# THE EMPOWERED CAREGIVER SERIES

# EXPLORING CARE AND SUPPORT SERVICES

An education program presented by the Alzheimer's Association®



# The Empowered Caregiver: Exploring Care and Support Services Presenter's Guide

Icon	Designation
	Instructions
Ť	Talking points
i	Notes

## **NOTES TO PRESENTER:**

## Response to personal questions

- Throughout this program, people may ask questions about their personal situations. The best way to respond is to acknowledge that everyone's situation is different.
- If a participant has questions about the disease or caregiving, encourage them to call the Alzheimer's Association 24/7 Helpline (800.272.3900) or visit alz.org.

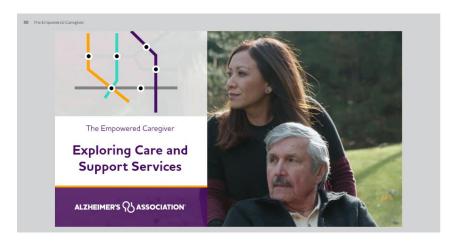
## **Advancing slides**

- This guide will show you where to click on the screen to advance to the next slide.
- Due to this program's interactive format, directions vary throughout.

## **Revisiting slides**

• If you need to revisit a specific topic in the program, click the Menu button in the top left corner of the presentation. Then select the slide you wish to revisit within "Exploring Care and Support Services."





## Introduction





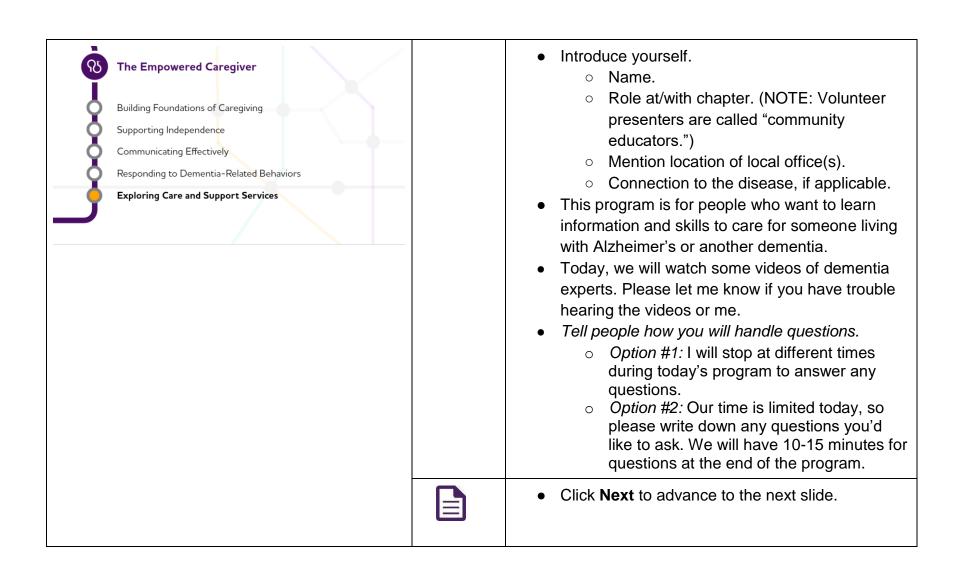
 Welcome to "Exploring Care and Support Services."



• Click **Next** to advance to the next slide.



Today's session is part of the Empowered
 Caregiver series presented by the Alzheimer's
 Association<sup>□</sup>.



## Learning Objectives

After this presentation, you will be able to:

- · Explain why it is important to plan for care changes.
- Describe kinds of respite care. This includes informal, home and day care.
- · Compare different kinds of long-term and residential care.
- · Describe end-of-life care options.
- Know what's important when moving a person from one care setting to another.
- Name Alzheimer's Association\* resources that can help you find the right type of care.





Let's take a look at our learning objectives for today.

- After this program, you will be able to:
  - Explain why it is important to plan for care changes.
  - Describe kinds of respite care. This includes informal, home and day care.
  - Compare different kinds of long-term and residential care.
  - Describe end-of-life care.
  - Know what's important when moving a person from one care setting to another.
  - And name Alzheimer's Association resources. These can help you find the right kind of care.



