

# AMBASSADOR PROGRAM



# Appendix

# THE BILL OF RIGHTS

All individuals experiencing memory loss deserve the following rights:

- To be informed of one's diagnosis and to be involved in one's medical plan
- To be productive in work and play as long as possible
- To be treated like an adult and not like a child
- To be able to share and express feelings that are then taken seriously
- To make decisions for him/herself as long as he/she can
- To be a vital part of society just as we always have been
- To have our voice heard
- To be treated with respect and dignity as anyone else
- To have my strengths continue to be recognized
- To be free from psychotropic medications, if possible
- To live in a safe, structured and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including caressing and hand-holding
- To be with individuals who know one's life story, including cultural and religious traditions
- To be cared for by individuals who are well-trained in dementia care



Source: Individuals of Memory Loss, "Forget-Me-Nots" Support Group 2011 The Best Friends Approach to Alzheimer's Care by Virginia Bell and David Troxel, p. 38.

# **COMMUNICATION TOOLS**

## Become a Better Listener:

# **ACTIVE LISTENING**

By JOHN M. GROHOL, PSY.D.

Nost people go through their daily lives engaging in many conversations with friends, co-workers, and our family members. But most of the time, we don't listen as well as we could or sometimes should. We're often distracted by other things in the environment, such as the television, the Internet, our cell phones, or something else. We think we're listening to the other person, but we're really not giving them our full attention.



Enter a skill called "active listening." Active listening is all about building rapport, understanding, and trust. By learning the skills below, you will become a better listener and actually hear what the other person is saying, not just want you think they are saying or what you want to hear. While therapists are often made fun of for engaging in active listening, it is a proven technique that helps people talk and feel free to continue talking even if the person they are talking to doesn't have a lot to offer the other person (other than their ear).

Are you as good a listener as you think you are?

# **13 STEPS TO BETTER ACTIVE LISTENING SKILLS**

Below you will find 13 different skills that help people be better active listeners. You do not have to become adept at each of these skills to be a good active listener, but the more you do, the better you'll be. If you even just use 3 or 4 of these skills, you will find yourself listening and hearing more of what another person is saying to you.

#### 1. Restating

To show you are listening, repeat every so often what you think the person said — not by parroting, but by paraphrasing what you heard in your own words. For example, "Let's see if I'm clear about this..."

#### 2. Summarizing

Bring together the facts and pieces of the problem to check understanding — for example, "So it sounds to me as if . . ." Or, "Is that it?"

#### **3. Minimal encouragers**

Use brief, positive prompts to keep the conversation going and show you are listening — for example, "umm-hmmm," "Oh?" "I understand," "Then?" "And?"

#### 4. Reflecting

Instead of just repeating, reflect the speaker's words in terms of feelings — for example, "This seems really important to you..."

#### 5. Giving feedback

Let the person know what your initial thoughts are on the situation. Share pertinent information, observations, insights, and experiences. Then listen carefully to confirm.

## 6. Emotion labeling

Putting feelings into words will often help a person to see things more objectively. To help the person begin, use "door openers" — for example, "I'm sensing that you're feeling frustrated. . . worried. . . anxious. . ."

#### 7. Probing

Ask questions to draw the person out and get more meaningful information — "What do you think would happen if you. . .?"

#### 8. Validation

Acknowledge the individual's problems, issues, and feelings. Listen openly and with empathy, and respond in an interested way — for example, "I appreciate your willingness to talk about such a difficult issue. . ."

#### 9. Effective pause

Deliberately pause at key points for emphasis. This will tell the person you are saying something that is very important to them.

#### **10. Silence**

Allow for comfortable silences to slow down the exchange. Give a person time to think as well as talk. Silence can also be very helpful in diffusing an unproductive interaction.

#### 11. "I" messages

By using "I" in your statements, you focus on the problem not the person. An I-message lets the person know what you feel and why — for example, "I know you have a lot to say, but I need to. . ."

#### 12. Redirecting

If someone is showing signs of being overly aggressive, agitated, or angry, this is the time to shift the discussion to another topic.

#### 13. Consequences

Part of the feedback may involve talking about the possible consequences of inaction. Take your cues from what the person is saying — for example, "What happened the last time you stopped taking the medicine your doctor prescribed?"



# 7 COMMUNICATION BLOCKERS

These roadblocks to communication can stop communication dead in its tracks:

- 1. "Why" questions. They tend to make people defensive.
- 2. Quick reassurance, saying things like, "Don't worry about that."
- **3.** Advising "I think the best thing for you is to move to assisted living."
- **4.** Digging for information and forcing someone to talk about something they would rather not talk about.
- 5. Patronizing "You poor thing, I know just how you feel."
- **6.** Preaching "You should. . ." Or, "You shouldn't. . ."
- 7. Interrupting Shows you aren't interested in what someone is saying.



# **5 SIMPLE CONVERSATION COURTESIES**

- 1. "Excuse me..."
- 2. "Pardon me...."
- 3. "One moment please..."
- 4. "Let's talk about solutions."
- 5. "May I suggest something?"

# THE ART OF QUESTIONING

The four main types of questions are:

# 1. Leading Questions

For example, "Would you like to talk about it?" "What happened then?" Could you tell me more?"

# 2. Open-ended Questions

Use open-ended questions to expand the discussion — for example, lead with: "How? What? Where? Who? Which?"

# 3. Closed-ended Questions

Use closed ended questions to prompt for specifics — for example, lead with: "Is? Are? Do? Did? Can? Could? Would?"

# 4. Reflective Questions

Can help people understand more about what they said — for example, someone tells you, "I'm worried I won't remember. . . " Reflective Q: "It sounds like you would like some help remembering?"

