Dementia or Alzheimer's Disease

Shepherd's Cove
Hospice

Quick Guide

Designed to **educate**, **encourage** and **empower** you,
as a caregiver.

Our Heart Sets Us Apart

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KNOWING WHAT TO EXPECT

When you or someone you love has been referred to hospice care, it is understandable that you may feel overwhelmed and experience many emotions. Shepherd's Cove Hospice (SCH) is here to support you in this time. It is not our intent to "take over" all care but to provide friendly guidance, helping you to find comfort – physically, emotionally and spiritually. SCH has a team of professionals (physician, nurses, nurse practitioners, social workers, aides, chaplains) and volunteers that are ready to work on your behalf. Because members of SCH's team will not be in your home 24 hrs. /day, this guide is to give you information so that you are comfortable and confident in providing care.

SCH believes most fears can be eliminated if you know what to expect. For most people, knowing what to expect is not as fearful as the unknown. With that in mind, this quick guide is given to you to:

- Explain what physical symptoms might be expected and what can be done to control those symptoms,
- Give you teaching tools for you to refer to as you need,
- Teach common end of life signs and symptoms,
- Share common emotions that may be experienced during this time,
- Promote open communication between family members and with SCH,
- Provide suggestions on how the caregiver can take care of themselves,
- Share tasks your hospice Social Worker can help meet your goals, and
- Direct you to additional resources for your own research, if you would like.

Throughout this journey, your SCH team members want to teach and **educate** you, **encourage** you and **empower** you. Educating you on how an illness affects our body and learning how to address symptoms gives you the tools and confidence you need. With SCH here to help, we want you to be encouraged - you are not alone on this journey. We also want to empower you to direct this journey so that it is lived out in the way you desire. SHC respects individual's unique goals and needs. We want to serve you by assisting you to fulfill <u>your</u> unique goals and needs.

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ADDITIONAL RESOURCES

www.shepherdscovehospice.org

www.nhpco.org

www.cancer.net

www.dignitymemorial.com

www.cancer.org/treatment/end-of-life-care/nearing-the-end-of-life.html

www.helpguide.org/harvard/dealing-with-a-loved-ones-serious-illness.htm

Book: Dying Well – Ira Byock, author

Book: CareGiving: Helping an Aging Loved One – Jo Horne, author

SYMPTOMS YOU MAY SEE	WHAT YOU CAN DO
Pain – *This is a common symptom for patients at end of life because of disease progression or even having limited to no mobility.*	• Administer medications ordered by doctor and directed by the nurse • Reposition patient • Encourage relaxation • Play favorite music • Decrease noise in patient area • Call nurse if these measures were not helpful. • Talk to your nurse about your concerns on their visit.
Weakness – *This is a common symptom for patients at end of life.*	• Offer patient help with normal activities (like walking, bathing, dressing or eating). • Do a few tasks, stop, and rest before completing more tasks. • Ask SCH for aide services to help with personal care. • Talk to your nurse about your concerns on their visit.
Skin breakdown – *This can result because the patient cannot eat enough or their body cannot process protein normally and because the patient cannot move on their own.*	• When a patient cannot turn himself or herself, help them to turn and reposition every 2-4 hours during daytime. Ask SCH nurse or aide how to turn patient without hurting yourself or the patient. • Keep skin clean and dry. • Increase protein in diet if patient able to eat. • Report to the nurse if you see skin that is red and does not go away after a time of being repositioning. • For patients using SCH's mattresses: these are designed to help prevent skin breakdown. • If patient is not using SCH mattress – ask nurse or aide how you can get one. • Talk to your nurse about your concerns on their visit.
Not eating or drinking – *This is a common symptom for patients at end of life and many lose weight.*	• Do not force patient to eat or drink fluids because this can cause choking. • Offer smaller amounts of food more frequently. • Change from solid foods to soft foods or liquids. • Supplement with homemade milkshakes using Carnation Instant Breakfast or Boost. • Talk to your nurse about your concerns on their visit.

