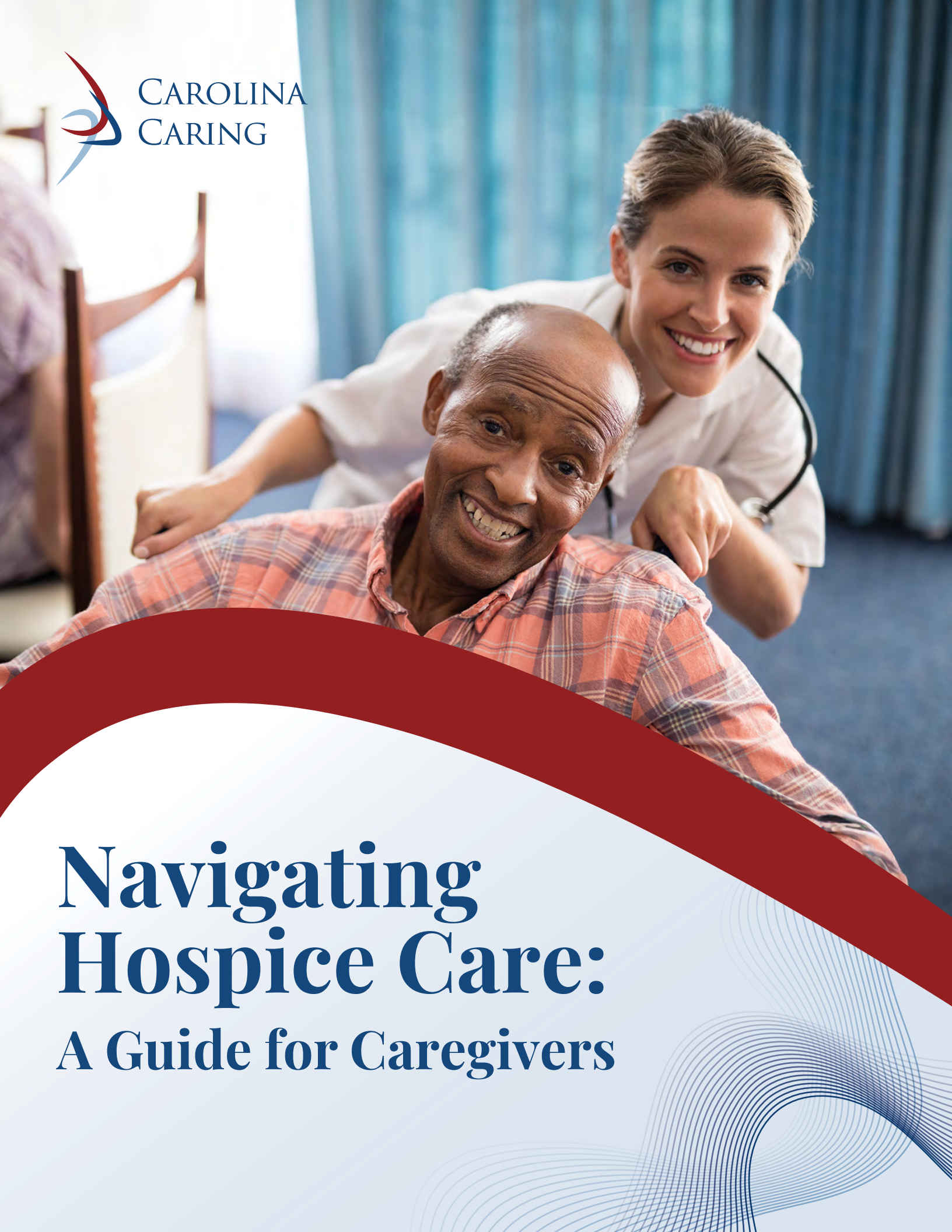




Navigating Hospice Care:

A Guide for Caregivers

Embracing the Role of a Caregiver

THE EMOTIONAL JOURNEY OF CAREGIVING

Becoming a caregiver for a loved one entering hospice care is a profound and emotional journey. It's natural to feel a mixture of fear, sadness, confusion, and even anger—and providing emotional support to someone facing the end of their life while going through your grief journey can be very difficult. This ebook is designed to provide the support and information you need to navigate this challenging time with compassion and confidence.