Source: Grohol, J. (2007). Become a Better Listener: Active Listening. http://psychcentral.com/ lib/2007/become-a-better-listener-active-listening/

> National Aging Information & Referral Support Center



# Self-Review of Active Listening Techniques

| 1. | Do you maintain eye contact?   | □ YES | □ NO |
|----|--|-------|------|
| 2. | Do you try to paraphrase what has been said before you respond?  | □ YES |      |
| 3. | Do you ask questions at the end of the speaker's statement in order to completely understand what has been said?                     | □ YES | □ NO |
| 4. | Do you make an effort to understand the speaker's point of view?   | □ YES |      |
| 5. | Do you give people the opportunity to finish what they are saying before you speak?  | □ YES | □ NO |
| 6. | Do you consciously watch other's body language for additional clues as to how they feel about the topic under discussion?            | □ YES | □ NO |
| 7. | Do you maintain eye contact with the person who is speaking at least 90% of the time?  | □ YES | □ NO |
| 8. | Does your facial expression, posture, and body language indicate your interest in what the speaker is saying?                        | □ YES | □ NO |
| 9. | Do you put aside preconceived opinions to really listen with an open non-judgmental mind?  | □ YES |      |
| 10 | . Do you refrain from offering advice?   | □ YES | □ NO |
| 11 | Do you periodically assess your listening skills by reflecting on your listening strengths and weaknesses?                           | □ YES |      |
| 12 | <ul> <li>Have you created a "warm", confidential, and safe environment<br/>for caregivers to openly share their emotions?</li> </ul> | □ YES | □ NO |
| 13 | . Has trust been developed between you and the person/people to whom you are speaking?   | □ YES | □ NO |

# **Common Dementias Explained**

#### **Overview**

Dementia can be caused by a number of different conditions; it is a symptom of neurodegenerative diseases like Alzheimer's, frontotemporal dementia or corticobasal degeneration. The term "dementia" describes a progressive, degenerative decline in cognitive function that gradually impairs memory and the ability to learn, reason, make judgments, communicate and carry out daily activities. While it often includes memory loss, memory loss by itself does not mean that a person has dementia. Dementia affects more than 50 million people worldwide.

#### Alzheimer's Disease (AD)

Alzheimer's disease is a progressive, degenerative brain disease that slowly erodes memory and thinking skills, and eventually even the ability to carry out simple tasks. It is the most common cause of dementia. Alzheimer's may occur in combination with vascular dementia, or other dementias.

#### Frontotemporal Dementia (FTD)

Frontotemporal dementia is a group of related conditions resulting from the progressive degeneration of the temporal and frontal lobes of the brain. These areas of the brain play a significant role in decision-making, behavioral control, emotion and language. Common forms of FTD:

Primary Progressive Aphasia (PPA)

Is caused by degeneration in the areas of the brain that control speech and language. This type of aphasia begins gradually, with speech or language symptoms that will vary depending on the brain areas affected by the disease.

Progressive Supranuclear Palsy (PSP)

A degenerative disease of the brain leading to difficulties with walking and balance, problems with eye movements, changes in behavior, difficulty with speech and swallowing, and dementia.

Corticobasal Degeneration

A progressive neurological disorder that affects nerve cells that control walking, balance, mobility, vision, speech and swallowing.

Behavioral Variant FTD (bvFTD)

Involves changes in personality, behavior, judgment. Behavior and poor judgment go unnoticed by the individual. Inappropriate and impulsive behaviors are common along with apathy and loss of initiative. Memory generally not affected.

#### Lewy Body Dementias

Lewy body dementias include dementia with Lewy bodies (DLB) and Parkinson's disease with dementia (PDD) and are the second most frequent cause of dementia in elderly adults. Common symptoms include problems with movement, visual hallucinations, and fluctuations in thinking skills or attention.

#### **Mild Cognitive Impairment**

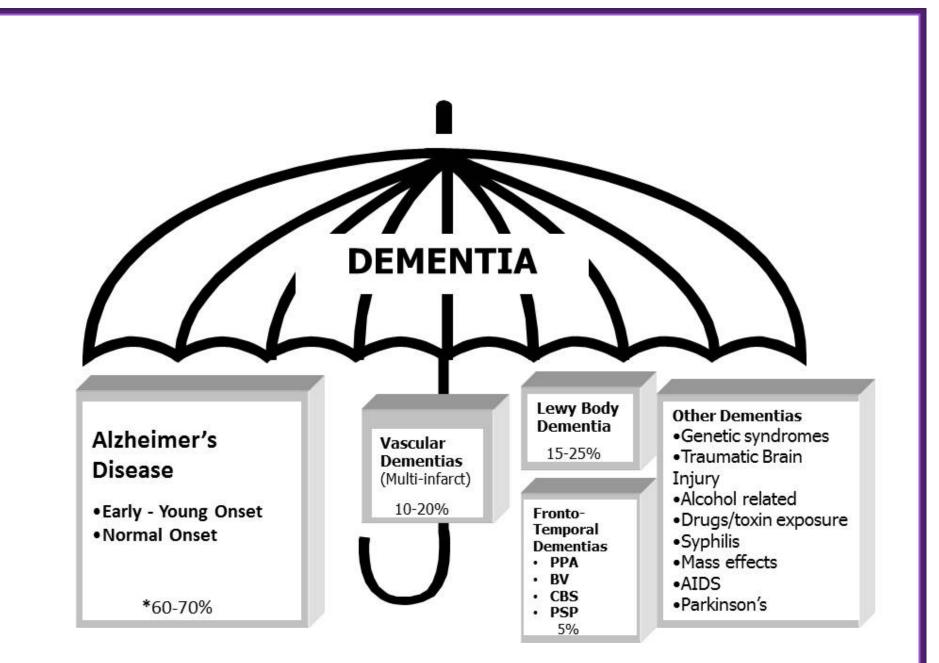
In contrast to Alzheimer's where other cognitive skills are affected, mild cognitive impairment (MCI) is defined by deficits in memory that do not significantly impact daily functioning. Memory problems may be minimal to mild and hardly noticeable to the individual.

