



Delaware Hospice
Caregiver Training Guide

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HOSPICE

Since 1982

Your hospice caregiver training guide

At Delaware Hospice, we are committed to providing the best hospice care possible and to supporting you, the caregiver. We recognize that this may be a time charged with many emotions and considerations. We want to hear what is important to the person you are caring for and what is important to you - that is where our care starts.

Our team members have the skills to help you in your new caregiving role, and we will:

- Help you find ways to meet needs and reach goals for this last part of life.
- Watch and observe with you as changes happen.
- Walk with you and guide you when you need it.
- Help you learn how to care for the person as things change.

We want to know what matters to you and the person you care for.

Please let us know if there are things we could do differently to make care more personalized and in keeping with your values and beliefs. Sometimes there are big things we can do, and sometimes there are small things that add up to showing you both the respect you deserve.

Ask us questions. Tell us how you're doing. Tell us about choices you have already made for end-of-life care, about going back to the hospital, and about other treatment options. Your Delaware Hospice team nurse, social worker, and chaplain are here to guide you.



Let us know if you have questions, concerns or if you see changes in the person you are caring for. Delaware Hospice staff is on duty 24 hours a day, 7 days a week to respond to your call. Use the phone number that's circled on page 25 of this booklet.

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What should I know about daily care?



As a person enters hospice care, they will probably need more help with their day-to-day activities. If you have been caring for this person for a while, you probably know what works. Tell us. As time goes on, you can expect changes in what the person can do and we can help you learn how to adjust care as their needs change.

You may have feelings come up as you do more things for the person. At times you may feel tired or overwhelmed. Let us know how we can help you and other family members who are involved or touched by the person's illness. For example, feelings of grief will not necessarily wait to come until after the person dies. Your Delaware Hospice Team has counselors for you and for children involved - let us know if you need help coping.

Delaware Hospice also has a **volunteer program** and a **respite program** to assist you and the person you care for. At times, volunteers may be available to come and sit with the person you are caring for. Sometimes the person may come into the Delaware Hospice Center for a respite visit so you can get a break from caregiving for a few days.

If the person you care for is a veteran, ask us about the **Vet-to-Vet Program**. We know that military culture can impact vets at the end of life. Volunteers who are veterans are especially trained to visit and share their military culture and that common military bond. Sharing stories and fellowship with each other can help bring closure and peace.

Ask your team about how to access these services. If you and other family members are sharing caregiving tasks, share what you have learned with them so care is consistent and all caregivers feel comfortable and know what they are doing.

If you are the family caregiver of a person who lives in a nursing home or other residential setting, tell us how and when to contact you for updates and to answer your questions. We want you to have the training and knowledge to feel comfortable while visiting with the person you care for.

Creating a calm and supportive environment

Having a calm space and a supportive environment promotes safety and comfort for you and the person you care for. Here are some tips that can help:

- Be present. When you enter the person's room or space, take a deep breath and think to yourself, "I am here for you at this time".
- Listen and use thoughtful language:
 - Always tell the person what you are going to do before you start doing it.
 - Listen to the person without judging or dismissing what they have to say. Sometimes just saying worries out loud can take some of the sting away. You can repeat back what the person has said or say: "Tell me more" to let them know you are interested.

- Listen for stories, which can help you understand what was and is important to them. Sometimes caregivers like to write down those stories.
- Develop a toolbox of distractions, which can help on hard days:
 - Visits from loved ones or doing familiar activities may provide a chance to not focus on pain or sadness.
 - Try things that gave the person comfort in the past. They may enjoy listening to their favorite music, watching a movie, listening to poetry, or listening to a book on tape. Some people with faith connections may like to hear or say prayers, hymns, or passages from holy texts.
 - Consider keeping their pet nearby, or bringing in pets to provide comfort.
 - Some people find comfort in a gentle relaxing massage, aromatherapy, or other healing arts. Lightly scented atomizers may be calming. Lavender has a calming effect, peppermint refreshes, cinnamon tea or baking aromas can be comforting.
 - Try helping the person into a different position if they seem uncomfortable.
 - Placing a heavier blanket on them can provide a sense of safety and security.