UNDERSTANDING THE HOSPICE CARE PROCESS

The goal of hospice is to provide compassionate care to relieve symptoms, control pain, and give patients the support they need to live their life as fully and comfortably as possible. Hospice care is a holistic approach that addresses the physical, emotional, and spiritual needs of the patient and can be provided wherever they call home.

Emotional Support for Caregivers

MANAGING A RANGE OF EMOTIONS

Caregiving can evoke a spectrum of emotions from compassion and worry to frustration and grief. Sometimes these feelings happen right away, and some don't surface until you have been caregiving for a while. Isolation and loneliness are often seen in those who have been caring for someone for an extended period of time. Caregivers are often reluctant to acknowledge or express their feelings but it is important to allow yourself to feel these emotions without bottling them up inside. Strategies like journaling, talking to a trusted friend, or seeking professional counseling can help you manage these emotions constructively.

ACKNOWLEDGE YOUR EMOTIONS

- **Cherish the moments of love and tenderness.** If there are moments of affection – hugging, kissing, holding hands, etc – these are moments of state stabilization and can give you and your loved one something to look forward to during the day.
- **Frustration:** Remember that feeling frustrated is not a sign that you're a bad caregiver. It is, instead, a typical reaction to the difficulties and uncertainties of caregiving.
- **Grief.** You are experiencing anticipatory grief. Some caregivers grieve before their loved one is actually gone. You may miss the person or relationship you once knew and mourn for what's to come. Acknowledge the grief and allow yourself to grieve at your own pace.

COPING STRATEGIES

- **Journaling:** Writing down your thoughts and feelings is a cathartic way to process information. Keeping a journal can help you reflect and gain insight into your

experiences by moving information through your emotions and into thought.

- **Talking to a Trusted Friend:** Often, talking to a trusted person about your feelings can help you feel better and gain a different perspective. Choose a friend who will be a good listener, sympathetic, and compassionate without lecturing.
- **Seeking Professional Counseling:** A counselor or therapist provides a safe place to process your emotions and learn coping skills. Professional therapy can also help you learn to manage intense feelings and stress, skills you can apply in other areas of your life.
- **Mindfulness and Meditation:** If you practice mindfulness and meditation, you will stay grounded in the present, which will help you manage stress and stay generally emotionally balanced.
- **Support Groups:** A support group for caregivers can help you connect with others going through the same challenges. Talking through your experiences and sharing advice can help build community and understanding.

COMMUNICATING WITH FAMILY AND FRIENDS

Be sure to communicate openly with your family and friends—share updates about your loved one's condition, express your needs and limitations, and ask for help when needed. Having a support system can make it easier to shoulder the caregiving role and can provide you with an emotional lifeline throughout the process. Here are some strategies to help you communicate effectively:

SHARE UPDATES AND EXPRESS YOUR NEEDS

- **Regular Updates:** Keep family and close friends informed about your loved one's condition and any changes in their care needs. This can prevent misunderstandings and ensure everyone is on the same page about your loved one's needs and wishes.

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- **Express Your Needs:** Be clear about what you need from others, whether it's emotional support, practical help, or simply understanding. Don't be afraid to ask for specific assistance, such as running errands, providing meals, or sitting with your loved one to give you a break.
- **Set Boundaries:** It's important to set boundaries to protect your well-being. Let others know your limitations and what you can realistically manage. For example, it's healthy to say, "I love you, but I am not doing well so let's not talk about COVID."

