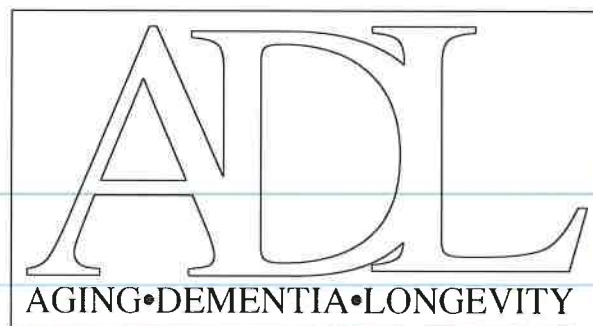
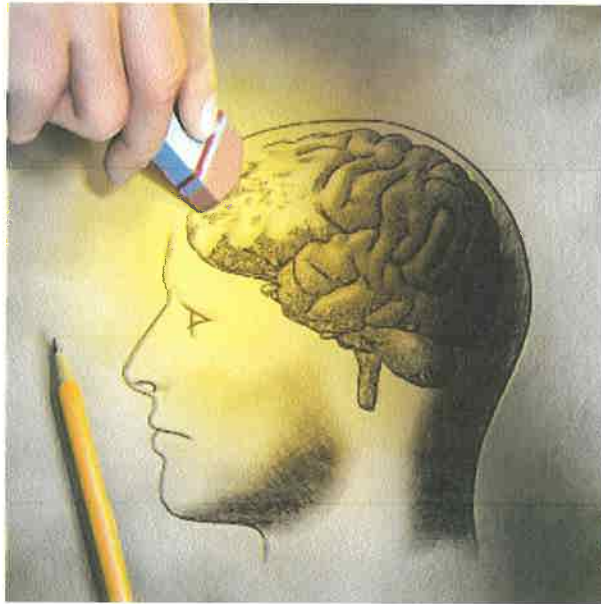


Guide to Explaining Dementia to Individuals with Intellectual Disabilities



Orange Grove Center
Chattanooga, Tennessee



ALZHEIMER'S DISEASE AND RELATED DEMENTIAS – WORKSHOP FOR INDIVIDUALS WITH ID/DD

AUDIENCE: Individuals with ID/DD (without dementia) who are being impacted by families, housemates, co-workers, friends with Alzheimer's disease and related dementias.

GOALS: To provide education, support, counseling and coping strategies to Orange Grove Center "Individuals Impacted by Family/Friends with Dementia"

The workshop will impart the following learned principles:

- Alzheimer's is a disease with no known cause; and YOU (the individual impacted by Family/Friends with Dementia) did not cause them to change their behaviors.
- Alzheimer's is a disease, but it does not mean that YOU (the individual impacted by Family/Friends with Dementia) will develop the disease.
- Alzheimer's causes people to lose their memory, their thinking skills and their behavior.... But YOU (the individual impacted by Family/Friends with Dementia) can learn how to communicate, how to show your love, support, devotion and how you can contribute to their overall quality of life (for the rest of their lives).

KEY WORDS AND CONCEPTS: (Exercises):

- Describe what you ate for breakfast this morning.
- Describe what you ate for breakfast two weeks ago.
- Describe the picture (pizza, hamburger): Question: How did you know this is a pizza? How did you know this is a hamburger?
- Describe where this goes (picture of a shirt – goes on the top of your body); (Picture of pants – goes over your legs). How did you know that?

- What do you think it would be like if you didn't remember what a hamburger was or didn't know the difference between a hamburger and a pizza?
- What do you think it would be like if you didn't know where the shirt went or how to put on the pants?
- CONCEPT OF MEMORY – what is it, where do you keep it, how do you use it, how do we use them (memories).
- CONCEPT OF MEMORY LOSS – what does losing your memory mean, what causes someone to lose their memory.
- Older people are the ones who might lose their memory. There are other things that happen to us when we get older, what are they? (Hearing, vision, strength, walking, hair becomes gray or white, become tired easier).
- How would you feel if your Mother or best friend forgot who you are? (Confused, angry, frustrated, anxious, mad, depressed)
- How should we act if that happens? (Understand that is because of the disease; be patient, don't fight or argue, remind them, use names, be kind, remember that they are still the same person, but with a different way of communicating, behaving and living).
- Understand that the person will continue to forget more and more things, until they cannot do very much without help, assistance and support. There are still many ways for you to show that you care for them, even though they may not tell you "thanks."
- Think of your own special memories with your family, friends and people you care about. Enjoy all the memories you have and share them with people who care about you.

