

Simple Pleasures: A multi-level sensorimotor intervention for nursing home residents with dementia (1997) (*training manual and instructions*) p.1-13.

Training the volunteers

Community groups often want to volunteer to make things or do things for local nursing homes. It is very difficult to do something meaningful for nursing home residents with dementia. Groups might come in once a year to sing at the holidays, make table decorations, or lap robes but the residents with dementia may not really benefit. The Simple Pleasures project is designed to help volunteers produce a useful and needed supply of recreational items for nursing home residents with dementia. The project targets two groups of volunteers: 1) retired older adults, and 2) youth groups.

If you are having difficulty finding volunteers you can write a letter to local organizations that take part in community service activities. Some of the organizations that have been helpful to us include: girl scouts and boy scouts, 4-H groups, junior high and high school classes, Sunday school classes, school service groups, senior citizens centers, Eastern Star groups, church craft groups, Office for Aging, Foster Grand Parents programs, and local hospital volunteers.

We feel it is important for volunteers to understand the symptoms of dementia, be aware of behavioral changes that occur, learn how to make recreational items that benefit the resident, and understand how to make a visit and use the Simple Pleasures items with the nursing home residents. The pages that follow include a sample-training program to use with your older adult volunteers and with youth groups. You can also ask your local Alzheimer's Association or Alzheimer's Education Center to help you provide education programs.

Training for adult volunteers: Alzheimer's disease Some things you can do to help

This education session will provide a brief medical overview of Alzheimer's disease in comparison to the other forms of dementia, discuss the differences of memory loss in normal aging, and provide a list of the stages of Alzheimer's disease. It will give the participants a way to help in the local nursing home setting.

Objectives:

Upon completion of this session the participants will be able to:

1. Define dementia and identify several possible causes.
2. Describe the symptoms and stages associated with Alzheimer's type dementia.
3. Explain how Alzheimer's disease is diagnosed.
4. Distinguish between normal memory loss associated with aging and the memory loss associated with dementia.
5. Be aware of some things that volunteers and family members can do to help in the local nursing home or adult day program.

WHAT IS DEMENTIA? Dementia is a syndrome; a group of signs and symptoms that cluster together without a specific identified causative disorder. It is an umbrella term that encompasses many different diseases. There are over 70 causes of dementia.

Alzheimer's Disease (AD) is the most prevalent type of dementia. A little more than 50% of all the dementias are considered Dementia of the Alzheimer's Type. The next most common type is Vascular or Multi-Infarct Dementia. This makes up about 20% of all dementias. Another fifteen percent of the dementias are combined Alzheimer's type and Vascular type. The final 10-15% are due to other causes.

WHAT IS ALZHEIMER'S DISEASE?

First of all it is a progressive, neurological illness in which brain cells are destroyed. The destruction results in structural & chemical changes in certain areas of the brain. The brain of older adults has slightly less mass, and the ventricles or open areas enlarge slightly. In Alzheimer's disease the brain mass loss is more pronounced, and the ventricles enlarge to a greater degree. Certain areas of the Alzheimer's brain are characterized by plaques and tangles. Less and less energy is metabolized in the brain as the disease progresses.

At this time there is no known cause, cure, or definitive treatment for Alzheimer's disease. There is good evidence to show that certain forms of Alzheimer's disease may have a genetic basis. Our best efforts in these cases may be spent in prevention of a "trigger" that kicks off the latent disease.

Symptoms

Alzheimer's disease does not come on suddenly. It has a gradual onset, some call it insidious. The family may notice memory changes in the patients for 1-2 years before seeking the opinion of a doctor, nurse, or other geriatric expert.

Little by little memory loss becomes apparent to everyone who knows the patient. He or she might not be able to manage a checkbook, get lost in his/her own neighborhood, or simply repeat questions or concerns over and over.

This is considered the early stage of Alzheimer's disease. Generally the person knows he or she has a problem. During this stage the individual has a decreased ability to learn new things, and has difficulty concentrating. This stage lasts from 2-5 years.

During Stage II (confusional stage) of the disease the patient shows poor judgment, is often disoriented, and withdrawn. He or she may not seem interested in past hobbies or social contacts. The patient in this stage often becomes preoccupied with his or her body, and sometimes appears paranoid. The patient may falsely accuse caregivers of stealing or hiding his or her things. It is during this stage that agitation and aggression are first displayed. This stage can last anywhere from 3-12 years.

