

Helpful Tools for End of Life



Home and Hospice Services

Understanding Disease Progression and Signs of Dying

Attending to the needs of a loved one who is dying can certainly provoke a great deal of anxiety and be emotionally upsetting. The following signs and symptoms of approaching death are offered as a guide to help families understand the natural progression of the dying process. Here we will identify some of the changes that may occur in the final days and hours of life and how you can respond. It is impossible to predict exactly which signs and symptoms will occur; however, the following signs and symptoms are common as bodily functions begin to shut down and death nears.

1. WITHDRAWAL

It is natural not to feel like socializing when a person is weak and fatigued. Speech may become slow or conversation difficult. Your loved one may even lose the ability to speak altogether. It can be disturbing to the dying person to have more than a few people visit at a time.

HOW TO RESPOND

Keep the environment quiet and calm, and reassure your loved one that it is okay to sleep. Limit visitors to brief periods of perhaps 15–20 minutes.

2. SLEEPING

Your loved one may spend an increasing amount of time sleeping and become unresponsive. At times, it may become difficult to arouse him or her. This is due, in part, to changes in the metabolism of the body. Hearing is said to be the last of the five senses to be lost. Hearing may remain very acute although the person may appear to be asleep.

HOW TO RESPOND

Be available for those short periods of time when your loved one is awake. Sit with your loved one; gently hold his or her hand. Speak softly, naturally and reassuringly. Do not say anything in his or her presence you would not say to him or her when awake.

3. CHANGE IN INTAKE OF FOOD AND FLUIDS

As your loved one's health declines, there will be little interest in eating and drinking. The reflexes needed to swallow may be sluggish.

HOW TO RESPOND

Allow your loved one to eat and drink whatever may be appetizing. Do not force him or her to eat as it may result in choking or inhaling food or fluids (aspiration). Remember that any nourishment should be taken slowly and in small amounts. Do not use a straw for fluids as it can also lead to aspiration. When your loved one can no longer eat, you may try offering him or her small chips of ice or popsicles. The use of oral swabs or sponges can be helpful.

4. RESTLESSNESS AND DISORIENTATION

Your loved one may make restless and repetitive motions such as picking or pulling at sheets or clothing. Your loved one may seem confused about time, place and identity of people around him or her, including close relatives and friends.

HOW TO RESPOND

Talk calmly and reassuringly with your loved one so as not to startle or frighten him or her further. Lightly massaging the hand/forehead, reading to the person, or playing soft music can also have a calming effect. Do not try to restrain such motions unless you become concerned for his or her safety—like falling out of bed. If you become concerned, speak with your hospice nurse.

5. INCONTINENCE

Your loved one may lose control of urine and/or bowels as his or her health declines and the muscles begin to relax. Just as food and fluid intake decreases, expect that urine output will decrease. Urine becomes more concentrated and may be darker like the color of tea. This is due in part to decreased fluid intake and to a lessening of circulation through the kidneys.

HOW TO RESPOND

Make every effort to keep your loved one clean and dry. The hospice nurse may suggest that a urinary catheter be inserted. Diapers or pads may help protect the bed and assist in keeping your loved one comfortable.

6. BREATHING PATTERN CHANGES

Your loved one's usual breathing patterns may change. Breathing may become shallow, irregular, fast or abnormally slow. He or she may develop a pattern of breathing irregularly with shallow respiration or periods of no breaths for five to 30 seconds, followed by a deep breath. He or she may also have periods of shallow and rapid panting. Sometimes there is a moaning-like sound on exhale. Be assured that this is not a sign of distress, but rather the sound of air passing over relaxed vocal chords.

HOW TO RESPOND

Elevating your loved one's head and/or turning your loved one onto his or her side may help him or her feel more comfortable. Contact your nurse to explore the need for changes in medication to provide comfort.

7. CONGESTION

Oral secretions may become more profuse and collect in the back of the throat. Your loved one may develop gurgling sounds coming from the chest.

These sounds can become loud and distressing to hear. These normal changes come from fluid imbalance and an inability to cough up normal secretions. Although distressing to you and others present, these secretions do not cause discomfort to your loved one.

HOW TO RESPOND

It may be helpful to raise the head of the bed or use pillows to raise the person's head so that the secretions will not pool and stimulate a gag reflex. You may try turning his or her head to the side and allow gravity to drain the congestion. You can also gently wipe the mouth with a moist cloth. The hospice team may start medications to control the congestion.

8. CIRCULATION CHANGES

Due to changes in circulation, your loved one's arms and legs may become discolored and feel cold or hot to the touch. This may be especially noticeable in the extremities of the body where the color may change to a shade of blue. This is normal and an indication that the circulatory system is drawing blood away from the extremities and toward the core to support the most vital organs. Irregular temperatures can be the result of the brain sending unclear messages. Sweating may occur, and there may be an odor resulting from the many physiological changes taking place in the body. The heartbeat and pulse may become slower, weaker and irregular.

HOW TO RESPOND

If your loved one appears cold, take steps to keep him or her warm; however, do not use an electric blanket. If your loved one continually removes the covers, cover him or her with a light sheet. If your loved one feels flushed, use a cool washcloth on the forehead and under his or her armpits to cool them down.

