

End-of-Life

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# How-to Prepare for a Loved One's End-of-Life

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eBook #17

## How-to Prepare for a Loved One's End-of-Life

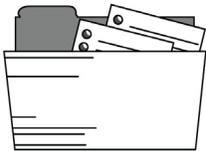
The end of a loved one's life, however long and well lived, brings with it a sense of loss and sadness. Yet preparing for what to expect encourages us to focus on the value of our relationships and the richness of life in the present. It empowers us to offer the support and care our loved one needs to experience the most peaceful, comfortable End-of-Life possible.

As part of our eBook series, Passare™ shares resources and guidance to help you prepare when a loved one's End-of-Life is near. Passare helps guide you through one of life's most important passages.



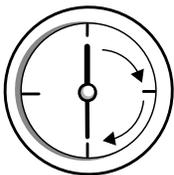
### You Will Learn About:

1. The Benefits of Preparing
2. Preparing for End-of-Life
3. What to do When End-of-Life is Near
4. Grieving and Your Loss
5. Embracing Your New Normal
6. Creating a Lasting Legacy
7. Summary



### The eBook includes:

- A. Checklist for How-to Manage After a Loved One Passes Away
- B. Frequently Asked Questions About Preparing for a Loved One's End-of-Life



### Estimated Time Required:

15 minutes

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## The Benefits of Preparing

Knowing that a loved one's End-of-Life is near is an emotionally challenging time. Your loved one has been a part of your life for as long as you can remember, or your time with them seems too limited.

Preparing helps ensure the most comfortable, peaceful End-of-Life experience for your loved one. And, it may also help you and your family better adjust to your imminent loss. Consider the following benefits:

- Provides companionship  
A loved one nearing End-of-Life has a real need for comfort and companionship. Your presence and support may ease their discomfort and fear, and help provide meaningful connections to family.
- Encourages healthy dialogue  
Communicating with loved ones about important concerns, choices and goals helps strengthen family bonds. It may help us value relationships, avoid regrets and make important, timely changes.
- Helps us make the most of life  
Living more mindfully in the present helps us enjoy all that we can with our loved one. It encourages us to live in gratitude and appreciate our lives and loved ones.
- Clarifies final wishes  
Reducing trauma, confusion and conflict that may occur at End-of-Life is important. When you understand a loved one's final preferences, you are able to dedicate more of your energy to care and compassion.
- Ensures peace of mind  
Building comfort and trust with a dying loved one reassures them that their final preferences will guide decisions when the inevitable happens.
- Helps us plan for respite care  
Respite care can help families rest and recover from the intensity of End-of-Life caregiving so that they may best support their dying loved one.
- Encourages grief support  
Consulting with bereavement specialists or spiritual advisors before End-of-Life may help your family prepare for the coming loss.

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*Take a few minutes to answer these questions.*

1. What meaningful experiences can you share with your loved one now?
2. What kind of respite care will provide you with proper rest and recovery during this time?
3. What emotional, spiritual or bereavement counseling is available to help you and other loved ones prepare for and cope during and after your loss?

## Preparing for End-of-Life

Even when we understand that a loved one's End-of-Life is near we may not feel prepared to cope with it. No amount of preparation will help us avoid feelings of loss and grief when a loved one passes away. Yet preparing ourselves and supporting our loved one may defuse the trauma and confusion that can occur when we aren't prepared. It may also help to lend comfort and dignity to your loved one's End-of-Life experience.

The following suggestions may help you manage this challenging time and ensure that your loved one's final wishes are honored:

- Accept your loved one's condition
- Talk with family or loved ones
- Help manage documents and tasks
- Respect your loved one's choices
- Help your loved one gain comfort and peace
- Get support for yourself and loved ones

## Accept Your Loved One's Condition

Someone you love is nearing End-of-Life. Acknowledging this is an important step toward helping your loved one live their remaining life as meaningfully as possible.

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You may find that you can best manage your loved one's new reality in phases. You may first understand it logically by perhaps learning the specifics of their condition and what medical steps may be taken. Over time you may move closer toward emotional acceptance of your loved one's condition.

