

Home Health & Hospice Care



Caregiver TRAINING GUIDE

**Information and support for people caring
for someone receiving hospice care**

**FOR ASSISTANCE,
CALL 603-882-2941 or 800-887-5973**

Welcome from Your Hospice Team



Dear Caregiver,

We want to know what's important to you and your loved one in hospice so that we can support your goals. It is challenging to be a caregiver for a loved one going through this phase of life. As your hospice team, we offer training and support so that you feel confident about caregiving. We're here with you throughout this journey. Help us to know what you need.

Hospice provides intermittent care to your loved one in the home. We are not with you all of the time, which is why your role as caregiver is so important, but members of our team come and go as needed to support you and your loved one through this process. It is important to know that you may call us anytime, day or night, with questions. No question is considered too small or insignificant. We would rather hear from you early on when a challenge is just beginning and be able to respond immediately, rather than have something unattended develop into a larger issue.

Even though you may call us anytime, don't be surprised if we also call you to check in. We work together as a team and we want to make sure you have everything you need and are satisfied with our service.

Sincerely,

Your Hospice Team at Home Health & Hospice Care



Your Team

ATTENDING PHYSICIAN

The doctor or nurse practitioner your loved one has chosen to oversee your hospice care and to work with the hospice team on your plan

PRIMARY NURSE (RN)

Visits consistently, educates, collaborates and manages the plan of care

NURSE

Visits intermittently or responds to calls after hours, assists with pain and symptom management, changes in the plan of care and ongoing education

NURSE

HOSPICE DOCTOR

Specially trained in symptom management, this physician or nurse practitioner works with the entire team to meet your goals and keep your loved one as comfortable and functional as possible

SOCIAL WORKER

Assists with family communication around coordinating plan of care, emotional support, advanced directives, long-term planning and connecting to community services

CHAPLAIN

Provides spiritual support to patient and family regardless of faith background, assists with coordinating rites such as Sacrament of the Sick, if requested

LNA (LICENSED NURSING ASSISTANT)

Provides assistance with feeding, bathing, transferring, and other personal care needs, as well as teaching and potentially respite support for the caregiver

LNA (LICENSED NURSING ASSISTANT)

VOLUNTEER

May be a companion, provide respite, help with shopping and errands or offer specialty services such as music, pet visits, Reiki, or therapeutic art

VOLUNTEER

OTHER TEAM MEMBERS



Please call Hospice anytime you have questions or need assistance. You may reach us day or night by calling 603-882-2941 or 800-887-5973.

WEEKDAY OFFICE HOURS

Our office is open Monday through Friday, 8:00 a.m. to 5:00 p.m., except during holidays. We try to be proactive and address issues during normal office hours.

Examples of issues that are best addressed during regular hours:

- Medication refills
- Messages for the primary nurse:
 - You need supplies (gloves, mouth swabs, etc.)
 - Questions about your visit schedule
- Calls for social worker, spiritual counselor or other staff
- Questions about the hospice aide/homemaker

ON-CALL GUIDELINES

A registered nurse (RN) is available 24 hours a day, 7 days a week to assist you and your loved one. The nurse will talk to you by phone to determine your needs and, when appropriate, a nurse will come to your home. We are available outside of regular office hours for situations requiring a timely response. The following is a list of some reasons you may need to contact us after hours or on weekends:

Examples of after-hours situations

- Pain that does not respond to pain medication on hand
- Difficulty breathing
- New onset of agitation or restlessness
- Falls, with or without injury
- No urine in 8 hours associated with discomfort
- Uncontrolled nausea, vomiting, diarrhea
- Uncontrolled or suspected bleeding
- Inability to awaken your loved one (if this is new)
- Catheter leaking
- Chest pain
- Your loved one is taken to the hospital
- Your loved one dies

Always call Hospice before dialing 911.



Role of the Hospice Caregiver

Your loved one has chosen hospice to help meet the needs of his/her care in this final phase of life. This is a mindful choice, not wishing to return to the hospital for additional treatment or care at this time, but preferring to have symptoms managed at home.