BUILDING A SUPPORT NETWORK

- **Delegate Responsibilities:** Don't be afraid to share caregiving responsibilities with other family members and friends. It will lighten the load for you and make sure your family member gets complete care.
- **Create a Care Calendar:** A care calendar helps designate and organize who can visit, offer meals, or do other tasks. Using Google Calendar or other apps that track a caregiver's plan throughout the day can make keeping a schedule easier.
- **Emotional Support:** Surround yourself with people who provide positive emotional support. Sometimes, just knowing that someone is there to listen can make a significant difference.
- **Join Online Communities:** Support groups and online forums for caregivers can be a great resource for talking about your experiences, getting answers to your questions, and getting help from others who are facing similar challenges.

EFFECTIVE COMMUNICATION TECHNIQUES

- **Active Listening:** Next time a family member or friend comes to you to discuss your loved one's care, try to actively listen. That means listening with your full attention, nodding and tracking their words, and summarizing what you've heard them say to show you're on the same page.

- **Be Honest but Tactful:** It's important to speak frankly about your loved one's condition and your own feelings, but do it sensitively and kindly.
- **Stay Calm:** Emotions can run high during difficult conversations. Try to stay calm and patient, and take breaks if the discussion becomes too heated.

Preparing for Hospice Care

CHOOSING THE RIGHT HOSPICE PROVIDER

Selecting the right hospice provider is a critical step. Consider factors like the provider's reputation, services offered, and whether they offer 24/7 support. Also consider who the staff cares for: do they focus just on long-time cases, or do they also accept last-minute referrals?

Don't be shy about asking questions and seeking recommendations from healthcare professionals—who often work closely with hospice providers—or friends who have gone through this journey themselves.



RESEARCHING PROVIDERS

- **Reputation:** Find out which hospice providers are widely respected in your community. Ask friends and family for reviews and testimonials from families who have recently used the service. Look for accreditation from government-recognized bodies, as well as organizations like the National Hospice and Palliative Care Organization (NHPCO).

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- **Services:** Make sure the hospice provider offers the full range of services – medical, pain care, emotional and spiritual counseling, and assistance with daily activities. Ask about specialized services that might be needed because of your loved one's condition.
- **24/7 Support:** Make sure the provider offers 24/7 support, especially if you have any critical needs or emergencies that might occur after business hours.

ASKING KEY QUESTIONS

- **Experience and Expertise:** How long has this specific hospice provider been operating? What level of experience do they have with your loved one's illness or condition?
- **Care Plan Customization:** What is the process from diagnosis to care plan? How does this hospice provider develop and update care plans based on the goals of the patient and family member?
- **Staff Qualifications:** What are the qualifications of the doctors, nurses, social workers and other staff or volunteers? Have they been professionally certified in hospice and palliative care?
- **Communication:** How will the hospice team communicate with you and your other loved ones? How often will they let you know how your loved one is doing?
- **Location of Service:** Will they provide care in your home or can your loved one live with them in a facility? If they provide in-home care, what services and aids will they provide to help you prepare your home?

SEEKING RECOMMENDATIONS

Consult with your loved one's doctors, nurses, and other healthcare providers: Many are a wonderful source of information and can recommend agencies they work with regularly.

Also ask friends, family, or co-workers who reveal whether they underwent an equally

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taxing experience. Their impressions might capture and convey useful details that will lend weight to your decision.

LEGAL AND FINANCIAL PREPARATIONS

It's crucial to ensure that all necessary legal and financial documents are in order **before** hospice care is needed. Of course, when you're in the thick of caregiving, it can be difficult to think about plans for when things aren't going to get better. But this work takes time, and some people can find it emotionally difficult to process while their loved one is still ill. One huge benefit of having hospice preparation done well ahead of time is that it can boost your confidence to make decisions once the time comes.