#### Vascular Dementia

Vascular dementia is a subtly progressive worsening of memory and other cognitive functions due to chronic, reduced blood flow in the brain, eventually resulting in dementia. Clinically, patients with vascular dementia may look very similar to patients with Alzheimer's, and the two diseases are very difficult to distinguish from each other. Vascular dementia may occur in with Alzheimer's disease.

(http://memory.ucsf.edu/education/diseases)





\*Percentages from D. Kaufer, MD, UNC-CH, Carolina Alzheimers Network, Aug. 2010

## Alzheimer's Disease (AD): What Everybody NEEDS to Know

## What is Dementia?

Dementia is a non-specific term used to describe a person having changes in brain function that interfere with ability to function and do everyday activities.

The person with dementia has problems in multiple areas of brain function. These problems can include; memory, language, impulse control, ability to do things for self, personality, understanding of time, etc.

Common types of dementia include: Alzheimer's disease, vascular dementia, Lewy body dementia, frontal-temporal dementia (FTD) and mixed dementia (more than one type of dementia occurring in the same brain). Different types of dementia impact the brain in different ways, have different symptoms, cause changes in different abilities...in different orders...and at different rates.

## What is Alzheimer's Disease?

Alzheimer's disease is one type of dementia. It is a progressive and terminal disease. The changes typically occur slowly, over months and years, not hours and days.

If the person has a sudden change in health status, living situation or caregiver system (for example, death of a spouse) he or she may APPEAR to change quickly. The brain has actually been changing slowly but since the person was in a routine, the person's abilities weren't being challenged and he or she was relying on OLD patterns and memories to function.

The pattern and progression of the disease is predictable BUT the experience is individual and ultimately, the person's entire life is affected by Alzheimer's disease.

## What are the early signs?

Early signs might include:

- Memory loss of recent events and information
- Confusion about place and time
- Familiar tasks become challenging
- Trouble finding words, finishing thoughts and sentences, following directions
- Decreased reasoning ability and altered judgment
- Changes in mood and personality, frequent mood swings, disinterest or withdrawal, suspicion
- Difficulty with complex mental tasks, planning, problem solving



# How is Dementia Different from Aging and Forgetfulness?

- Aging happens to everyone. Dementia is ALWAYS a disease; it DOESN'T happen to everyone.
- With forgetfulness, new information can be stored; it may take more effort or practice, but new information can "stick". With dementia, new information cannot be predictably retained.
- Forgetful people can use reminders, calendars, lists and to be able to DO. With most dementias, these prompts CANNOT help after the earliest stages.
- Being forgetful makes an independent life *difficult;* having dementia makes independent life *impossible.*

# What is "Normal Aging"?

Normal aging includes:

Being more forgetful

Taking longer to learn new information

Requiring more practice to learn new skills or technologies (you can do it, just have to try harder than you used to)

Having more trouble recalling people's names (more than you used to have)

Knowing the word you want but hesitating, eventually finding the word (more often than you used to)

## Diagnosis makes a difference!

Early diagnosis is important and accurate diagnosis is critical!

Why?

- 1. Early treatment is more effective than waiting.
- 2. Early and accurate diagnosis allows for *better* planning and opportunity to *include* the person with dementia in the process. Planning makes a difference in options the person may have as the disease leads to changes in abilities and needs.

How is Alzheimer's disease diagnosed?

Diagnosis is complicated and includes gathering lots of information, including:

- 1. History of the changes
- 2. Health history
- 3. Medication review
- 4. Physical exam (especially focusing on neurological and cardiovascular systems)
- 5. Laboratory studies
- 6. Imaging study of the brain (MRI, CT, PET)
- 7. Cognitive assessment (what's working well and what's not working well)
- 8. Emotional assessment
- 9. Other tests (ECG, EEG etc. as indicated)



# What is Normal and What is Not?

#### Normal Aging Changes:

- Slower to think
- Slower to do
- Hesitates more
- More likely to 'look before you leap'
- Know the person but not the name
- Pause to find words
- · Reminded of the past
- For you, it's harder than before...
- Prompts help! (reminders)
- You can learn NEW Things It takes longer!

#### Not Normal Aging Changes:

- Can't think the same
- Can't do like before
- Can't get started
- Can't seem to move on
- Doesn't think it out at all
- Can't place the person
- Words won't come even later
- Confused about past versus now
- For you it's TOTALLY DIFFERENT
- Reminders DON'T Help!
- You can't hold onto NEW stuff

## **Ten Warning Signs:**

- 1 memory loss for recent or new information repeats self frequently
- 2 difficulty doing familiar, but difficult tasks managing money, medications, driving
- 3 problems with word finding, mis-naming, or mis-understanding
- 4 getting confused about time or place getting lost while driving, missing several appointments
- 5 worsening judgment not thinking thing through like before
- 6 difficulty problem solving or reasoning
- 7 misplacing things putting them in 'odd places'
- 8 changes in mood or behavior
- 9 changes in typical personality
- 10 loss of initiation withdraws from normal patterns of activities and interests

## What Could It Be... It Might NOT be Dementia

- Worsening of another medical condition
- Medication side-effect
- Undetected hearing loss or vision loss
- Depression
- Acute illness
- Untreated emotional or physical pain
- Other things...

# SO... Get it CHECKED OUT ... Carefully & Thoroughly

# What is Dementia?

- It is NOT part of normal aging! It is a disease!
- It is more than just forgetfulness which is part of normal aging
- It makes independent life impossible

#### Dementia

- is an umbrella term that includes many cognitive loss conditions
- includes some reversible conditions so should be checked out carefully

#### Alzheimer's Disease -

- is the most common type of dementia
- is caused by damage to nerves in the brain and their eventual death
- has an expected progression with individual variations about 8-12 years
- will get worse over time we can't stop it!
- is a terminal disease there is NO known cure at this time!