SYMPTOMS YOU MAY SEE	WHAT YOU CAN DO
Constipation – *This is a common symptom for patients who are less mobile, who are eating/drinking less and are requiring pain medications.*	• Increase fluids in the diet. Offer liquids hourly during waking hours. • Prune and apple juices may stimulate bowel movements. • If patient is eating well, increase fiber in diet. (Ask nurse for tips on how to do this.) • If patient is able to walk, encourage at least short walks in the home to stimulate bowel movements. • Patient may need bowel stimulants or laxatives to have regular bowel movements. The goal is for the patient to have daily bowel movements. • The patient may need a potty chair so they do not have to walk longer distance to the bathroom. Ask your nurse or aide. • Talk to your nurse about your concerns on their visit. • If no bowel movement in three days, call the nurse.
Confusion, Agitation, Restlessness – *This is a common symptom for patients at end of life because of disease progression.*	• Administer medications ordered by doctor and directed by the nurse. • Decrease noise in patient's area. • If the patient is saying things that do not make sense, do not argue but report to the nurse at the next visit. • Talk to your nurse about your concerns on their next visit. Medications may be needed to help patient with these symptoms. • Call nurse if these measures were not helpful. • If the patient is combative (physically aggressive to the point of possibly hurting themselves or others) – CALL NURSE NOW.

SYMPTOMS YOU MAY SEE	WHAT YOU CAN DO
Difficulty breathing *– This is a common symptom for patients at end of life because of disease progression.*	• Sit patient in upright position • Make sure oxygen is on at the flow rate ordered by doctor (at least at 2 L/M) and nasal prongs are in nose. • Swap long oxygen tubing to shorter tubing (no more than 5-6 feet) • Decrease room temperature • Turn on fan so that it is blowing on patient • Administer medications ordered by doctor and directed by the nurse • Call nurse if these measures were not helpful. • Talk to your nurse about your concerns on their visit.
Secretions/Gurgling *– This is a common symptom for patients at end of life because of disease progression and the patient is too weak to cough up the secretions or fluids in the lungs. You may have heard it called "the death rattle".*	• Talk to your nurse about your concerns on their next visit. Medications may be needed to help patient with these symptoms. • Administer medications ordered by doctor and directed by the nurse. • This symptom is typically more distressing for the family than it is the patient. • Raise the patient's head & chest on pillows or raise the head of the bed if using a hospital bed. • Turn the patient to either their right or left side. • Call nurse if these measures were not helpful.
Leg and feet swelling *– This is a common symptom for patients because of disease progression*	• Elevate legs and feet. Use pillows or sit in a recliner and elevate legs. • Administer medications ordered by doctor and directed by the nurse. • Call nurse if these measures were not helpful. • Talk to your nurse about your concerns on their next visit.

COMMON SIGNS AND SYMPTOMS THAT INDICATE A PERSON IS NEARING THEIR FINAL SEASON OF LIFE

Note: The following are signs and symptoms that suggest a person may be experiencing a decline, but it is important to be aware that each person is unique and people's experience may vary. Also, the order in which signs occur may differ. It is important to talk openly with your hospice care team regarding changes in a patient's condition.

- Increase weakness and exhaustion- meaning usually the patient cannot get out of bed and has trouble moving around in bed.
- Needs help with almost everything
- Less and less interest in food, sometimes having very little food and liquid intake for days. Do not feel the need to force food or liquids on a patient. Discuss questions/concerns with the care team.
- Having trouble swallowing pills and medicine
- More drowsiness- the patient may sleep much of the time even when pain is relieved, and may be hard to rouse or wake. The patient may not be as aware of his/her surroundings.
- No talking as much. Little interest in doing things that were important before
- Short attention span, may not be able to focus on what is happening
- Confusion about time, place, or person
- Limited ability to cooperate with caregivers
- Unable to control bowels or bladder
- Wanting to have only a few people nearby or desiring to see people he or she hasn't seen in a while.
- Increase in pain. Generally not feeling well.

