

DOULAGIVERS HOSPICE HANDBOOK

Filling the *"Hospice Gap"*



Doulagivers Institute™

*"With the right education, kindness & support,
the end of life can be the beautiful, natural
& sacred experience it was meant to be."*

- Suzanne B. O'Brien RN

DOULAGIVERS ADVANCE DIRECTIVE FORM



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What You Will Learn:

1. What Hospice Care Is
2. What Hospice Care Isn't
3. The "Hospice Gap"
4. Who's on the Hospice Team
5. What YOU Need to Know to Fill the "Hospice Gap"
6. The Doulagivers 3 Phases of End of Life Model of Care
7. The Hospice Comfort Kit (Medications)
8. End of Life Caregiving Supplies
9. Creating a Solid Support System
10. When to Call Hospice
11. Questions to Ask a Potential Hospice
12. Valuable Adjunct Resources



1. What Hospice Care Is:

According to The National Hospice and Palliative Care Organization (NHPCO), Hospice Care is considered to be the model for quality, compassionate care for people facing a serious or life-limiting illness or injury. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. Healthcare providers use Medicare guidelines to determine eligibility for hospice care. According to Medicare, you're eligible for hospice if your life expectancy is six months or less if your illness were to run its natural course. Some of the most common diseases that qualify for hospice services are:

ALS, Alzheimer's Disease, Cancer, Dementia, Heart Disease, Kidney Disease, and Parkinson's Disease.



2. What Hospice Care Isn't:

Hospice is not 24 hour bedside care. Although a beautiful model in theory, the present medical model of hospice is just not working well.

According to a recent Medicare study, a hospice worker is only in the home of a dying patient for an average of 30 minutes a day. This means that **98% of the hands-on care falls on the immediate family of the patient.** In addition to the limited time in the home, hospice staff such as nurses, doctors, home health aides, and social workers can only be accessed outside of scheduled visits if staffing allows. Because the majority of hospices today are for-profit businesses and the medicare hospice benefit pays a fixed per diem rate regardless of the quality of care provided, many hospices are inadequately staffed.

A family caregiver that recently attended one of our Doulagivers trainings shared that when they were finally referred to hospice care, the hospice was so short staffed that it was over two weeks before their loved one was admitted to the services. End of life cannot be put on hold and someone who is actively dying cannot be without proper care for days on end.



3. The “Hospice Gap”:

Deficiencies exist in the mainstream end of life care industry, namely hospice, that are harming people at the most vulnerable time in their lives. **An average of 2.5 to 3 million people experience the end of life each year in the United States, 75% of which are expected, rather than sudden.** At the same time, **there are an estimated 44 million Americans aged 18 and older who provide unpaid assistance and support to the elderly and those at the end of life.** Evidence shows that most of these caregivers are ill-prepared and provide care with little to no assistance. Family members of dying patients are being thrown into caregiver roles with no prior experience or adequate training because a massive “gap” in support exists in the mainstream end of life care system.

- There are **gaps in care** in the present hospice model.
- There is a **gap between the time** required at the bedside by patients and families and what can be fulfilled by overtaxed hospice workers.
- There is a **gap in family caregiver education.** As a hospice nurse I would visit the home of my patients for one hour once a week if they were in stable condition. I was expected to teach the family how to care for their dying loved one in addition to providing care and evaluating the patient in this short amount of time. I could only share so much information and hardly anything would be absorbed because people are emotionally distressed and frightened.
- There is a major **gap between the type of end-of-life experience most people want for themselves and those they love and what is actually being provided** by the current system we have.



4. Who's on the Hospice Team:

It can be very confusing to families who are in the throes of an end of life crisis to keep track of everyone on the hospice team and what services are provided by whom. Most of the time, with the exception of home health aides, everyone dresses in business casual clothing - even the nurses. To help you understand who is on the hospice team here is a list of "Hospice Helpers" and the roles they play and the services you should expect them to provide for you and your dying loved one.

Admissions Nurse: The initial admission will be done by an Admissions Nurse. This process will be filled with many questions and intake forms. This is the only time you will see this nurse. It will be a longer visit than the subsequent nursing visits and typically lasts about 2 hours.

Case Manager: You will be assigned a Case Manager who is a registered nurse. She or he will be in charge of your loved one's "case." You can expect a visit from your Case Manager RN once a week for approximately an hour, unless there is an emergent/acute need or extenuating circumstances.