The Advanced Stage or Stage III of Alzheimer's is often the period that is most difficult for caregivers. Communication becomes a serious problem in this stage. Both

communicating one's needs and understanding the wishes of others are now difficult. In addition, the patient has a significant loss of daily living skills by this time. Most individuals need help with dressing, bathing, and grooming. He or she may become difficult to manage. The caregiver may need to assist the patient with personal care, but the patient may become angry, confused, and sometimes aggressive toward the caregiver because of the loss of dignity and independence. The individual at this stage needs adapted recreational items to stay busy and to promote interactions with the environment. Boredom is a major problem that leads to behavioral disturbances.

The final stage is referred to as the Terminal Stage. It can last a year or more, and is characterized by substantial physiological decline. The patient is often spoon fed, incontinent, and unable to recognize family members. He or she may be unable to talk, walk, or move around. The individual at this stage still needs sensori-motor stimulation and comforting activities. Repetitive movements and noises may be displayed in this stage. At the end of this stage the individual lives a vegetative existence.

The entire course of the disease generally lasts 5-10 years, but sometimes as long as 20 years. The average life span after diagnosis is 8 years. The decline is gradual, without plateaus. The individual appears to show a reverse pattern of learning. That is, the loss of skills occurs in the reverse order that they were ordinarily attained.

How Big Is the Problem?

Over four million people in the United States have been diagnosed with Alzheimer's disease. It is a major health problem for older people and their families. The cost of caring for the person with Alzheimer's disease is enormous. For those receiving home care the average estimated cost is 18,000 dollars per year. For those cared for in nursing homes the cost more than doubles.

How Is It Diagnosed?

Alzheimer's disease is diagnosed by exclusion. That means by ruling out all other causes of memory and intellectual losses. The Diagnostic and Statistical Manual of the American Psychiatric Association requires the following to diagnose AD:

1. Presence of a dementia syndrome.
2. Insidious onset/gradual progressive course.
3. Exclusion of all other specific causes.
4. Physical examination, which includes a neurological exam.
5. Laboratory tests.

A good diagnostic evaluation for intellectual deterioration takes time, sometimes weeks or months, before a diagnosis can be made. A diagnosis is important in that many treatable disorders are often believed to be Alzheimer's disease. A diagnostic work-up usually includes:

1. Physical exam to identify possible health problems; e.g. poor nutrition, diseases that cause confusion and memory impairments.

2. Routine lab tests; e.g. blood and urine analysis to assess health status.
3. EKG and x-rays.
4. Personal and family medical history.
5. History of recent medications and alcohol use.
6. Neurological exam; e.g. mental status test, alertness, muscle strength, sense of smell, hearing and vision.
7. Assessment for Depression; e.g. Geriatric Depression Scale or Cornell Depression Scale.

THE OTHER FORMS OF DEMENTIA

- A. Vascular or Multi-infarct Dementia (15-20% of cases) is the second most prevalent form of dementia. More men than women have multi-infarct dementia. It is caused by multiple small strokes. This leads to a step wise deterioration rather than the gradual deterioration that is seen in Alzheimer's disease.
- B. Combination of Alzheimer's type dementia and vascular type dementia is common in 15% of cases. It is usually treated as if the diagnosis is Alzheimer's disease.
- C. Dementia in Parkinson's disease shows up as memory loss and slowness in thinking. Between 14-40% of Parkinson's patients have dementia symptoms. The added problem of gait disturbance and tremors make this dementia difficult to manage due to added safety issues.
- D. Metabolic Dementia such as vitamin B12 deficiency, hypothyroidism, and repeated episodes of hypoglycemia are treatable dementing illnesses. The laboratory tests used in the diagnostic phase can identify these problems and lead to successful treatment.
- E. Infectious Dementing Disorders include AIDS, Creutzfeldt-Jacob Disease, and Neurosyphilis. At this time AIDS is not curable. Creutzfeldt disease is either familial or virally transmitted and involves a rapidly progressing dementia due to brain lesions. Neurosyphilis is now rare with widespread use of antibiotics.
- F. Alcoholic Dementia (Korsakoff's syndrome) shows significant brain changes due to chronic alcoholism. A thiamine deficiency due to the excessive consumption of alcohol leads to neuronal deterioration.
- G. Huntington's Chorea is another rare cause of dementia that is genetically transmitted. The first signs might be minor such as increased irritability, but as the disease progresses severe personality and motor changes occur.
- H. Lewy Body Dementia is an irreversible brain disease associated with protein deposits called Lewy bodies. Lewy bodies appear in deteriorating nerve cells and are often found deep within the brains of people with Parkinson's disease. When Lewy bodies are found in other areas of the brain, such as the cortex, a dementia

syndrome occurs with symptoms similar to those with AD. Hallucinations are common in this disease.