Learning about Dementia - a guide for teaching people who have intellectual disabilities.

Dementia, whether Alzheimer's or a related form, affects everyone eventually. Sooner or later you will have dementia or know or care for someone who does. You will be or know someone who's life is changed by this insidious condition. While training support staff and families, we came to realize that "everyone" includes people with intellectual disabilities.

Some of the people we support will eventually develop Alzheimer's or another form of dementia. Many more of them will have parents or house mates or friends who are affected. They do not understand why the other person is changing. They are confused by repetitive questions or different behavior. They are afraid they will "catch it" or that they caused it. People with intellectual disabilities are definitely among the "everyone" who needs to be educated about dementia as it affects more and more people.

Things to discuss

- 1) What is memory?
- 2) What does our brain do?
- 3) What is Dementia? Is it the same as Alzheimer's?
- 4) What happens when people have dementia?
- 5) How can I help a person with dementia?
- 6) Who can I go to for help?

What is memory?

This is a basic concept that we need to make sure people understand before talking about how dementia may affect someone's memory.

Show the participants two pictures, one of a hamburger and one of pizza. Ask, "What are these?" Most will know and respond with the correct answers. Then ask, how do you know?

This should prompt a discussion of shape and taste or maybe just "because it is". Discuss how they are alike and different. Pizza is usually round, but if it is square is it still a pizza? Hamburger buns are round but does that make them the same as a pizza?

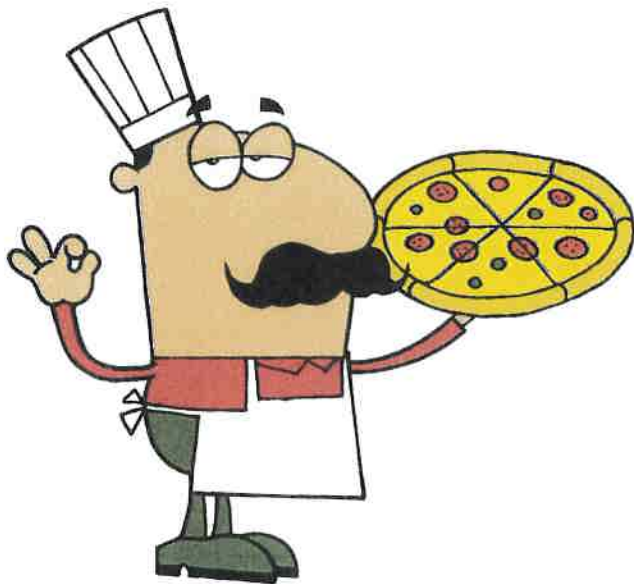
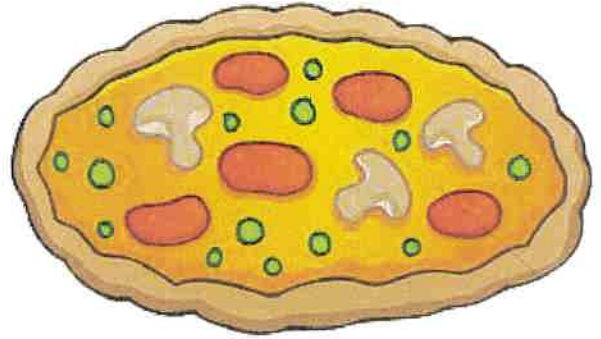
Show two more pictures, one of a shirt and one of a pair of pants. Ask, "What are these?", pause for answers.