Accepting your loved one's End-of-Life often means living in the present. This is easier said than done. Though it may seem difficult, accepting your loved one's reality may help you to find ways to enrich their remaining life and add meaning to important relationships.

### *Recognize Your Limitations*

Not everyone can offer ongoing support to a loved one who is facing End-of-Life. If you feel unable to cope with this difficult new reality, try to understand your hesitance and learn from it. Try asking yourself, "Why am I uncomfortable with this?", and "What can I do to become more compassionate to my loved one?"

### *Do What You Can*

As challenging as this is for you to face, do what you can to provide support. Phone rather than visit. Write if you find telephoning difficult. Arrange or coordinate a delivery of food or flowers. Try to remember that friends and family sometimes avoid loved ones at this time, leaving them more lonely and depressed. Find a way to let your loved one know that you care. This may help you both process feelings of sadness and loss during this challenging time.

## Talk with Family or Loved Ones

If they haven't yet done so, encourage your loved one to tell family and friends that they are nearing End-of-Life. Offer to assist them or find a trustworthy, compassionate person who can help. The sooner your loved one shares the reality of his or her condition with others, the sooner they may receive important support to manage this difficult time.

### *Understand Variable Responses*

It's important to understand that everyone responds differently to serious news. Shock, sadness and disbelief are common reactions. Some may spring into helpful action by offering practical and emotional support. Others may not know how to respond. Help your loved one focus precious energy where they may receive the most support.

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## Use Special Care with Children

If children must be told about a loved one's End-of-Life, use sensitivity and make special considerations. Ask appropriate medical or hospital professionals, trusted friends who have children, a minister or spiritual advisor, or a licensed clinical social worker or child psychologist to help you address the sensitive issues of death, loss and grief.



Note: Visit: [www.passare.com](http://www.passare.com) for more information and resources on talking with loved ones, including youth, teens and adult children when a loved one is nearing End-of-Life.

## Help Manage Documents and Tasks

There are important decisions that your loved one will need to make as they near End-of-Life, including healthcare, financial, legal, funeral and other personal considerations.

Hopefully your loved one has made these decisions in advance. Helping them manage End-of-Life activities helps remove the decision-making burden from family members and can ensure that your loved one's final wishes are honored after they pass away.

- Prepare an Advanced Healthcare Directive (AHD) or Medical Power of Attorney  
These legal documents provide direction for what kind of treatment a person wants if they become unable to make their own decisions.
- Choose Legal Representatives  
Your loved one may consider appointing legal guardians for minor children, a healthcare proxy or healthcare agent or a financial power of attorney (FPOA) to make healthcare decisions or act on financial matters.
- Prepare a Will  
A will can outline your loved one's final wishes for their funeral services and for distributing their financial and digital assets after their death.
- Complete a Do Not Resuscitate (DNR) Order  
A DNR prevents medical personnel from doing cardiopulmonary resuscitation (CPR) to save or prolong a life.
- Complete a Physicians Order for Life-Sustaining Treatment (POLST)  
A POLST is a physician-signed order that becomes part of an official medical record and explains a person's wishes for End-of-Life care.

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- Prepare an Organ Donor Form  
This form provides legal proof that your loved one wishes to donate organs or tissue after their death.
- Decide on Funeral Options  
Consider service option preferences.

We encourage you and your loved one to discuss their thoughts, concerns and choices with family, healthcare providers and other trusted advisors.

Surviving loved ones should know that a plan exists and where important documents are stored. Please visit: [www.passare.com](http://www.passare.com) for more information and expert resources on managing End-of-Life documents and tasks.

## Respect Your Loved One's Choices

Few things are more personal than how a person chooses to experience their End-of-Life. It's important to remember that everyone deserves a peaceful, comfortable End-of-Life experience, even if those choices differ from our own.