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# **Preparing for the Future**

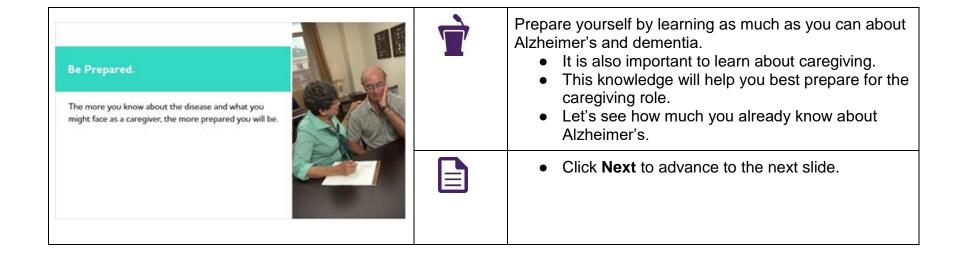


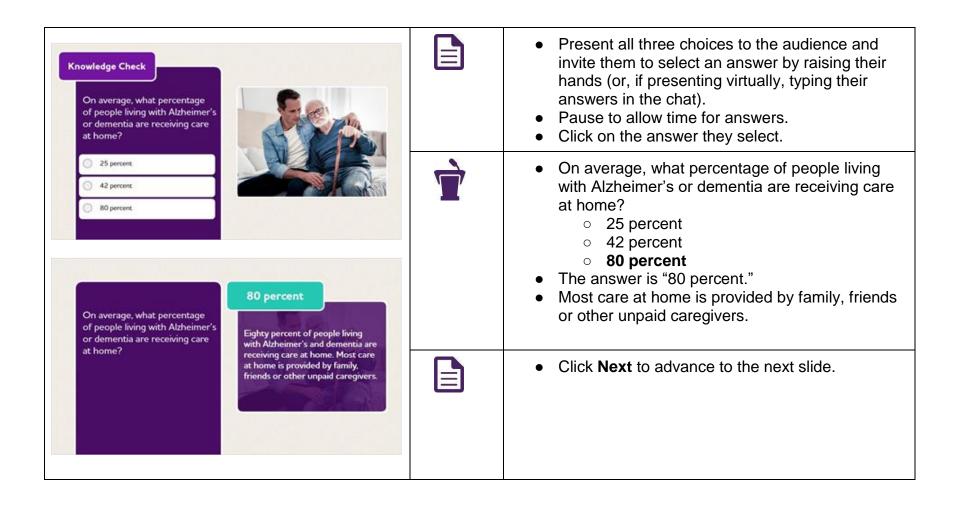


• To start, let's talk about preparing for the future.



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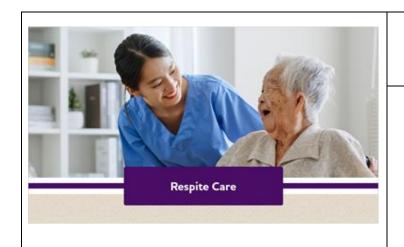
Let's learn a bit more about Alzheimer's to help you prepare for the road ahead.

- Alzheimer's is a progressive brain disease.
- It progresses in three stages.
  - In the earliest stage, brain changes occur but there are no symptoms.

	1	
Understanding the Disease  Alzheimer's progresses slowly in three general stages:  • Mild		<ul> <li>Eventually the individual will experience problems with memory and thinking as the disease progresses.</li> <li>Health professionals sometimes describe these three stages as mild, moderate and severe — sometimes called early, middle and late.</li> </ul>
Moderate     Severe  These stages are sometimes called early, middle and late.		Click <b>Next</b> to advance to the next slide.
Understanding the Disease  Alzheimer's affects people in different ways.  We can't always neatly place an individual living with the disease into a specific stage because each person has a unique experience.  Care needs change and increase as the disease gets worse.  Eventually, the person will need 24-hour care.		<ul> <li>Alzheimer's affects people in different ways.</li> <li>Because each person living with the disease has a unique experience, we can't always neatly place an individual into one specific stage.</li> <li>In fact, some people may exhibit symptoms that overlap stages.</li> <li>Care needs change and increase as the disease gets worse.</li> <li>Eventually, the person will need 24-hour care.</li> <li>They will need help with all of their activities of daily living. This includes eating and drinking, taking a bath or shower, getting dressed and using the toilet. It also includes walking and moving from one position to another.</li> </ul>

	Click <b>Next</b> to advance to the next slide.
Understanding the Disease  Know when and where to get help.  It can be challenging to care for someone living with dementia, but you don't have to do it alone. Resources and support are available at every stage of the disease.  Be sure to check your insurance coverage before hiring anyone to help with care.	<ul> <li>Know when and where to get help.         <ul> <li>It can be challenging to care for someone living with dementia, but you don't have to do it alone.</li> <li>There are resources and support for every stage of the disease. This can help you feel more confident as a caregiver.</li> </ul> </li> <li>We will learn about different care options today.</li> <li>Make sure you check your insurance before you pay anyone for help.         <ul> <li>This includes Medicare, medical insurance or long-term care insurance.</li> <li>These types of insurance can sometimes help you pay for care.</li> </ul> </li> </ul>
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# **Respite Care**

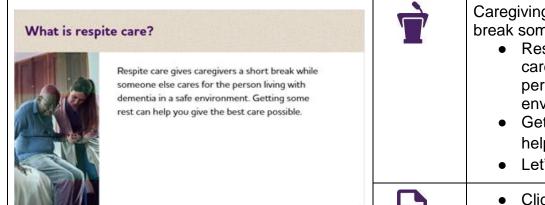




The first care option we'll explore is respite care.