Health Insurance, Medicare, and Medicaid

- **Understand Coverage:** Make sure you know what's covered under your loved one's health insurance. Most plans, including Medicare and Medicaid, provide extensive coverage for hospice care, but it's important to know the specifics.
- **Eligibility Requirements:** Familiarize yourself with the eligibility requirements for hospice care under Medicare and Medicaid. Typically, hospice is covered if a doctor certifies that the patient has a life expectancy of six months or less if the illness runs its usual course.
- **Cost and Billing:** Ask the hospice provider what, if any, out-of-pocket costs you are likely to incur. Clarify the billing process and determine what is covered by the hospice benefit, including prescription and over-the-counter medications, medical equipment, respite care, and hospital and inpatient services.

Preparing Legal Documents

- **Healthcare Power of Attorney:** This document appoints someone to make healthcare decisions for your relative if they are unable to do so themselves. Make sure this person knows your relative's wishes and is ready, willing, and able to carry them out.



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- **Living Will:** A living will outlines your loved one's preferences for end-of-life care, including what medical treatments they do or do not want. Having a living will can prevent unnecessary and unwanted interventions after your loved one is no longer able to speak for herself.
- **Do Not Resuscitate (DNR) Order:** A DNR order says your loved one does not want to receive cardiopulmonary resuscitation (CPR) if their heart stops or they stop breathing. Your loved one's healthcare providers should have a copy of the DNR available at all times.
- **Medical Orders for Scope of Treatment (MOST):** A MOST form works in conjunction with a living will and a DNR order by spelling out the types of medical treatment your loved one wants to receive or avoid outside of a hospital setting. Intended for patients with serious illness, it details end-of-life care choices such as code status, extent of interventions, and preferred location for care. In general, a MOST will be more detailed than either the living will or DNR order. The original form, bearing the NC State Seal, serves as a medical order that guides EMS and ER staff, so it should be periodically updated as your loved one's wishes change and kept accessible in an emergency.

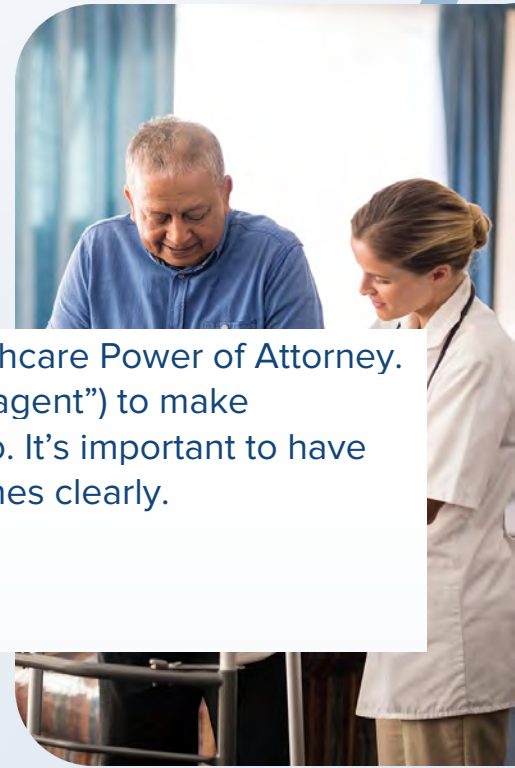
Financial Planning

- **Review Financial Situation:** Assess your loved one's financial situation and find out how their nest egg is holding up. What investments have they made? How much debt do they have? Understanding your loved one's financial situation can help ensure their care is paid for from the right sources.
- **Access to Accounts:** Make sure you have access to your loved one's accounts and can manage their finances if they are unable to. A financial power of attorney can allow you to do this.
- **Estate Planning:** Review or revise your loved one's will or trust so the beneficiaries are up to date. Make sure all of their assets are accounted for.

By carefully selecting a hospice provider and making other legal, financial, and domestic preparations, your time with your loved one can be focused on comfort. This proactive approach can help alleviate some of the stress and uncertainty during this challenging time, allowing you to cherish the moments you have together.

