

CROSSING

A GUIDE TO CARING IN THE LAST DAYS OF LIFE



A POEM BY HENRY VAN DYKE
COMPARES THE EXPERIENCE OF DYING
TO A SHIP MAKING A JOURNEY FROM
ONE SHORE TO ANOTHER. THE SHIP
BEGINS TO GROW SMALLER TO THOSE
ON SHORE AS IT GLIDES AWAY, FINALLY
MOVING OUT OF SIGHT. IT IS GONE
FROM SIGHT, BUT ITS ACTUAL SIZE HASN'T
DIMINISHED. THE SHIP ARRIVES, IN ALL
ITS WHITE-SAILED BEAUTY, TO THOSE
WAITING ON THE OTHER SIDE.



As a caregiver to someone who is living his or her last days, you are witness to the readying of a journey from one shore to another. Each person's final days and hours are unique and unpredictable, but there are signs that can help you better understand and navigate this process.

At Agape, we are here to help you and your family during this time. Please get in touch with your care team with questions, concerns or for additional support.

WE ARE HERE FOR YOU: 720.482.1988.

How do geese know when to fly to the sun? Who tells them the seasons? How do we, humans, know when it is time to move on? As with the migrant birds, so surely with us, there is a voice within, if only we would listen to it, that tells us certainly when to go forth into the unknown.

— *Elisabeth Kübler-Ross, M.D.*



WHAT'S NATURAL?

As control over the physical side of life diminishes, it's natural for people who are dying to think about larger issues, such as relationships, spirituality, tying up loose ends, and their life's impact and legacy. They can have insights, deepen relationships, find healing and achieve a sense of completion.

The process and experience varies from person to person and family to family. Practitioners who work with people in the last stage of life will say that even amidst great difficulty and sadness, this can be a rich time of coming together, healing and even hope.

SAYING THE FOUR THINGS

Please forgive me. I forgive you. Thank you. I love you...
Comprising just eleven words, these four short sentences carry the core wisdom of what people who are dying have taught me about what matters most in life.

— *Dr. Ira Byock, "The Four Things that Matter Most: A Book About Living"*

PULLING AWAY

Withdrawing from family, friends and the physical world is a natural part of dying. This may happen weeks or days before death. A person may spend more time asleep than awake, often finding less of a need to communicate. It's natural for people at this point to seem unresponsive, even appearing to be unconscious.

While often difficult for outsiders, this separation is a natural part of the preparation process. Here are some things you can do as a caregiver:

- Plan visits for times of day when the person seems most alert.
- Speak in your normal tone of voice, and say the things you want to say. Hearing is believed to remain intact, even when other senses are not.
- Hold his or her hand gently.
- Identify yourself, and let the person know what you are going to do before you do it.
- Try not to say anything in front of your loved one that you wouldn't say if he or she were awake.
- Be present with the person who is dying, and know that it is okay to sit in silence.

COMMUNICATION WITH FAMILY

Family dynamics, trying in the best of times, can become intense when a loved one is facing the end of life. Family members' responses may vary, based on their relationship to the person who is dying or their unique method of coping. One sibling may stay close to the bedside, offering help. Another may find the situation overwhelming and stay away. An adult child who lives out of town may feel guilt about not being present and offer a stream of "helpful" information or advice in order to feel connected.

This time demands tremendous emotional, physical and mental energy. It is also sacred, a brief interlude for family to come together and focus on what's most important. Extend grace to one another. Support each other, encouraging family to be a part of this experience as they are able. Often, one person has the role of primary caregiver. If that is you, express your wishes and what you need in terms of support.

Your loved one is in the midst of a process, crossing from one place to another. As a family, you can extend the gift of peace by creating an environment that is free from tension and discord. If you would like help, please don't hesitate to contact us. Our experienced social workers and chaplains can gently support you through this time.



CHANGES

The following signs and symptoms are typical when a person's body is preparing for death. They don't occur at the same time or in the same way for everyone but are general indications for the final stage of life.