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Caregiving can be rewarding. But everyone needs a break sometimes.

- Respite care gives caregivers a short break from caregiving while someone else cares for the person living with Alzheimer's in a safe environment.
- Getting some rest and taking care of yourself can help you give the best care possible.
- Let's look at the different kinds of respite care.



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# Kinds of Respite Care



Informal help includes accepting offers for help from family, friends and other trusted individuals. When someone offers their help, take it. Be sure to tell them exactly what you need.

This could include:

- · Making appointments.
- · Paying bills or helping to manage finances.

Informal help

· Visiting with the person living with dementia so you can take a break.





Caregivers might want to find informal caregiving support. This means getting help from people you know.

- This could include family, friends and other trusted members of the community.
- Accept offers of help from friends and family. Tell people exactly what you want help with.
- People can help you with:
  - Making appointments
  - Paying bills or helping manage the person's finances
  - Visiting the person living with dementia.
     Friends and family can keep them company while you take a break



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### Kinds of Respite Care



#### Home care



Home care involves paid professionals who help with daily living. It does not include medical care. Examples include:

- · Companion services: Help with supervision, recreational activities or visiting.
- Personal care services: Help with baths or showers, getting dressed, using the toilet, eating, exercising or other needs.
- · Household services: Help with cleaning the house, shopping or making meals.

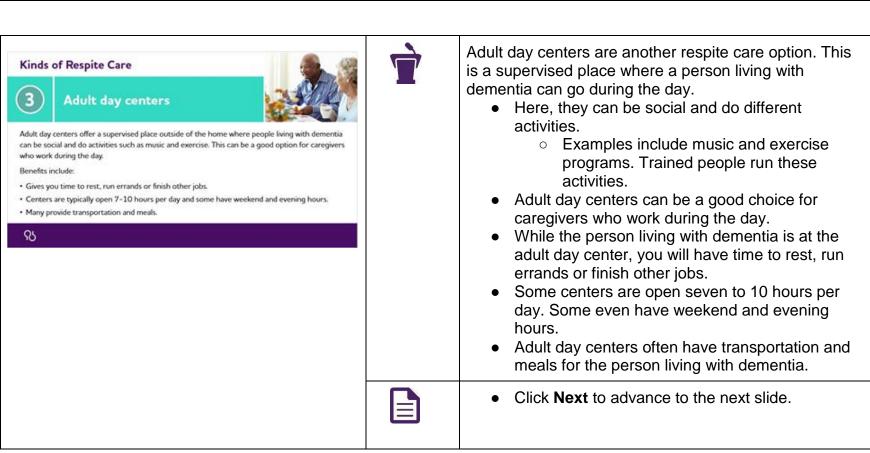
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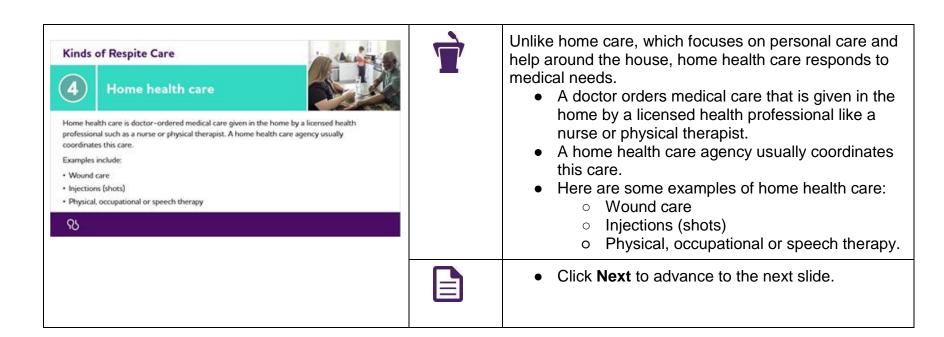


There are also respite services that you can pay for. Not all in-home respite care services are the same. Let's explore two kinds of respite care.