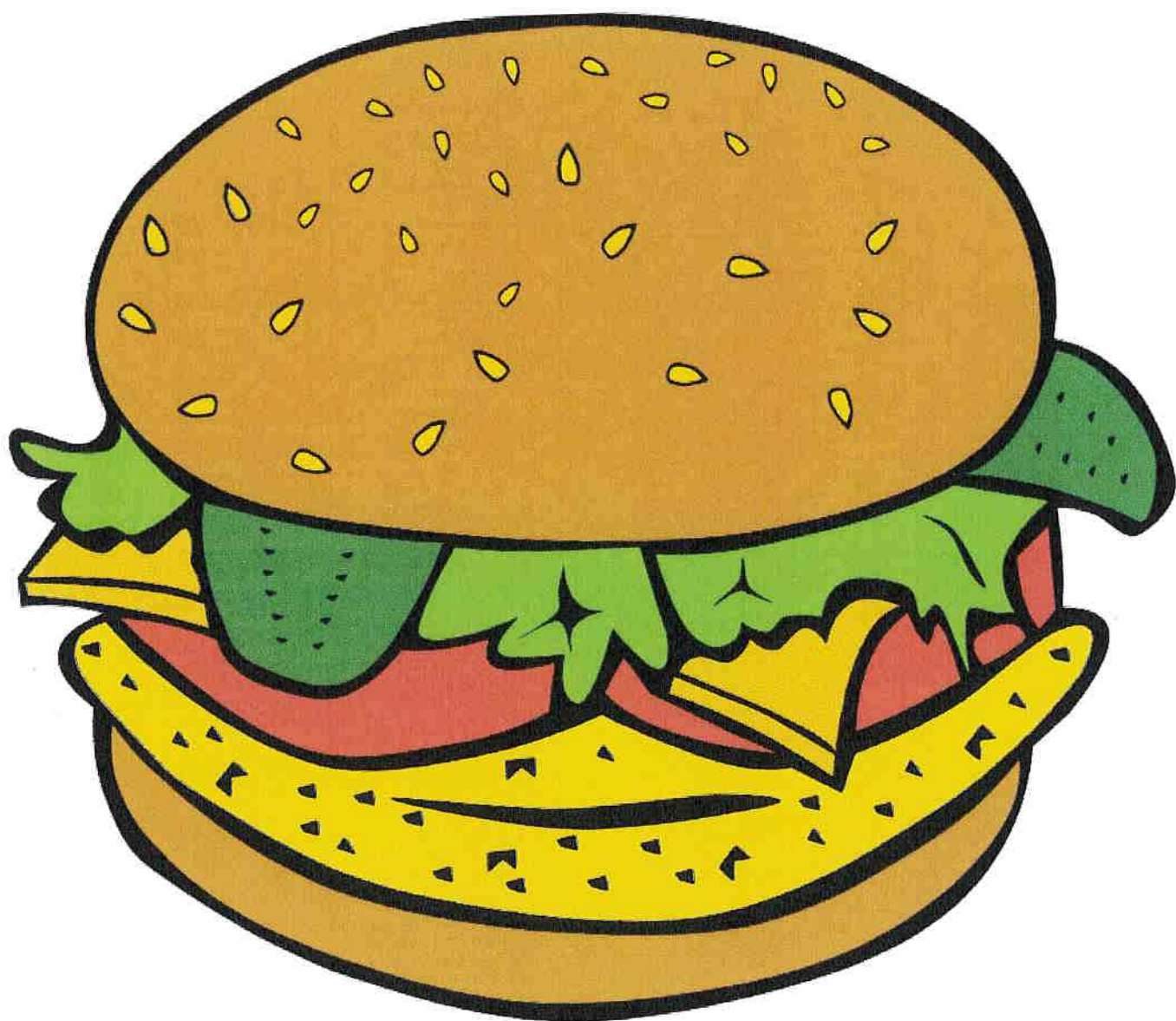
Ask "How do you know?"

This will prompt a discussion similar to the one about the food items. After talking awhile, someone may finally say "I remember what they are" or a similar statement. You respond, "Great, you are using your memory!"

If no one utters the magic phrase, give it to them. Say, "When you were young someone, a teacher or your parents, told you what these things are and you remembered. You are using your memory."

Memory helps us learn and remember all the things we know.







What does our brain do?