Reversible Causes

A. Delirium

There are many causes for delirium; associated with physical illnesses. The onset is usually acute and related to: infections, brain tumors, head injuries, nutritional deficiencies, depression, cardiac or pulmonary changes, or medications. It shows up as restlessness and behavioral agitation. A sudden change in behavior should be evaluated by a medical professional.

B. Depression

Depression is a serious mental disorder affecting many older people. It is often not recognized, not diagnosed, and not treated. Memory problems may be a sign of depression. Depression is medical illness and is pervasive, persistent, intense, and interferes with functioning. Depression in the elderly can be effectively treated with medications and therapy.

Age of Onset

- Usually between the ages of 40 & 90; most often after 65; 10.3% of people over 65 years have probable AD.
- Highest risk after 85 years; 47.2% of people over 85 years have probable AD.
- AD affects one out of three families in the U.S.
- Two thirds of individuals are cared for in family homes until late stages.
- Sixty to 70% of nursing home residents have AD or a related disorder.
- Four million people currently have AD in the U.S.; with the projection of eight million by the year 2020.
- Fourth leading cause of death in adults.

What you can do to help:

- Volunteer at the local Alzheimer's Association or join next year's Memory Walk to raise money for local services.
- Nursing home residents with dementia need appropriate things to do to prevent boredom and reduce behavior problems. There are lots of wonderful handmade recreational items that volunteers can make. The items have been specifically designed for nursing home residents with dementia. The items were tested for safety, appeal, and durability. The designs must be strictly adhered to so they remain both safe and appealing to the residents with dementia. Nursing homes need a constant supply of items. You can make them as gifts for holidays or as a service project that continues all year long.

Alzheimer's Disease and Children

Many youth organizations and elementary school classes volunteer to visit nursing homes and adult day centers. Children may not know about dementing illnesses because for many years they were not understood or talked about. Families often hid the fact that older members developed a dementia. Children were rarely included. However, with the proper preparation and education the children can provide a wonderful and therapeutic benefit to the residents of nursing homes, including those who have dementia. The information in this section is appropriate for children in the fourth through the sixth grades.

Objectives for this session are:

1. The children will understand the difference between aging and disease.
2. The children will realize that older adults with Alzheimer's disease have memory problems.
3. The children will be cognizant of the fact that Alzheimer's disease cannot be passed from person to person.
4. The children will understand that Alzheimer's disease is a brain disease.
5. The children will be aware that sometimes people with dementia act in unexpected ways for an adult.
6. The children will be able to demonstrate 3 activities that might be enjoyable and engaging to a person with Alzheimer's disease.

Aging is not the same as disability or disease.

Everyone is getting older. We classify people according to ages. When you are 5-12 years old you are called (kids or children). When you are 13-19 you are called _____(teenagers). After age 18 people are usually called _____(adults). After age 65 we often think of people as older adults or senior citizens. Just because an individual is in a certain age category does not mean he or she has a disease. You get different diseases or illnesses at different stages during your development.

Learning experience

For example, how many of you have had a) tonsillitis, b) chickenpox, or c) allergies? Have the children stand up if they had tonsillitis. Point out how many did and did not have tonsillitis. Do the same for chickenpox, and allergies.

Those are thought of as children's illnesses.

Alzheimer's disease is a brain disease that older people sometimes get. Just like not everyone here has had the chickenpox, not all older people have Alzheimer's disease.

The difference is you cannot catch Alzheimer's disease from another person. Some people get Alzheimer's disease because others in their family genetically passed it on. This is like when children have the same hair color or eye color as their parents, those traits were passed on from generation to generation.