Do your best to respect your loved one's care preferences and their physical and emotional needs. If your loved one needs help choosing their best care option, offer to talk with their healthcare team or a social worker. You may ask for a referral to palliative or hospice care specialists. End-of-Life care options include the following:

- Home care  
Your loved one may choose to pass away at home or in the home of a family member. You can assume or support the role of caregiver, hire home care services or engage hospice care services.
- Inpatient care  
Your loved one may opt for 24-hour care at a nursing home, hospital or dedicated inpatient facility.
- Hospice care  
Hospice provides services, support and resources for people at End-of-Life, typically with six months or less of expected life remaining. Hospice includes spiritual support and bereavement services for family.
- Palliative care  
Palliative care is specialized medical care that provides patients with relief from the symptoms, pain and stress of any illness.

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## Help Your Loved One Gain Comfort and Peace

As your loved one nears End-of-Life, they and those important to them can find comfort and peace in how they are able to live their remaining life. Finding meaning through faith, spirituality and important relationships helps ensure peace.

### *Embracing Spirituality*

If faith is important to your loved one, encourage them to express it in ways that feel appropriate to them. They may find comfort and hope in reading spiritual texts, attending religious services or praying. Encourage the companionship of people who understand and support their religious beliefs.

### *Saying Goodbye*

Knowing End-of-Life is imminent offers your loved one a unique privilege: expressing important final words to those they love. Encourage them to share their feelings including thanks or forgiveness, and to give others a chance to say goodbye. This may help strengthen family bonds. It may also inspire conversation about important previously unstated thoughts, which may be meaningful for all.

### *Creating a Legacy*

Your loved one may find it comforting to create a lasting legacy, such as a recording about his or her life or writing letters to loved ones, especially about important potential future events, like a wedding or the birth of a child. Sharing special family heirlooms or keepsakes is a powerful way to express love and farewell to loved ones.

## Get Support for Yourself and Loved Ones

When someone you love and care for is facing End-of-Life, you will need support to help you manage the loss you are experiencing. It's important to find someone who will listen without judgment as you talk about your feelings and mourn your loss. Take good care of yourself and your family. Eat nutritious meals. Get as much rest and exercise as you can. Try to spend time doing things that are calming and soothing to your soul.

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*Take a few minutes to answer these questions.*

1. What resources can help you learn more about your loved one's condition?
2. What decisions does your loved one need support with as they near End-of-Life?
3. What hospice programs do your physicians, friends or caregivers recommend?
4. Which family, friends or neighbors can offer you or your loved one the most support during this challenging time?

## What to Do When End-of-Life is Near

Just as every life is unique, so is each person's End-of-Life. End-of-Life may happen suddenly or slowly. You may need to ask a healthcare provider if your loved one's End-of-Life is approaching. Remember, the provider can only give you an estimate of when that time may occur. Consider doing the following when your loved one's End-of-Life is very near:

- Gather close support
- Offer reassurance and emotional support

### Gather Close Support

When End-of-Life is near, help your loved one gather those who are closest. Remember to reach out for support for yourself and your own family too. Consider gathering these people when a loved one's End-of-Life is imminent:

- Family, friends, neighbors
- Healthcare proxy or Will executor
- Hospice or palliative care providers
- Religious or spiritual advisors
- Therapists, counselors or psychologists

### Offer Reassurance and Emotional Support

Your loved one's physical strength and cognitive functions may diminish, yet their capacity to feel frightened or at peace, loved or lonely, and sad or secure may remain.

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They may no longer recognize you, but may still draw comfort from your companionship, touch or the sound of your voice.

Each person's emotional needs differ in the final stages of life, although some emotions are common to those nearing End-of-Life. Many worry about loss of control and dignity as their physical abilities decline. It is also common for patients to fear being a burden to their loved ones yet at the same time they fear being alone. Reassuring your loved one that it is okay to pass away may help both of you through this emotionally challenging process.