#### Vascular Dementia (Multi-Infarct) -

- is caused by damage to the *blood supply* to the nerves in the brain
- is spotty and *not* predictable
- may not change in severity for long periods, then there are sudden changes

#### Lewy Body Dementia -

- problems with movement falls & stiffness
- visual hallucinations & nightmares
- fluctuations in performance day/day

#### Symptoms Common to Most Dementias... Over time...

- It affects a person's entire life...It causes the brain to shrink & stop working
- It steals memories the most recent first, but eventually almost all...
- It steals your ability to use language ... leaves you with some 'skills'
- It steals your ability to understand what others mean & say
- It steals reasoning and logic
- It robs you of relationships
- It makes even the 'familiar' seem odd and scary
- It steals your ability to care for yourself and move around safely
- It robs you of impulse control takes away emotional and mood control

#### **Drug Treatment for Alzheimer's**

- Drugs to improve chemicals in the brain so nerve activity might happen
- Drugs to treat depression
- Drugs to control distressing hallucinations, severe paranoia, or unprovoked violence
- No vaccines or cures...yet
- No way to stop the disease...yet

#### Prevention -

- Have a good family history for staying alert and 'with it' – genetics do play a part
- Eat healthy & moderately (Heart-Smart)
- Exercise your body --- 100 minutes/wk \*\*\*
- Exercise your brain --- challenge yourself
- Eat fish --- 1 time a week
- Control your BP & sugar & weight
- \*\* consult your MD first

of normal aging e loss conditions be checked out carefully

**Frontal-Temporal Dementias -**

Difficulty with word finding

Problem behaviors – poor impulse control

• Rapid changes in feelings and behaviors



# Interacting with Someone Living with Dementia

- 1. **Knock** on door or table to get attention signal your approach
- 2. **Stop moving** at the boundary between public & personal space 6 ft out get permission to enter or approach
- 3. **Open hand motion near face and smile** look friendly and give the person a visual cue make eye contact open hand near face –cues eyes to look there
- 4. Call the person by preferred **name** OR at least say "Hi!" avoid endearments
- 5. Move your hand out from near your face to a greeting **handshake** position make sure they notice you hand out to shake then stand tall and move forward SLOWLY
- 6. Approach the person from the **front** come in within 45 degrees of center visual
- 7. **Move slowly** one step/second, stand tall, don't crouch down or lean in as you move toward the person
- 8. Move toward the right **side of the person** and offer your hand give the person time to look at your hand and reach for it, if s/he is doing something else offer, don't force
- 9. Stand to the side of the person at arm's length respect intimate space & be supportive not confrontational but don't go too far back' stay to the front visual
- 10. Shake hands with the person make eye contact while shaking
- 11. Slide your hand from a 'shake' position to **hand-under-hand** position for safety, connection, and function
- 12. Give your name & greet "I'm (name). It's good to see you!"
- 13. **Get to the person's level** to talk sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
- 14. NOW, deliver your message...

#### Approaching When the Person is DISTRESSED! -Some CHANGES -

- 1. Look concerned not too happy, if the person is upset
- 2. Let the person move toward you, keeping your body turned to the side (supportive not confrontational) –
- 3. *If the person is* seated & you DON'T get permission to enter personal space turn sideways & kneel at 6' out offer greeting & handshake again look for an OK to come into their personal space it will usually come at this time (submissive posture)
- 4. After greeting... try one of *two* options...
  - a. "Sounds like you are (give an emotion or feeling that seems to be true)???"
  - b. Repeat the person's words to you... If s/he said, "Where's my mom?" you would say "You're looking for your mom (pause)... tell me about your mom..." If the person said "I want to go home!", you would say "You want to go home (pause)... Tell me about your home...".

#### **BASIC CARD CUES – WITH Dementia**

- Knock Announce self
- Greet & Smile
- Move Slowly Hand offered in 'handshake' position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly -make a 'nice' comment or smile
  - Give your message... simple, short, friendly



# **Communicating - Talking**

#### First -

ALWAYS use the positive physical approach!

#### Then -

- Pay attention to the **THREE** ways you communicate
- 1 How you speak
  - **Tone** of voice (**friendly** *not* bossy or critical)
  - Pitch of voice (deep is better)
  - Speed of speech ( slow and easy not pressured or fast)

#### 2 - What you say

- THREE basic reasons to talk to someone
- 1 To get the person to DO something (5 approaches to try)
  - 1 give a short, direct message about what is happening
  - 2 give simple choices about what the person can do
  - 3 ask the person to help you do something
  - 4 ask if the person will give it a try
  - 5 break down the task give it one step at a time
  - step at a time
  - \*\* only ask "*Are you ready to…*" If you are willing to come back later \*\*

# 2 - Just to have a *friendly interaction* - to talk to the person

- go slow Go with Flow
- acknowledge emotions "sounds like..., seems like..., I can see you are..."
- use familiar words or phrases (what the person uses)
- know who the person has been as a person what s/he values
- use familiar objects, pictures, actions to help & direct
- be prepared to have the same conversation over & over
- look interested & friendly
- be prepared for some emotional outbursts
- DON'T argue... BUT don't let the person get into dangerous situations
- REMEMBER the person is doing the BEST that s/he can

AND GO with the FLOW!

- 3 Deal with the person's distress or frustration/anger
  - Try to figure out what the person really *NEEDS or WANTS*
    - ("It sounds like..." "It looks like..." "It seems like..." "You're feeling...")

- Use empathy not forced reality or lying
- Once the person is listening and responding to you THEN -
  - Redirect his attention and actions to something that is OK OR
  - Distract him with other things or activities you know he likes & values

#### Always BE CAREFUL about personal space and touch with the person especially when s/he is distressed or being forceful

- 3 How you respond to the person
  - use positive, friendly approval or praise (short, specific and sincere)
  - offer your thanks and appreciation for his/her efforts
  - laugh with him/her & appreciate attempts at humor & friendliness
  - shake hands to start and end an interaction
  - use touch hugging, hand holding, comforting only IF the person wants it

#### If what you are doing is NOT working -

- STOP!
  - BACK OFF give the person some space and time
    - Decide on what to do
      - differently...
        - Try Again!