- Home care professionals usually help with daily living. It does not include medical care.
- Here are some examples of home care help.
  - Companion services: Help with supervision, activities the person may enjoy, or visiting.
  - Personal care services: Help with baths or showers, getting dressed, using the toilet, eating, exercising or other personal care needs.

	<ul> <li>Household services: Help with cleaning the house, shopping or making meals.</li> </ul>
	Click <b>Next</b> to advance to the next slide.





# **Long-Term and Residential Care**









Someday, the person living with Alzheimer's or another dementia may require more care than you can give at home.

- They will need 24-hour supervision and more intensive care.
- There are professionally staffed residential care communities that give this level of help.
- These care communities include:
  - Independent living
  - Assisted living and
  - Skilled nursing homes
- Let's look closer at each type of care community. We'll start with independent living.



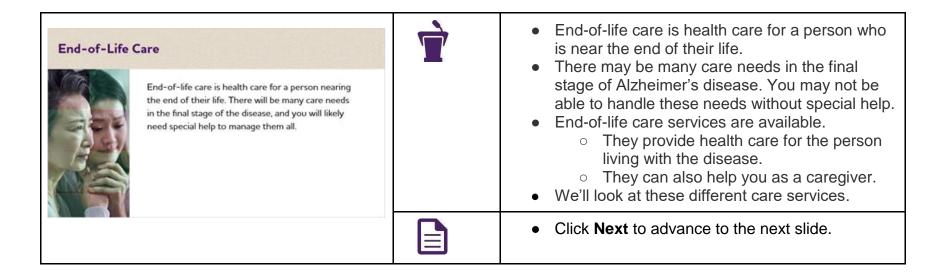
• Click the "Independent living" icon.

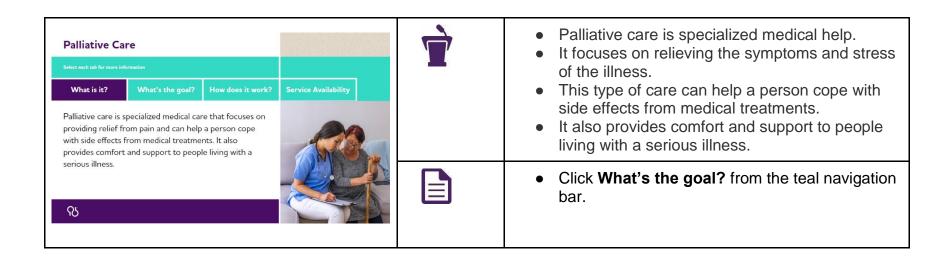
Long-Term and Residential Care	<ul> <li>These communities may be good for people who can still mostly take care of themselves.</li> <li>These centers usually have limited supervision.</li> <li>Many offer social activities, transportation and other services.</li> </ul>
Independent living centers may be a good option for people who can still mostly take care of themselves. These centers usually have limited supervision. Many offer social activities, transportation and other services.	<ul> <li>Click Back to menu to return to the "Long-Term and Residential Care" slide.</li> <li>Then, click the "Assisted living" icon.</li> </ul>
Assisted living  Assisted living centers may be a good option for people who can no longer live at home, but do not yet need nursing home care.  These centers usually include a mixture of:  Housing  Meals  Supportive services  Health care  The federal government does not regulate assisted living homes, and assisted living can mean different things in different states.  Not all assisted living row mean different share programs for people living with dementia. It is important to ask.  Back to menu	<ul> <li>Assisted living is also called "board and care," "adult living" or "supported care."</li> <li>It is a kind of care for people who can no longer live at home but do not yet need nursing home care.</li> <li>It usually includes a mixture of: <ul> <li>Housing</li> <li>Meals</li> <li>Supportive services</li> <li>Health care</li> </ul> </li> <li>It's important to know that the federal government does not regulate assisted living homes.</li> <ul> <li>The words "assisted living" can have different meanings in each state.</li> </ul> </ul>