COOLNESS, as a person's body temperature changes. Hands, arms, feet, and then legs may be increasingly cool to touch. Skin color may change, which is a normal indication that circulation of blood is decreasing to the body's extremities and increasing for vital organs.

You can use a blanket to keep your loved one warm (avoid electric blankets). Some caregivers will warm a blanket in the dryer for added comfort.

DISORIENTATION may lead a person to be confused about time, place, and the identity of people, including close and familiar people.

While difficult, try not to take this shift personally, knowing that your loved one will benefit from your continued attention and love. Speak softly and clearly. Tell the person what you are about to do and why. For example: "I'm going to give you some medicine to help with pain."

INCONTINENCE, as muscles in the bladder and bowel areas relax.

Ask your hospice caregiver the best way to attend to this and keep your loved one clean and comfortable.

CONGESTION, marked by gurgling sounds from the throat. This noise can be loud and disconcerting, sounding like a collection of rolling marbles. This typical change is due to the decrease of fluid intake and an inability to cough up normal secretions.

This noise, while difficult for loved ones to listen to, does not indicate new or severe pain. It's natural to want to suction with the thought of relief, but this only increases secretions and can cause sharp discomfort.

You can gently turn a person's head to the side and allow gravity to drain the secretions. Wipe the mouth with a moist, clean cloth.

RESTLESSNESS, marked by repetitive motions, like pulling at bedding or clothing.

Allow these motions and avoid interfering or restraining, as long as you're sure your loved one is safe. Such repetitive motions may be therapeutic for a person working through this process. You can speak in a quiet voice, lightly massage the forehead, read or play soothing music.

CHANGE IN BREATHING PATTERN (APNEA), perhaps shallow breaths with periods of no breathing from five to 30 seconds, even up to a minute. A person may also experience periods of rapid shallow breathing.

You may elevate the head and/or turn a person onto his or her side, which may bring comfort. Hold your loved one's hand and speak gently.

FLUID AND FOOD DECREASE, with a person wanting little or no food. This is the body's natural response to conserving energy. Families often have trouble with this change, feeling as if allowing a loved one to stop eating and drinking is deprivation. At this point, food and water actually can cause discomfort and distress. You may also see a decrease in urine output or urine that is dark in color.

Your Agape nurse can give you guidance in regards to ice chips, frozen Gatorade or juice, which can be refreshing. Use glycerin swabs to help keep the mouth and lips moist for comfort. Use a cool, damp washcloth on the forehead, if tolerated, for comfort.

SHORT PERIOD OF ENERGY, some patients have been known to rally with a surge of energy where, even days or hours away from death. They may be more alert and coherent than in previous days, wishing to eat, sit up and communicate.

If this happens, enjoy the time, simply being present and open to what it may offer.

HOLDING ON & LETTING GO

A person living the last days and hours of life is withdrawing and may seem different from the person you've known. Even so, your loved one may need something important from you: *permission* to let go.

People may try to hold on, even if it brings prolonged discomfort, waiting for reassurance. Many do so because they are seeking an answer to the question: Will they be all right when I am gone?

Your ability to answer this question and release the person you love from concern is a gift. *You may kiss, hug, or hold your loved one. Cry and say whatever you need to say. Then extend permission: We love you. We will miss you, but we will be all right. When you are ready, it's okay to go.*

At Agape, we are here to help. If you have questions or concerns, please get in touch at 720.482.1988.

SUMMARY: WHAT TO EXPECT

Each person's situation is unique, but the following are characteristics and symptoms people often experience prior to death.

One to Three Months Prior

- Pulling away from friends, family and the physical world
- Focus on spirituality and meaning
- Reviewing life and legacy
- Eating and drinking less
- Communicating less

Weeks Prior

- Disorientation or confusion (people, time, place and circumstances)
- Further decrease of eating and drinking
- Changing body temperature
- Communication with people who are not there or seeming to "look beyond" the room
- Increasing sleep
- Skin color changes

Days or Hours Prior

- Restlessness
- Nearly constant sleep
- Congestion
- Labored breathing with rattling noise
- Decreased or no urine output
- Lowered blood pressure



FINAL MOMENTS & BEYOND: WHAT TO EXPECT

No one can know the precise moment of death. Some people have been known to hold on until a loved one from out of town arrives, or until they complete a spiritual or emotional task, even if this process isn't apparent to people around them. Some will wait to "let go" when no one is present, while others take their final breaths in the presence of family or caregivers.