Building an Advance Care Plan

One of the key elements of an advanced care plan is the Healthcare Power of Attorney. This document allows your loved one to assign someone (an “agent”) to make healthcare decisions on their behalf if they can no longer do so. It’s important to have these conversations early and document your loved one’s wishes clearly.



IMPORTANCE OF EARLY CONVERSATIONS

- **Initiate Early Discussions:** If you’re not already doing this, it’s extremely important to have discussions with your loved ones about what they would want if they’re unable to respond in a crisis. Identify situations in which your loved one might not be able to communicate, and think about what types of interventions they would be likely to choose or reject (for example: CPR, a ventilator, or a feeding tube).
- **Select the Right Person:** Choose an agent who is trustworthy, calm under pressure, and willing to advocate for your loved one’s wishes. This person should be capable of handling hard and sometimes stressful work.
- **Document Clearly:** Ensure that the HCPOA document is completed correctly and clearly outlines your loved one’s healthcare wishes. Have this document signed, witnessed, and (if your state requires it) notarized.

ROLE OF THE AGENT

- **Healthcare Decisions:** The agent can act in a broad range of healthcare decisions. These include consenting to or refusing treatments, choosing healthcare providers, and making end-of-life decisions.

- **Advocacy:** The agent must advocate for your loved one's wishes, even if the agent disagrees with these wishes. The agent should be able to talk to medical staff and family respectfully.

ACCESSIBILITY

- **Keep Accessible Copies:** You want copies of the HCPOA to be easily accessible to the agent, family members, and healthcare providers. It's also wise to keep a copy in a secure, yet accessible place at home.
- **Inform Key Individuals:** Inform relevant individuals, such as other family members and your loved one's primary care physician, that the HCPOA has been created. You'll also want to let others know who the agent is.

LIVING WILL AND LIFE INSURANCE

A living will, or advance directive, is a legal document that describes your loved one's preferences for end-of-life care. This is typically used when your loved one can't make their own decisions about medical treatment. A living will helps guide healthcare providers and family members in making decisions that align with your loved one's wishes.

LIVING WILL

- **Detail Preferences:** A living will typically addresses life-sustaining treatments, such as mechanical ventilation, tube feeding, dialysis, and pain management. It should clearly state which treatments your loved one wants to receive or avoid.
- **Discuss with Healthcare Providers:** Talk with your loved one's healthcare providers about the living will and see if it is consistent with their medical history and current health status. Providers can help explain what a particular treatment involves.
- **Regular Updates:** The living will needs to be reviewed and updated periodically, particularly if your loved one's health status has shifted or their values have

changed. Life circumstances and medical advancements can influence these decisions.

LIFE INSURANCE

- **Policy Review:** Review your loved one's life insurance policies to understand the benefits and coverage. Who is their beneficiary? What are they covered for? How do you file a claim?
- **Financial Security:** Life insurance can provide financial security and help cover expenses such as medical bills, funeral costs, and other end-of-life expenses. It can also provide ongoing financial support for dependents.
- **Communicate with Beneficiaries:** Make sure that a life insurance policy's beneficiaries are aware of the policy and know how to access the benefits. Provide them with the necessary information, such as the policy number and the insurance company's contact details.

DNR AND MOST FORMS

Do Not Resuscitate (DNR) orders and Medical Orders for Scope of Treatment (MOST) forms spell out whether your loved one wants to be resuscitated or receive other life-sustaining, potentially invasive treatments. These documents are invaluable to have filled out and available.

DNR ORDERS

A DNR order is a medical directive that instructs healthcare providers not to perform cardiopulmonary resuscitation (CPR) if the patient's heart stops or if they stop breathing.

- **Understanding DNR:** A DNR order is an important decision for patients who do not wish to have CPR because of either what is wrong with them or because of their overall prognosis (outlook) – that is, they do not wish to be revived even if they can be. Discuss the implications of a DNR with healthcare providers to make an informed decision.

