

A HANDBOOK FOR ADULTS WITH MEMORY PROBLEMS OR DEMENTIA

STEP 1: UNDERSTANDING HOW YOUR MEMORY WORKS

Memory problems are a common complaint in older persons. The brain has two kinds of memory – recent and remote. Recent memory includes facts or events that occurred within several hours, while remote (old) memory stores facts or events from the distant past, for example, college memories, high school memories, etc. Your brain works like a PC (personal computer). Your recent memory is like the computer workstation while remote or old memory is like the hard disk. The brain remembers facts or events by loading them into recent memory, a part of the brain like a workstation on your computer. Then your brain moves them to old memory, like the hard disk. Unimportant information is not stored. Your hard disk becomes saturated somewhere around 40 to 60 years of age and after 60 it becomes slightly more difficult to hold on to facts or events.

Scientists recognize four general types of memory states for older people: 1) good as new, 2) good as almost new, 3) mild impairment, and 4) dementia. “Good as new” means that you can remember things as well as when you were 20 or 30 years of age. “Good as almost new” means that it’s harder to remember large amounts of new information but you can still commit normal amounts of information to memory. Mild impairment, sometimes called mild cognitive impairment, means that your memory is impaired to the point where you have difficulty, but you do not have other evidence of dementia. Dementia means that memory is lost and other intellectual functions are also damaged, for example, communication, motor skills. Dementia will disrupt your normal life.

STEP 2: UNDERSTANDING THE DIFFERENT TYPES OF MEMORY PROBLEMS

Some older people are “good as new” but many older people will complain that their memory requires more work than when they were 20 or 30, or “good as almost new”. “Good as almost new” takes longer to memorize large amounts of new information. This increased memory effort is a normal part of aging and is not considered part of dementia. Mild cognitive impairment means that a person has a specific memory problem that affects their everyday life and requires special interventions, for example, memory books, frequent reminders, etc. Dementia means that a person is seriously impaired. A good example of each type of memory problem is a trip to the store. A normal, young person can be given a list of 15 items and go to the store where they remember 14 items. A “good as new” memory will function the same way. A “good as almost new” memory may come back with 10 or 11 items and the person is upset that they cannot remember the last 3 or 4 items. A mild, cognitive impairment person would go to the store and get 2 or 3 items or no items or may have trouble remembering where the store is located. A demented person may not be able to find the store or remember why they were in the parking lot of the store.

STEP 3. WHAT IF I HAVE FAMILY MEMBERS WITH DEMENTIA? WHAT IS THE ROLE OF GENETICS?

Genetics refer to human genes that control all aspects of our body and life. Genes are highly complex proteins and each human being has a unique set of genes. Genes can wear out over time. Genetic disorders mean that a person inherits the disease from one or more relatives. Every cell in the human body has a complete set of genes.

Genes can cause body malfunction by producing defective proteins or by interacting with other health conditions to cause disease. Some genetic causes of dementia, like Huntington's disease, are almost always unavoidable when the gene is present. Other genetic disorders are more complex and cause disease when certain other health problems occur in middle or later life.

A small number of persons with Alzheimer's disease (2% or less) have genes that destine them to develop dementia. This gene causes intellectual loss early in life.

Most people develop dementia in later life. Late onset dementia has certain genes that maybe risk factors for developing intellectual loss; however, some people may not get the disease even if they have some of the "risk" genes. The gene for the protein APOE is considered a risk gene for dementia and the presence of "high risk" APOE (APOE 4) may cause a person to develop intellectual loss 10 years before their brain will show this change under normal circumstances.

Genes may account for between one-third and two-thirds of risk factors for older people. This fact means that environment and life choices may also account for one-third to two-thirds of dementia.

Genes are very complicated parts of the human brain cells and scientists presently lack the ability to repair broken genes. While scientists study ways to fix damaged genes, people can work on other risk factors that may work with genes to reduce the risk of Alzheimer's disease. Certain kinds of dementia, such as alcohol-induced dementia and vascular dementia, probably have no significant genetic risk.

STEP 4: WHAT CAN BE DONE?

All new clinical research shows that early intervention for dementia will significantly slow the loss of memories. Any person over the age of 65, who believes that they are suffering from memory problems, should have an evaluation by a doctor. A dementia evaluation must be conducted by someone who is trained to assess intellectual function, for example, geriatrician, psychiatrist, neurologist, neuropsychologist, or other professionals with specific training in the early recognition and diagnosis of dementia. Early dementia cannot be diagnosed with a brain scan such as MRI or blood test. Mild cognitive impairment and early dementia require a careful evaluation by a specialist that takes about one hour of the doctor's time.

Persons with evidence of dementia should receive appropriate therapy. People with mild memory impairment may choose to take medication that slow memory loss. People with simple memory complaints, i.e., “good as almost new”, need follow-up evaluations but no therapy. People with normal intellect do not need any investigation, but rather congratulation for holding on to their youth-like intellectual vitality. Present medical technology that is available to patients cannot predict the early onset of dementia; however, specialized scanning, i.e., PET scans, probably predict risks for dementia in some groups of at-risk individuals. A specialist can advise you on the availability and wisdom of seeking a PET scan. Most people should not have PET studies; however, some high-risk individuals may be candidates for PET scans.