Our brain helps us do everything. It helps us remember what we learn. It helps us think. We use our brain all day and even when we sleep. Our brain lets us dream.

Sometimes, as people get older, they may have a problem called DEMENTIA. Dementia is often caused by a brain illness called Alzheimer's, but it may also be caused by other things. When a person has dementia their doctors will ask lots of questions and may do lots of tests to see what is causing the dementia. This is so they will know how to best help the person.

What is Dementia? Is it the same as Alzheimer's?

Dementia is a condition where the brain is not working the way it usually does. Dementia is often caused by a disease called Alzheimer's. Many people use the words "dementia" and "Alzheimer's" to mean the disease, no matter what caused it. Dementia can be caused by other illnesses and only the doctors can tell for sure. All kinds of dementia make the person's brain not work as well as it used to.

Even though it is caused by a disease, dementia is not contagious, which means you can not catch it from anyone else!

What happens when people have dementia?

People who have dementia may forget things or get mixed up more often than usual. They may start to act different than before. They might ask or say the same thing over and over, because they do not remember that they just said it. The person may be sad or not want to do things that they used to enjoy. They might sleep more during the day or be awake late at night. They might cry or be confused.

How can I help?

Most of all, try to be calm and patient when you are with them. You might want to look at photo albums or magazines with the person. You can listen to music with them, music calms some people. Be sure to choose the kind of music that they like.

Some people with dementia will do things slower. Be patient and wait for them. Do not ask them to hurry.

If the person gets things mixed up, stay calm and do not argue with them. Remind other people to stay calm.

Learning about dementia is a good way to help. You will understand better and can help other family members or friends to understand. The person with dementia might even forget your name someday, but they will still know that you care about them.

Who can I ask for help?

When you have a friend or family member with dementia, it can sometimes be scary and frustrating. Even though we can help them some of the time, we can not cure the problem. Sometimes you may be sad that the person you care about has changed.

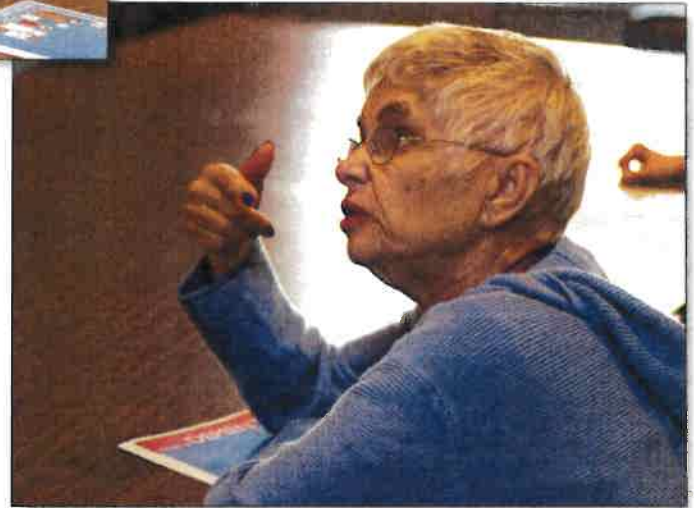
You should talk to people you trust about your feelings. This might be other family members, a favorite staff person, a friend, someone at church or your doctor. It is natural to worry and talking about your feelings can help.

You can also talk to Patti Wade, Dr. Rader or Amy Jo Schamens if you have questions about Alzheimer's or Dementia. We can help answer your questions and you can tell other family members or friends that they can talk to us, if you need help explaining dementia to them.

The most important thing to remember is that dementia is not your fault and it is not the other person's fault. Doctors can not cure dementia (yet) but we can all help each other if we all care.