As the final days approach you may see the following signs and symptoms:

- Noisy breathing, with congestion and gurgling or rattling sounds as the person becomes unable to clear fluids from the throat.
- Cool skin that may turn a bluish, dusky color, especially in the person's hands and feet
- Little to no urine
- Loss of bladder or bowel control
- Restless
- Seeing or hearing people or things that are not there such as loved one's that have passed on. This is common and usually normal.

What caregivers can do:

- Help the patient change positions often in the bed.
- Give a back rub or massage as long as touch does not contribute to pain. Rub the patient's hands with lotion.
- Elevate the patient's head, if doing so is comfortable, or turn the person onto his or her side to help make breathing easier.
- Use blankets to keep the person warm. Do not use electric blankets because they can cause burns.
- Speak in a clear, calm voice, and remind the person of the time, place, and people present.
- If the patient is unresponsive (unaware) and unable to verbally respond, instead of asking, "How are you?" consider saying reassuring statements such as:
  - Everything is alright.
  - We are here with you.
  - We are supporting you.
  - We love you.
- Just be there. (Sometimes, the best ways to comfort and reassure include sitting with the person, talking, offering gentle touch, or holding the person's hand. Such steps not only help ease loneliness but also can be healthy expressions of love for the person that is dying.
- Monitor the patient's pain. When a patient can no longer tell you he/she is hurting learn how to recognize pain (restlessness, moaning, frowing).

Know when to call for help.

- The patient has pain that is difficult to manage or relieve.
- The person is unable to take prescribed medications.
- The patient shows signs of distress, such as pain, breathing or agitation.
- The patient has a sudden change in consciousness, becoming less responsive or confused, or has a seizure.
- The caregiver is overwhelmed by the person's condition and needs.

COMMON EMOTIONS EXPERIENCED AS ONE NEARS THE END OF LIFE

1. Fear

People are often afraid to die, but pinpointing what part of death they are afraid of can be helpful. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid they will die and there will be nothing beyond earthly life? Is there a fear that their lives had no purpose or meaning? These are some of the more common reasons that people fear death.

Trying to figure out what you fear can help you face it and manage it. It will also help others support and care for you better. For example, if you are afraid of being alone, share this with your family and loves ones so they can try to always have someone with you. Sharing with loved ones and your health care team gives them a chance to help you find ways to cope with and ease some of your fears. It gives them a chance to correct any wrong ideas you may have, too. It can also give you a chance to look at and deal with some of your fears in new ways.

2. Anger

Anger is sometimes hard to identify. Very few people actually feel ready to die. It is perfectly normal to feel angry about your life ending- maybe earlier than you expected. It is unfair and you have a right to be mad! Unfortunately, anger often gets directed at those closest to us, the ones we love the most. We feel safest with these people and know they will probably accept our anger and forgive us for it. But, it might help to try to direct your anger at the disease and not your loved ones. Also, you can try to channel your anger as a source of energy to help you take action where it's needed. You can use it as fuel to solve problems, to become assertive, or to get your needs met. Try to re-channel your anger to do meaningful, positive things.

3. Guilt and Regret

Sometimes the best thing to do is to decide to "let yourself off the hook" and spend your last days and months not feeling guilty about things that are out of your control. Simply let it go. You cannot change the past, but there are things you might be able to do today. Apologize for the things you regret and ask for forgiveness. Be willing to forgive others and yourself. Fix what can be fixed and try to let go of the things that cannot be changed.

This is a good time to talk with your children about important topics you want them to know.

It is also good to talk to them about how to handle their feelings and the loss they will soon go through. You may want to write letters to the people you love, record messages for them, or make videos they can watch- give them things they can keep to remember their time with you. Tell those you love who they can talk with when you are gone and encourage them to be open when they are hurting. Spend your time focusing on your loved one's future, not feeling guilty about the past. Strengthen your relationships with loved ones. Live the best life you can now, and use your time for what is most important to you.