Write down the comfort measures that work so that other care providers and family members know what to do.

Bathing and using the toilet

Taking a bath or using the toilet are activities we usually do alone. Both of you may be uncomfortable at first when the person you care for starts to need help. Here are some things you can do to promote privacy and comfort:

- When getting ready for a bath, gather supplies, such as towels, washcloths and clean clothes, before you begin so the person is not left alone or uncovered.
- Encourage the person to do as much as they can or want to do themselves. This may lessen their feelings of being dependent on you.
- Keep the bath or toilet area private - close the doors, ask visitors to step outside, and keep the person covered as much as possible.
- Use matter-of-fact, adult language, and always tell the person what you are going to do before you do it, even if they don't seem to understand.
- Offer hand cleanser or another way for the person to wash hands after they used the toilet, even if you have done all the work.
- If the person uses a bedside commode or bed pan, empty it right away once they are done.
- If you step outside to provide privacy, make sure the person has a way of letting you know when they're done.

What kinds of problems can happen during daily care, and how can I help?



Pain

During hospice care, the goal is to relieve pain and promote comfort while maintaining the person's ability to be engaged with life and familiar activities. Another goal is to help you, the caregiver, feel confident giving pain medicines and managing symptoms. We also want to show you some other ways to promote comfort.

Pain at the end of life can have many causes:

- As diseases get worse, pain may get worse.
- Sitting or lying down a lot can lead to stiffness and sore muscles.
- Coughing, trouble breathing, or throwing up can be painful.
- Constipation can be painful and is a common side effect of some pain medicines.
- Fluid building up in the body can cause discomfort.
- Injuries, like falls, can cause pain.

Pain is very personal. No one "feels" pain exactly the same way. It can help to listen to the person describe their pain and how it gets in the way of doing things.

Pain is more than a physical feeling

Pain is usually more than just hurting in a body part. Thoughts and feelings that might come with pain make the person feel worse:

- Pain that is getting worse may be a reminder that a disease is getting worse, or that life is drawing to a close. This can be hard to accept.
- People may ask: "Why Me? Why is this happening to me?"
- They may feel angry, sad, frustrated or guilty.

Pain often prevents people from doing the things they like or need to do. If this is the case, pain medicine may help.

How to find the right dose and type of pain medicine

In hospice, the wisdom is to start low and go slow. The dose and how often the medicine is given may change depending on how well a person responds to it. Occasionally pain will become severe depending on what is causing it. In these cases, higher doses given more often may be necessary to get through a severe pain episode.

When common pain medicines like ibuprofen (Advil) or acetaminophen (Tylenol) don't work to relieve pain, opioids may be ordered. Opioids block the pain message sent from the body to the brain.

Your healthcare provider and the Delaware Hospice Team will work with you and the person you care for to adjust the dose or add another medicine if needed. You can help us find out how well a medicine is working by rating (measuring) pain and pain relief.

How to rate pain

To find out how well the medicine is working, we have to find a way to “rate” pain. If the person you care for is still able to use words, you can use a number scale.

It is simple to use: Ask the person, “On a scale of 0-10, where “0” is no pain and “10” is the worst pain, how would you rate your pain right now?”

If the person isn’t able to express themselves using words, they may be able to point at a visual scale such as this one:



You can also watch the person and look for pain behaviors, such as:

- Facial grimacing
- Moaning
- Furrowed brows
- Clenched hands
- Holding or rubbing an area of their body
- Refusing to change positions, get out of bed, or get bathed because it hurts to move

Over time, you will learn what pain looks like for the person you care for and how they look and act when the pain is relieved. Share these observations with your hospice team. Pain medicines often need adjustment as the disease or condition causing pain gets worse.

Side effects

Like most medicines, opioids or other pain medicines can have side effects. The most common ones are:

- Drowsiness
- A dry mouth
- A sick stomach (nausea)
- Dizziness

These side effects usually diminish a few days after starting a new medicine.

People who have been in pain for a while, or had pain that was worse than usual, may fall asleep once the pain is relieved. Pain can wear a person out and sleep may provide comfort.