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- **Implementing DNR:** The DNR order must be written and signed by a physician. It should be easily accessible, and copies should be given to healthcare providers, the hospice team, and any others who may be involved.
- **Visible Placement:** In a home setting, the DNR order should be placed in a visible location, like on the refrigerator or near the bed, to ensure that emergency responders can see it at a glance.

MOST

A MOST form complements a living will by spelling out the specifics of what life-sustaining treatment or medical interventions a patient wants (or doesn't want). These instructions span multiple care settings, from the hospital to the nursing home and even back home. This form includes a medical order that physicians sign and instructs healthcare providers to follow it wherever the patient goes.

- **Detailed Medical Orders:** The MOST form includes specific instructions on treatments such as intubation, mechanical ventilation, feeding tubes, antibiotics, and comfort measures. It turns a patient's wishes into actual medical orders.
- **Consistency Across Care Settings:** The MOST has a unique dual function: not only does it go beyond the directive, allowing a broad variety of wishes to be addressed, but it can also be honored throughout care settings – including the hospital, the nursing home or in an emergency room. This ensures continuity of care according to the patient's wishes.
- **Periodic Review:** As with all advanced care planning directives, the MOST form should be reviewed periodically and revised as required to reflect changes in the patient's condition or preferences.

ENSURING ACCESSIBILITY

Distribute Copies: Distribute copies of the DNR and MOST forms to all healthcare providers and facilities that are providing medical services to the patient. Give copies to family members, physicians, nurses, EMTs and hospice workers.

- **Emergency Preparedness:** Make sure family members and caregivers know to show these forms to emergency first responders. If these documents are easy to find and clearly labeled, they can help prevent unwanted interventions.

If you take the time to educate yourself about these important documents and complete them in advance, you'll be well-positioned to make sure that your loved one's wishes will be honored. This helps you prepare to make the best life-and-death decisions for your loved one when necessary.

Managing Daily Care

COORDINATING WITH THE HOSPICE TEAM

In addition to your loved one's doctors and nurses, the hospice team includes social workers, chaplains, and volunteers. Regular communication with this team is essential to ensure your loved one's needs are being met. Don't hesitate to ask questions and advocate for your loved one's comfort and care.

CREATING A COMFORTABLE HOME ENVIRONMENT

You can make your loved one's home more calm, safe, and pleasant by rearranging the furniture, providing good lighting and encouragement to rest, or surrounding them with comforting pictures, colors, and objects.

ENGAGING IN MEANINGFUL ACTIVITIES

Engaging your loved one in meaningful activities can provide emotional and mental stimulation. This might mean putting on music so the person can listen, reading aloud, watching old movies or favorite TV shows, playing cards or board games, or just having a visitor sit quietly, reminiscing and engaging in small talk.



Self-Care for Caregivers



RECOGNIZING AND ADDRESSING CAREGIVER STRESS

Caregiving can be tiring, and physically and emotionally draining – if you sense that you’re stressed, and can catch any of these symptoms early, reach out for respite care, go to a support group or do something you love to regroup.

BALANCING CAREGIVING DUTIES WITH PERSONAL LIFE

Maintaining a balance between caregiving duties and your personal life is crucial. Delegate tasks to other family members or friends, and prioritize your own health and well-being. Remember, you can’t pour from an empty cup.

End-of-Life Planning

HOUSING ARRANGEMENTS

Talk about your relative’s housing situation. Should they stay at home, or would a hospice facility (or assisted living or a nursing home) be better? Figure out what they want and need.

MANAGING DIGITAL ASSETS AND FUNERAL INSTRUCTIONS

Ensure that your loved one’s digital life (including online accounts and social media) is managed according to their wishes. Preplanning funeral arrangements can also ease the emotional burden during a difficult time.

Conclusion: Finding Hope and Healing

RESOURCES FOR GRIEF SUPPORT

Grief is a natural part of the caregiving journey. Seek out grief support groups, counseling, and other resources to help you navigate the emotional aftermath of your loved one's passing.