#### Key Points About 'Who' the person Is....

- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a 'detail' or a 'big picture' person
- work history favorite and most hated jobs or parts of jobs
- family relationships and history feelings about various family members
- social history memberships and relationships to friends and groups
- leisure background favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs dislike of music or songs
- hot buttons & stressors
- behavior under stress
   what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful



# **#DA-NCBetterBrainHealth**





# CONNECT WITH US!



O'

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@DementiaAllianceofNC

# WHAT IS BETTER BRAIN HEALTH?

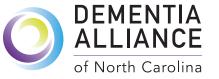


Dementia starts with small, unnoticeable changes in the brain that can begin 20 years or more before symptoms appear. While there is no cure in sight, there is strong evidence that you can potentially prevent or reverse those changes by taking steps towards better health today:

**EAT WELL** focusing on vegetables, fruits and lean protein, particularly protein sources containing omega-3 fatty acids.

**HEALTHY HEART** lifestyle to reduce vascular risk factors, high blood pressure, high cholesterol and diabetes.

**STRESS LESS** to calm blood pressure, lower cortisol levels and maintain positive mental health.



**MOVE MORE** every day including some aerobic exercise

**SLEEP WELL** to aid your body in flushing toxic beta-amyloid proteins from the brain

**STAY SOCIAL** and engaged with family, friends & community.

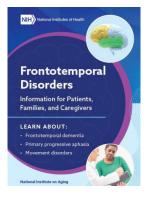
**KEEP LEARNING** and developing cognitive skills throughout entire lifetime

9131 ANSON WAY, SUITE 206 RALEIGH, NC 27615 919.919.832.3732 WWW.DEMENTIANC.ORG

# **ADDITIONAL DEMENTIA RESOURCES:**

A wide variety of booklets, fact sheets and videos are available from National Institute of Health at: https://order.nia.nih.gov/view-all-alzhemer-pubs

Below are a few booklets that are great to have on hand:



Frontotemporal **Disorders:** Information for Patients, Families & Caregivers

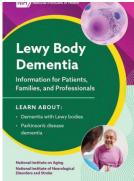
https://order.nia.nih.gov/ publication/frontotemporal-disorders-information-for-patients



**Caring for a Person With Alzheimer's Disease** 

## Caring for a Person with Alzheimer's Disease

https://order.nia.nih.gov/ publication/caring-for-aperson-with-alzheimersdisease-your-easy-to-usequide



THE DEMENTIAS

Hope Through Research

LEARN ABOUT

## Lewy Body Dementia: Information for Patients, Families, and Professionals

https://order.nia. nih.gov/publication/ lewy-body-dementia-information-for-patients-families-and-professionals



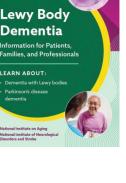
## Legal and Financial Planning for People Living With Dementia

https://order.nia.nih.gov/ publication/legal-and-financial-planning-for-people-living-with-dementia

provided by



9131 Anson Way, Ste. 206, Raleigh, NC 27615 (919) 832-3732 www.DementiaNC.org



#### The Dementias: Hope Through Research

https://order.nia.nih.gov/ publication/the-dementias-hope-through-research

# **ADDITIONAL DEMENTIA RESOURCES:**



## www.lbda.org

LBD Caregiver Link: 800.539.9767

The Lewy Body Dementia Association (LBDA) is a 501(c)(3) nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. The Association's purposes are charitable, educational, and scientific.

Our Vision: A cure for Lewy body dementias and quality support for those still living with the disease.

Our Mission: Through outreach, education and research, we support those affected by Lewy body dementias.

History: LBDA was formed by a group of caregivers who met in an online LBD caregiver support group. Discussions about the need of support for LBD caregivers and the lack of public awareness about LBD led to the organization's incorporation. The directors of the LBDA Board are located throughout the United States, and LBDA volunteers are from the United States, Canada, and the United Kingdom. The association consists of a dedicated group of people from all walks of life who understand the struggles of other caregivers due to their personal LBD experiences.



The Association for Frontotemporal Degeneration Opening the gateway to help and a cure

# www.theaftd.org

866-507-7222 (toll free/ Helpline)

We envision a world where FTD (frontotemporal degeneration) is understood, effectively diagnosed, treated, cured and ultimately prevented.

Our mission is to:

- Promote and fund research into finding the cause, therapies and cures for FTD (frontotemporal degeneration)
- Provide information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers
- Educate physicians and allied health professionals about frontotemporal degeneration and how to improve patient care
- Bring about greater public awareness of the nature and prevalence of frontotemporal degeneration and the needs of those who are coping with it
- Advocate with public officials and promote public and private programs that provide appropriate, affordable and high-quality, long-term health care and social services
- Facilitate the international exchange of ideas.

provided by



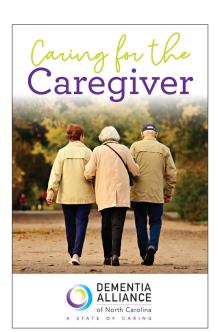
9131 Anson Way, Ste. 206, Raleigh, NC 27615 (919) 832-3732 **www.DementiaNC.org** 



A STATE OF CARING

# It is Our Mission to Provide FREE Materials & Resources for Patients in Your Practice.

Simple fill out the form on the reverse side and mail back to us. Allow 2-3 weeks to receive your materials.