Hospice Home Health Aide: A hospice aide can be provided anywhere from 1 to 2 hours per week Monday-Friday. This is based on patient acuity with the maximum allotted time available 2 hours 5 days a week. The caveat with this is that a hospice aide will only be dispatched for this extended timeframe if one is available. I have had many patients that "qualified" for a Home Health Aide, but died before one ever made a visit because hospices are so chronically understaffed.



4. Who's on the Hospice Team: (continued...)

Hospice Social Worker: You can expect to see a hospice social worker approximately once every 2 weeks for an hour long visit. Additional visits are granted by request only, but again... you will only have access to them if they are available. Many times they are not.

Hospice Volunteer: Hospice volunteers are wonderful and have hearts of gold. Unfortunately, they are not able to provide the much needed "time" that hospice families so desperately need. Hospice medicare reimbursement guidelines require that 5% of patient contact be done by a volunteer, so most hospice volunteer programs are solely focused on meeting this requirement. Hospice volunteers are limited in what they can and can't do because they are not thoroughly trained. Volunteers visit a patient's home only one hour once a week on average. When I inquired about this to a hospice volunteer coordinator I was told, "We don't want to burn the volunteer out." What about the family caregivers?

Hospice Chaplain: Spiritual care provided by non-denominational ministers who are available by request only.



5. What YOU Need to Know to Fill the "Hospice Gap":

These 2 things are critical to ensuring a positive end of life experience and a good death for your loved one.

A. Learn the skills on how to care for your dying loved one before you need them. Knowing what to expect and being able to anticipate a patient's needs is so important as the end of life process unfolds. Waiting until you are in an active situation where you need this information and are scrambling to learn while needing to care for the patient can create an extremely stressful situation for all involved and does not allow you to provide optimal care. Being proactive and getting ahead of things makes all the difference in the world for both you and your loved one. We know we are going to need these skills one day - learn them NOW!

- **[The FREE Doulagivers 90-Minute Level 1 End of Life Doula and Family Caregiver Training](#) is a great way to learn the essential skills for caring for someone who is dying.** This training includes the Doulagivers 3 Phases of End of Life Model of Care we use in our professional certification programs, as well as interventions to use for comfort in each phase.

B. Learn the different medications provided in the Hospice Comfort Kit and how to administer them properly. You will need to use these medications to manage your loved one's symptoms and being in a crisis situation is not the time to try to figure out what to use and how. Practice drawing up medications with your Case Manager RN when she or he is in the home and review the contents of the comfort kit on each visit until you are fully confident in how and when to administer medications.



6. The Doulagivers 3 Phases of End of Life Model of Care:

The Doulagivers Level 1 End of Life Doula and Family Caregiver Training

Introduction:

Congratulations! You are taking part in one of the most important areas of care you could ever learn. It is never easy to lose someone we have loved for a long time, but knowing how to care for someone and their family in this precious last phase of life can make this inevitable part of our life's journey a more positive and peaceful experience for everyone involved.

Nine out of ten people polled by the National Hospice Organization said that they want to be kept at home if terminally ill, yet half are dying in the hospital. The same poll found that 70% of families said that they felt they were referred to hospice care too late in the dying process.

Fact: 78 million Baby Boomers started turning 65 last year. How can we as a society support them and their loved ones to stay at home during this precious last phase of life as so many wish?

End of Life Doulas will change how we handle end of life care.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

What is an End of Life Doula?

An End of Life Doula is a non-medical person who is trained to care for a person and their family holistically in the last phase of life. Holistic means “whole” and encompasses the physical, emotional, mental, and spiritual components of care. The End of Life Doula knows what to expect physically, emotionally and spiritually as someone’s body declines and what interventions to suggest for optimal comfort and quality of life each day. Many Certified Doulagivers are also retired healthcare professionals (nurses, doctors, home health aides, social workers, ministers, and wellness practitioners). They may have many years of clinical experience on their resume, but they do not wear their “clinical hats” when practicing as a Doulagiver. Doulagivers is the new, specialized area of non-medical healthcare for the elderly and those at the end of life.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Our Mission:

The goal of Doulagivers Institute is simple and powerful - to provide affordable and accessible education and support to everyone in the world so that every person has the opportunity to die with comfort and dignity in their own home. Death is something that we all have in common no matter our race, religion, or socioeconomic status. We believe that this education to support people to have the most positive end of life experience is a human right, not a privilege.