9. VISIONS OR VISITS FROM DECEASED RELATIVES

In the final days or weeks, it is not uncommon for the dying to speak or report having spoken to people who have already died. They may see visions of places not visible to you. These are commonly referred to as hallucinations, and are sometimes attributed to oxygen deprivation to the brain or as a reaction to medication. However, the origin and meaning of these visions remain a mystery to medical science. These occurrences often signify that a person is detaching from this life and preparing for whatever may follow.

HOW TO RESPOND

Accept this as transitional time. There is no need to contradict, explain away, belittle or argue about what your loved one claims to see or hear. Listen with respect to whatever the person has to say; allow free expression of feelings and offer comfort through touching and/or talking reassuringly and calmly.

10. PERMISSION TO GO— SAYING GOODBYE

It is also common to see a dying person trying to “hold on” even though it brings prolonged discomfort. It seems that he or she is often waiting for reassurance that those left behind will be all right. A family’s ability to give their loved one permission to “go” is sometimes a final gift of great love.

HOW TO RESPOND

You may want to reassure your loved one that it is OK for him or her to go. Tell your loved one that everyone loves them and will miss them but that those who remain will be all right. Reassure him or her of your love and give your permission to let go.

Tears are a normal and natural part of saying goodbye and should be allowed to be expressed freely and without apology. Tears often express more eloquently than words about the love that endures.

It is also important to know that while it is a common wish of many family members to hold vigil and be present at the time of death, many people appear to wait to die until there is no one in the room.

11. AT THE TIME OF DEATH

When someone enters the final moments, his or her body begins the process of shutting down, which ends when all the physical systems cease to function. The series of physical changes described here are a normal part of the dying process, not a medical emergency that requires emergency services or invasive interventions.

It may be helpful for family members to discuss ahead of time what to do when the final moments arrive. At the time of death, breathing ceases, the heartbeat ceases, and the person cannot be aroused. The eyelids may be partially open with the eyes in a fixed stare, the mouth may fall open as the jaw relaxes, and there is sometimes a release of bowel and bladder contents as the body relaxes.

HOW TO RESPOND

Honor and express your emotions. Attend to your spiritual needs. Comfort one another. Refer to the information on the following page to help guide you as to how to proceed.

Call NorthShore Hospice with any questions or concerns at [\(847\) 475-3002](tel:847-475-3002).

What Can We Expect at the Time of Death?

WHAT TO DO IMMEDIATELY

If you suspect that your loved one has died, DO NOT call 911. Contact NorthShore Hospice through the 24-hour patient line—**(847) 475-3002**—and a registered nurse will come to your home or the assisted living facility where your loved one lives. *(If you call 911 without calling NorthShore Hospice, you may be responsible for the ambulance and emergency room bill.)*

At that time, the nurse will record the time of death, assist with making procedural calls and, encourage and assist with the immediate and proper disposal of all narcotic and prescription medications.

THINGS THE HOSPICE NURSE WILL HELP ADDRESS

1. Contact the funeral home or cremation society you have chosen. (It is important that you have a plan in place prior to the time of death.)
 2. Contact the coroner if the death occurs in Lake County.
 3. Contact the medical equipment company to arrange a time to remove equipment that is no longer needed.
 4. Contact your primary care physician and the rest of your NorthShore Hospice team to inform them of the date and time of death.
- You will likely feel overwhelmed and unsure of what to do at this time no matter how much you prepared or planned.
 - You may ask the funeral home or cremation society to delay arriving until family and friends have gathered.
 - You may want to bathe your loved one or to put some particular clothing on him or her.
 - You may want to say prayers, sing songs, play favorite music or take some time individually or collectively to say goodbye.

- Cultural and religious traditions important to your family will be honored to the best of our ability. Please inform the hospice team in advance of any personal desires for the end of life that are meaningful to you and your loved ones.

WHAT TO DO NEXT

After the body is removed, you will want to meet with the funeral home or cremation society to complete any unfinished details for the funeral or memorial service. Once you have a plan in place, you will want to notify relatives and friends. The funeral director will also assist you in submitting an announcement to the newspaper and in securing a number of certified copies of the death certificate (15 or more), which will be needed for some immediate and long-term tasks, including:

- Changing the deed on any property owned
- Changing the title/ownership of any vehicles owned
- Transferring assets in banks and other financial institutions
- Changing the primary name on credit cards
- Addressing what is required to execute the will
- Getting distributions from life insurance policies
- Canceling voter registration
- Securing government death benefits for survivors

Most of these tasks can be done over a protracted period of time. Your primary focus during the days and weeks surrounding the death of a loved one is to grieve. If you would like a hospice chaplain or team member to participate in the service, please contact them as soon as possible. Hospice team members make every effort to attend the services of their patients. For information about the availability of bereavement support services, please call **(847) 982-4364**.

11 Words to Help You Say Goodbye

*Sam was a hard worker and a good provider. He and Sally had been married for 63 years—and when she died, he noted that a light had gone out of his life. Sally had been in charge of the home and family. One of her daughters said that Sally set the emotional tone—she was the one the children talked to when there were problems. Sam could fix anything, except broken hearts. He used to say that he was incompetent with words of emotions. Three of Sam’s four children were frequent visitors as he declined. His daughters arranged for caregivers and kept the cupboards stocked. His older son took over the finances. The youngest son, Jon, lived on the other side of the continent. Since the death of his mother, he rarely visited, although he was aware of his father’s illness. Sam and Jon always had a rocky relationship. Jon was a photographer who took after Sally with his ability to read people and emotions. Before Jon’s visit, Sam’s daughter gave Sam a short book, *The Four Things That Matter Most: A Book About Living* by Ira Byock, MD. In the book, which Sam skimmed, he found 11 words that he could easily say to Jon. Both Jon and Sam found that the words began to repair a broken relationship.*

Dr. Byock suggests that 11 words might help us say goodbye, and then hello, a little more easily and cleanly. They are:

Please forgive me.