Constipation: a common side effect

Morphine or other opioids can make a person constipated. Your healthcare provider may recommend a laxative, which is a medicine to cause a bowel movement.

Sometimes caregivers don't want to give laxatives because they fear it may be difficult to manage. What if the person has to go, but can't get out of bed in time? Since many people have a certain time of day when they normally have a bowel movement, it may be a matter of giving the laxative at the right time.

Your hospice team can help you find the right dose and time to give laxatives. You can help by keeping a log of:

- When the person has a bowel movement
- How often they urinate
- When they took their pain medicines
- How much the person is eating and drinking

How to give pain medicine

You are part of the person's hospice team. When the person can no longer manage their medicine alone, this may become your job in partnership with the hospice nurse. Your hospice nurse will do a pain assessment and discuss medicines on scheduled visits, or when there is a change in how the person is doing.

We want to make sure you have what you need and know what to watch for. Ask your hospice team all of your questions about pain medicines until you are comfortable giving them.

We will teach you:

- When and how to give the medicine safely. Usually, giving pain medicine by mouth works best. If a person has trouble swallowing, medicine can be given other ways as well.
- What to expect after you give the medicine
- Side effects of the medicines ordered
- How to keep track of the times you give the medicine and note how it worked

A note on opioids

Opioids are given to lessen or stop pain when over-the-counter medicines no longer work.

Opioids can also ease restlessness and help with severe shortness of breath. Giving opioids like morphine to people with advanced illnesses is safe. It is also non-habit forming, which means you do not have to worry about the person you care for becoming addicted to their medicine.

Opioids must be stored safely and used only as ordered. Like other medicines, opioids cannot be shared with other people. If you have concerns about opioid safety, please tell a member of your hospice team so we can discuss how to safely store and give the medicine.

It can be helpful to keep a medicine log that you can share with your hospice nurse during visits. Here's an example of a medicine log:

Medicine log

About the medicine

How did the medicine work?

Medicine name	Date/time given	Dose	Relief of symptoms (full, partial, none)	How long did relief last?	Did you notice any side effects?	Any changes in how well it works or how you give it?



Let the hospice nurse know if the person you care for uses any herbal remedies or supplements because they may affect how well the medicine works.

Gather your medicine log and all medicines before the nurse visits. The nurse will check:

- The medicine label
- The doctor's order
- The list of medicines in the EMR (electronic medical record)
- Any changes you have made in timing and/or doses

Trouble breathing

Trouble “catching my breath”, “breathing too fast”, or “breathing hard” are some of the ways people describe shortness of breath. People with lung disease or heart conditions have probably already adapted the way they do everyday tasks. Sometimes, people are just worn out from being sick for a long time and find themselves short of breath from loss of energy and getting less exercise.

At this time of life, it's a good idea to prioritize things that are important to the person you care for. If the person plans to spend time with their grandchildren next Tuesday, don't schedule a healthcare provider visit the same day. In general, you will find that a routine of activity followed by rest will work best.

You are likely to see shortness of breath and lack of energy get worse over time. Schedules and routines will change as the person's disease or condition gets worse.

During this time, tell your hospice team about any changes in activities and when you notice shortness of breath getting worse. We can help you find ways to adapt caregiving, adjust medicines and do other things to promote easier breathing for as long as possible.

Medicines to help with trouble breathing

Medicines may help relieve shortness of breath. Some medicines help the lungs work better, while others slow down the breathing rate. Some medicines help lower the feeling and fear of not being able to catch another breath. Oxygen may be helpful in some cases.

In hospice care, people may change from using an inhaler (a hand-held spray that releases medicine at the push of a button) to using nebulizers. Nebulizers turn medicine into a fine mist that people inhale over a period of time. This can be a better way to adjust and monitor the dose and timing of treatments.

Other tips to help with trouble breathing

- Don't "hurry" the person through an activity. Let them set the pace.
- Summon your calm energy:
 - Keep yourself and visitors calm.
 - Move quietly and slowly around the person.
- Make the environment comfortable:
 - Raise the bed so the person can sit up.
 - Use a cool wash cloth to cool the forehead.
 - Avoid heavy aromas or fragrances.
- Cool the air:
 - Use a fan to direct cool air across the person's cheek. The airflow to the face will ease the feeling of being short of breath.
 - If the weather allows, put the bed near an open window so the person feels like there is plenty of air to breathe.
 - Keep the room cool (around 70 degrees is best).