BASIC FACTS ABOUT DEMENTIA

WHAT IS THE MEANING OF DEMENTIA?

Dementia is the loss of multiple intellectual functions over time. Dementia is caused by many diseases including Alzheimer’s disease, strokes, and alcohol abuse, as well as many others. Intellectual loss often begins with memory problems and then progresses to communication difficulties or problems with complex motor skills like driving. No two persons with dementia follow the same path. Some individuals may develop memory problems and then remain stable for years. Scientists cannot predict the course of a person’s intellectual loss.

Dementia can be caused by many types of brain diseases. Each disease has a different course and treatment. Genetics play some role in the development of dementia, although family history cannot predict the speed at which your symptoms will change.

Dementia can be produced by Alzheimer’s disease, multiple strokes (vascular dementia), alcohol abuse, or many other diseases. Some health problems can hasten the onset of intellectual loss and speed the progression of symptoms. Serious heart disease or uncontrolled high blood pressure may further damage a person’s brain. The person with dementia should do everything possible to control health problems that may cause or worsen intellectual problems. Individuals should seek healthcare for heart problems and follow doctor’s instruction to control irregular heartbeats or high blood pressure. Persons with thyroid disease or vitamin deficiencies should have appropriate medical therapy.

Alcohol abuse and prescription drugs can worsen memory problems. Anybody with dementia should stop drinking completely. Persons with dementia should limit the use of mind-altering drugs and avoid all other over-the-counter medications that cause drowsiness or confusion. Persons with dementia need to keep their brains as clear as possible. A drug advisory is provided that lists medications which can cause confusion or other serious side effects for persons with Alzheimer’s disease.

WHAT THINGS WILL WORSEN MEMORY PROBLEMS?

Heavy drinking, excessive amounts of mind-altering medications, like sleeping pills or nerve pills, and poor medical care will probably worsen the symptoms of dementia. Medications with an “anticholinergic side effect”, that cause dry mouth and blurred vision, may increase confusion. People with dementia must do everything to keep their brain healthy and functioning for as long as possible to enjoy their family and friends.

CAN I PREDICT THE COURSE OF MY MEMORY PROBLEMS?

The course of memory loss is dependent upon the causes of the intellectual problem. There is no fool-proof, clinical test that absolutely distinguishes one type of dementia from another. Each patient has a different course for his or her disease. Many patients progress very slowly, especially those who undergo treatment. Sometimes patients can plateau and retain a certain level of function for months or years. The best strategy to deal with dementia is to take life one day at a time and enjoy every moment with your family and friends.

HOW DOES FAMILY HISTORY PREDICT MY RISK FOR DEVELOPING DEMENTIA?

The risk for developing dementia depends on the specific kind of brain disease that produces the memory loss. For example, alcohol-induced dementia has no family risk factors except for the genetic risk of alcoholism. Alzheimer’s disease has a specific genetic risk. A small group of individuals have the strongly inherited autosomal dominant form of Alzheimer’s disease (1-5%) and the presence of this gene in your family will substantially increase your risk for dementia. Persons with Down’s syndrome have a very high risk for developing Alzheimer’s disease because one of the risk genes that produce the toxic protein associated with dementia, called “amyloid” is on chromosome 21. Other individuals have a variable risk for developing dementia. Your risk partially depends upon 1) the number of family members with the dementia, 2) the onset of the symptoms for those family members, and 3) the family members’ closeness in the blood line. For example, if you have a great aunt who developed Alzheimer’s disease when she was 84, you have a slightly higher risk for developing dementia. On the other hand, if your father developed Alzheimer’s when he was 52 and your brother has Alzheimer’s at age 56, your risk for developing dementia is substantially increased.

DEALING WITH THE POSSIBILITY OF DEMENTIA

TREATMENT FOR DEMENTIA

Medications that increase the amount of a chemical messenger in the brain called “acetylcholine” help persons with dementia. Brain cells that produce this messenger are damaged by Alzheimer’s disease and these medicines increase the amount of the deficient chemical. There are four medications that are widely used to increase this chemical messenger – Aricept, Exelon, Razedyne, and Namenda. All four medications work by the same mechanism and all three drugs will slow the memory loss in dementia. These new drugs will

not restore lost memory, although sometimes patients will notice improvement of memory function when they are taking the medications. These medications help Alzheimer patients to hold on to memory. These drugs are not addictive and people will not become hooked on these medications. These drugs have few side effects and most patients tolerate the medicines well.

Several other drugs are presently under study for the treatment of Alzheimer's disease. These medicines hold great promise and people with memory problems could expect new drugs that slow the disease and help people to hold on to their memory.

All available treatments are effective in the early stages of memory problems; however, most treatments are not helpful for people with advanced dementia. People with mild, early memory problems should have an evaluation and they should take prescribed medication that slows or stops the disease.

WHAT CAN I DO IF MY DOCTOR TELLS ME I HAVE DEMENTIA?