I forgive you.

Thank you.

I love you.

FORGIVENESS

In all relationships, it is easy to step on toes. In challenging relationships, there are usually bigger issues that have severed the bonds. We become entrenched in a position, waiting for peace offerings that never arrive. Forgiveness may not be readily offered, but it can have tremendous healing power.



When we ask for forgiveness, we recognize that we have not always been right or that our approach may not always have been the only way for another to go. We might admit we failed in a task or role in spite of all our best efforts. It is not even necessary to list all the failings, as one might in confession. A

person might state what he or she knows to be true, like “I demanded a lot” or “I always wanted the best for you,” before saying, “Please forgive me.”

“I forgive you” implies that a person can let go of grudges. A close relationship may still be elusive, but the anger and hurt feelings might be set aside. One might discover a sense of peace as a result of forgiveness. Remember, the act of asking for and granting forgiveness is the focus. Explanations can lead to retrenchment. Let simple, sincere words state the reality: “I’m sorry. Please forgive me.”

GRATITUDE

In all relationships, even the rocky ones, we give and we receive. Sometimes, as illnesses loom or death approaches, we become far more aware of the gifts we have received in this life—fidelity, friendship, amazement, grandchildren, one more day to breathe. In the opening story, Jon was not aware that his father carried a picture of Sally in his wallet. His father often showed the picture of his beautiful wife, and each time he noted that Jon had taken the picture as part of a high school photography class. Sam *spoke with pride* of his son the photographer, even though Sam rarely *spoke* to Jon. Sam found he could easily name the gifts Jon had given, starting with the photo and stretching across the years. He wound up saying, “Thank you for being my son.”

LOVE

We love those people who have shared our lives, even if the words are not easily spoken. Sometimes people need to hear or read the words. Sometimes actions just are not enough, partly because loving actions may have been overshadowed by hurts or

slights. Unfortunately, our brains hold on to angry, painful moments, while the loving tidbits can easily slip away, unnoted and unremembered. Again, the words do not have to be flowery or even spoken. A simple note might allow one to attest to a lifetime of gruff love. “Love ya” may suffice.

In the best-possible scenario, this might be a two-way street, with time for the other person to say his or her 11 words. But this is not necessary. Letters or cards can be used, or even an inscription in a book. Dr. Byock talks about the power of the words, for both the dying and the living. Words can repair relationships and bring a sense of peace. They can leave a legacy, while offering the truth to grieving people. Above all, when you make these 11 words your own, remember to KISS (**k**eep it simple and **s**incere).

A Celebration of Life

For thousands of years, a funeral/memorial service has been a means of expressing our beliefs, sharing our sorrow and acknowledging what a loved one has meant to us. A funeral or memorial service:

- Helps us acknowledge that someone we love has died
- Gives us an opportunity to say goodbye
- Honors the person's legacy as stories and memories are shared
- Provides a social support system for the family and friends of the deceased
- Offers hope for the living

In recent years, many people choose to hold a memorial service instead of a funeral. A *funeral* is conducted with the body present and is usually planned within a few days of death. A *memorial service* (without the body) can be delayed as long as you want to meet the convenience or needs of the family.

Many funeral directors will be glad to assist with memorial service planning, but there will be a charge for such services. However, many families have found it therapeutic and loving to take charge without the help of a funeral director. Having something to do takes away the sense of helplessness survivors often feel at a time of death.

Memorial services are conducted in a variety of ways. Those who adhere to a particular faith tradition may choose to participate in the rites and rituals that are practiced by their faith community. But memorial services are not only for the religiously observant. A service of remembrance can be completely designed around the life of a loved one.

Creating a unique memorial experience, whether for a few immediate family members or friends far and wide, is an opportunity to begin the process of healing for those who are grieving. Remember that funerals are for the living—for those who endure the trauma of losing a loved one.

PLANNING A MEMORIAL SERVICE

The major purpose of a memorial service is to recognize, honor and celebrate a particular life. There are a variety of possibilities for creating a unique service. Here are a few tips to consider when planning a gathering to celebrate a loved one's life.

THE SETTING

First consider what type of service will best reflect the personality and wishes of the deceased. Marcia was a leader in her church and had strong ties to that community, so it was logical that her memorial service was held at her beloved church. Harold lived a quiet life on the farm, tending to the fields that his family had farmed for generations, so his immediate family gathered on the hillside as the sun was setting, shared stories, said a simple prayer and buried his ashes. Larry was an active member of the American Legion, so his family planned a service that honored his many years of military service and included a party in the same building where he had participated in many legion events throughout his lifetime. Dean was an artist and musician, so his memorial service was held in an art gallery with many of his paintings hanging on the walls for people to enjoy.

WHO WILL COME?

Decide if there will be a public announcement in the newspaper or a social networking site, if the information will be shared through the "grapevine" or word of mouth, or if it will be by invitation only.

WHO WILL LEAD THE SERVICE?