Late-stage caregivers or loved ones can offer emotional comfort in the following ways:

- Provide company  
Talk to your loved one, read to them or simply sit and hold their hand
- Promote a calm environment  
Create a soothing atmosphere; communicating through sensory experiences such as touch or singing
- Bring small pets  
Contact with pets or therapy animals may bring comfort and pleasure, and ease transitions
- Offer familiar remembrances  
Surrounding your loved one with pictures and mementos, reading treasured books and playing favorite music promotes dignity and comfort
- Remain attentive  
Avoid burdening your loved one with your feelings of fear, sadness and loss; discuss your feelings privately with an appropriate listener instead
- Listen without interruption  
Let your loved one express their fears about death without disruption; communicating fears may help them accept the reality of their End-of-Life
- Allow them to reminisce  
Encourage them to recall positive life stories to help promote dignity and comfort
- Provide information  
Include them in discussions that concern them or their care
- Honor their wishes  
Reassure your loved one that you will honor their wishes, including legal or personal requests

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- Respect their requests and privacy  
For most people, End-of-Life is about preserving dignity and ending their life as comfortably as possible

## When End-of-Life Occurs

Although you may have prepared for your loved passing, you may not be prepared for the moment when they pass away. It may be helpful for you and your family to consider and discuss what to do if you or they are present when your loved one passes away.

Your loved one's remains do not have to be moved until you are ready. Any action taken should be consistent with your deceased loved one's final wishes. For example, if you or your loved one's family chooses to assist in preparing the deceased's remains by bathing or dressing or following religious or spiritual practices, that may be done in accordance with your loved one's choices.

When a loved one passes away, family members and caregivers may get comfort from taking some time to say final goodbyes, talk or pray before proceeding with final arrangements. Give yourself and other loved ones that time if you need it.

For more information and step-by-step instructions on what to do during the first 24-hours after End-of-Life, please visit: <http://www.passare.com/resources/First-24-hours>.



*Take a few minutes to answer these questions.*

1. What music, pets or people will be most comforting to your loved one as they near End-of-Life?
2. What will you do if you are present when your loved one passes away?
3. What spiritual or religious rituals are important to you and surviving loved ones when End-of-Life occurs?

## Grieving and Your Loss

A loved one's End-of-Life may evoke many emotions: from relief to sadness. Try to accept your feelings and grief as a natural part of the End-of-Life process.

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Allow yourself to mourn. Expressing your grief in constructive ways will help you to heal. Take time to reflect on your loved one's life and remember the experiences you shared together.

Processing your grief may not happen quickly. Grief is a process, not an event. Be patient and tolerant with yourself. Remember that the death of someone you loved changes your life forever.

Talking with family and friends, consulting hospice services, bereavement experts and spiritual advisors can help you process feelings of grief and loss and begin to focus on the reality of your "new normal."

## Embracing Your New Normal

From the moment a loved one nears End-of-Life, a caregiver or surviving loved one's life is never the same. Exploring new relationships or enjoying activities after a loss can be challenging. Consider these suggestions to ease yourself back into your new reality of living life without your loved one:

### Reconnect

- Join a bereavement support group  
Being with others who know your situation can help you understand your feelings
- Get involved in something new  
Enroll in an adult education or fitness class, join a book club or volunteer

### Use your loss

- Establish a tribute to your loved one  
Consider setting up an online memorial site, scholarship, plaque, scrapbook or charitable fund to honor their memory
- Share your knowledge to help another  
Contact a medical association, hospice provider or support group and ask how you may help others who are experiencing a loved one's End-of-Life

### Gain perspective

- Express yourself  
Write a story or poem, make a musical or video recording, or keep a journal
- Talk to a therapist or grief counselor  
Talk through your feelings and experiences to help you process your grief and set new goals

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Your acts of care and connection sustained your loved one through a difficult, and perhaps long passage. Sharing what you have learned, cultivating happiness and finding new meaning can inspire hope as you experience your “new normal.”

## Creating a Lasting Legacy

You can keep your loved one’s memory alive by creating a legacy for future generations to honor. You may also do special things to remember them throughout the year on holidays, birthdates or on the anniversary of their passing.