Minutes prior to death, your loved one likely will take shallow breaths with longer pauses in between. The mouth may remain open. He or she will likely not respond to you and may be unable to close his or her eyes completely. These are manifestations of a process: the separation from the physical body.

At the time of death, there is no breathing or heartbeat. Eyes may remain open. The body relaxes, resulting in the release of the jaw and typically bowels/ bladder. As much as you may feel prepared, the loss of a loved one is supremely difficult, leaving some feeling panicked, in a state of shock or several emotions at once. It is appropriate and healthy to express your emotions, to hug and cry with friends and family and to take all the time you need to say goodbye.

Empty-handed I entered the world,
Barefoot I leave it.
My coming, my going
Two simple happenings
That got entangled.

— *Kozan Ichikyo (d. 1360)*

PRACTICAL MATTERS: WHAT NOW?

If you are not present at the time of death: If your loved one is in a nursing facility, the nursing staff will contact your family. If a hospice team member is present, that individual may be the one to contact you.

If you are present and an Agape team member is not with you, please contact Agape. There is no need to call 911 or notify law enforcement at this time. Agape staff will help you with the necessary protocol, according to your wishes.

Regardless of the situation, be assured that our staff will do everything needed to help you and your family this day – and in the weeks and months ahead through bereavement services. Initially, Agape support may include:

- Confirming the death and completing a death certificate (if facility staff has not done so)
- Caring for your loved one's body (bathing and preparing the body, if family desires).
- Notifying the doctor and care team
- Disposing medications and arranging for removal of medical equipment
- Contacting the mortuary, if desired by family
- Other practical help as needed or requested.

This is the time to attend to special customs or ritual based on your religious, ethnic, cultural background or your family's wishes. You can let your hospice team member know when you would like the mortuary staff to arrive. Let the people from the funeral home know whether or not you wish to be present when they remove the body. Remember, there is no right or wrong decision, but only what feels comfortable to you and your family. The mortuary will help guide you through making arrangements for services.

Agape Healthcare: 720-482-1988

AFTERWARD

Death can come like a thief in the night or after a long period of illness or struggle. In any case, each loss is defined by two states: Before and After. Your loved one may be gone, but you will continue on a journey: honoring and remembering, saying goodbye and grieving.