Some people get Alzheimer's disease because he or she was exposed to a dangerous substance or because he or she had a head injury earlier in life. Scientists are not sure about all the ways this disease starts. We do know, however, that it is not passed on person to person through personal contact. You do not have to worry that you will "catch" it from visiting an older person who has it.

Symptoms

1. Memory problems. The person with Alzheimer's disease may look just like any other older person. But when he or she interacts with others there is a difference. The area of the brain used for storing memories and communication may be damaged by the disease. The individual with Alzheimer's disease can often remember things from long ago, but not things that just happened. Sometimes the person thinks he or she is a child and may want to go to school with you. The best thing to do is simply "go along with what he or she said". Don't try to correct the person or change his or her mind.
2. Repeating questions or movements. The person with Alzheimer's disease forgets what he or she has just done or just said. The person may forget your name and ask you over and over "What is your name". Don't get upset about it. The best thing to do is to wear a big name tag. Sometimes if the person with Alzheimer's is bored or confused about what to do, he or she will repeatedly rub the table or an item of clothing. The best thing to do is give the person something else to think about. Try showing him or her some pictures or a magazine to divert his or her attention.
3. Trying to eat the wrong things. Sometimes people with Alzheimer's disease forget what to do with objects. For example, a person might try to brush his or her teeth with a spoon. Small objects like beads, cubes of water color paint, or dominoes might appear to be a piece of candy or food to the individual with Alzheimer's disease. It is best to use large objects with the person so he or she does not mistakenly try to eat the item. If the older person puts something in his or her mouth that you think might be dangerous, get help from a nursing home staff member right away.
4. Getting lost or not knowing where he or she is. The individual with Alzheimer's disease sometimes wanders and is confused about where he or she is. The person might be looking for "the way home" or to a place from long ago. Walk with him or her and talk about things you are interested in. Point out things you may notice along the way. Show the individual the way back to the activity area or nurses station.
5. Getting loud or upset. People with Alzheimer's disease cannot handle too much noise or confusion. If the room is too crowded with too much noise some people might react by yelling or getting upset. This person might need some quiet time to calm down. The best thing to do is to try to prevent this from happening. Try to focus face-to-face on your resident only. Don't get loud. Try to move slowly, walking is better than running. You might scare the person if you come up quickly from behind or from the side. Call his or her name first and approach the resident from the front whenever possible. Do things one step at a time.

Visiting the nursing home or day center

The older adults in nursing homes and day centers love to have visitors. Most are very lonely. Your visit will probably be the best thing that happened all week. Visiting is hard the first time. The smells and sounds are different than in school or at home. It might seem almost like a hospital, but it is not. Some people will be in wheelchairs, others may not see or hear well. Some might say things that don't make sense. Don't let this worry or scare you. On your second and third visits you will feel more at ease.

Although the resident seems to enjoy your company most of the time, be aware that he or she may not always feel like visiting. Don't take it personally, the resident might not feel well, or might simply be tired. Ask an adult to find you someone else to visit. Sometimes residents might try to give you something that belongs to them. You should not take anything. It is very good to talk to the resident about the object, but be sure you leave it there when you leave.

Residents get upset at times if you introduce something new. Always talk to the person first. Ask, "Have you ever seen one of these?" Whatever the item is, the resident might try to keep it. Be prepared to leave the object with the resident once you introduce it.

Things to do when you visit:

- Bring something with you that you made like a card, a picture, or an art project.
- Talk to the person about his or her family. Ask one question at a time.
- One person only should visit with each nursing home resident. Visit with pets.
- Sing or dance together.
- Play ball games (tethered volleyball, bowling pins down, catch and throw at targets)
- Do arts and crafts projects.
- Go for walks.
- Have a snack together.(Ask a nurse before giving any food or drinks to a resident. Some residents are on special diets.)
- Make a scrapbook, write a story, or read together.
- Arrange flowers.
- Draw or write on a chalkboard or large poster board.
- Make a collage or mural.
- Plant some flowers.
- Play cards, large dominoes, table games.
- Make Simple Pleasures items and bring them to residents. See the Simple Pleasures Manual for things you might like to make and use when you visit.

Visits should last about 30 minutes. People with Alzheimer's disease have short attention spans. Several 30-minute visits spread out over a few weeks will be more beneficial than one or two long visits. Thank you for volunteering to visit these individuals. You will be an important part of their lives.