## Remember Your Loved One on Holidays and Anniversaries

Remembering and honoring a deceased loved one can be different for each person. Some people will spend time in quiet reflection, some may prefer a brief acknowledgement, and others may want to focus on their memories. Consider creating a new ritual to celebrate the life of your loved one, perhaps one that can be repeated annually. Consider the following ways to honor and remember your loved:

- Take flowers to the gravesite or memorial site
- Look at favorite photos and videos with family and friends
- Turn digital photos into a digital photo album
- Donate some of your loved one’s belongings to a shelter or charity
- Make a charitable donation or establish a scholarship or fund in their name
- Volunteer with a charity or cause that was important to your loved one
- Plan a memorial service or candle light vigil on the anniversary of their passing
- Update a memorial website with new memories or share condolences from others
- Reach out to someone who has experienced a similar loss
- Host a dinner party and invite those who knew your loved one
- Cook your loved one’s favorite dish, use one of their recipes to prepare a meal, or host a pot luck and ask people to bring a dish that your loved one enjoyed
- Light a candle in honor of your loved one
- Visit or spend time in a place where you feel close to your loved one
- Read special notes, a letter, email or card from your loved one
- Make a CD mix of music that reminds you of your loved one
- Do something your loved one would have enjoyed
- Watch your loved one’s favorite movie
- Create a personal memorial or keepsake box with photos and personal items
- Spend time journaling about your feelings and memories of your loved one

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- Make a toast or say a prayer or blessing in their honor
- Plant a tree or shrub in your loved one's name
- Commemorate your loved one with a dedicated bench, plaque or other item
- Celebrate the strengths you have developed as a result of your loved one's death
- Finish a project your loved one was working on



*Take a few minutes to answer these questions.*

1. What memories, music, places or experiences are positive reminders of your time spent with your loved one?
2. What positive ways can you express or explore your grief?
3. How will you honor your deceased loved one on holidays or the anniversary of their passing?

## Summary

"If not for death, would we appreciate life? We bring a deeper commitment to our happiness when we fully understand that our time left is limited and we really need to make it count." This profound statement from American author and pioneer in near-death studies, Elisabeth Kübler-Ross, reminds us that End-of-Life is a natural passage that all of us will experience. Preparing for a loved one's End-of-Life offers us a chance to appreciate and deepen our relationship with them now, and add meaning and peace to their End-of-Life experience when the inevitable occurs.



From birth to death, life is a series of passages. Only Passare allows you to connect and collaborate with your family any time, anywhere to easily explore and plan for End-of-Life.

With Passare, you can engage with trusted End-of-Life experts and relevant resources that guide you through one of life's most important passages and ensure that the specific needs and wishes of you and your family are honored.

Please visit [www.passare.com](http://www.passare.com) for more information, experts and resources that can help simplify End-of Life Management.

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# Checklist: How-to Manage After a Loved One Passes Away

Losing someone close to you makes this a challenging time of grief and loss. We suggest that you begin by allowing yourself to mourn. Take care of yourself and your family, and allow yourself to connect with supportive friends. Give yourself time to reflect on positive experiences you shared with your loved one. Talk with loved ones to help you begin to process your grief.

During this time, there are also many practical End-of-Life matters to settle. Managing these important tasks will take some time, and you may need help. Passare suggests how to settle practical matters after your loved one's death:

## *Gather Important Documents*

- | Locate your loved one's will, birth and marriage certificates, and other vital records

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- | Locate Social Security card; Veterans Administration and Medicare cards; and any employer W2 forms

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- | Request copies of your loved one's death certificate from your funeral service provider or your county office

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## *Verify Benefits*

- | Contact the Social Security Administration at 800-772-1213 or visit: <http://www.ssa.gov/pubs/EN-05-10084.pdf>

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- | Contact the Veteran's Administration at 800-827-1000 or visit: [www.va.gov/opa/persona/dependent\\_survivor.asp](http://www.va.gov/opa/persona/dependent_survivor.asp)

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## *Notify Insurance and Change Titles*

- | Notify automobile, business, home, life and health insurance

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- | File claims for all policies in your loved one's name

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- | Include a certified copy of your loved one's death certificate with each claim

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- | Change the beneficiary name on all insurance policies

| Revise titles on your vehicle(s), and home(s)

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### *Settle Financial Matters*

| Review your finances and draft a budget to pay mortgage(s) and other financial debts or obligations that you shared with your loved one