Our mission is to expand and enhance quality end of life care for all people anywhere in the world and establish the gold standard for the certification of holistic, non-medical end-of-life care professionals. Doulagivers Institute offers state of the art educational programs and resources to help family caregivers perform their duties with confidence and to train and certify professional Doulagivers. Certified Doulagivers help navigate and guide patients and families through the entire end of life journey, providing support before, during and after death. They are a huge tool for empowerment, knowledge and advocacy on behalf of patients and family caregivers.

The Doulagivers Free Level 1 End of Life Doula and Family Caregiver Training is divided into 3 “Phases” of care:

- 1. The Shock Phase**
- 2. The Stabilization Phase**
- 3. The Transition Phase**



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Phase 1: The Shock Phase

What it is: The Shock Phase is when someone initially receives a terminal diagnosis. Oftentimes there is an overwhelming feeling of shock for both patients and their loved ones. This shock can present itself in many ways, such as depression, denial, anger and withdrawal just to name a few.

What you can do: It is helpful to remember that the person who has just gotten a terminal diagnosis and their family have just lost all control over their lives. Telling someone that they are terminally ill and that there is no reversing the process requires those around the family to be a strong supportive presence.

Be an incredibly good listener. Ask the family and the patient, “What can I do for *you*?”

Allow them to give direction and tell you what they need. This gives them back some feeling of control in a time when they need it most. Another important thing to do is to look for any immediate issues that need to be addressed. Acute issues to look for include safety concerns, pain management issues, and signs of exhaustion (of the patient AND the caregivers).

Why it is important: It is vital to establish trust and security with a patient and family at this time when their world has been turned upside down. The best way to achieve this is through being a strong solid support for them. Never try to take over. Meet the patient and the family “where they are” in their process and work from there. Building trust sets the tone for your entire journey with them.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Phase 2: The Stabilization Phase

What it is: This is the phase of end-of-life where wonderful work can be done. It is hopefully a time when the patient's pain is under control, and all acute issues identified in the Shock Phase have been fully addressed - leading to the highest quality of daily living for both the patient and family. When things are stable, meaningful conversations can be had, goodbyes can be said and unresolved issues can be addressed.

What you can do: This is the perfect time to sit with a patient and talk to them about his/her life. Ask them questions and take an interest in who they are. This will often uncover issues or situations that need to be looked at more closely and resolved. Forgiveness is the path to unconditional love. It is during this phase that we encourage giving and receiving forgiveness of things that have happened during our lives. Patients oftentimes will conduct a "life review" on their own and reflect on beautiful insights and contributions they had in this world. Validate their feelings. Be a great listener. Encourage family members to have one-on-one alone time to share with the patient. There are conversations that need to be had that will not take place in a room full of people. These "goodbyes" and "I love yous" are vital components of reaching peace and acceptance during the end of life journey and allow for a positive passing.

Why it is important: Unresolved issues will prevent a person from having the most peaceful death possible. It is imperative to use this window of opportunity while the patient is able to communicate and engage in lucid conversations to wrap up loose ends. Patients can do much of this work simply by talking about past regrets with the end of life doula or a trusted loved one.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Phase 3: The Transition Phase

What it is: The Transition Phase is the time right before a person dies. It is the “transition” from this world to the next. This period can last anywhere from hours to days.

What you can do: As an end of life doula you should be aware of the way that the body physically shuts down as it is nearing death. Systematically we all die the same way. No matter what disease process someone has, the body goes through many of the same steps in the end. Not everyone goes through every step every time, but it is best practice to be familiar with them all so that you can identify what is happening and suggest interventions for comfort or simply let the family know that what they are seeing is natural and not to be afraid.

Why it is important: The Transition Phase may be the most stressful period of care due to the quick changes the body goes through as it starts to shut down. It is during this phase that the patient will go into a deep sleep and then eventually die. There are several changes to be aware of so that you can offer suggestions for comfort or simply reassure the family that what is happening is a natural part of the dying process. (This knowledge alone can be very comforting for distressed loved ones).