A small gathering of family members can be more informal and spontaneous than a planned ceremony and can revolve around storytelling filled with both laughter and tears. If a more formal ceremony is planned, a clergy member, trusted friend or sibling may be necessary to preside over the service. Will there be one or more speakers to provide reflections on the deceased, or readers of poetry/scripture, or musicians? Roles for children may include handing out flowers or programs.

THE SERVICE ITSELF

If there are no religious dictates, you may want to pick a theme of remembrance that exemplifies the deceased's life. Will she be remembered for her civic activities, volunteering or excellent culinary skills? Will he be remembered for his love of gardening, charity work or practical jokes? Are there favorite readings of the deceased—Bible verses, Zen philosophy, quotes from political leaders or comedians? Did he or she leave any letters or instructional writings? Perhaps relatives and friends could be invited to write their own letters or memories to be read aloud during the service. There are a variety of ways to include everyone in the sharing of memories and honoring the person who has died: lighting candles, signing a guest book, bringing photos or mementos of the loved one and sharing with others, planting a tree. Be creative and have fun planning something that is unique to the one who has died.

PHOTOGRAPHS AND MEMORY BOOKS

Photographs and videos often help break the ice for teary family members and friends. As people look at the photos together, memories are stirred and life is celebrated. Consider making a photo collage to display in the gathering space or create a video montage of beloved photos to play at the service. If possible, include awards or special recognitions the person has received.

REFRESHMENTS

Sharing food during times of bereavement is a time-honored tradition. Whether it is casseroles shared at the person's home, a lunch at a restaurant, or simply cookies and tea after the service, eating together is an important part of sharing our grief.

IN CLOSING

We hope the guidelines provided here are helpful to you if you decide to plan a memorial service on your own. If you desire further assistance, please contact the NorthShore Hospice chaplains who are available to help plan or lead a memorial service for your loved one.



How to Write and Deliver a Eulogy

You have been asked to write and deliver a eulogy for a family member or friend. Admittedly, giving a eulogy can be a bit intimidating if not outright frightening. First, let us remind you what a privilege and honor it is to speak on someone's behalf. Know that there is a reason why you were chosen—perhaps others think highly of your ability to speak in public or you had a close relationship with the deceased, or both. Remembering that other people have confidence in you is encouraging, but then what? Whether you approach this task with humility or trepidation, if this is your first time to give a eulogy or the tenth, the following three questions are always worth reflection as you begin to organize your thoughts.

- Is it possible to summarize a person's life in 5–10 minutes?
- Where do I begin?
- What happens if I become emotional?

IS IT POSSIBLE TO SUMMARIZE A PERSON'S LIFE IN 5–10 MINUTES?

That's right, we said 5–10 minutes. From our perspective, 10 minutes is about all the time you should take to share your reflections. Typically, your eulogy is only one part of a larger ceremony. There may also be other speakers in addition to you. The truth of the matter is there is no way you can summarize anyone's life in such a brief amount of time, so do not try. Our point is, do not summarize. You do not need to give everyone a detailed outline of the deceased's life—facts by themselves are usually pretty boring anyway. If there are important dates or events that need to be mentioned, they can be printed in the order of service or memorial card. Think of it this way: Your eulogy should offer snapshots of the person's life. Your job is to communicate three basic points: 1. This person lived within the context of a specific family, culture and time period; 2. His or her life had an impact on other people (particularly you); and 3. He or she will be missed. Some facts are essential, but what you want to give voice to is the emotional connection

that those gathered feel for the deceased. We can do this best by sharing stories that give insight into the deceased's character and highlight his or her personal experiences. Try to capture the essence of the deceased in one or two stories. You may want to mention the things you admired about the person. If the deceased had a great sense of humor, use humor. If he or she was generous, explain how. Be honest—if the deceased had faults, you can simply acknowledge this in a subtle, even humorous way. Do not try to make the deceased into someone he or she was not. However, this is not the time to air dirty laundry or disclose embarrassing facts. Finally, you will want to communicate what you will miss the most about the person and acknowledge others who share in the loss.

WHERE DO I BEGIN?

If you are wondering if you should *write it out vs. wing it*, we always advocate having a written text. However, we do not think you should read from your script verbatim—in fact, we discourage that whenever possible. That being said, it is a good idea to at least have some notes that you can place on the podium prior to the start of the service. Having attended hundreds of funerals, we can tell you that few people can give a eulogy without at least having a few notes. Speaking extemporaneously or “off the cuff” usually results in the person stumbling for the right words, forgetting an important point and talking far too long! Remember that good stories need a beginning, middle and end.

You were chosen to speak on behalf of those gathered. As you begin to organize your thoughts, you may want to speak to a few people who knew the person well and incorporate some of their thoughts. Their stories may fill in some details or times of life for which you were not present. Choose two or three stories that capture what kind of person he or she was and will resonate with those gathered. As you are telling your stories, include details that place the deceased in a particular time or place: “During World War II,” “After her youngest child was born,” etc. You might begin with a summary

statement such as, “John was quite a character.” Then fill in the details and tell a story about *why* he was a character. Finally, you might conclude a particular story with your summary statement, “...and I think that’s one of the things I’m going to miss the most.”

We can think of another reason why you will want to write out your text—people will want a copy of it. Funerals and memorial services can be emotionally upsetting experiences for those who attend. They will treasure your reflections; they will want to revisit your words or possibly share them with someone who could not attend the service. You might even want to make a few extra copies and bring them with you to the service.

WHAT HAPPENS IF I BECOME EMOTIONAL?