Hospice will treat you and your family with dignity and respect, working to keep your loved one as functional, independent, and comfortable as possible. We will provide education and choices each step along the way and help to prioritize goals. While many people wish to receive their care at home, they and those who may become their caregivers often do not realize the extent of commitment this choice may involve.

Hospice has an entire team to support your loved one and is available to be called anytime day or night, but does not “move in”. There will likely come a time when your loved one is not safe to be home alone and your role as caregiver will become very important.

In planning for your loved one’s care, it is important to anticipate what may happen as the disease progresses. Symptoms may increase and become more complicated. Our nurses will train you and your loved one how to manage medications. Our nursing assistants will teach you how to assist your loved one, if necessary, with personal care, and how to maximize comfort in bed.

As you can see, your role as caregiver is critical. Identifying a caregiver (or multiple caregivers) early in the process is important so that Hospice can help you help you develop your care coverage plan.

If an individual does not have a caregiver, or the caregivers will not be able to provide 24/7 care as a person declines, we need to know this as soon as possible so that we can make a plan. Hospice can provide a list of paid caregivers. Or, if financial constraints do not allow for caregivers, we will explore other options with you, which can include moving to another setting such as a skilled nursing facility. This can be paid for with private funds or by applying for and receiving Medicaid.

When Is a Caregiver Needed?



Please know that Hospice is here so that you do not feel alone through what we know is a difficult process. Hospice is here to guide and educate you in meeting the daily needs of your loved one and keeping him/her safe. We will work with you to adapt the plan as needs change.

We have created this guideline to help you to know when it is time for 24/7 care and supervision. The following questions will help you know if it is time for you to step in as an active caregiver or activate your long-term plan:

Is your loved one

- Unable to get out of the house safely if there is a fire?
- Unsteady on his/her feet, or afraid of falling?
- Unable to get to the bathroom in time?
- Unable to safely get out of bed independently?
- Incapable of preparing /eating meals?
- Experiencing any problems with thinking that interfere with good decision-making?
- In danger of turning on the stove or oven and forgetting to turn it off?
- Unable to manage his/her own medicines?
- Incapable of calling the Hospice 24-hour number if help is needed?
- Needing emergency medications to handle difficult symptoms?
- Feeling unsafe to be alone?

If you are answering yes to any of these questions, it is time to put your 24/7 plan of care into place.

Let us help you plan ahead.

Caregiving can be a very difficult job, often too much for one person's shoulders. Hospice is proactive in helping you think about the team of people you can pull from among your own acquaintances to help if the need arises.



Your Caregiver Plan

Is there a caregiver in the home? _____

If necessary, who would move into the home and become a caregiver?

What other friends or family members might be called upon to help with check-in visits, meals, medications, rides, respite or other kinds of support? _____

If your loved one could no longer safely stay in his/her home, what would be the plan? _____

Remember to speak to your nurse before scheduling services outside of hospice.

Please speak with your hospice nurse if you are considering any of the following:

- Doctor or nurse practitioner visits
- Emergency room visits and/or hospitalizations
- Any tests or procedures

Your loved one's hospice benefit is like an HMO; certain things require prior authorization and certain things may not be covered at all. By speaking to your hospice nurse ahead of time, you can help to avoid unexpected expenses for any of these services.

If there is an emergent issue, please **DO NOT CALL 911** unless instructed to do so by a hospice nurse.

A Comfort Kit will be provided as part of your loved one's admission to hospice. You may never need to use the medications in this Comfort Kit, but they will be on hand should you need them. In addition, you may also receive regular medications from the pharmacy.

As part of your hospice care, your loved one's nurses will work with you and under the direction of a hospice physician to create a medication plan that maximizes comfort and minimizes potential side effects.

For some people, taking new medications can be frightening. For others, the word "morphine" brings up a particular fear of hastening death. Hospice does not use medications to hasten death. It's important to know that we always start new medications at a very low dose and adjust them in small increments until we find what works to manage a symptom.

With some new medications, side effects such as sleepiness are usually temporary. It may take the body a day or two to adjust to metabolizing or processing new medications. If this is the case, we'll talk with you ahead of time and educate you on the process so that you are not surprised and know what to expect.