Think about what worked in the past and see if it works now. Anything that comforts and calms the person may help ease the feeling of shortness of breath.

Work on breathing techniques

At times, trying to catch a breath may come with restlessness or agitation, which makes it even harder to breathe. If this is happening, encourage slow deep breathing, and teach pursed lip breathing, progressive relaxation techniques, and counting with breaths. Your hospice team can help you learn all of those breathing techniques.

There is some evidence that teaching a person to use a mantra, and practicing it while the person is still able to, may help as breathing problems get worse.

Here is a way to get started:

1. Ask the person to pick a word, image, or phrase that conveys comfort to the person – this will be their mantra.
2. Lead the person through a relaxation exercise while they repeat the word or phrase, or direct attention to the image while breathing through the nose (may be done out loud or quietly).
3. Fill the belly with air, say the word, and listen to 'the rush of the ocean' on the exhale through the nose.
4. Then feel the calm at the bottom of the breath.

Repeat for a couple of breaths or longer if the person enjoys this activity. You can do this 2-3 times during the day if desired. The calm that this practice brings will help the person when their health gets worse.

Don't encourage relaxation breathing if the person becomes more restless, short of breath, or agitated.

Restlessness and agitation

Sometimes people become agitated and restless. They may start to fidget or grimace, move around and try to get out of bed for no known reason, or pull at their clothes or covers. Your goal is to try to find out what is causing the agitation, treat the cause if possible, and promote a more comfortable state for you and the person.

To help you find out the cause, ask yourself these questions:

- Does the person need to urinate or have a bowel movement? If there is a catheter, is it draining urine?
- Have they been eating and drinking enough?
- Are they constipated?
- Has the person been in one position for a while and needs help turning over?
- Is the person getting enough sleep?
- Are they taking a new medicine? Some medicines, like benzodiazepines or antihistamines, can cause restlessness.
- Is the person in pain?
- Do they have trouble breathing? Sometimes agitation is caused by not enough oxygen getting to the brain.

Sometimes there is no known physical cause for restlessness and agitation. In those cases, you may have to look for emotional problems that might weigh on the person you care for:

- Did the person recently get bad news or have a visit that didn't go well?
- Do they have unmet spiritual needs?
- Is there unfinished business?
- Is the person worried how you, the caregiver, or other loved ones will cope after their death? If so, talking about it may help.

Here are some other things you can try:

- Turn off the TV and remove other distractions.
- Try different ways the person calmed themselves in the past, such as breathing techniques, relaxing music, or aromatherapy.
- Talk calmly to the person. If there are other people in the room, make sure only one person talks at a time.
- Keep words to a minimum. If you ask a question, wait for their response.

- Calm yourself. Sometimes people can sense that you are upset and it may make their restlessness worse. Try taking a deep breath when you feel overwhelmed. It is your body's natural way to feel relaxed. When you breathe out, you can feel muscles calm and tension ease.

Your hospice team can help you come up with a treatment plan to help with agitation and restlessness.

Anxiety and stress

People in hospice care and caregivers may have times when they worry, feel anxious, restless, or unsettled. Anxiety is a feeling that things are not right or are out of control.

These feelings may come when a person is having a physical symptom like pain or trouble breathing. Even constipation can leave a person feeling anxious. On the other hand, a person may worry about everyday things, like who will walk the dog or pay the electric bill?

Perhaps the person might be focusing on a time in life when things did not end as expected and worry about what they could have done differently. It may help to listen to those fears and concerns and talk about how things might be settled. If a person is dwelling on the past, maybe there is a specific person they need to talk to who could help them be at peace, such as an old friend.