4. Grief

It is natural to feel intense feelings of grief the last months of your life. You are grieving the loss of the life you planned and expected. You can no longer look ahead to a seemingly "endless" future. And, you may have lost many things already, such as the strength to walk or get around like you used to, or the interest in eating the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from friends who cannot handle the fact you are going to die soon. This is another loss that can cause sadness and grief. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. They know they are about to lose you. How can you and those who love you find meaning in what is happening? Try to talk to your loved ones about the grief and loss of dreams you are all going through. Being able to rise above the grief and connect spiritually to something greater than one's self might help your loves one's heal after you are gone. Talking with someone about these feelings can help you process these feelings so that they no longer weigh you down.

5. Anxiety and Depression

What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant. Some anxiety is expected, but if it is severe, it may need to be treated through counseling or with medicine. If you are unsure talk with your with hospice nurse, social worker or chaplain. Depression is more than just feeling sad. Depression includes feeling hopeless or helpless, feeling useless, feeling sad for weeks at a time, and having no joy in any activity. These feelings are NOT normal, not even when life is ending. Depression can sometimes be helped with medicine, counseling or a combination.

6. Feeling Alone

When someone knows for sure they are facing their last months of life, there can be a loneliness of the heart, even when you have people around you. There may be very few people who can really talk with you in a way that helps you feel less lonely. Some of them may be experts who are caregivers. They may have that special gift for silence or listening when you need it. Finding a few people that you can truly connect with is critical to ease this sense of intense loneliness.

7. Seeking Meaning

Almost everyone wants to feel their life had purpose- that there was some reason for their being on earth. Some people find meaning in their work. Others find that raising a family has brought them the greatest sense of joy and accomplishment. It is helpful to go through a process of reviewing your life and figuring out for yourself what your purpose in life has been. What was your special contribution to the world? What have you done to make the world a better place? How would you like the world of your children, family, and friends to remember you? What were the things that you thought were really important and want your children to know about for their future? It does not have to be something huge or earth-shaking; look for those things that have been important to you and those around you. The end of life experience is full of meaning that can be uncovered using personal reflection. Sharing your thoughts, experiences, and wisdom is a gift that your friends and family can cherish for years to come.

TIPS TO CARE FOR YOURSELF WHEN CARING FOR SOMEONE ELSE

- Drink lots of water.
- Rest. Embrace your fatigue and understand when you are tired your body is telling you it needs rest. Lie down for short rest periods throughtout the day. Take an afternoon nap if you feel like it.
- Take the phone off the hook. Unplug the computer.
- Reach out to others for help. Seek out what works for you. Attend a caregiver support group. Schedule time with a trusting friend or counselor. Talk to your hospice social worker or chaplain.
- Exercise. Take a walk as often as you can. Exercise allows for more energy and it can give you focused thinking.
- Eat balanced meals as frequently as you can.
- Express your feelings. When you feel like crying. Cry. Do not yield into the pressure to hold it all together.
- Journal your feelings

HELPING YOURSELF WHEN SOMEONE YOU LOVE IS DYING

When it is clear that doctors cannot save the life of a terminally ill person, we often hear, "There is nothing more that we can do." While that may be true in the healing sense, caregivers can still work to minimize the sources of distress. You can seek medical assistance to manage pain and provide tender, loving care- tucking your loved one in bed, fluffing a pillow or feeding him a cup of soup. Anyone who is willing to be helpful can simply offer his or her presence, reducing the sense of isolation and abandonment that affects so many ill and dying people.

Below is a list of suggestions to offer support to both the patient and the caregiver.

- Focus on what you can do.
- Help them cope.
- Reach out for help as needed.

Understand that the illness impacts more than the patient's physical body. Patients and caregiver's are affected physically, emotionally, socially and spiritually. The hospice care team provides trained social worker's, chaplains and bereavement counselors to support you as you experience a multitude of emotions. Talk with your hospice care team.