Typically after a short time, the body becomes accustomed to working with a new medication, and having symptoms under control maximizes functionality. Our goal is not only to help you manage distressing symptoms, but also to keep your loved one functioning at his/her best.

The plan for how these medications are used may change as your loved one's symptoms change. This is not unusual for a hospice plan of care. We are here to work with you to make sure that you understand the medications and how they are used. It's our job to make sure you feel confident in every situation. Please let us know if you are feeling dissatisfied or having difficulty with something.



Comfort Kit Medications

MORPHINE SULPHATE LIQUID

This medication will help if your loved one is experiencing:

- **Pain or Discomfort**
- **Difficulty Breathing**
- **Breathing Changes**

This liquid does **NOT** need to be swallowed.

This liquid medication can be absorbed by the tissues in the mouth. Give between the teeth and gums or under the tongue.

The nurse will instruct you on how much medication to give and how often to give it.

LORAZEPAM (ATIVAN) TABLETS

This medication will help if your loved one is experiencing:

- **Anxiety**
- **Agitation and Restlessness**

These tablets can be swallowed or crushed.

Crushed tablets can be dissolved in a small amount of water and can be absorbed by the tissues in the mouth. Give between the teeth and gums or under the tongue.

The nurse will instruct you on how much medication to give and how often to give it.



HALOPERIDOL (HALDOL) LIQUID

This medication will help if your loved one is experiencing:

- **Nausea**
- **Agitation and Restlessness**

This liquid does **NOT** need to be swallowed.

This liquid medication can be absorbed by the tissues in the mouth. Give between the teeth and gums or under the tongue.

The nurse will instruct you on how much medication to give and how often to give it.

ATROPINE 1% DROPS

This medication will help if your loved one is experiencing:

- **Noisy Breathing**

This liquid does **NOT** need to be swallowed.

This liquid medication can be absorbed by the tissues in the mouth. Give between the teeth and gums or under the tongue.

The nurse will instruct you on how much medication to give and how often to give it.

Pain & Discomfort

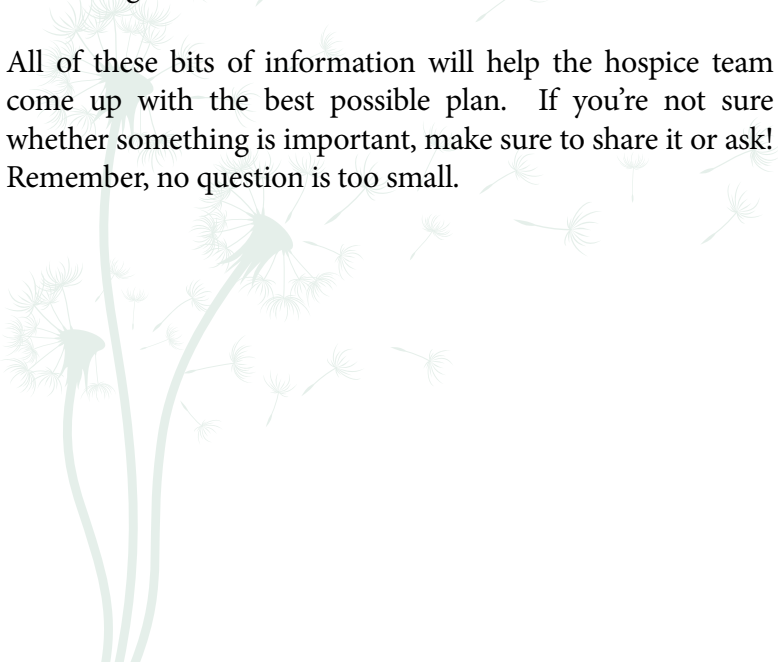
Your hospice team has a lot of experience managing different kinds of pain and discomfort. In every instance, we'll work with you and your loved one to understand your goals and create a plan specifically for you.

How pain and discomfort are perceived varies from person to person. We rely on you and your loved one to be able to report on pain and discomfort so that we can work together.