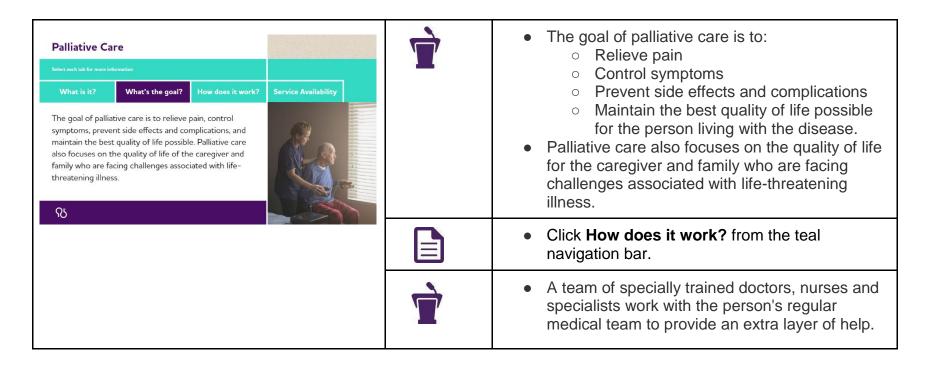
Skilled nursing homes provide care 24 hours a day and long-term medical help.  Most include services and staff to help with needs such as:  Nutrition/food  Care planning	<ul> <li>Not all assisted living providers have programs for people living with dementia. It is important to ask.</li> <li>Click Back to menu to return to the "Long-Term and Residential Care" slide.</li> </ul>
Recreation activities     Spirituality/religion     Medical care     Activities of daily living  Back to menu	<ul> <li>Then, click the "Skilled nursing homes" icon.</li> <li>Skilled nursing homes are also called "skilled nursing facilities" or "custodial care."</li> <li>They give care 24 hours a day. They also give long-term medical help.</li> <li>Most nursing homes have services and staff for these needs: <ul> <li>Nutrition and food</li> <li>Care planning</li> <li>Recreation activities</li> <li>Spirituality and religion</li> <li>Medical care</li> <li>Activities of daily living, such as taking a bath or shower, using the toilet, getting dressed and eating</li> </ul> </li> </ul>
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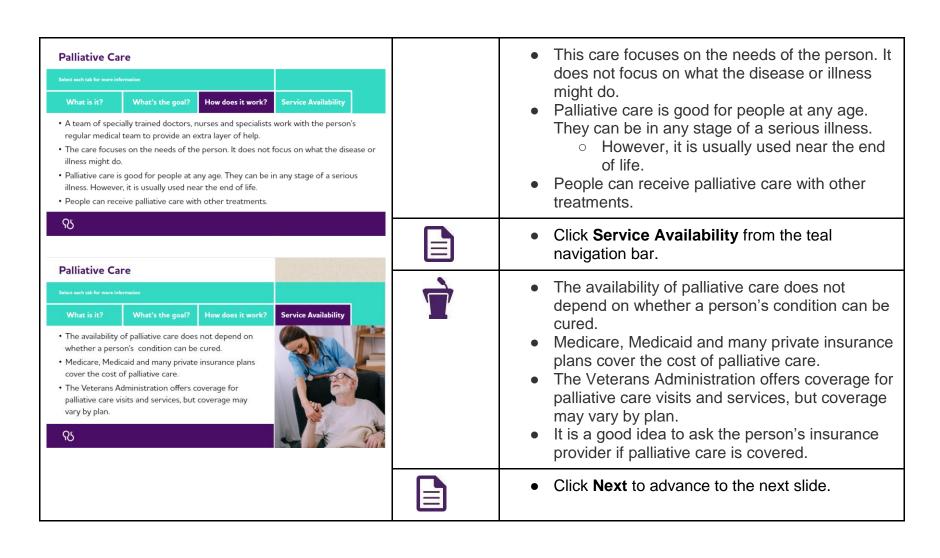
## **End-of-Life Care**

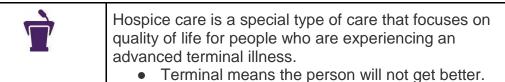
	Ť	We will now look at end-of-life care.
	i	Be aware that some audience members may be sensitive to the topics outlined in this section.
End-of-Life Care		Click <b>Next</b> to advance to the next slide.