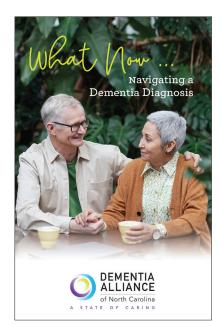
Caring for the Caregiver, 8 page booklet focused on self-care for caregivers.

| The Ten Ab             | solutes o | f   |
|------------------------|-----------|---|
| Caregi                 | vin       | J   |
| NEVER ARGUE            | INSTEAD   | Agree                                     |
| NEVER REASON           | INSTEAD   | Divert                                    |
| NEVER SHAME            | INSTEAD   | Distract                                  |
| NEVER LECTURE          | INSTEAD   | Reassure                                  |
| NEVER SAY "REMEMBER?"  | INSTEAD   | Reminisce                                 |
| NEVER SAY "I TOLD YOU" | INSTEAD   | Repeat<br>& Regroup                       |
| NEVER SAY "YOU CAN'T"  | INSTEAD   | Find out what<br>they CAN do              |
| NEVER COMMAND, DEMAND  | INSTEAD   | Ask & Model                               |
| NEVER CONDESCEND       | INSTEAD   | Encourage<br>& Praise                     |
| NEVER FORCE            | INSTEAD   | Reinforce                                 |
| www.DementiaNC.org     |           | DEMENTIA<br>ALLIANCE<br>of North Carolina |
|                        | A STAT    | C CI CARINO                               |

Ten Absolutes, 2 sided information card.



Is There a Problem?, 8 page booklet comparing dementia to normal aging.



What Now ..., 8 page booklet for those newly diagnosed with dementia.



Connect Card, Pocket size, laminated card with helpful tips.



Individual Memory Loss Cards, Business card sized,



Companion Memory Loss Cards, Business card sized,



# Educational Materials Reorder Form

TITLE

 $\Box 10 \Box 25 \Box 50$ 

10 25 50

□ 10 □ 25 □ 50

You can also reorder materials online at www.dementianc.org/orderform

Please print clearly:

PRACTICE NAME

CONTACT NAME

STREET ADDRESS

CITY

**EMAIL** 

STATE

ZIP

PHONE

| Check both material and quantity requ                  | lested:  |
|--|----------|
| Please call if you need larger quantities for a specie | al event |

 $\Box$  Caring for the Caregiver Booklets

□ Is There a Problem? Booklets

What's Next ... Booklets

Ten Absolutes Cards

Connect Cards

Individual Memory Loss Cards

Companion Memory Loss Cards

Mail completed form to: Dementia Alliance of North Carolina 9131 Anson Way, Suite 206 Raleigh, NC 27615

Or Call Us at: 919-832-3732

You can also reorder materials online at www.dementianc.org/orderform



# **FEEDBACK & EVALUATION**

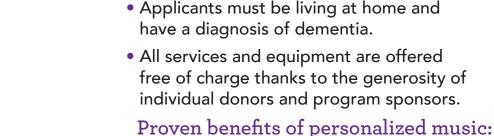
| 1. Ho     | w would y                 | ou rate this | s event over  | all?           |         |                    |
|-----------|---------------------------|--------------|---------------|----------------|---------|--------------------|
|           | 🗌 Poor                    | 🗌 Fair       | Good          | Great          | 🗆 Ex    | cellent            |
| 2. Di     | d this even               | it meet you  | r expectatio  | ns?            |         |                    |
|           | □ Yes                     | 🗆 No         |               |                |         |                    |
|           | Other (ple                | ease specify | /):           |                |         |                    |
| 3. W      | ould you re               | ecommend     | this event to | o others?      |         |                    |
|           | □ Yes                     | 🗌 No         |               |                |         |                    |
| Comments: |                           |              |               |                |         |                    |
|           |                           |              |               |                |         |                    |
| 4. My     | y understar               | nding of thi | s topic is no | w:             |         |                    |
|           | 🗆 Not imp                 | oroved       | □ Somew       | hat improve    | ed      | □ Greatly improved |
| 5. W      | hat areas w               | vere the mo  | ost helpful d | uring this tra | aining? | ,                  |
|           |                           |              |               |                |         |                    |
|           |                           |              |               |                |         |                    |
| 6. W      | hat areas n               | eed more t   | ime or furth  | er explanati   | ion?    |                    |
|           |                           |              |               |                |         |                    |
|           | e there any<br>en include | •            | didn't touch  | n on that yo   | u would | d liked to have    |

# What is MUSIC & MEMORY AT HOME?









# IMPROVED:

Health & Wellbeing Mood Quality of Life

# **REDUCED:**

Depression Agitation & Anxiety Rejection of Care

# When you can use personalized music?

**Music & Memory at Home** is a unique program for North Carolinians living with dementia to find renewed joy, wellbeing and connection

through access to musical favorites.

- Around mealtime
- Before bathing
- Before appointments
- Before family visits
- Before bed time
- Dance Party!
- Instead of TV
- On walks
- Hospice
- When traveling

# **INTERESTED?**

Visit: www.DementiaNC.org/Music Email: musicandmemory@dementianc.org Call: (919) 832-3732

# What is involved:

- 1. Complete an application form
- 2. Music detectives create a draft playlist
- 3. Zoom music listening party
- 4. You receive playlist, equipment & tech support

Presented by



Sponsored by



| Dementia Alliance o<br>Music and Memory a  |                 | pplication                           |  |  |
|--|-----------------|--------------------------------------|--|--|
| Program Listener (name of person living with dementia):  |                 |                                      |  |  |
| Caregiver Applicant Name:  |                 |                                      |  |  |
| <b>Does the caregiver live in the</b> and the second se | same household  | as the program listener?             |  |  |
| What is the relationship betwe   | en the caregive | r and program listener:              |  |  |
| □spouse/partner □parent □i   | n-law ∏sibling  | □friend □other                       |  |  |
| Caregiver phone:   |                 | Caregiver email address:             |  |  |
| Mailing Address for Kit:   |                 |                                      |  |  |
| Town/City:   | Zip:            | County:                              |  |  |
| Program listener's date of birt  | h:/             | /                                    |  |  |
| <b>Please list any known places o</b><br>Example: Childhood - Greens   |                 | n childhood through early adulthood: |  |  |
| Race & Ethnicity (check all that   | apply)          |                                      |  |  |
| Black / African-American   |                 | n 🗌 White 🔲 Asian<br>Other           |  |  |
| Native Language(s) if other the  | an English:     |                                      |  |  |
| <b>Dementia Diagnosis</b> (check all t<br>Alzheimer's Dementia<br>Other  | ]Lewy Body      |                                      |  |  |
| Estimated Year of Diagnosis (N   | /Ionth, Year)   |                                      |  |  |
| Other Medical Conditions (list)  |                 |                                      |  |  |