It is difficult to speak from the heart about a loved one who has died and not become choked up. Those assembled may be tearful, and seeing them cry may affect you as well. If you do become emotional, stop for a moment and take a few slow, deep breaths. Your audience will be patient and understanding. You may want to have a glass of water placed nearby so that you can clear your throat and gather your composure. Practice many times in front of a mirror or with someone whose opinion you trust. If you have a chance to practice in the space where the eulogy will be given or with a microphone, all the better. The more times you practice, the more confidence you will have when the time comes to deliver it.

If you become emotional, remember this: Emotions are perfectly acceptable at this point! Tears often speak more eloquently than words. Someone you care about has died. And if you cannot regain your composure, someone you have preselected can take your script and finish the eulogy.

A FEW MORE THOUGHTS FOR YOUR REFLECTION

You may have strong personal beliefs about the existence of an afterlife. Did the deceased and those assembled share the same perspective? You will want to use your best judgment as to whether or not you should express those thoughts. In most cases, we think it is best to leave that kind of theological reflection up to the minister who will share it in his or her sermon. It would be perfectly acceptable, however, for you to express a hope for the future. You may want to include your hope for a future reunion with this person and all those who have died, or simply say that the memory of the deceased will continue to live on in the hearts of those who knew him or her.

On a practical note, if you have never attended a service in the deceased’s faith community, you may want to check with a clergyperson in advance to find out what to expect. You can also go to the library and check out a book titled *How to Be a Perfect Stranger: The Essential Religious Etiquette Handbook*, Fifth Edition by Stuart M. Matlins and Arthur J. Magida. It is a great book that reviews the customs of all the major faith traditions and offers instruction for how visitors should behave. You can also go online and read about the customs of various traditions before you attend. If the memorial service is not taking place in a religious setting, check with the person organizing for any pertinent details.

Finally, as you prepare your thoughts, keep in mind that if you write from your heart, you are less likely to go wrong. As you prepare and then deliver your eulogy, you might imagine that you are speaking directly to the deceased, giving voice for all those who are gathered. Do not worry so much about finding the right words. When you speak from your heart, those who are gathered will find comfort in whatever you say.

10 Things You Need to Know About Grief

1. GRIEF DOES NOT START THE MOMENT SOMEONE DIES

When a family receives the news of a serious or life-threatening illness, patients and their loved ones are confronted with a mix of reactions that is sometimes called *anticipatory grief*. In reality, it is hard to pinpoint exactly when grief begins. It may reach all the way back into childhood, to the very first awareness that you and your loved ones would not live forever. With every subsequent illness, including a terminal diagnosis or admission to hospice, we are confronted with the prospect of loss.

WHAT TO DO ABOUT IT

Acknowledge all the losses and honor the grief that you are feeling right now. Allow yourself time to absorb the full impact of what is happening. Take steps to comfort everyone who is struggling to come to terms with the news.

2. GRIEF TAKES LONGER THAN YOU THINK

Despite what you might hear in the media or popular culture, there is no timeline for grief. In fact, it dishonors the depth and length of a relationship to suggest that you should let go, move on or be over it in six to 12 months. Death leaves a hole in your heart that can never be filled. However, it is important to remember that grief changes over time. The depth of loss you feel right now will be tempered by focusing on the bond that endures beyond death.

WHAT TO DO ABOUT IT

Try not to worry about the future. Focus on the practical ways to cope with the moment at hand. Take it one step, one day at a time.

3. GRIEF IS NOT A PROCESS

Contrary to popular belief, there are no stages that a person should or must pass through in order to successfully resolve his or her grief. Negotiating through all of the stresses of life at a time when you

are emotionally distraught rarely proceeds in an orderly and predictable way.

WHAT TO DO ABOUT IT

Stop judging yourself because your grief does not look like someone else's. Allow your grief to unfold naturally and trust in your ability to adapt to the difficulties of life.

4. EVERY PERSON'S EXPERIENCE OF GRIEF IS UNIQUE

Remember that all members of a family have their own unique temperament and personality. They also have their own set of life stressors and their own relationship with the person who is threatened with this terminal diagnosis. We get into trouble when we make the assumption that everyone in the family will grieve in the same way.

WHAT TO DO ABOUT IT

Be patient with each other. Do not judge. Allow everyone the chance to grieve at their own pace and in their own way. Keep channels of communication open, and try to be supportive of everyone involved.

5. ADDITIONAL STRESSORS WILL MAKE GRIEF MORE DIFFICULT

Perhaps you or another family member has recently lost a job or one of your adult children is going through a divorce. Maybe the kids are having a hard time at school or the responsibility of caring for another elderly parent now falls upon your shoulders. All of these other life stressors happen at a time when you have less emotional energy to deal with them.

WHAT TO DO ABOUT IT

Remember to take time out for yourself and take advantage of all the stress-reducing techniques you can think of: Eat right, exercise and rest as much as you can. Ask for help. Remember that you cannot give what you do not have. Take time to recharge your batteries.

6. SOMETIMES YOU CANNOT BE THERE WHEN THEY DIE

Ideally, we would all like the death of a loved one to have a peaceful, Hollywood type of ending. The truth of the matter is, no one can accurately predict or control the time of death. Sometimes a loved one will die in the middle of the night. Sometimes he or she dies the moment you step out of the room. Realistically, with family and friends spread out across the country, we are not always able to be with a loved one at the time of death. Sometimes family members are left with feelings of guilt and regret for not being present at the exact moment of death.