I HAVE THE RIGHT TO…

1. To take care of myself. (This is not an act of selfishness. It will give me the capacity of taking better care of my relative.)
2. To seek help from others even though my relative may object. (I recognize the limits of my own endurance and strength.)
3. To maintain parts of my own life that do not include the person I care for, just as I would if he or she were healthy. (I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.)
4. To get angry, be depressed and express other difficult feelings occasionally.
5. To reject any attempt by my relative (either conscience or unconscious) to manipulate me though guilt, anger or depression.
6. To receive consideration, affection, forgiveness and acceptance for what I do for my loved ones for as long as I offer these qualities in return.
7. To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
8. To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full time help.
9. To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in out country, similar strides will be made toward aiding and supporting caregivers

-Jo Horne, author of CareGiving: Helping an Aging Loved One

COMMUNICATION DURING THE END OF LIFE JOURNEY

When diagnosed with a terminal illness, a wide range of emotions can be experienced for the patient AND the family. Communicating through the entire journey is very important for everyone involved. Dealing with changes and losses often occur during the journey, and being able to share the questions, fears, and concerns are extremely important. It is important to realize these emotions are "normal" although, for some, difficult to address. Your social worker can help you address these emotions and assist in finding ways to cope. Some emotions typically experienced during this time:

Sorrow	Acceptance
Anxiety	Anger
Depression	Denial

We think of the emotion of grief occurring following a loss or death. However, there is another emotion people can tend to experience called anticipatory grief. Anticipatory grief is when one deals with the loss before it completely unfolds. The person experiencing this is anticipating the changes in their life because of the loss. Not everyone experiences anticipatory grief, but if these emotions are experienced, they, too, are normal.

Social Workers are part of your care team to help in several areas. One area is to help make communication easier and to help guide you in coping with the many emotions experienced during the end of life journey. It is ok to express your feelings and emotions with your hospice care team. We want to help.

Saying Goodbye

Going through a terminal illness can allow time to show appreciation for the ones in your life or make amends with family and friends to whom life circumstances could have created a wedge in the relationship. Five common phrases have been found to powerfully affect peaceful transitions. As you travel this end of life journey you may want to consider conversations with those most important to you using these phrases. Those phrases are:

- I love you
- I forgive you
- Forgive me
- Thank you
- Goodbye

WHEN TO CALL YOUR SOCIAL WORKER

Knowing and understanding the role of your social worker, as a part of your care team, may be confusing. The role of the social worker is to assist with needs that are not physical in nature. Typical tasks your social worker can assist you with are:

- Understanding the impact of the disease progression
- Understanding and coping with emotions
- Helping children understand and cope with a sick loved one
- Accessing community resources
- Estate and Will planning
- End of life wishes
- Life Legacy Projects
  - Letter writing
  - Videos or recordings
- Advanced Directives
- Do Not Resuscitate Forms
- Disability Applications
- Following up with Insurance benefits
- Funeral and Burial arrangements

If you or your loved one would like assistance with any of the topics listed above, or feel you need assistance with any other need, please feel free to ask you social worker.

It is the mission of **Shepherd's Cove Hospice,** a non-profit agency, to provide, with a servant's heart, exceptional individualized care for those coping with end-of-life issues.

If you should have a concern your Shepherd's Cove Hospice team is not providing the service you expect, please call Stormy Dismuke, Chief Nursing Officer, or Rhonda Osborne, Chief Executive Officer at 256-891-7724 or 1-888-334-9336 (toll free).

You may also contact our Compliance Hotline by phone at 256-279-0549, or email at compliance@shepherdscove.org. After speaking with the Shepherd's Cove Hospice representative, you are not satisfied with the results, you can make a formal complaint through the State of Alabama Department of Licensure by calling 1-800-356-9596 (toll free).

Shepherd's Cove Hospice complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. ATTENTION: If you do not speak English, language assistance services, free of charge, are available to you. Call 256-891-7724.

Shepherd's Cove Hospice cumple con las leyes federales de derechos civiles aplicables y no discrimina por motivos de raza, color, nacionalidad, edad, discapacidad o sexo. ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 256-891-7724.

Shepherd's Cove Hospice 은(는) 적용 민권 법률 준수하며 인종, 피부색, 출신 국가, 연령, 장애 또는 성별을 이 유로 차별하지 않습니다. 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 256-891-7724 번으로 전화해 주십시오

Shepherd's Cove Hospice, a non-profit agency, is a member of the following organizations:

United Way Community Partner

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