Your loved one will get used to being asked about his/her level of pain, with "0" being no pain, and "10" being the worst pain imaginable.

He/she might also be asked to describe where the pain is, and whether it has a particular quality. For example: is it dull, aching, sharp, burning, radiating, shooting, intermittent, fluctuating, constant, etc.?

All of these bits of information will help the hospice team come up with the best possible plan. If you're not sure whether something is important, make sure to share it or ask! Remember, no question is too small.



As a caregiver, you might know when your loved one is in pain if you notice any of the following:

Signs of pain /discomfort may include

- Clenching of fists
- Breathing at a faster rate / increased respirations per minute
- Panting
- Restlessness / agitation
- Facial grimacing / furrowed brow
- Lying in fetal position
- New tremors or shaking
- New verbal noises or attempts to communicate
- Any change in usual behavior or patterns

The goal is to relieve the pain and discomfort.

In addition to following your loved one's medication plan, there are other things that you can try to relieve pain and discomfort:

- **Repositioning**—see if another position is more comfortable; use pillows as props, if they are helpful.
- **Make adjustments to the environment**—eliminate unnecessary stimulation, dim the lights, put on music or find other ways that make your surroundings more calm and peaceful.
- **Practice relaxation**—have your loved one close his/her eyes and think about a place that feels safe and happy—a mental trip to the beach, out in the woods, or experiencing a favorite activity can make a big difference.



To learn more, read pages 6-7 of your *Butterflies* book.

Difficulty Breathing

Difficulty breathing or catching one's breath can be a very distressing symptom, for both the person experiencing it as well as for caregivers who may feel powerless to help in the moment.

We'll work with you to make sure you know how to respond if this situation arises.

Often difficulty breathing and anxiety are very closely intertwined. Therefore, in addition to helping to relieve the shortness of breath, we may also work with you on decreasing any sense of anxiety to help your loved one feel more relaxed.



Difficulty Breathing

As a caregiver, you might know when your loved one is experiencing difficulty breathing if you notice any of the following:

Signs of difficulty breathing may include

- Inability to catch breath
- Breathing at a faster rate / increased respirations per minute
- Panting
- Inability to lie down
- Blue-tinged lips, fingers, and/or toes
- Restlessness / agitation

The goal is to ease the difficulty breathing and help with relaxation.

In addition to following your loved one's medication plan, there are other things that you can try to relieve difficulty breathing:

- **Check oxygen**—if your loved one has oxygen, make sure the tubing isn't obstructed or kinked.
- **Circulate air**—angle a small fan in the direction of your loved one's face, blowing gently—this can stimulate a nerve in the face, relieving the sensation of breathlessness.
- **Use relaxation techniques**—breathlessness creates anxiety which creates more breathlessness—you can disrupt this cycle with a calm presence and tools such as relaxing music.

Managing Bowels and Constipation

Bowel management can be an easily overlooked symptom, but anyone who has experienced this difficulty knows how distressing it can be.

Some of the medications used in hospice care can also cause constipation. Because we are accustomed to working with these, we will be proactive and make sure that if your loved one is taking one of these medications, there is also a bowel plan in place to avoid any difficulty.



Managing Bowels/Constipation



As a caregiver, you might know when your loved one is having difficulty with bowels or possibly experiencing constipation if you notice any of the following:

Signs of bowel issues or constipation may include

- No stool for 2 or more days
- Feelings of fullness / bloating
- Abdominal discomfort / cramps
- Difficulty passing stool
- Restlessness / agitation

The goal is to relieve feelings of constipation and enable regular passing of stool.

In addition to following your loved one's medication plan, there are other things that you can try to relieve constipation:

- **Adequate fluids**—if your loved one is still drinking fluids, make sure he/she has plenty of access to water and other fluids throughout the day.
- **Fiber-rich foods**—if your loved one is eating regularly, offer a diet with plenty of fruits and vegetables.
- **Avoid fiber supplements**—please do not use Metamucil or other fiber supplements if there is minimal fluid intake.



To learn more, read page 13 of your Butterflies book.