People with memory problems should use every possible skill to stay independent. Memory books, schedules, reminders from family members, and other tricks can reduce the likelihood of forgetting important events.

Things to Consider:

1. DON'T PANIC! Do not be embarrassed or ashamed. Memory problems are a very common problem in older people.
2. You are not going crazy.
3. You are still the person you were last year.
4. Your family will stand by you, but you need to help them.
5. No two patients are the same. Only the Almighty knows whether you will get worse or not.
6. Stay positive, active, and committed to fighting this disease.
7. You will have good days and bad days. Don't panic on the bad days.
8. New treatments are being developed as we speak.
9. Your personal strength and devotion will remain because no dementia can erase your soul.
10. Take medications as prescribed by your doctor to slow memory loss.

ATTACKING THE ILLNESS

Persons with the diagnosis of dementia should know that help, hope, and health are available. Hope comes from new medications and rapidly advancing research that provides doctors with better treatments for Alzheimer's disease and other types of dementia. Health means that dementia only affects the brain and the other parts of the body should continue to function

relatively well. Persons with dementia should exercise regularly and care for their body that nourishes their brain. Help comes in the form of immediate treatment to slow the progression of Alzheimer's disease. Available medications often slow the worsening of symptoms when the person takes the medications early in the disease. Individuals who suffer from Alzheimer's disease should receive early, aggressive treatment and frequent checkups by their doctor. Patients should do everything necessary to protect their brain from other types of injury, for example, high blood pressure, mini strokes, drinking, etc.

SHOULD I ATTEND A SUPPORT GROUP?

Some people with dementia attend support groups to cope with the disorder. Support Groups can help people with mild memory problems. Memory problems can be stressful, frightening, and disheartening. Sharing these feelings with other people helps lighten the burden and lift the spirits. People with memory troubles need to maintain a positive outlook on life and their role in society.

WHAT IS THE ROLE OF DIET IN MEMORY PROBLEMS?

A good diet with vitamins promotes healthy aging. A poor diet rarely causes memory loss but vitamin deficiencies might worsen dementia. Dietary aluminum does not cause Alzheimer's disease. The role of diet in dementia is unclear; however, most physicians would recommend a balanced diet that is filled with basic vitamins, and nutrition. Older people need adequate amounts of folic acid to maintain the health of their blood vessels. Vascular or blood vessel damage may accelerate the onset of intellectual loss. Older people need to take adequate amounts of the B- complex vitamins and a standard daily vitamin should be sufficient. Vitamin E is probably beneficial because this substance will neutralize harmful toxic molecules in the brain, called free radicals. Calcium supplementation and vitamin D are important to tone your bones. Older people must do everything possible to avoid fractures of the hip or the spinal bones. For more about proper nutrition, please refer to the book "Successful Aging" by John W. Rowe, MD, and Robert L. Kahn, Ph.D., or the DETA website.

HOW TO TAKE CONTROL OF YOUR DESTINY

All older people should decide how they want their life to unfold. Older persons should decide where they want to receive healthcare and to set priorities for quality of life. Persons with dementia can decide whether they want home care as they grow older with the disease. These individuals should provide the families with legal guidance through powers-of-attorney or living wills in case they lose the ability to choose and control their destiny. Breathing machines and heart pumps rarely work for older persons with advanced dementia. These aggressive medical treatments often require nursing home care. Persons with dementia should decide who will make decisions for them when necessary and what treatment options that family member should request. Any person who faces a serious health problem should

organize their affairs and leave instructions with family members to lift this burden from their shoulder and assure control of their own destiny.

WHAT DO I SAY TO MY FAMILY IF I HAVE ALZHEIMER'S DISEASE?

Tell your family that you are still you. Memory problems do not change your soul – but dementia does complicate your life. Tell your family that Alzheimer's disease is a journey and no one knows where this life travel will end. Assure your family that you want to travel this road with dignity and set an example for your children or grandchildren about courage and humor. Tell your family that Alzheimer's disease may place a cloud over your memory but it will never darken your spirit.

WHAT LEGAL STEPS SHOULD I TAKE TO HELP MY FAMILY?

A person with memory problems should visit an attorney who is an expert on legal issues for older people, for example, an elder law attorney. They should ask a trusted family member to assist them. Memory loss increases the chance that a person can become acutely confused during unrelated illnesses such as pneumonia. Persons with memory problems may remain in hospitals longer than other individuals. The person with memory difficulties should arrange for help with their personal and business affairs while they are recovering from health problems. The family or trusted individual should know where important papers and documents are located, for example, insurance papers, bank records, etc.

HOW LONG CAN I DRIVE WITH MEMORY PROBLEMS

Any person with serious memory problems should have a driving test to determine whether they have the physical, intellectual, and sensory ability to safely operate a vehicle. Memory loss or dementia does not protect a person from a lawsuit resulting from an accident. No one with dementia wants to put their family through a terrible legal battle following an accident. Persons can protect their family from lawsuits by limiting their driving or avoiding the operation of motor vehicles. Persons with dementia have greater risks for motor vehicle accidents and law enforcement may assume that the person is at fault regardless of who caused the accident.