breathing.

As a patient approaches death, breathing often becomes irregular, shallow and labored. The exhalation (out-breath) is longer than the inhalation (in-breath). For some patients, a distinctive pattern of breathing, known as Cheyne-Stokes respirations, occurs. Cheyne-Stokes respirations consist of loud, deep, and rapid respirations (up to 30-50 per minute) that involve the whole rib cage, followed by a pause in breathing (apnea) for a period of approximately five seconds to as long as a full minute. Following this period of apnea, the loud, deep breathing resumes. The patient is not aware of this altered breathing pattern. The cycle of loud breathing with pauses may continue for a few days, several hours or minutes until death occurs, and can be stressful for caregivers to observe.

Sometimes congestion and excessive secretions create coughing or loud, gurgling sounds during inhalation and exhalation. These sounds are often referred to as the “death rattle.” When a patient can no longer swallow, this “rattle” is caused by the accumulation of saliva in the back of the throat. While the noise can be distressing to caregivers, it does not seem bothersome to the patient. Many patients continue to sleep comfortably, unaware of the loud sounds of their breathing. If a patient appears to be sleeping comfortably, loved ones should simply allow them to rest. Because the pool of secretions is too far down the throat, the use of suctioning devices is not recommended. Suctioning can result in increased oral secretions. It is sometimes beneficial to reposition the patient with their head to the side to allow secretions to naturally drain from the mouth.

Changing the patient’s position often alleviates noisy respirations. Elevating the patient’s head with pillows, elevating the head of the bed, or gently rotating the patient’s head or body slightly to the side may lessen audible respirations. Keeping the patient’s mouth and lips moist with mouth swabs, a wet cloth or lip balm also lessens noisy breathing. Additionally, oxygen and a room vaporizer add moisture that quiets breathing.

Unexpected Alertness and Increased Energy

As previously discussed, a few days before death a patient may stop interacting with loved ones completely. Surprisingly, however, in the last days or hours, a patient may experience an unexpected period of clarity, lucidity and energy. During this surge of energy, which can last less than an hour or up to 24 hours, the patient may wake up, become alert, and eat, talk or spend quality time with loved ones. This is a very special time for final spiritual practices and mental preparations which can be shared with loved ones.

As quickly as it occurs, the period of attentiveness grows faint, and the patient again returns to an unresponsive state. Caregivers should treasure this fleeting period of alertness, because, once it passes, the patient is usually moving closer toward death.

Signs of Imminent Death

In the days or hours prior to death, patient symptoms often become more intense. These symptoms include:

- Little or no bladder or bowel activity
- Occasional grimaces, groans, or scowls
- Eyes may tear or become glazed
- Glassy fixed stare with large pupils
- Unresponsive to voice or pain
- Unable to swallow
- Unconsciousness or drifting in and out of consciousness
- Faint or irregular pulse and heartbeat
- Falling body temperature
- Mottling of the skin of the knees, feet, and hands (once the mottling starts, death often occurs within 24 hours)
- Very rapid or very slow breathing through mouth (often with rattle) with pauses of 20-50 seconds between breaths

Saying Good-bye

It is often difficult to determine when the time has come to call family and friends to the bedside to say a final goodbye. When it becomes evident that death is near, family members and close friends should be notified and given the option to visit the patient one last time. This also allows family and friends the opportunity to support one another.

Clinical Death

Clinical death is hallmarked by the following:

- No breathing (chest does not move)
- No heartbeat (no pulse)
- Pupils large, do not change
- Sometimes release of bowel or bladder

Embracing the Journey

Caring for a loved one facing a terminal illness is a very difficult task, both physically and emotionally. Family members, friends, and other caregivers play a vital role in providing comfort and support to someone entering the final phase of life. Although dying is a natural part of life, many family and friends do not have experience caring for someone who has weeks or days to live. As caregivers attempt to meet the ever-changing physical and emotional needs of their dying loved one, fear and feelings of uncertainty are common. Understanding and recognizing the symptoms of dying prepares caregivers for the changes their loved one will be experiencing. The information provided in this booklet is intended to teach and guide caregivers, while enhancing caregiver confidence.

Being well informed of these signs and symptoms also assists patients and their loved ones to reach acceptance of the impending death. Enhanced acceptance empowers family, friends and other caregivers to surround a loved one with comfort and peace, enabling their loved one to experience a natural death in God's time—a beautiful gift and privilege.

Help is Available:



Assistance for the medically vulnerable and their loved ones and caregivers in the brokenness of our current healthcare climate

HAO HELPLINE

1-888-221-4256

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**ABOUT THE AUTHOR:
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Dr. Krebs is a graduate of Robert Morris University's Doctor of Nursing Practice Program with twenty-eight years of commitment to care of individuals living with advanced and terminal illnesses. Certified as an Adult Nurse Practitioner, Dr. Krebs has worked in both inpatient oncology and out-patient palliative/hospice care settings. Focusing on providing patients with relief from the physical symptoms and stress a progressive illness brings, Dr. Krebs strives to improve the quality of life for both the patient and family members.

In 1997, Dr. Krebs began the first faith-based, non-profit hospice serving Pittsburgh and surrounding counties-*Good Samaritan Hospice*. Additionally, Dr. Krebs' vision to enhance care of the dying was the driving force for building *The Good Samaritan House*, the first free-standing hospice residence in southwestern Pennsylvania.

Embracing the Vatican's teachings on care for individuals with advanced and terminal illness, in May 2007, Dr. Krebs incorporated *Catholic Hospice and Palliative Services*. From 2007 to 2019, she served as the director of this pro-life non-profit hospice and palliative care agency in Pittsburgh, caring for all faiths while upholding the end of life teachings of Pope John Paul II.

Dr. Krebs remains dedicated to providing excellence in palliative and hospice care and spearheads education for both healthcare professionals and healthcare consumers regarding Medicare Hospice Law, Medicare Hospice Fraud and Abuse, and Hospice Patient Rights and Entitlements.

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**Judie Brown,
President, American Life League**

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