Anxiety

Anxiety is a symptom that is sometimes overlooked. It can, however, have a significant impact on every aspect of life. Also, if unmanaged, anxiety can get in the way of what's most important to you and your loved one.

We will work with you to recognize and relieve feelings of anxiety in your loved one because we know how much it can affect a person's quality of life. We can help to alleviate anxiety, which opens up emotional energy for the people and things that matter most.



As a caregiver, you might know when your loved one is experiencing anxiety if you notice any of the following:

Signs of anxiety may include

- Difficulty concentrating
- Expressing feelings of anxiousness / fear
- Inability to rest / sleep
- Restlessness / agitation

The goal is to relieve feelings of anxiety.

In addition to following your loved one's medication plan, there are other things that you can try to relieve anxiety:

- **Distraction or re-direction**—focusing on anxiety can heighten it further; try spending time with your loved one and focusing on more positive things (tell stories, look at pictures, invite visitors).
- **Relaxation techniques**—experiment with things such as music, Reiki, foot rubs, or massage.
- **Guided imagery**—ask your social worker for guided imagery techniques or take advantage of audio resources to help walk your loved one through a guided experience.

Confusion, Agitation, and Restlessness

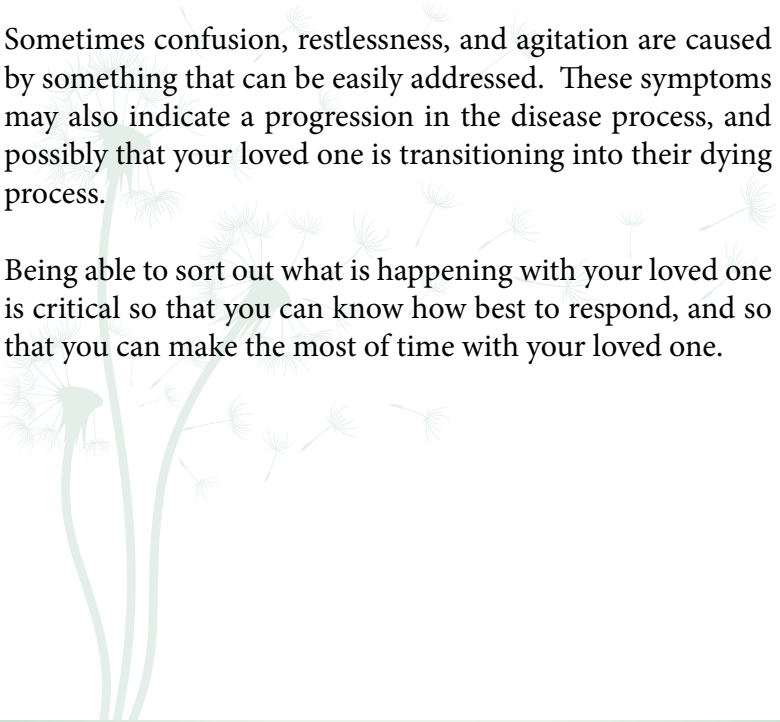
Confusion, agitation, and restlessness are among the most difficult symptoms for caregivers to witness because their loved one's behavior may seem so "unlike" themselves.

These are important symptoms to report to your hospice team right away so that we can help identify what's happening and come up with a plan.

When your loved one is experiencing episodes of confusion and agitation, it's helpful for your hospice nurse to know if these patterns shifted gradually over time, or if this is a sudden change.

Sometimes confusion, restlessness, and agitation are caused by something that can be easily addressed. These symptoms may also indicate a progression in the disease process, and possibly that your loved one is transitioning into their dying process.

Being able to sort out what is happening with your loved one is critical so that you can know how best to respond, and so that you can make the most of time with your loved one.



Confusion, Agitation, Restlessness



As a caregiver, you might know when your loved one is experiencing confusion, agitation, and/or restlessness if you notice any of the following:

Signs of these symptoms may include

- Difficulty concentrating
- Confusion about things that are normally known
- Expressing feelings of anxiousness / fear
- Inability to rest / sleep
- Attempting to do things he/she is no longer capable of doing, sometimes without awareness
- Unable to stay in one position for any length of time, i.e. moving from chair to chair, or repeatedly trying to get out of bed

The goal is to relieve confusion, restlessness, and agitation in order to keep your loved one safe.