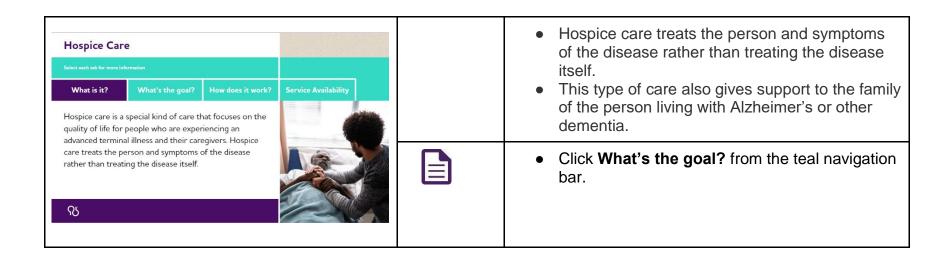


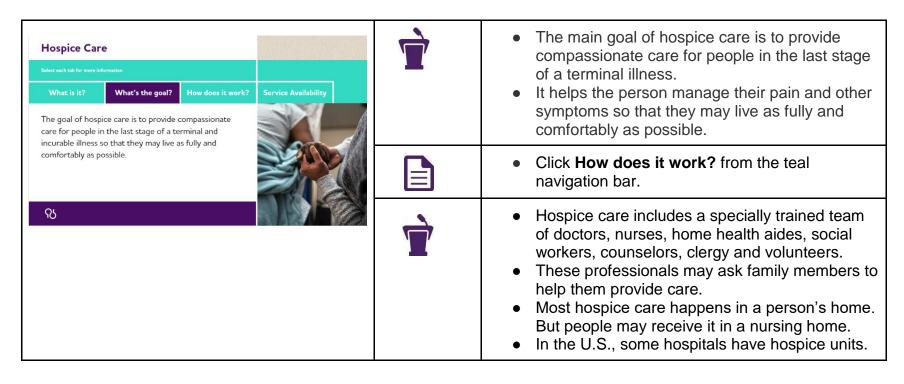


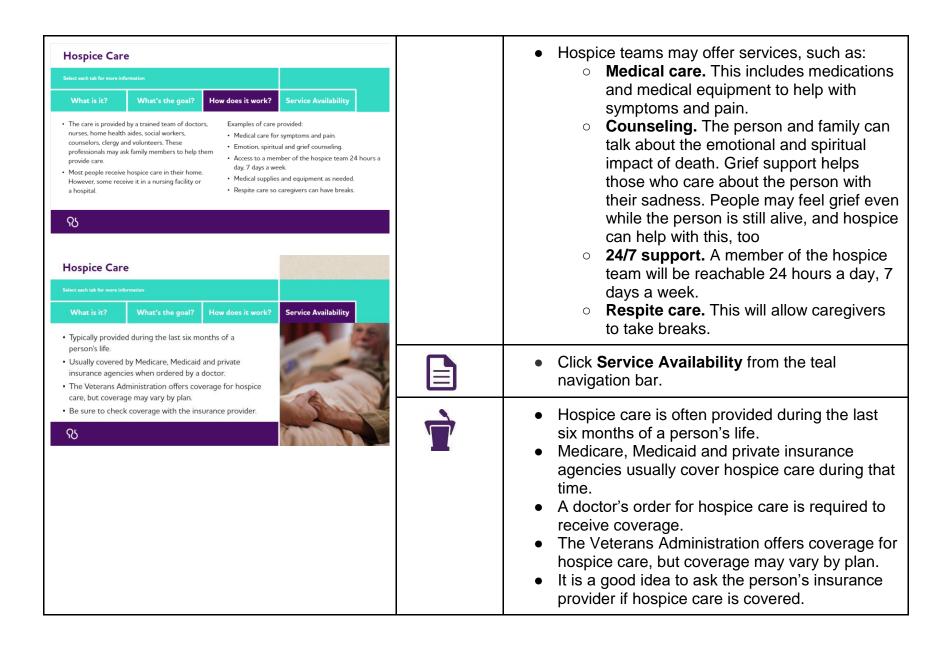








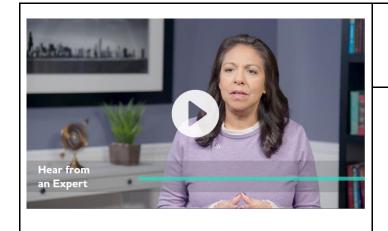




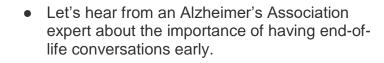
i	If an audience member raises questions about this topic or wants to know more, encourage them to call the Association's 24/7 Helpline at 800.272.3900 for more information.
	Click <b>Next</b> to advance to the next slide.

## We will now cover tips for having end-of-life conversations. **End-of-Life Conversations** Start early. · Start early. This will let the person living with dementia share o It's important to talk about end-of-life their wishes and choices. wishes and choices early. · Prepare legal and financial documents. These are called o This way, the person living with dementia advance directives. Do this early. Then the person with the disease can tell you what they want written in these can be part of the conversations. These conversations can also help you Think about the person's quality of life when you make medical decisions. feel more confident as a caregiver as you make decisions for the person in the future. Prepare legal and financial documents. These are called advance directives. o These documents include a living will and health care power of attorney. They let the person living with dementia choose what kind of treatment and care they want at the end of their life. The documents may also include wishes for comfort care and funeral planning.

	<ul> <li>These documents can help families so they won't have to guess what the person would want.</li> <li>Think about the person's quality of life when you make all medical decisions for them.</li> <li>This includes the goals for care and medical treatments.</li> <li>Consider each treatment's benefits, risks and side effects.</li> </ul>
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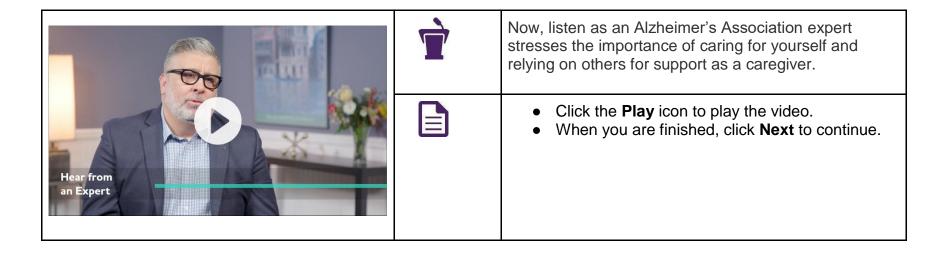




- Click the **Play** icon to play the video.
- When you are finished, click **Next** to continue.

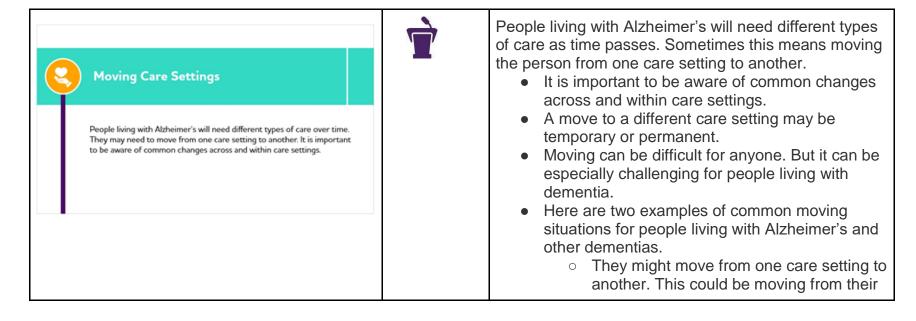
### When considering the goals for care and medical treatment, remember that situations can be different for Medical decisions everyone. Think about goals for care and medical treatment. Situations • You might choose a person's comfort and better can be different for everyone. You might choose a person's quality of life instead of a longer life. comfort and quality of life instead of a longer life. Some medical decisions include: Some of these medical decisions include: Click on the purple **Do Not Resuscitate (DNR)** Life-sustaining treatm square. **Do Not Resuscitate:** A DNR is a legal order that a doctor writes. It stops people from using Cardiopulmonary Resuscitation (CPR) or other life-saving procedures to help a person when their heart or breathing stops. **Medical decisions** People with a DNR can still get chemotherapy, antibiotics, dialysis or any Think about goals for care and medical treatment. Situations can be different for everyone. You might choose a person's other appropriate treatments. comfort and quality of life instead of a longer life. o However, a DNR will stop doctors from Some medical decisions include: using CPR or other life-saving A DNR is a legal order that a doctor Do Not Resuscitate (DNR) writes. It stops medical professionals from procedures in certain situations. using cardiopulmonary resuscitation (CPR) or other life-saving procedures to Life-sustaining treatments help a person when their heart or Click on the purple Life-sustaining treatments breathing stops. square. Life-sustaining treatments: Medical care for late-stage Alzheimer's disease may include certain treatments to keep the person alive. You may need to decide whether to use, stop, limit or refuse these treatments for the person. These could include: Respirators to help with breathing Feeding tubes

Medical decisions  Think about goals for care and medical treatment. Situations can be different for everyone. You might choose a person's comfort and quality of life instead of a longer life.		<ul><li>IV hydration</li><li>Antibiotics</li><li>CPR</li><li>Or Surgery</li></ul>	
	Some medical decisions include:  Here are some examples of medical care for late-stage Alzheimer's disease.  Respirators (help with breathing)  Feeding tubes  IV hydration  Antibiotics  CPR  Surgery	Click <b>Next</b> to advance to the next slide.	

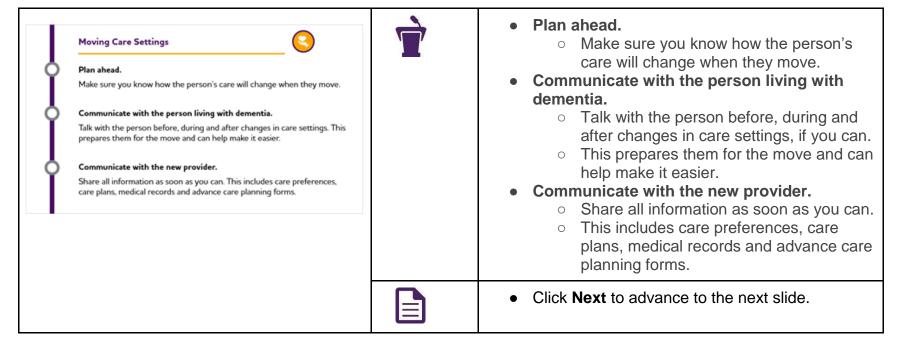


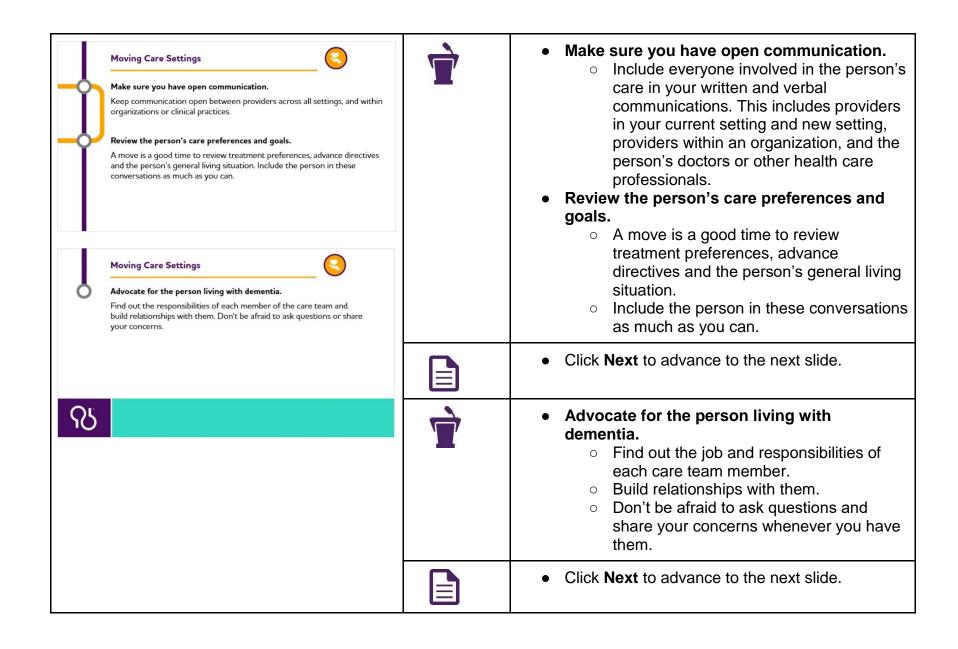
# **Moving Care Settings**





	own home to a hospital or nursing home. Or from a nursing home to an emergency department.  They also might move within a care setting. For example, they may move from independent living to assisted living when more assistance is needed.  Here are some ways to help prepare for a move to a different care setting. This can make everyone feel more comfortable.
	Click <b>Next</b> to advance to the next slide.





## **Alzheimer's Association Resources**





- We offer many local resources as well.
   Find your Alzheimer's Association chapter at alz.org/findus.
  - We offer local support groups for caregivers, people living with Alzheimer's, and others facing the disease. Some groups are led by professionals, and others are led by specially trained caregivers just like you.
  - The Alzheimer's Association & AARP Community Resource Finder (alz.org/crf) is a database of dementia and aging-related resources.
    - It is an online tool that can help you find programs and services in your area.
  - Our website, alz.org, has free information and resources for people facing Alzheimer's and other dementias.
    - alz.org/care has information for caregivers.
    - alz.org/safety and alz.org/driving offer information on staying safe at home and how to know when it is time for the person to stop driving.
- ALZConnected (alz.org/alzconnected)
   is a free online community for people
   living with dementia and their caregivers.
- Alzheimer's Navigator
   (alz.org/alznavigator) is another

	interactive online tool. You answer questions about your situation, and then it creates an action plan with customized information, support and local resources.  We offer a number of education programs like the one you've attended today. These programs can help you learn more about the disease and various caregiving topics. We have free in-person, online and virtual programs.  Only to be said if your chapter is presenting other parts of The Empowered Caregiver series:  Please be sure to join us on [date, next week, etc.] for the next part of our series called [program name(s)].
	Click <b>Next</b> to advance to the next slide.

# **Questions/Closing**





- That is the end of today's presentation.
  - o Are there any questions?
  - Was there anything we covered that you were unclear about?
  - What information did you find most helpful?
  - Is there anything you would like to learn more about?

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