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| Transfer all assets into your name or a trust

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| Change tax identification numbers on shared financial accounts

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| Update or close checking, savings, money market, CD, IRA and/or investment and retirement accounts

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| Check safe deposit box(es)

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| Cancel or re-direct direct deposit payments

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| Change ownership and beneficiary designation on all jointly-owned or solely-owned mutual funds, stocks and bonds

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### *Address Legal Issues*

| Talk to an attorney about settling legal matters, including the probate process related to your loved one's will

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| Get advice on transferring assets into your name or a trust as appropriate

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| Ask if you need to file specific legal paperwork

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# Preparing for a Loved One's End-of-Life Frequently Asked Questions (FAQ)

## 1. *What is End-of-Life care?*

End-of-life care is the support provided after an End-of-Life prognosis is made, when care goals transition from curative measures to comfort and quality of life. It may include hospice and palliative care. It can be provided at home, in hospice care centers and nursing homes, or in a hospital.

## 2. *What emotional challenges may affect my loved one?*

Emotions like depression, anxiety or fear are common at End-of-Life. Many people worry about loss of control and dignity as their physical abilities decline. Some patients fear being a burden to loved ones, while also fear being alone. Encourage your loved one to talk about their feelings, either with you or a close friend, or religious or spiritual advisor. Hospice professionals and some counselors specialize in End-of-Life support.

## 3. *How can I comfort my loved one when End-of-Life is near?*

Each person's needs differ in the final stages of life. Some ways to provide support include being physically present and listening without interruption. Promote a calm environment through music and art and lighting. Surround your loved one with comforting remembrances like family pictures, artwork, flowers, and other personal items. If End-of-Life is close, reassuring your loved one that it is okay to pass away may help both of you at this emotionally challenging time.

## 4. *What is respite care and how can it help caregivers?*

Respite care can help families rest and recover from the intensity of End-of-Life caregiving. Respite care providers can ease the day-to-day demands of caregiving by assisting with bathing, medication, housecleaning and other tasks. A person may receive respite care in their home, adult day centers and in nursing homes.

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### *5. How can caregivers best enlist the help of friends and family?*

Ask friends and family for help with specific tasks such as grocery shopping, preparing a meal or helping with laundry or childcare. If you know someone who enjoys reading, ask them to read to your loved one. Someone who enjoys cooking may be happy to prepare a meal for you and your family.

### *6. What should I do right after someone passes away?*

Your loved one's remains do not have to be moved immediately. Any action taken should be consistent with your deceased loved one's final wishes. Family members and caregivers may want to say final goodbyes, talk or pray before proceeding with final arrangements.

### *7. When and how does a death become official?*

As soon as possible after your loved one passes away, a person with legal authority should "pronounce" the death, like a healthcare provider or hospice nurse. They will complete the forms certifying the cause, time and place of death. Pronouncing the death is required for an official death certificate to be prepared. A death certificate is a legal form that is required for many reasons including filing a life insurance claim and settling financial and property issues. If your loved one's passing happens at home without hospice, contact a healthcare provider, local coroner or medical examiner, health department or a funeral home representative and ask how to proceed.

### *8. What resources are available to help my family manage grief?*

Many resources exist including hospice providers, bereavement support groups, books and websites. A trained counselor can provide therapy, or your religious or spiritual advisor can help you process your grief and accept your loss.

### *9. What support exists for caregivers?*

Community-based services can supplement the support of family caregivers. They may offer companionship visits, meal programs, caregiver respite, adult day care services and transportation. To find community-based support services, contact the Eldercare Locator at 800-677-1116 or visit [www.eldercare.gov](http://www.eldercare.gov).

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## 10. *What if I have difficulty accepting that End-of-Life is near?*

Everyone manages the End-of-Life experience in his or her own way. As challenging as this is for you, do what you can to provide support. Phone, visit or write. Arrange or coordinate a delivery of food, flowers or other support. Remember that friends and family sometimes avoid loved ones at End-of-Life, leaving them more lonely and depressed. Finding some way to let your loved one know that you care may help you both process feelings of loss.

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