WHAT TO DO ABOUT IT

Do not wait to tell your loved one how you feel. If for some reason you are not there when your loved one dies, accept that life (and death) seldom happens the way we plan. If you are left with regrets, seek the help of a counselor who can provide you with resources to address unresolved issues.

7. IT IS IMPORTANT TO PUBLICLY ACKNOWLEDGE A LIFE/LOSS

Occasionally, for privacy or other reasons, a patient or a family may decide to forgo a public funeral or to delay a memorial service for an extended period of time. When this occurs, family and friends are denied the consolation of the larger community. Rituals serve multiple purposes; chief among them is that they help facilitate acceptance of the reality of the loss. Without some form of public acknowledgment, accepting the loss can be more difficult.

WHAT TO DO ABOUT IT

Find some way to balance these competing values, and find some way to memorialize your loved one in a timely manner.

8. YOU MAY BE DISAPPOINTED BY A LACK OF SUPPORT

Death is an uncomfortable subject, and sometimes people will avoid the topic completely or make stupid and insensitive remarks. Friends may not always be able to be there in your time of need. If your spouse has not experienced a similar type of loss, he or she may not be able to relate to how you feel. As time passes, people return to the business of their daily lives and forget that you are still grieving.

WHAT TO DO ABOUT IT

Be your own best advocate. Tell people what you need and be specific. Realize that not everyone is comfortable with grief, but that does not mean that they do not care. Seek out alternative sources of support.

9. ANTICIPATE CERTAIN THINGS

Grief affects the entire person—body, mind and spirit. Although every person's experience will be unique, you can expect grief to manifest in your life in many different ways. Some people experience headaches and heartaches, or changes in appetite and sleeping patterns. You may feel anxious, depressed, disoriented or confused. It is also not uncommon for people to experience spiritual distress or question their long-held religious beliefs.

WHAT TO DO ABOUT IT

Typically, all of these symptoms will dissipate as time passes. Educate yourself about grief and take appropriate action. See your primary care physician if you have any questions or concerns about your personal health.

10. YOU ARE NOT ALONE

In addition to your friends and family members, do not forget that there are many other resources you can call upon in times of need. NorthShore Hospice sponsors grief support groups and grief counseling at no charge to families, friends and caregivers of NorthShore Hospice patients.

WHAT TO DO ABOUT IT

Contact NorthShore Hospice Bereavement Support Services at **(847) 982-4364**.

Helping Children Deal with Death

When a loved one is admitted into hospice, a common concern for families is how to explain illness and death to children. Understandably, talking to children about death is often complicated by the fact that adults have trouble sorting out their *own* feelings. Your hospice team is able to support you in this part of the dying process. Chaplains, social workers and grief counselors in the hospice program have a wealth of experience and resources to help you and your children explore the thoughts and emotions surrounding the death of a loved one. We can help you create a developmentally appropriate approach to talking and playing and being present with your grieving children.

We recognize that you know your children better than anyone else. There is much you can do to relieve some of your child's distress by simply trusting your own instincts. Here are a few general points to keep in mind as you guide a child who is grieving in a way that seems right for him or her and for your family.

USE LANGUAGE THAT IS CLEAR AND DIRECT

As a child's loved one is admitted into hospice, it is important to acknowledge the healthcare shift. Hospice care is best described to children as a shift from trying to "make someone better" to trying to "make someone comfortable." It is important that you clearly explain that the loved one will likely die but that we have surrounded the loved one with an excellent care team to make the death peaceful. Although it can be uncomfortable, it is extremely important to prepare children, when possible, for an upcoming death. Communicating this information early and often to your children establishes further trust within your family. This will lay a foundation that demonstrates how it is okay and expected to share thoughts and feelings about the family member's anticipated death.

Euphemisms like "Grandma passed" or we "lost your sister" might confuse or frighten a child. Clear, honest and truthful explanations are always best. "Grandma did not get better from her illness" or "Your sister was very strong, but her disease could not be cured and she died today" are typically better choices. While we may think that the euphemisms might ease the pain of our child, they can be confusing and interfere with an opportunity to dialogue about what has happened.

KEEP YOUR EXPLANATIONS SIMPLE

The stress from grief can interfere with a person's ability to retain and/or process the information given to him or her. For this reason, it is important to give only the basic information that the child needs to know. A toddler or preschooler may only need to know that his or her loved one is sick and will not get better; however, a school-age child might need to know the diagnosis and a teenager may want information regarding treatment plans. Allow your child's questions to guide how much information you give beyond the basics. For children of any age and developmental level, remember to answer what questions remain after you deliver new information. It may be helpful to prompt your child to come up with two questions or concerns; it is unlikely that the new information is perfectly clear. Revisit the conversation in the following days to confirm that your child understands the information and that he or she knows you are there should he or she need clarification. Establishing that it is okay (and helpful) to talk about the death and dying process will aid in your child's long-term coping and likely yours as well.

ALLOW CHILDREN THE OPPORTUNITY TO PARTICIPATE

Ask your child if he or she would like to be present when the death occurs. Explain that there is no right or wrong answer to that question. Respect your child's decision regardless of your opinion. Explain that you will do your best to accommodate his or her wish and then follow through. It is important to allow children to engage with the end-of-life process at his or her own pace.