CELEBRATING THE STRENGTH AND RESILIENCE OF CAREGIVERS

Caregiving is rooted in love and commitment. Take joy in your strength, resilience, and ability to bring care, comfort and relief. Remember, you're not alone, and support is there with every step you take



This ebook is designed to offer guidance, support, and reassurance to caregivers during one of life's most challenging journeys. By being prepared and informed, you can focus on what truly matters—spending meaningful time with your loved one and cherishing every moment.

Hospice Care Planning Checklist

Carolina Caring understands that entering hospice care can be overwhelming, and you or your loved ones might feel uncertain about where to begin with estate planning, building a care plan, or managing other important documents. To support you during this challenging time, we have created a comprehensive checklist designed to guide you through each step of the process, ensuring you have everything you need to feel prepared and at ease.

Estate Planning

1. LAST WILL AND TESTAMENT

- ☐ Appoint a guardian for minor children
- ☐ Assign a guardian for your pets
- ☐ Inventory all personal property and determine the individuals or charities to receive each asset
- ☐ Designate an executor to implement the terms of your will

2. ADJUSTABLE LIVING TRUST

- ☐ Itemize all personal property and decide which individuals or charities will inherit each asset
- ☐ Transfer your personal property into the trust
- ☐ Appoint a successor trustee to oversee your trust after your passing

3. BENEFICIARY DESIGNATIONS

- ☐ Identify a beneficiary for all non-probate assets, such as:
 - ☐ 401(k) and IRA accounts
 - ☐ Life insurance policies
 - ☐ Pensions

4. DURABLE FINANCIAL POWER OF ATTORNEY

- ☐ Select a financial agent to make key financial decisions on your behalf
- ☐ Specify which financial decisions your agent is authorized to make
- ☐ Ensure your document states that the power of attorney is durable

5. PET TRUST

- ☐ Create and fund a trust for the care of your pets
- ☐ Appoint a successor trustee to manage the trust after your passing
- ☐ Assign a guardian for your pets
- ☐ Provide detailed instructions on how the funds should be used for your pet's care, including medical needs, preferred nutrition, and favorite toys

Build An Advance Care Plan

6. HEALTHCARE POWER OF ATTORNEY

- ☐ Select a healthcare proxy to make crucial medical decisions on your behalf
- ☐ Define which medical choices your proxy is authorized to make
- ☐ Clearly state in your document that the power of attorney is durable

7. LIVING WILL

- ☐ Detail your medical treatment preferences for your doctors and healthcare proxy to follow
- ☐ Share this document with your healthcare proxy to ensure they understand your wishes

8. LIFE INSURANCE

- ☐ Evaluate your age, expenses, and number of dependents to choose a plan with suitable coverage
- ☐ Review your policy every few years to see if your needs have changed

9. DNR AND MOST FORMS

- ☐ Typically used by individuals with serious health conditions or existing diagnoses
- ☐ Request your doctor to prepare a DNR
- ☐ Ask your doctor to document your end-of-life care preferences in MOST forms

Other Important Documents

10. END-OF-LIFE HOUSING ARRANGEMENTS

- ☐ Decide where you want to spend your final days, considering cost, convenience, and other factors
- ☐ Communicate your preferences with your loved ones so they understand your wishes

11. INSTRUCTIONS FOR YOUR DIGITAL ASSETS

- ☐ Use a digital vault or password manager to securely store important logins and passwords, including keys to cryptocurrency wallets
- ☐ Appoint a digital executor in your will to manage your digital assets

12. FUNERAL INSTRUCTIONS AND PREFERENCES

- ☐ Specify your choice between burial, cremation, etc.
- ☐ Describe the type of service you prefer
- ☐ Identify preferred charities for donations
- ☐ Draft or outline your obituary
- ☐ Provide instructions for what should be inscribed on your tombstone