Tips for caregivers to relieve stress

As a caregiver, you may be so focused on caregiving that you stop taking good care of yourself. Anxiety and stress can harm your health. Remember that you won't be able to be there for anyone else unless you also take care of yourself. Here are some things you can do if you feel anxious and stressed:

- Take a break. Ask a friend or family member to take over caregiving duties for a while, or use our hospice respite program.
- Remember that you are doing your best. It's normal to feel guilty sometimes, but know that no one is a "perfect" caregiver, and that's ok.
- Social connections are important to your wellbeing. Try meeting with a close friend to decompress and talk things out.
- Take care of your health:
 - Even though this can be hard to do, try getting enough sleep. 7 hours a night is recommended.
 - Eat a healthy diet and drink plenty of water.
 - Movement helps relieve stress. Take 5 minutes every hour to stand, stretch, and fill your lungs with fresh air.

If you or the person you care for are having severe anxiety, or if you feel constantly overwhelmed, talk to your hospice team or healthcare provider.

Sadness

It's not surprising that people in hospice may feel down or sad from time to time. While no one can escape death, it's normal for them to think about future things they won't be here for. They may also be sad at the thought of missing you, friends, or family members. Sometimes, it's thinking about the past that makes a person sad.

You may be having some sad feelings yourself from time to time. This is normal, you are not alone. It's okay to talk about these feelings if the person you care for is open to it. Saying something like "Hey Dad, what are you thinking about? You look kind of sad" may open up a space for Dad to talk about feelings of sadness. It may be a hard for both of you, but the peace and comfort it can bring may be worth the conversation.

Sometimes, just sitting and being present brings comfort. Other times, listening to music, curling up with a pet, or looking at photos or family memorabilia may be soothing. If the weather allows, you can open a window and position the person so they can look outside. Many people find comfort in nature. Sometimes a heavier or weighted blanket can help.

Let your hospice team or healthcare provider know if the person you are caring for has a history of depression, and what worked in the past to get them through the rough patches.

You might have to see what works for the person you are caring for. Each person is different. **Delaware Hospice bereavement counselors** are available during your hospice journey, as well as after the person dies to help you cope with grief. We also offer support for children struggling with sadness and grief through our **New Hope program**.



NOTES

Signs of change: The months and weeks before death



In the past, you may have seen the person you care for get worse and then bounce back. This cycle of getting worse and getting somewhat better eventually leads down the path of just getting worse. The body begins to shut down.

We'd like you to be aware of the signs of change that usually happen at this stage of the hospice journey so you can be prepared. Some of those signs are physical, while others are emotional or spiritual in nature. The focus of caregiving changes from keeping the person up and active to offering comfort. This section looks at changes that may happen over the months to weeks before a person dies.

Focusing inward

During this time, a person may seem to withdraw from the people around them. They may become quieter and less engaged with the world. Some may stop doing the things they enjoyed in the past. This is partially due to a lack of energy and also a growing desire to look inward.

Feeling tired (fatigue) and loss of energy

Near the end of life, fatigue is very common. The body just slows down. Tasks take longer to complete, and the person may sleep longer at night and take naps during the day. It may feel like they are resisting care or not wanting to move. This can be frustrating when trying to help a person, but keep in mind they are not necessarily "giving up" - it is normal and expected for people at this stage to feel tired and to need more rest.

- Slow down. Let the person set the pace and plan activities around naps.
- Review the section on "Trouble breathing" as the person may be breathing faster when trying to move.
- Honor their wishes about visitors. It may be tiring to have too many people visit at the same time.
- Give them time and space to talk about what is happening - they may see needing more rest as a sign of getting worse, which can be upsetting. Talking may be comforting to you both.
- Listen. Let them say things out loud - don't hush them or tell them not to say things about not being here. Sometimes saying things out loud stops the swirling of ideas in a person's head.

Changes in eating and appetite

Food means more to us than just supplying energy to the body. Eating together is an important part of many families' daily routine and may have cultural values or beliefs attached to it.

When people near the end of life refuse to eat, there could be many reasons: The smell of food might make them sick, or maybe food just doesn't taste good anymore. Some health problems that affect breathing or the digestive system can make it hard to eat and keep food down. Be gentle to yourself - it's not about your cooking, it's just that their body is slowing down.

Not wanting to eat may last for a day or two, or it may become part of the new normal.