Invite your child to participate in the funeral or rituals of remembrance. It can be helpful to have a trusted adult or babysitter with you so you can freely participate and be certain your child's needs are being met as well. You may elect to have young children present for only part of the rituals around the death; there is no wrong way for a willing child to participate. Resist the temptation to force his or her participation in any end-of-life ritual. Explaining what to expect during the rituals can help alleviate misconceptions or fears your child has and help him or her make an informed decision. Each child needs to feel some sense of self-advocacy and control during times of grief. Be certain to explain, listen well, clear up misconceptions and then respect his or her decision.

ENCOURAGE YOUR FAMILY TO EXPRESS EMOTIONS

As you and your children begin to cope with an anticipated death, your children will model your behavior. It is important to remember that it is acceptable to cry, be angry, laugh or feel any range of emotion. Children often learn to express their feelings from their parents. Be honest with your child about your own grief and the emotions you feel. This not only keeps your child from the anxiety of not understanding you or your actions, but also gives you the opportunity to normalize the tears a child is holding back or the anger he or she is feeling. It can be helpful to acknowledge that it is okay to feel different emotions at different times.

CHILDREN TEND TO GRIEVE IN CYCLES

They may be playing happily one minute and then crying hysterically the next. Grieving erratically is normal. Wanting to go to school or play with friends does not mean that the child is not grieving or does not care; these cycles allow for opportunities for distractive play or activities. Doing familiar and pleasant things can be useful in calming and reinforcing the reality that everyday life will continue even after the death of a loved one.

Additionally, children show their grief in a variety of different ways; withdrawal, acting out and being unusually "grown up" are common reactions in children of all ages. While you do want to exercise as much compassion as possible, do not hesitate to address these behaviors. Typical family norms such as no yelling or no slamming doors should be upheld to the best of your ability. This helps establish that your family boundaries are still intact. However, use your discretion and your caregiver instinct as you navigate conflict.

COMMUNICATE WITH YOUR CHILD'S SCHOOL

Inform your child's teacher and appropriate school staff of the situation at home as early in the process as possible; they can be wonderful resources as you navigate this season of loss and grief. Many schools have social workers and psychologists who are trained to work with students struggling with significant losses. It is possible that your child will find it difficult to pay attention in class or may need a safe space to retreat to from time to time at school. These professionals will be able to help you accommodate your child's needs. Additionally, they can assist your child with course expectations while he or she takes time to grieve and cope. It is important that you share with your child that you are informing his or her school. Again, keeping secrets from your children during this time is not advised.

GET CONNECTED

NorthShore Hospice believes that parents and caregivers are the best support system for children; however, we understand that it can often feel overwhelming to help your child navigate his or her grief as you are simultaneously navigating your own. We are happy to connect with and provide services to your children. Additionally, we can provide you with resources and tips so that you feel better equipped to care for your grieving child. If at any time you would like additional support, please remember that the hospice team remains available to you and can be an invaluable resource.

After-Death Checklist for Survivors

Plans change when a loved one dies. Without a concrete list, it is typical to stumble through the first months of your new life developing your own strategies in order to do what needs doing. The other option, of course, is to be so overwhelmed that little gets accomplished. You will be in this place of developing new systems, too, and it is for this reason that we offer you a checklist. It is intended to help with things like dealing with the death certificate. Acquiring death certificates issued by the hospital and delivered through the funeral home or cremation society (20 of them) is a sacred reflection of the fact that you are—and will always be—bereft of your loved one. But it is also a functional tool needed to move forward. You will need to get past the sentimentality far enough to see the long, blue-green page with its raised seal as a key to make things happen. It may seem that everyone except the guy at Starbucks will want an original proof of the death of your loved one. After a while, you might decide to keep a few copies in the glove compartment of your car. Yes, really. It saves quite a few return trips to the craziest places. You will develop ways that work for you to make sense of much of the chaos: Have someone supportive accompany you when you need to go to the bank or DMV or an attorney's office, take a notepad with you, ask as many questions as you can think of and have someone else record the answers for later review when you are thinking more clearly.

The death of a loved one is rarely a single event. Typically, it is a season of gradual awareness and gnawing fear. The rebuilding of life in the wake of dying and death is similarly a collection of realities and awareness and rebuilding. It is our hope that this checklist will help you be pragmatic in the midst of being appropriately sentimental. This is a very difficult season in part because a grieving soul needs to mourn the part of the world that stopped at the same time that the survivor needs to accomplish tasks for the part of the world that goes on. Hopefully, finding it easier to identify and manage some of these issues will be part of transitioning you to your own new normal. So just as you will break down the tasks one by one and step by step, let us deconstruct the whole idea of a checklist.

AFTER-DEATH

When your loved one is terminally ill, it is difficult to think of life without him or her in it. It is difficult because of the parts that are imaginable—all the tasks that will need to be learned, like paying the bills and cleaning the gutters and tending the flowers and honoring the grandchildren's birthdays and filling the pantry. And it is maybe even more difficult because of the parts that could never have been imagined—how terribly long some of the evenings would stretch, the ache for just one more glimpse of that impish grin with its deep dimples, one more hearing of the heartfelt "I love you" and one more dance. If it was your spouse who died, you could have never imagined how it would feel to go without him or her to weddings and funerals and formal events, or to be the third, fifth or seventh at a gathering of couples. You will covet the gentle care of remaining family and friends, but it is normal to wish that the absence of your missing loved one were not so conspicuous and their memory so raw for all who knew them. Still, the "after-death" part does indeed come. Priorities shift instantly from the care of the loved one and a desire to simply be present with them to the responsibilities of winding down that loved one's "affairs." Waves of the reality of loss roll in and out. Mostly in. Those waves force unsteadiness in even the most sure-footed. Still, there is no way to keep the water line and splash residue from making your situation apparent to perfect strangers. And sometimes those strangers are perfect simply for that fact. They do not know that you are suddenly and irrevocably different and so they treat you normally. What a lovely luxury—a glorious pretense.