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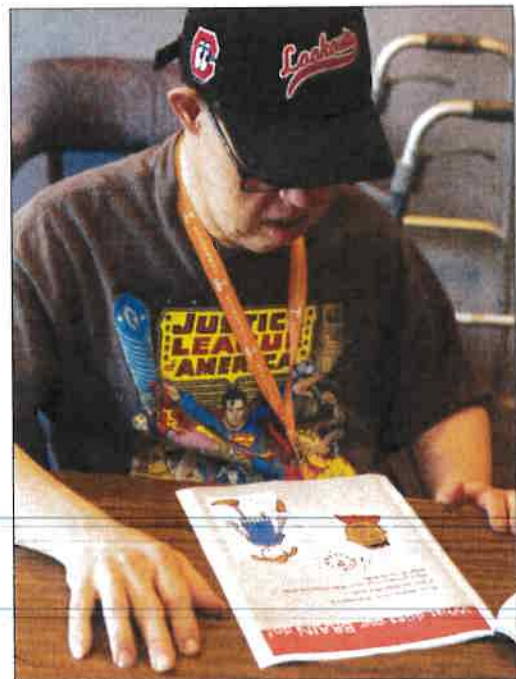
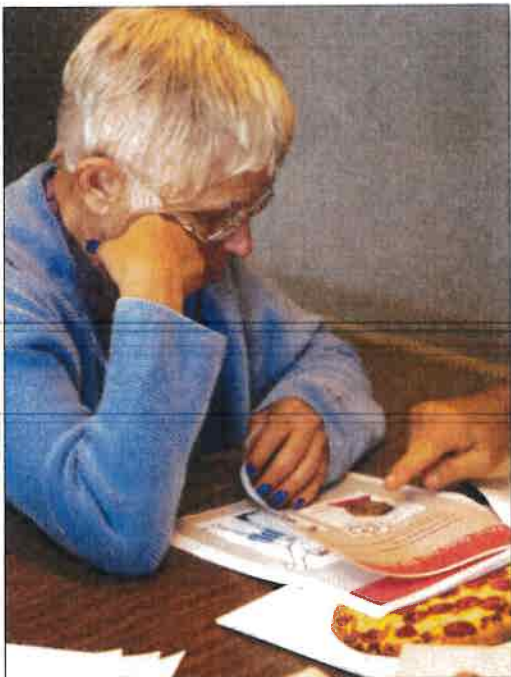
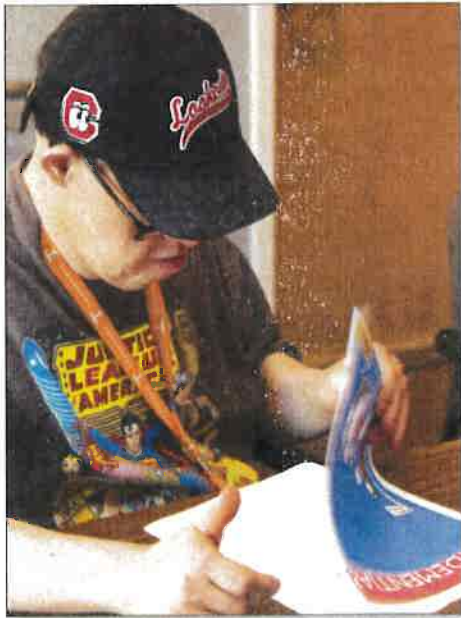
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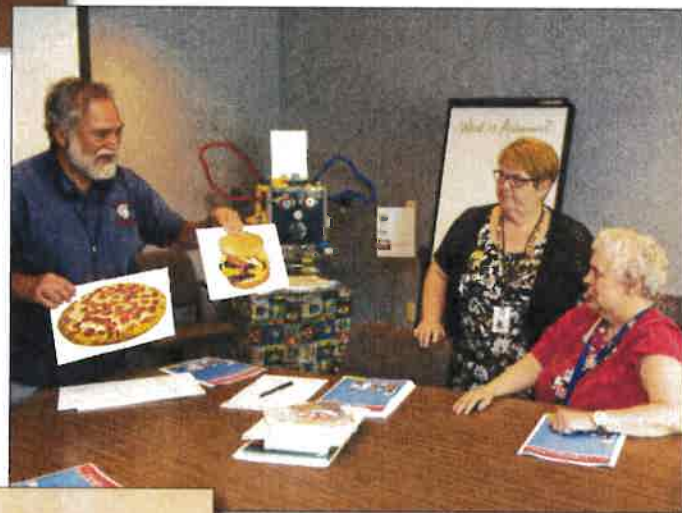
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