Here are some things you can try:

- Ask the person what they want to eat (if there are choices).
- Smaller, more frequent meals may work for a while.
- If the person is staying in bed, raise the head of the bed or use pillows to prop the person up so their mouth is higher than their stomach. Let them stay in this position after eating, which will help digest the food.
- Help keep their face, mouth, and hands clean during meals. This will make them feel more comfortable. Aprons help keep clothing and bed linens clean.
- Help them eat if they can't handle the silverware or dishes.
- Choose the best foods:
 - Soft foods like pudding, or cold foods like ice cream are easy to swallow and taste good too.
 - Soups with chunks of meat or vegetables may be hard to swallow. Try pureed or creamed soups.

If the person you care for has a favorite food that brings them comfort, go ahead and offer it even if it's not the healthiest choice. At this stage, it's more about feeling better than it is about nutrition.

Tell your hospice nurse if certain medicines make the person throw up or feel sick. They may need to be adjusted.



Changes in using the bathroom

As the body begins to shut down, the bowels and kidneys may work more slowly. This is normal and expected at this time in life. Usually, a person will not need as many trips to the bathroom, and the urine might be darker (although some medicines may make a person go more often). Bowel movements may happen less often and be smaller. As the person becomes weaker and has less energy to get up and walk to the bathroom, your hospice staff may suggest medical equipment, such as:

- A bedside commode, which is a portable toilet that can be put next to the bed
- A bedpan, which is a small, toilet-shaped bowl that can be used in bed if a person is no longer able to get up
- A urinary catheter, or foley catheter. A catheter is a tube inserted into the person's bladder that drains the urine into a collection bag.
- Disposable adult underwear if the person is still able to use the toilet, but accidents might happen.

Final moments: The days and hours before death



There is usually a period of time when a person is actively dying or “transitioning”. For some people this may be a week, for some it may be days or hours. No one can predict when and how someone is going to die. Each person dies in their own way. Your hospice team and healthcare provider can help you understand what is likely to happen.

At this time, the person’s comfort is most important. This section is about some of the things that may happen, and the physical, spiritual, and emotional signs that someone is dying. Know that there are no right or wrong answers, and that your hospice team is here to support you every step of the way.

How to be prepared for the time of death

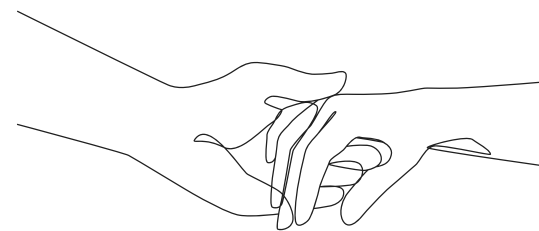
In addition to knowing what to watch for and what to do about it, your hospice team can help you plan ahead.

Think about people who need to know right away when the person has died, and about who you would like to be there for support when the time comes. Thinking about these things before the person is actively dying is hard, but it will give you the opportunity to be present during the last stage of life. Also, consider spiritual practices or cultural traditions that may be comforting or expected.

Writing things down can help you when the time comes. Consider making a folder with the most important information:

- A list of people to call. Write down names and contact information in case you want someone else to make these calls for you.
- Contact information for your hospice team
- Paperwork for the funeral home or information on alternative after-death arrangements

Things may happen fast at the time of death. You might feel sad or numb, you might feel relief, guilt, or anger. There is no right or wrong way to feel. It is easy to be overwhelmed and feel exhausted. Take the time you need to sit with the person and let someone else take care of things for a while. Move at the pace that’s best for you.



Physical signs that death is near

One of the first signs that death is near may be the loss of appetite. The person may refuse to eat or drink altogether (usually for 2 or

more days). Don't worry - they won't feel hungry, thirsty, or uncomfortable. Near the end of life, giving food and drinks can make a person feel worse. The digestive system slows down, so food sits in the stomach longer.