In addition to following your loved one's medication plan, there are other things that you can try to relieve confusion, restlessness and agitation:

- **Remain calm**—speak in a slow, gentle voice.
- **Eliminate unnecessary stimulation**—try to create a soothing, uncomplicated atmosphere; perhaps turn off the TV and try some soothing music, or just allow quiet.
- **Limit the number of visitors**—or consider limiting visits to a shorter amount of time.



To learn more, read page 11 of your *Butterflies* book.

Breathing Changes

As a person is dying, breathing can change in a variety of ways.

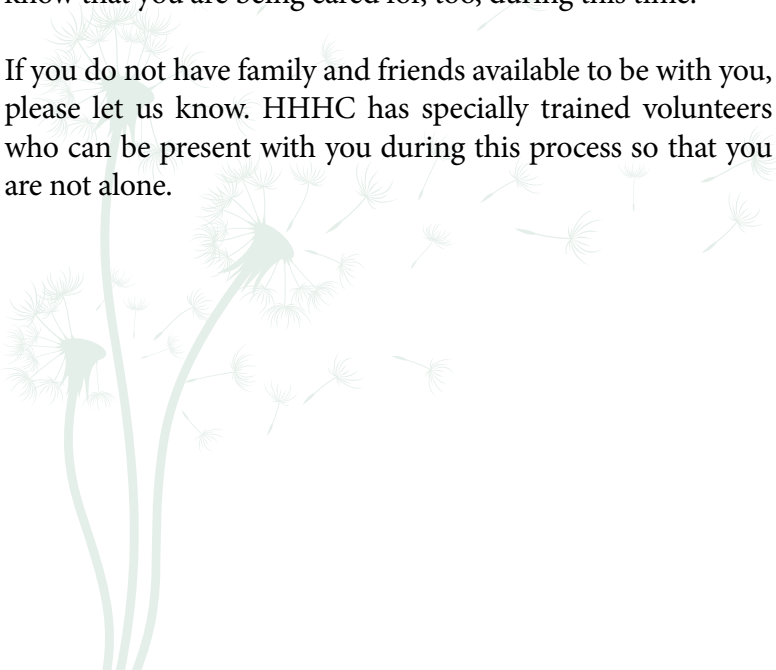
How this happens is unique to each person. It is important as a caregiver to understand that these changes are a normal part of the dying process.

These changes are usually not distressing to your loved one, but they can be difficult for you as a caregiver to be with, particularly because they communicate to us that time is likely short.

Your hospice team will help to explain changes as they are happening and to keep your loved one comfortable.

This is a time for family to gather and to make sure that you as a caregiver have the support you need. Your loved one needs to know that you are being cared for, too, during this time.

If you do not have family and friends available to be with you, please let us know. HHHC has specially trained volunteers who can be present with you during this process so that you are not alone.



Breathing Changes



As a caregiver, you might know when your loved one is experiencing breathing changes if you notice any of the following:

Signs of breathing changes may include

- Difficulty swallowing or coughing
- Gurgling or rattling sounds
- Rapid, shallow breathing followed by deep, slow breathing
- Periods between breaths that get longer over time (this is called apnea)
- Restlessness / agitation

The goal is to help reduce noisy breathing and increase awareness of a changing timeline.

In addition to following your loved one's medication plan, there are other things that you can try to maximize comfort and make the most of this time:

- **Try to focus on what you see, not what you hear**—it can be difficult as a caregiver or family member to hear this kind of noisy breathing, but it is typically not distressing to your loved one—try imagining that you do not hear the sound and focus on what you see:
 - Is your loved one's body tight or relaxed?
 - Is there any grimacing in the forehead or is the face peaceful and at ease?
- **Gather loved ones and share stories**—even if your loved one is not responsive, we always assume that people are still able to hear what is being said and are aware, on some level, of their surroundings.