The list is organic, changing, bulging, shrinking and morphing as days fill weeks and those weeks stack into months that will some day—likely very far from today—be your history. Everyone is different—unique in all the world—as Saint Exupéry's Little Prince proclaimed. You will need to tackle the "to-dos" in ways that suit you. What we are offering is intended only as a guide. You do not need to change the title on a car you do not own, and much that is unique to you will not be on this paper. This list will omit some elements of singular importance like "make sure cousin Tom gets the ugly, dark lamps before someone puts them at the curb" or "hire a teenager to mow the lawn."

The list is also a paradox. While daunting at times, it serves to impose a form on the griever's days and allows the brain to attend to something other than raw pain. Sometimes the list is overwhelming. Sometimes it is an almost welcome diversion. It provides a reason to plow through a day heavy with grief without needing to deny the powerful sense that there is a part of self that is always and everywhere mindful of the loss of the loved one.

CHECKLIST

Once you get yourself past the length of the list provided here, it is our hope that you will indeed find it helpful. Some of you are organized by temperament or are grieving the loss of a loved one who anticipated many of the mechanical tasks and had addressed these before the death. For you, this checklist can serve as a reminder of how well you were cared for and as an affirmation that you are on track. Many others of you, by nature and experience, could never have imagined all that would need to be done after the focus of tending to your loved one is over. Wasn't that supposed to be the end? Wasn't this supposed to be the time to grieve? Well, yes—but this is part of that process. You are moving from a season that was centered on your loved one to a season that is centered on you.

The list is really part of the bridge between your loved one and you. At once, you are ending the loved one's attachments to life on this Earth. That can bring up all sorts of feelings. Your heart might ache as the DMV office changes the title on the car you will then sell. You might resent needing to tell the Social Security office that your loved one is dead and filing all the papers they ask of you.

Canceling subscriptions to magazines might leave your chest tight now even though you had formerly thought of them as simply junk mail. But you are still here—and if you are faithful with these tasks, you will begin this next phase of your life on this Earth held steady in part by these very same attachments. Your loved one, indirectly or not, has entrusted to you a legacy. On this legacy you will stand more assuredly to claim your place in this world. Work through the checklist. Steady your footing. Stand tall. You are getting there...wherever "there" is for you.

FOR SURVIVORS

"Survivor" is such a loaded word. It hints at the tragedy that rests squarely on your chest. It clearly identifies the ones still living and moving and having their earthly being. This list was created for you who have lost your loved one. It is a nod to the reality that you have much to do in a season where it can be difficult to corral your thoughts and your energies and when your days seem hopelessly fragmented. On the other hand, it seems to imply some sort of victory—and right about the time you have lost your loved one, victory seems a long way off. Surviving in this early stage is far more about getting out of bed and climbing back into it, ingesting some food and feeling nauseous, accomplishing some task and getting nothing done, crying and being stoic, wishing all the people would go away and being terrified about the time when they will go back to their part of the real world.

In spite of the bouts of desperate loneliness, you are not alone. And you do not need to tackle the list alone. In fact, the list is a wonderful tool to share with all those well-meaning people who ask if there is anything that they might do for you. Check the list; there are TONS they can do so do not go quickly to "No, but thank you so much for offering." Instead, practice saying, "I'm so sad and so overwhelmed. Would you be willing to look over this list with me and see if there's anything here that you might be able to do? I would be so grateful." If the old adage that many hands make light work is ever true, it is true now when you are not 100 percent yourself. Delegating these tasks is also a way for you to let others help you for their sake. We all need to be needed. So, do your friends a favor and give them something useful to do. After all, you can only freeze so many lasagnas.

Checklist

IMPORTANT CONTACT INFORMATION

Accountant

Attorney

Banker

Broker

Insurance agent

- Shred identification cards
(Passport, Social Security card, credit cards,
voter reg., driver's license, military ID, etc.)

PERSONAL

- Birth certificates
- Marriage certificates
- Death certificates (at least 20 copies)
- Citizenship papers
- Children's documentation

LEGAL

- Powers of Attorney for finances
- Divorce/separation papers
- Guardianship of minor children
- Will
- Trust

INSURANCE POLICIES

- Life
- Health
- Long-term care
- Auto
- Residential

GOVERNMENT BENEFITS

- Social Security
- Social Security Disability Insurance
- Military benefits

FINANCIAL

- Checking accounts
- Savings accounts
- Credit cards
- Deferred compensation payments
- Disability reimbursements
- List of investments
- Loans
- Pension
- Retirement benefits
- Safe deposit box and contents
- Stocks and bonds
- Tax returns
- Trust agreements

RESIDENCE

- Mortgage/title/lease agreements
- Other personal property
(e.g., boat, 2nd home, etc.)
- Utilities
- Cable company

AUTOMOTIVE

- Title
- Loan

OTHER

There are many tasks that must be addressed following the death of a loved one. This checklist is offered as a starting point for organizing your loved one's affairs. Please feel free to use the back of this page to customize your checklist.