#### Please answer the following questions and check N/A for any that do not apply:

Did the program listener enjoy singing, perform in singing groups or at religious services? (Please specify denomination) \_\_\_\_\_

Did the program listener play a musical instrument either solo or as part of a band? What kind of music did they perform (orchestral, marching band, jazz, rock 'n roll etc)?

Did the program listener enjoy dancing? Did they ever perform in public or frequent social dances?

Does the program listener have any military history (Branch, Dates of Service and Location)?

What to expect next: After receiving this application, our team will create a draft playlist of 80-100 songs for inclusion in your music kit. Our playlists are focused on the artists/favorite tunes you will list on pages 3-4 as well as others our "music detectives" imagine your loved one may have enjoyed around the ages 10 to 30. This is a time of life known as the "reminiscence bump" where neural activity is strongest and musical favorites are more deeply felt by people living with dementia.

Next, we will reach out to schedule a one-hour virtual "music party" to fine-tune your playlist based on your loved one's reactions to our selections. If a zoom meeting is not possible for your family, we can arrange for an in-person listening session instead.

Once the final playlist is determined, we will load it onto a digital mp3 player and ship it to your home along with high-quality headphones and a bluetooth speaker. This will allow you to share music with your loved one as well as offer them the solitary pleasure of enjoying it on their own.

Thank you for joining us to bring the unique and therapeutic joy of personalized music into the lives of people living with dementia. We are grateful to the many donors and sponsors who make this program free of charge for residents of North Carolina.

#### **Caregiver Consent**

I, as the caregiver, grant permission to Dementia Alliance of NC the use of photographs, videos and any feedback I share with program staff, for presentation under any legal condition, including but not limited to: publicity, copyright, illustration, advertising, web content and research.

Printed Name (First and Last)

**Return by Email:** musicandmemory@DementiaNC.org Subject Line: Music and Memory Application Signature

Date

**Return by Mail:** Dementia Alliance of North Carolina 9131 Anson Way, Suite 206 Raleigh, NC 27615

ΠN/A

ΠN/A

ΠN/A

□N/A



# Music & Memory at Home

**TOP 10 SONGS:** Please list specific song names with artists, if known. Focus on the music recipient's all-time favorite songs. If there are any "must have" songs, this is the place to let us know! Do not list genres here, instead use the genre listing to the right >

#### Example:

10.

✓ O Sole Mio by Pavarotti

#### **✗** Italian Music

| 1 |  |
|---|--|
| 2 |  |
| 3 |  |
| 4 |  |
| 5 |  |
| 6 |  |
| 7 |  |
| 8 |  |
| 9 |  |
|   |  |

**FAVORITE ARTISTS OR GENRES:** Select up to 15 artists from the list below who the Music Recipient was a big fan of, especially between the ages of 10-30. If you are unsure of specific preferences, or the recipient loves a particular genre, select O Mix.

# Country 50s

- O Chet Atkins
- O Faron Young
- O George Jones O Hank Williams
- O Jim Reeves
- O Johnny Cash
- O Kitty Wells
- O Marty Robbins
- O Patsy Cline
- O Patti Page
- O Ray Price
- O Mix

#### Country 60s

- O Buck Owens
- O Conway Twitty
- O Glen Campbell
- O Loretta Lynn
- O Merle Haggard
- O Roger Miller
- O Tammy Wynette

# O Mix

- Country 70s O Charley Pride O Dolly Parton O Emmylou Harris O Hank Williams Jr. O Kenny Rogers O Waylon Jennings
- O Willie Nelson O Mix

## Country 80s

- O Alabama
- O Randy Travis
- O Reba McEntire

#### O Mix Pop 40s

- O Bing Crosby
  O Frank Sinatra
  O Judy Garland
  O Mills Brothers
  O Perry Como
  O Vaughn Monre
- O Vaughn Monroe O Mix

## Pop 50s

- O Bobby Darin
- O Connie Francis
- O Dean Martin
- O Doris Day O Edith Piaf
- O Jim Reeves
- O Johnny Mathis
- O Kingston Trio

- O Nat King Cole
- O Rosemary Clooney
- O Tony Bennett
- O Mix

#### Pop 60s

- O Andy Willaims
- O Barbara Streisand
- O Bobby Vinton
- O Burt Bacharach
- O Dionne Warwick
- O Englebert Humperdinck
- O Jimmy Roselli
- O Joni Mitchell
- O Judy Collins
- O Righteous Brothers
- O Simon & Garfunkel
- O The 5th Dimension
- O The Monkees
- O Tom Jones
- 0 Mix

## Pop 70s

## O ABBA

- O Carly Simon
- O Carole King
- O Gordon Lightfoot
- O Jackson 5
- O James Taylor
- O Jim Croce
- O Jimmy Buffet
- O John Denver
- O Neil Diamond
- O Paul Simon
- O Rod Stewart
- O The Carpenters

#### O Mix Pop 80s

- O Billy Joel
- O Gloria Estefan
- O Kenny G
- O Lionel Ritchie
- O Michael Jackson
- O Rick Astley
- O Whitney Houston O Mix

#### Rock 50s

- O Bill Haley
- O Buddy Holly
- O Chuck Berry
- O Elvis Presley
- O Everly Brothers
- O Fats Domino
- O Jackie Wilson