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Indications that Someone is Entering the Transition Phase:

- They lose the desire to eat/ability to swallow.
- They become agitated/restless - sometimes they talk about having to “go home” or go on a trip.
- They start to sleep most of the time.
- They talk about being visited by loved ones who have passed away already or even angelic figures.
- They become incontinent.
- They experience confusion and/or hallucinations.
- *They have a surge of energy* (*Your window of opportunity*).
- They give loved ones permission to go.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Signs that Someone is Actively Dying:

1. **Sleeping Coma** - you can turn and position the patient and pad bony prominences to provide comfort.
2. **Breathing Changes** (Cheyne Stoke, Agonal Breathing, Periods of Apnea, Rapid or Shallow Breathing - you can suggest that the caregiver/nurse administer a Morphine/Ativan (liquid) formula in the cheek of the mouth.
3. **Temperature Changes** in the Body (Increase or Decrease) - cover the patient in warm blankets if they are cold and use a cool cloth on the forehead/administer a Tylenol suppository for high temperatures.
4. **Skin Color Changes** such as pallor (pale skin), bluish nail beds and lips, or mottling of extremities - help keep the patient warm by gently rubbing extremities with your hands.
5. **Secretions in Chest** - put the head of the patient's bed at a 45 degree angle and put a pillow folded in half lengthwise behind their back so that they are turned to the side. This will help dislodge the secretions and the gurgling noise should stop.
6. **Giving permission to go** (saying goodbye) - encourage the family members to visit the bedside and let the patient know that it is okay to leave.



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Setting a Sacred Space:

When someone is transitioning from this life to the next it is a sacred, spiritual experience. Here are a few suggestions to create a beautiful and loving space for that transition to occur.

1. Soft Background **Music**
2. Dim **Lighting/Candles**
3. **Aromatherapy** (Lavender or whatever the person desires)
4. **Gentle Touch** (It is the most comforting feeling for the dying patient to know that someone is there taking care of them and holding that trusted space for them)
5. **Talking Softly** (Hearing is the last of the senses to go. The person can still hear you even if they are in a sleeping coma. Talk to them and encourage family and friends to talk to them as well)
6. **Pets** (Allow these unconditionally loving beings to be present and snuggle or lay next to their loved one. They bring incredible comfort to the patient)



6. The Doulagivers 3 Phases of End of Life Model of Care: (continued...)

Congratulations on Learning the 3 Phases of End of Life!

Having this knowledge will allow you to be of service to someone who needs your support at one of the most important times of their lives.

If you would like to participate in the full [**FREE Doulagivers 90-Minute Level 1 End of Life Doula and Family Caregiver Training**](#), you can register for the next available training [here](#).

If you are in an active end of life journey and need this information now, please email support@doulagivers.com to request a replay of an earlier webinar.



7. The Hospice Comfort Kit (Medications)

The hospice comfort kit is a set of medications provided to hospice patients to help manage symptoms and provide comfort at the end of life. The contents of the comfort kit usually includes medications for pain management, anxiety, shortness of breath, and nausea. The hospice comfort kit is considered an important part of hospice care as it allows patients to quickly receive medications to manage symptoms and improve their comfort without the need for additional trips to the pharmacy or hospital.

The specific medications included in a hospice comfort kit may vary depending on the patient's needs and the hospice organization, but here are some common medications and their uses that may be included in the kit:

- **Liquid Morphine/Roxanol** used for pain relief and shortness of breath.
- **Benzodiazepines** such as Lorazepam/Ativan used for anxiety and agitation management.
- **Compound Antiemetics** in the form of creams or pills for nausea and vomiting.
- **Antipsychotics**, such as Haloperidol, for delirium and other mental health symptoms.
- **Scopolamine** patches for the treatment of drooling and secretions.
- **Haldol drops** for confusion or agitation.
- **Tylenol Suppository** used for fever.



7. The Hospice Comfort Kit (Medications)

*****Doulagivers Pearl*****

Make sure that the hospice comfort kit is delivered and in the home within 24 hours of your loved one being admitted to hospice services.

*****Doulagivers Pearl*****

Make sure to have the hospice nurse teach and reteach you how to use the medications and when. Ask her to watch you “draw up” the medication so that you know the correct dosages. The time that your loved one is screaming in pain is NOT the time to learn this. Proper use of medications is the most missed learning in hospice care and not knowing how to utilize the hospice comfort kit has devastating consequences for the end of life journey.

*****Doulagivers Pearl*****

The top 3 medications you need to know that are most frequently used are liquid morphine, Ativan, and the antiemetic.

*****Doulagivers Pearl*****

Make sure to understand what sublingual medications are and how/when they should be administered. This will be vital to understand when your loved one is no longer able to swallow - one of the first natural signs that they are entering the Transition Phase.