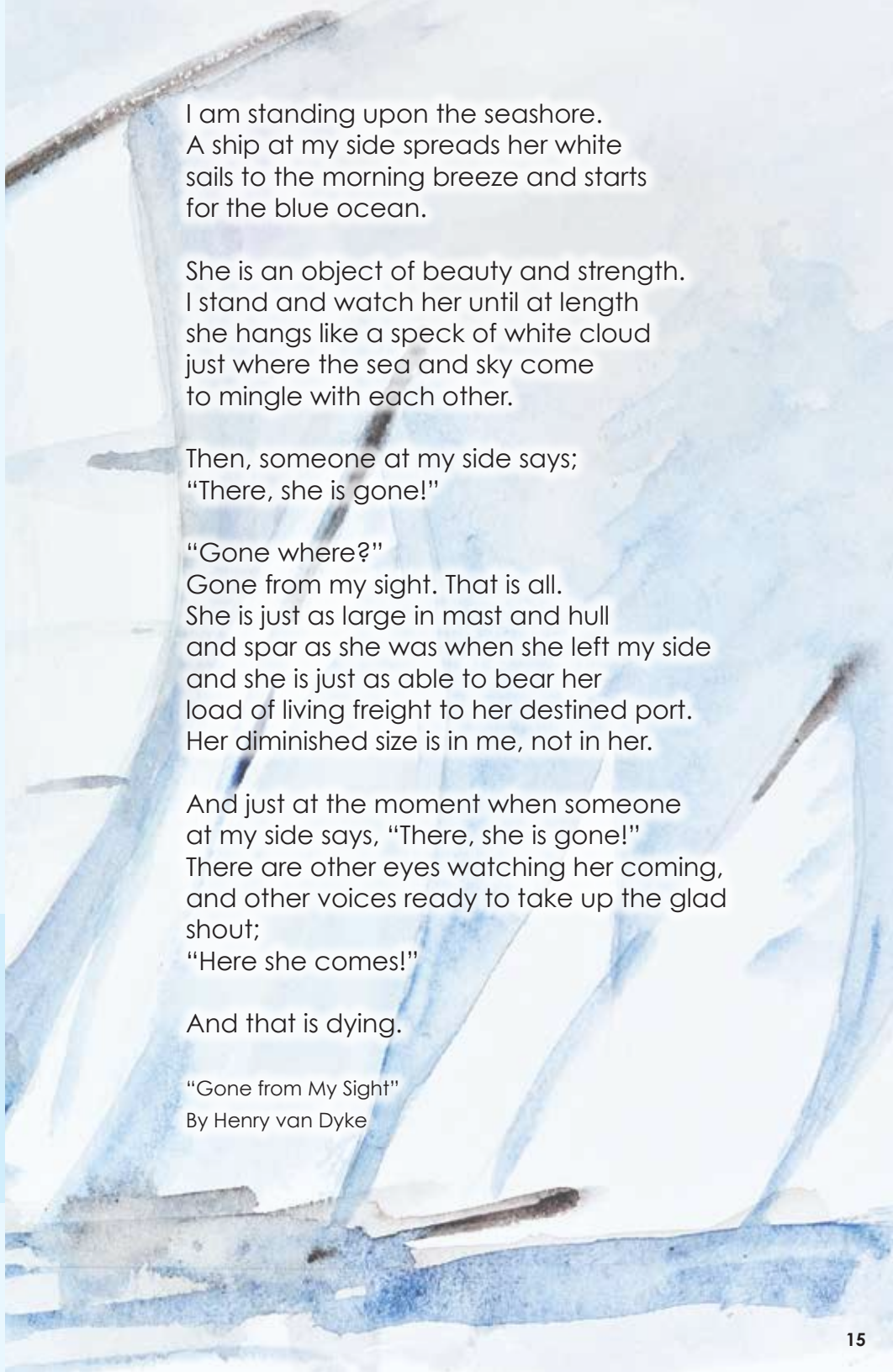
Grief is a natural involuntary response to loss, and everyone grieves differently. Know that losing someone is a traumatic event that requires time to heal, though at this time you may not feel like you will ever be whole again. The journey that follows as you grieve will not be tidy, predictable, or easy, but it is one we all must take.

Please know that you don't have to go it alone. You can find support and guidance from many sources, including Agape Bereavement Services. Don't hesitate to contact us, or you can go to our website for resources to help you and your family through the time ahead.

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You will heal and you will rebuild yourself around the loss you have suffered. You will be whole again but you will never be the same. Nor should you be the same nor would you want to.

— Elizabeth Kubler-Ross and John Kessler



I am standing upon the seashore.
A ship at my side spreads her white
sails to the morning breeze and starts
for the blue ocean.

She is an object of beauty and strength.
I stand and watch her until at length
she hangs like a speck of white cloud
just where the sea and sky come
to mingle with each other.

Then, someone at my side says;
"There, she is gone!"

"Gone where?"

Gone from my sight. That is all.
She is just as large in mast and hull
and spar as she was when she left my side
and she is just as able to bear her
load of living freight to her destined port.
Her diminished size is in me, not in her.

And just at the moment when someone
at my side says, "There, she is gone!"
There are other eyes watching her coming,
and other voices ready to take up the glad
shout;
"Here she comes!"

And that is dying.

"Gone from My Sight"
By Henry van Dyke

AGAPE | ä-‘gä-pā |

Unselfish love of one person
for another. Unconditional love.



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