Here are other changes you may see:

- The face, arms, and legs may be cool to the touch and feel moist or clammy.
- Sometimes even though the limbs are cool, the person may have a fever. You can gently wipe their face with a cool cloth if it brings them comfort, or remove their blanket if they seem hot. Sometimes your hospice nurse can order Tylenol for a fever.
- The arms and legs may show faint patches of purple or red (called "mottling").
- The skin may look blue or have a yellowish hue. This is normal and expected.
- The eyes may not focus and look like the person is staring off into the distance.
- Pain may become worse at this stage, depending on what condition is causing the pain.

Changes in breathing

When death is near, the way a person breathes will change. They may start to breathe through their mouth, with their mouth opened. To keep their mouth and lips moist, try using a mouth swab that hospice staff will provide. A clean sponge or warm wash cloth will work as well.

Breathing may also get ragged or labored, with their mouth opening and closing with short bursts of breathing. There may be long periods when a person doesn't seem to take a breath, followed by rapid breathing. Sometimes their mouth will open and close, like catching a gulp of air.

Sometimes, you will hear fluids moving around in the back of their throat, which sounds like gurgling. Turning the person slightly and raising the head of their bed can help. While this may be difficult for the caregiver and others to hear, it is normal and expected and shouldn't cause the dying person any discomfort.

If it becomes necessary to give medicines to help with troubled breathing and comfort, your hospice team can help you. You can also read the section on "Trouble breathing" for more ways to offer relief.

Behavior changes

Here are some behaviors you may notice when death is near:

- The person may withdraw from family and friends. They will likely be less able to pay attention and talk to you. Their focus is turning inward.
- At times, they may seem confused, lost, or delirious
- Sometimes their face will appear completely peaceful and sometimes like they are involved in thought or conversation elsewhere. Some people make hand gestures, reach for or hold unseen objects, or wave to unseen beings.

- The person will likely be very tired and sleep a lot. Over time, their consciousness starts to diminish.
- The dying person may or may not want to be touched at this point.
- They may seem distracted at people talking and prefer a quiet room or soothing music.
- Sometimes, people near the end of life will tell you exactly when they are going to die.

We think hearing is a sense that remains until the end. If the person does not look irritated when you talk, continue to use calm, caring messages. Say what you would like to say - don't end up with regrets about what you should have said.



Some people consider this a very sacred time and honor it with a quiet presence and focusing on the person. Little else needs to be done now - just being there is enough.



If you or another caregiver can't be present, hospice vigil volunteers are trained to sit with a dying person. Tell your hospice team if you would like a vigil volunteer.

Terminal agitation

When death is near, some people can suddenly become very restless, anxious, or even delirious. This is called terminal agitation. While there's no good way to predict whether it will happen to the person you care for, it can be very upsetting. Please know that we are here to support you during this time.

Call your hospice team if you see any signs of terminal agitation:

- Restlessness, like there is someplace else the person wants to be
- The person may pick at their sheets or blankets or make repetitive hand movements
- They may seem "out of it" or disconnected and unable to pay attention to caregivers
- They may try to stand or walk when weakness or medicine make it unsafe to do so. It is not unusual for a person to have unusual strength and drive to get up or get somewhere.

If the person is showing some of these behaviors, check for:

- Physical needs not being met - Dry mouth? Need to go to the bathroom? Having trouble breathing? Fever? Constipation?
- Comfort needs not being met - Is the person having greater pain? Discomfort from staying in one position for a while? Too hot? Too cold?

- Medicines - Was a new medicine started within the last 24 hours that might have restlessness as a side effect?
- Stimulation - Is there too much going on in the room? Make sure the room is calm and that people are calm. Limit what you are saying to short supportive statements. We think people can hear us even when they can't focus on us with their eyes. See the section on "Creating a calm and supportive environment" on Page 2 for tips.
- Rituals - Are there rituals or certain behaviors that the person might expect as a part of the dying process? Some religions have prayers or rituals for this time of life.
- Anticipation - Is the person waiting to see someone in particular? Perhaps a phone call would help if the expected one cannot get there.

You can also talk to your hospice team about medicine to help with terminal agitation. But sometimes, despite our best efforts, nothing works. The focus then changes from trying "to fix it" to being with the person and keeping them safe.

What happens at the time of death

Keep in mind that each person's experience at the end of life is different. There is no one way people die. This section is meant to prepare you for what might happen.