To learn more, read page 10 of your Butterflies book.

Visions and Symbolic Language

When people are approaching the end of life, it is not unusual for them to have visions or speak symbolically. As a caregiver you may initially think your loved one is delirious or out of touch with reality, or you may even wonder if this is a reaction to medication.

Such instances can certainly feel disconcerting, but they are not reason to be alarmed. It is important to know that for many people, these visions and communications are a normal part of the dying process.

What your loved one is describing may not make sense to you, but the experiences he or she is having feels entirely real. People nearing the end of life often report having visitations, most significantly by individuals who have died previously. These visitors may communicate with your loved one, indicating that it is now time to go, or reassuring them that it is not yet time.

The words your loved one uses may not make literal sense, but can be symbolic of how he/she feels. At times people have indicated that they are lost or confused and can't make the necessary transition. *"Where is the door? I don't see the door."* *"My key isn't working."* *"I can't find the map."* *"The elevator won't stop on my floor."* While it is stressful to observe this, your loved one may be reassured to know that he or she will have all that is needed when the time is right.

Your Hospice Team is experienced in working with these kinds of nearing death communications and can help to support you in this time and navigate these mysteries. Most visions and symbolic experiences are not disturbing, and in fact may be quite comforting. We want to know right away if something is causing distress to your loved one.

Visions and Symbolic Language



As a caregiver, you might know when your loved one is experiencing visions or speaking symbolically if you notice any of the following:

Signs may include

- Staring at a fixed point or looking upward and tracking from side to side with the eyes
- Talking to pre-deceased loved ones as if they are present in the room
- Seeing groups of people (often children), whether known or unknown
- Reporting seeing angels or other spiritual beings consistent with their spiritual tradition
- Talking about needing to get ready for a trip, a meeting, or an important gathering
- Hand motions demonstrating that they are packing items or grooming
- Asking or insisting on needing to “go home”

The goal is to help you understand your loved one’s symbolic communication so you can be supportive and alleviate any distress that may be experienced.

In addition to alerting your hospice team to the communication changes or visions being experienced, there are other things that you can try:

- **Acknowledge your loved one’s experience**—calmly validate what your loved one is sharing with you. Do not discount this. It is very real for your loved one. At end of life, people are straddling two existences and their accounts of what they are seeing reflect this.
- **Be curious**—respectfully ask your loved one to explain more about what is happening. Clarify what he/she is feeling. Most importantly, you want to be sure your loved one is not distressed.



To learn more, read page 11 of your *Butterflies* book.



Visions and Symbolic Language

- **Join your loved one in their symbolic language and provide reassurance—**
 - *“You are working hard to get ready for your meeting. I know you will be ready when the time comes.”*
 - *“I can see you are putting everything in order. You are doing a good job of making sure everything will be all set.”*
 - *“I can see you are putting your make-up on.”* (Often done with hand motions) *“You look terrific.”*
 - *“You tell me you see a brick wall, but you are working so hard, I bet you will find a way around this. I wonder if Dad (pre-deceased) could help you?”*
- **Clarify what is meant by “I need to go home.”**—Ask for details of what your loved one wants to accomplish at home. It is helpful to understand whether he/she is talking about something tangible to be completed, or whether this is symbolic language.
 - If the need is for some wish to be completed—to sit on the porch or play with the dogs—then your loved one is missing home.
 - If your loved one is uncertain why he/she needs or wants to go home, it is more likely a need to seek the sense of security experienced by being at home, or he/she may be speaking about a spiritual home, or a ‘homecoming’ with loved ones.
 - If this symbolic language of home is accompanied by restlessness, it may reflect a feeling of not being able to settle. In this case, medication may be needed to help settle restlessness.

Your Care Plan



For this symptom: _____

Nurse signature: _____ Date: _____

For this symptom: _____

Nurse signature: _____ Date: _____

Contact Hospice if this does not provide relief—603-882-2941

Medication Diary



Date	Time	Pain/Symptom	Medication Taken & How Much	Severity 1-10	Effectiveness 1-10