TURN OVER FOR MORE MUSIC SELECTION POSSIBILITIES

- O James Brown
- O Little Richard
- O Ritchie Valens
- O Sam CookeO The DriftersO The Platters

O Beach Boys

O Mix

Rock 60s

O Beatles

O Bee Gees

O Bob Dylan

O Eric Clapton

O Frankie Valli/

Four Seasons

O Jerry Lee Lewis

O Linda Ronstadt

O Mamas & Papas

Underground

O Bruce Springsteen

O Doobie Brothers

O Fleetwood Mac

O John Lennon

O Led Zeppelin

O Pink Floyd

O Tom Petty

O Air Supply

O Bon Jovi

O Mix

Rock 80s

O Queen

O Lynyrd Skynyrd

○ Steve Miller Band

O Three Dog Night

O The Allman Brothers

O Rolling Stones

O Roy Orbison

O The Band

O Mix

Rock 70s

O Boston

O Chicago

O Eagles

O Heart

∩ David Bowie

O Elton John

O Bread

O Aerosmith

O Bob Segar

O The Velvet

O Chubby Checker

O Crosby, Stills, Nash

O Creedence Clearwater

#### Rock 80s cont.

- O Daryl Hall & John Oates
- O Dire Straits
- O The Cars
- O ZZ Tops
- O Mix

#### Folk

- O Bob Dylan
- O Clancy Brothers
- O Doc Watson
- O Irish Rovers
- O Joan Baez
- O Pete Seeger
- O Peter, Paul, & Mary O Mix

## R&B/Soul

- O Aaron Neville
- O Al Green
- O Aretha Franklin
- O Barry White
- O Ben E King
- O Commodores
- O Diana Ross
- O Four Tops
- O Gladys Knight
- O Lou Rawls
- O Martha Reeves
- O Marvin Gaye
- O O'Jays
- O Otis Redding
- O Percy Sledge
- O Ray Charles
- O Smokey Robinson
- O Stevie Wonder
- O The Temptations
- O Mix

#### Latin

- O Celia Cruz
- O El Gran Combo de Puerto Rico
- O Javier Solis
- O Julio Iglesias
- O Leo Dan
- O Los Panchos
- O Roberto Carlos
- O Tito Puente
- O Willie Colon
- O Mix

#### Blues/Reggae

- O B.B. King
- O Bob Marley
- O Muddy Waters
- O Mix

#### Gospel/Hymns

- O Alan Jackson
- O Albertina Walker
- O Andrae Crouch
- O Aretha Franklin
- O Bill & Gloria Gaithers
- O CeCe Winans
- O Edwin Hawkins Singers

- O Elvis Presley
- O George Beverly Shea
- O Mahalia Jackson
- O Mormon Tabernacle

**Big Bands/Swing** 

O Cab Calloway

O Duke Elington

O Lawrence Welk

O Tommy Dorsey

O Count Basie

O Glenn Miller

O Mix

Classical

O Chopin

O Handel

O Haydn

O Mahler

O Mozart

O Vivaldi

O Mix

Opera

O Mix

Disco

O Schumann

O Yo-Yo Ma

O Tchaikovsky

O Beethoven

O Boston Pops

O Leonard Bernstein

O Vladimir Horowitz

O Andrea Bocelli

O Barry White

O Donna Summer

O Earth, Wind & Fire

Sunshine Band

O Kool & the Gang

O Chairmen of the Board

O Village People

O The Embers

O Bee Gees

O KC & the

O Mix

Beach

O Mix

O Luciano Pavarotti

O The Three Tenors

O Bach

O Benny Goodman

O Artie Shaw

**MULTICULTURAL & OTHER** 

from many cultures, religions,

**GENRES:** We have music

languages, and decades

most requests.

entire form).

Wedding Song:

Favorite TV/Movie

Memorable Concerts:

**OTHER MIXES:** 

entire form).

(specify additional genres,

not exceeding 3 on the

Theme Songs:

in our library and can fulfill

**OTHER ARTISTS:** If there

recipient is a fan of other

form, please list them here

than those listed on this

(not to exceed 15 on the

are any artists that the music

- Choir O Pandy Tra
- O Randy Travis
- O Rev James Cleverland
- O Shirley Caesar
- O The Canton Spirituals
- O The Cathedrals O The Williams Brothers
- O Walter Hawkins
- O Zion Harmonizers
- O Zion Harmoniz O Mix

#### Jazz Vocal

- O Billie Holiday
- O Dinah Washington
- O Ella Fitzgerald
- O Etta James
- O Julie London
- O Louis Armstrong
- O Nancy Wilson
- O Nat King Cole
- O Nina Simone
- O Pearl Bailey
- O Sarah Vaughan
- O The Ink Spots
- O Mix

#### Jazz Instrumental

- O Art Tatum
- O Charlie Parker
- O Dizzy Gillespie
- O Gene Krupa
  - O George Shearing
  - O Herb Alpert
  - O Herbie Mann
  - O John Coltrane
  - John Coltrane
  - O Lionel Hampton
  - O Miles Davis

O Mix

O Cats

O Grease

O Guys & Dolls

O Les Miserables

O Mary Poppins

O Sound of Music

O South Pacific

O The King and I

O The Music Man

O Westside Story

O My Fair Lady

O Oklahoma

O Pippin

O Mix

O Camelot

O Quincy Jones O Thelonious Monk

**Broadway/Movies** 

O Fiddler on the Roof

O Phantom of the Opera



# **Emergency Contact Form**

| Participants Name:                |  |
|-----------------------------------|--|
| Emergency Contact's Name:         |  |
| Relationship to Participant:      |  |
| Emergency Contact's Phone Number: |  |
| Emergency Contact's Address:      |  |
|                                   |  |

**Notes:** Please list allergies and other medical conditions: