

## Managing Dementia Through Effective Caregiving ALZHEIMER'S ASSOCIATION®

## What is Dementia?



Umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.



Mixed dementia: Dementia from more than one cause

## Alzheimer's disease is a continuum







Approximately how many Americans are currently living with Alzheimer's?

#### **Over 3 million**

#### More than 6 million

#### **About 8 million**

#### **About 11 million**

Approximately how many Americans are currently living with Alzheimer's?

## MORE THAN 6 MILLION AMERICANS ARE LIVING WITH ALZHEIMER'S

**Over 3 million** 

More than 6 million

**About 8 million** 

**About 11 million** 



About how many Americans provide unpaid care for people living with Alzheimer's or other dementias?

#### **About 8 million**

#### **Over 11 million**

**Over 14 million** 

#### More than 18 million

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OVER **11 MILLION** AMERICANS **PROVIDE UNPAID CARE FOR PEOPLE** WITH ALZHEIMER'S OR OTHER DEMENTIAS

## What is Communication?

with others BODY LANGUAGE Attitude Tone of voice Conversation Self-expression Attitude Tone of voice nessages **Interaction** Relationships Body istening language Making WORDS FACIAL Decisions **EXPRESSIONS** 

## Communication Changes Throughout the Disease

#### Early stage (Mild)

Convey thoughts and feelings through language. Able to make decisions about future care. May misinterpret what others say.

#### Middle stage (Moderate)

Use basic words and sentences.

Rely more on tone of voice, facial expression & body language. Continue to need emotional connection& meaningful activity.

#### Late stage (Severe)

May still respond to familiar words, phrases or songs. Use body language and the five senses to connect.







## Communication in the Early Stage Changes you may notice:

- Difficulty finding the right words.
- Taking longer to speak or respond.
- Withdrawing from conversations.
- Struggling with decision-making or problem-solving.



## **Communication in the Early Stage**

## To connect:

- Ask directly how to help with communication.
- Keep sentences clear and straightforward.
- Leave plenty of time for conversations.
- Include the person in conversations that affect him or her, including planning for the future.



## **Communication in the Early Stage**

## Keep in mind:

- Avoid making assumptions.
- Speak directly to the person.
- Communicate in the way that is most comfortable for the person. Options include phone, email, and in person.
- Laugh together.
- Be honest and stay connected with each other.

#### Changes you may notice:

- Increased difficulty finding the right words.
- Using familiar words repeatedly.
- Inventing new words to describe familiar things.
- Easily losing train of thought.
- Speaking less frequently.
- Communicating through behavior rather than words more often.

\*\*Consult a doctor when you notice major or sudden changes\*\*



#### To connect, approach the person gently

- Approach from the front, say who you are and call the person by name.
- Maintain eye contact and get at eye level if seated or reclining.
- Avoid criticizing, correcting and arguing.
- Pay attention to your tone.
- Take your time.



#### **To connect, join the person's reality** Keep respect and empathy in your mind, then:

- Assess the person's needs.
- Let the person know you hear his or her `concerns, whether they are expressed through words, behavior or both.
- Provide a brief answer.
- Respond to the emotions behind the statement.



#### To connect, keep it slow and basic

- Use short sentences and basic words.
- Speak slowly and clearly, one person and one question at a time.
- Limit distractions.
- Be patient.
- Offer a guess or fill in words if acceptable.



#### To connect, give multiple cues

- Provide visual cues and gestures.
- Avoid sudden movement.
- Write things down for the person.
- Put answers into your questions.
- Repeat as needed.
- Turn negatives into positives.
- Avoid quizzing.



#### To connect, respond empathically and reassure

- Join the person's reality.
- Provide reassurance that you hear and understand.
- Focus on the feelings, not the facts.
- Validate and redirect the person if necessary.





#### Changes you may notice:

- Communication is reduced to a few words or sounds.
- Possible responses to familiar words or phrases.

### To connect:

- Listen for expressions of pain and respond promptly.
- Help the person feel safe and happy.
- Continue to bring respect to each conversation.
- Keep talking.
- Use all five senses to communicate.



#### **Connect through touch:**

- Feel different fabrics.
- Identify shapes by touch.
- Give lotion hand massages.
- Identify everyday items in a bag by touch.
- Visit with animals.
- Sculpt using non-toxic materials.
- Hold the person's hand or stroke his or her arm or back.



#### **Connect through sight**

- Laminate brightly colored pictures to look at together.
- Watch videos of animals, nature or travel.
- Look at photo albums together.
- View photos of famous paintings, favorite settings or prominent people from the past.
- Go bird-watching or visit an aquarium.
- Paint with watercolors.
- Go outdoors or sit by an open window together.



#### **Connect through sound:**

- Listen to familiar music.
- Listen to recordings of the sounds of nature, farms, cities or animals.
- Identify musical instruments by sound.
- Listen to songs or speech in the person's native language.
- Read books, poetry, scripture, or newspaper articles to the person.
- Let the person hear the gentle tone of your voice.



#### **Connect through smell:**

- Make small plastic bags containing items for the person to smell, such as:
  - Herbs or spices.
  - Cotton balls dipped in essential oils.
  - Grass clippings or fragrant flowers.
  - Teas or coffee beans.
- Use fragrant lotions for hand massages
- Cook or feed the person foods that smell good, such as apple pie or chicken soup.



#### **Connect through taste:**

- Favorite foods.
- Home-baked goodies.
- Popsicles.
- Flavored drinks.
- Ice creams and puddings.

### **Communication in All Stages of the Disease**

- Join the person's reality to connect.
- Understand and accept what you can and cannot change.
- Remember that the person retains a sense of self despite the losses of the disease.
- Demonstrate respect and connect through feelings.
- Always treat the person as the adult he or she is.
- Try to decode the person's communications.
- Recognize the effects of your mood and actions.
- Try to understand the source of reactions.
- Help meet the needs while soothing and calming the person.



## Some of the most difficult conversations are:



Going to the doctor



Deciding when it is necessary to stop driving



Making legal and financial plans to cover future care needs



# Remember, no one can provide all of this support alone.

Form a care team and talk with family about concerns as they arise.

## **TALK ABOUT IT**



#### **Alzheimer's Association Key Resources**

We're available wherever and whenever you need reliable information and support.



On the phone – 24/7 Helpline, 800.272.3900

Online – alz.org

In communities nationwide - alz.org/CRF

ALZHEIMER'S RASSOCIATION

## **ALZConnected**<sup>®</sup> www.alzconnected.org

ALZConnected<sup>®</sup> is a free online community for everyone affected by Alzheimer's or another dementia, including:

- People living with the disease
- Caregivers  $\bullet$
- Family members  $\bullet$
- Friends
- Individuals who have lost someone to Alzheimer's or another dementia







"Caring for someone with

Alzheimer's can make you feel alone. Now, I've found others like me."

#### View Message Boards from others like you

#### **Caregivers Forum**

#### Moving Advice

My mom was recently diagnosed with mild-moderate Alzheimer's disease and was started on Aricept. We have convinced her to move into an independent living facility. As you can imagine she initially agreed and now does not want to go.

#### Tell me I'm not alone

Hi, I just stumbled upon this discussion board tonight and thought it would be a great way to help cope with my mother's recent diagnosis of early onset Alzheimer's.

#### If I hear...one more time.

Just this morning I saw this on Facebook "People will never truly understand something until it happens to them". After I read that, I came on the Message Board to get my strength for the day and saw this post. Just when I think I have come to the end of my rope, something or someone gives me just enough to keep going until I can right myself. Thank you everyone for your unseen, non judgmental and loving support.?

#### I have Alzheimers

#### Screening

I pestered the Neuro office and they at least told me that I won't be scheduled for another screening until late fall/early winter. I understand this can be good - maybe the forgetfulness, etc. was due to another cause and it could work itself out by that time.

#### Early-onset Alzheimer's Disease

I am new to this site, however I just recently started a blog about Early-onset Alzheimer's, as my mother was diagnosed a couple years ago at age 52.

#### Parent as Caregiver

I'm wondering if anyone knows of a situation where an elderly parent is caring for an adult child with Alzheimer's, and how their experience differs from many of us in the opposite situation.

#### ALZHEIMER'S navigator

alzheimer's **R**S association

#### What do you want to know?

Choose one of these topics to develop a personalized action plan.



Working with Your

Doctor



Symptoms

SI

**Financial Planning** 



Safety

Driving



Legal Planning





**Caregiver Support** 

## Alzheimer's Navigator<sup>®</sup> www.alzheimersnavigator.org

Alzheimer's Navigator is a free online tool that helps guide caregivers to answers by creating a personalized action plan and linking you to information, support and local resources.









**ASSOCIATION**<sup>®</sup> **ALZHEIMER'S** 



## ALZHEIMER'S ASSOCIATION®

## **Questions?**

### 800.272.3900 | alz.org<sup>®</sup>