We really don't know if a person has any control over how and when they die. Many caregivers want to stay with a person until their final breath. However, you may leave their side for a few minutes, to get the mail or go to the bathroom, and come back to find the person has died in that short time. Some believe that a dying person might wait to be alone because they want to spare their loved one's feelings. Some people just want to die on their own.

A person may become more and more distant to anything or anyone in the room and quietly slip away. Another person may have a moment of clarity and say something to you or others in the room and then die. Others may seem to be looking at something beyond their bed or appear to be talking to family or others who have passed. Sometimes a person will suddenly wake up and say something or even cry. Some people look like they are struggling with letting go.

You may sense a profound quiet when the person dies. It may also become very emotional for you and those around you - there is no right or wrong way to feel. It is not uncommon to watch for the next breath to come for what seems like a long time.

After death

When the person's heart stops, their body will drain of its color and become pale or waxy yellow. There will be no more breaths, except for one last escape of air from their chest. The person's mouth and eyes may stay open. It's fine to gently close the eyes and roll up a small towel to place under the chin to keep their mouth closed.

Many people find it comforting to talk to the person at this time, expressing their thoughts

and feelings. Go ahead and do this if it is helpful to you. We don't really know what happens to the person. We only know their body dies.

How much time you want alone with the person is up to you. Maybe family and friends will want to know and come over - there is no right or wrong way to do things. If you have a vigil volunteer, it is up to you to tell them to go or to sit with you.

Some caregivers may want to wash and dress the person before anyone else gets there. Whether you choose to do those things on your own, with your family, or whether you want to wait for the hospice nurse to come and help, is up to you.

Whenever you're ready, call your hospice team. The hospice nurse will come and:

- Listen for the person's heartbeat and for any breathing. They will acknowledge that the person has died.
- They will note the time of death and call your healthcare provider and our office.
- Let the nurse know if there are any rituals or actions to be aware of at this time in order to honor the person's wishes. Some faith beliefs have rules for what should happen to the body after a person has died.
- The nurse will help prepare the person to be transported to the funeral home.
- They will take off any medical devices that are connected to the person.
- The nurse will help you dispose of medicines according to policy and regulations.
- Your hospice team will schedule a time to pick up any medical equipment that we supplied.

Feel free to call hospice any time with questions or concerns. You can also expect a call from your hospice team shortly after the person has died to see how you are doing.

A few weeks after the person you care for has died, a member of our bereavement team will reach out and offer services to help you during your grief journey. If you need help before the call, please call Delaware Hospice and ask for a member of the bereavement team. We are here to support you.



Resources



Delaware Hospice resources

- Visit our website for general information: <https://www.delawarehospice.org/>
- Contact us at:
 - **Newark office**
16 Polly Drummond Center, 2nd floor
Newark, DE 19711
Phone: (302) 478-5707
 - **Pennsylvania office**
1786 Wilmington-West Chester Pike
Glen Mills, PA 19342
Phone: (484) 259-0017
 - **Dover office**
911 S. DuPont Highway
Dover, DE 19901
Phone: (302) 678-4444
 - **Milford office**
100 Patriots WayMilford, DE 19963
Phone: (302) 856-7717
 - **Delaware Hospice Center**
100 Patriots Way
Milford, DE 19963
Phone: (302) 856-7728

Suggested reading

Byock, Ira (2014). *The Four Things that Matter Most*. New York: Simon & Schuster.

Callanan, Maggie and Kelley, Patricia (2014). *Final Gifts: Special Awareness, Needs and Communications of the Dying*. New York: Simon & Schuster.

Gwande, Atule (2017). *Being Mortal: Medicine and What Matters in the End*. New York: Metropolitan Books.

Kalanithi, Paul (2016). *When Breath Becomes Air*. New York: Random House.

Lynn, Joanne et al. (2014). *Handbook for Mortals*. New York: Oxford University Press. We recommend chapters 7 and 8.

Spathis, Anna and Booth, Sara (2008). End of life care in chronic obstructive pulmonary disease: In search of a good death. *International Journal of Chronic Obstructive Pulmonary Disease*: 3(1): 11-29. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2528206/#b29>



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