8. End of Life Caregiving Supplies

Caring for a loved one at the end of life can be a challenging experience for family caregivers. **Having the supplies you need can make a huge difference in the quality of care you are able to provide.** Here is a list of the supplies that are necessary for family caregivers to provide the best care possible for their dying loved ones.

Have these supplies in the home *BEFORE* you need them!

- Barrier Cream/Skin Protectant
- Mouth Swabs
- Mouth Lubricant
- Chux Pads (Washable)
- Disposable Blue Chux Pads
- Disposable Diapers
- Disposable Gloves
- Baby Monitor
- Hospital Bed
- Draw Sheet
- Bedside Table
- Urinal (For Men)
- Bedside Commode
- Sippy Cups

***** Doulagivers Pearl*****

Have these items in the home as soon as possible. Changes in a patient's condition can happen quickly at the end of life and being prepared by having the things you need available in the home can make all the difference in your loved one's comfort level and your ability to address acute issues.



9. Creating a Solid Support System

Caregiver Syndrome is the proper term for the stress that people experience when caring for those at the end of life. It is used to describe the physical, emotional, and mental health symptoms that arise due to the overwhelming burden caregiving places on individuals.

The End of Life requires 24/7 care. Ask for help. Let family members, friends, and community members help fill in shifts to provide respite care for you as a primary caregiver. Hire extra help when possible. Rotate the care and schedule shifts so people can make themselves available. This will prevent any one person from burning out and depleting themselves physically, mentally and emotionally - a common occurrence in end of life caregiving.

*****Doulagivers Pearl*****

Plan for the long haul! We never know how long an end of life journey will be. Plan for it lasting a long time so that you are fully covered and can meet your needs.

*****Doulagivers Pearl*****

If your doctor is refusing to make a hospice referral (it happens) or you do not have a doctor and feel your loved one is ready for hospice care, you can call your local hospice yourself and they will send out a nurse to do an assessment. If your loved one is hospice appropriate, the medical director of that hospice will admit them.



10. When to Call Hospice

You should feel free to call your hospice anytime you feel you may need to. Do not wait. Do not think you are bothering the on-call nurse or overreacting. They are working overnight for this very reason. If you have a question or concern you need to address with a professional - CALL!

11. Questions to Ask a Potential Hospice

- **How much help can I expect to have?** How much time will a hospice worker be in the home daily/weekly?
- **Do you provide in-person on-call visits?** Some hospices no longer offer this and only provide phone support.
- **Will your hospice provide me with all the necessary supplies I need to care for my loved one or will I need to purchase them on my own?**
- **What is the expectation about the family's role in caregiving?** See if what the hospice expects from you and your family is consistent with what you are able to do.
- **Does your hospice offer extra services beyond those required?** Some services fall in a gray area. They are not required by Medicare but may be helpful to improve the comfort of the patient.



11. Questions to Ask a Potential Hospice (continued...)

- **How rapid is crisis response?** If you need someone to come to the home at 3 AM on a Saturday, where would that person come from? What is their average response time?
- **What are the options for inpatient care?** Patients being cared for at home may need to go to an inpatient unit for management of complicated symptoms or to give their family respite. Facilities can vary from the hospice having its own private inpatient unit to leased beds in a hospital or nursing home. Visit the facilities if necessary to ensure that they are conveniently located and that you are comfortable with what they offer.
- **How are patient/family concerns handled?** Is there a clear process for sharing concerns with appropriate hospice staff and making sure they are addressed, including a process for escalation if the concern is not adequately addressed at lower levels?



12. Valuable Adjunct Resources

- [FREE Doulagivers Family Caregiver Community on Facebook](#)
- [Doulagivers Death Doula Guide](#)
- [Life Café](#)
- To access more valuable resources, visit [The Doulagivers Institute FREE Resource Center for Family Caregivers Here](#)



Conclusion:

Hospice care is a beautiful concept and model of care that unfortunately falls short in reality. With major gaps existing in time, education, and support, hospice alone does not provide the type of 24/7 care required at the end of life to facilitate a good death for patients in their home. Understanding how to bridge these gaps in care by learning the skills and information you need to know will empower you and your family to provide the best possible end-of-life journey for your dying loved one.

In Love & Service,

Suzanne B. O'Brien RN and the entire Doulagivers Team

