

A PATIENT’S GUIDE FOR PERSONS WITH DEMENTIA OR ALZHEIMER’S DISEASE

1. WHAT IF I THINK I HAVE ALZHEIMER’S DISEASE OR MY DOCTOR TELLS ME I HAVE DEMENTIA?

1.1. Understanding How My Memory Works

Memory problems are a common complaint in most older persons. The brain has two kinds of memory – recent and remote (old). Recent memory includes facts or events that occurred within the last hour so, while remote (old) memory is facts or events from the distant past, e.g., college memories, high school memories, etc. Recent memory is like a computer workstation while remote memory or old memory is like the hard disk. The brain remembers facts or events by loading them into recent memory and then moving them to old memory. 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 bodies of information but you can still commit normal amounts of information to memory. Mild cognitive impairment means that memory is impaired to the point where people have difficulty, but they do not have other evidence of dementia. Dementia means that memory is lost and other intellectual functions are also damaged, e.g., communication, motor skills.

1.2. Understanding Different Kinds Of Memory Trouble

Many 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. This increased memory effort is a normal part of aging and not considered part of dementia. These individuals take longer to absorb large amounts of new information. Mild cognitive impairment means that a person has a specific memory problem that disrupts their everyday life and requires special interventions, e.g., memory books, frequent reminders, etc. Dementia means that a person is significantly 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 return with 14 items. A “good as new” memory will function the same way. A “good as old” 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 1 or 2 items or no items or may have trouble remembering where the store is located. A demented person would not be able to find the store or remember why they were in the parking lot of the store.

1.3. What Is Dementia?

Dementia is the slow loss of at least two kinds of intellectual function. Dementia is a nonspecific term that implies many possible causes of permanent brain problems. Dementia rarely occurs in less than six to twelve months. The most common problems include recent memory loss, problems finding words, problems operating household appliances or home equipment like power tools, and problems recognizing persons or objects. People with early dementia often repeat themselves without knowing. They have asked the same question several times. These people also get a lot of words stuck on the tip of their tongue. These symptoms indicate brain malfunction that may be caused by many degenerative diseases or treatable conditions including medication toxicity, hormonal problems, slow growing brain tumors and others. Alzheimer's is the most common type of degenerative disease but other common diseases include diffuse Lewy body disease, frontotemporal dementia, and vascular dementia.

1.4. Am I Losing My Mind?

NO. People with dementia are not "crazy" and these people should be treated like any other person with a health problem. Family and friends should treat them like any other adult. People with memory troubles should protect themselves against complications like forgetting medications, misplacing important mail. These protections are no different than the person with heart disease who avoids heavy work in hot or cold weather.

1.5. Does Treatment Help?

New clinical research shows that early intervention for dementia will significantly slow the progression of the disease. Any person over the age of 65, who believes that they are suffering from memory problems, should have an evaluation. A dementia evaluation must be conducted by someone who is trained to assess intellectual function, e.g., 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 CAT scan or blood test. Mild, cognitive impairment and early dementia require a thoughtful, careful evaluation by a specialist that requires about one hour of clinical time.

Persons with evidence of dementia should receive appropriate therapy. People with mild memory impairment may choose to take medication if they and their physician decide that the clinical situation warrants this intervention. People with memory complaints but no other intellectual problem need only to be re-evaluated in the event that the clinical condition changes. People with normal intellect do not need any further testing, but rather they should receive congratulations for holding on to their youth-like intellectual vitality. Most technology that is presently available to patients cannot predict the early onset of dementia; however,

specialized scanning, i.e., PET scans probably predict risks for dementia in specific groups of individuals. A specialist can advise you on the availability and prudence of seeking a PET scan. The general population should not have these studies; however, high-risk individuals may be candidates for PET scans.

1.6. How Does Family History Predict My Risk For Developing Dementia?

The risk for developing dementia depends on the specific kind of disease. 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, really low 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 the amyloid gene 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 disease, 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; while 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.

The genetic risk for Alzheimer's disease is unclear. Scientists believe that multiple genes may be involved as well as health or environmental conditions that hasten the onset of the disease.

2. WHAT SHOULD I DO TO PROTECT MY BRAIN?

2.1. What Can I Do If I Believe I Might Have Alzheimer's Disease?

1. Seek an evaluation from a trained specialist.
2. Complete all studies and assessments required by the specialist.
3. Follow the instructions of the specialist.
4. Stay intellectually active.
5. Avoid excess alcohol, i.e., more than 1 oz. per day.
6. Control heart disease, high blood pressure, and diabetes.
7. Exercise on a regular basis.
8. Stay positive. 90% of people over age 65 are intellectually intact.
9. Over half of very old, i.e., over age 85, people are intellectually intact.
10. Practice physical, mental, and spiritual wellness.

2.2. Does Diet Cause Dementia?

Aluminum intoxication does not cause Alzheimer's disease. The role of diet in dementia is unclear; however, prudent 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, i.e., 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 toxic molecules in the brain, i.e., 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 the book "Successful Aging" by Rowe and Kahn.

2.3. How Can I Predict The Course Of My Disease?

The course of dementia depends on the type of dementia. There is no 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 requiring several years to experience important changes. Some patients level-off and retain a certain level of function for many months or years. The best strategy to deal with dementia is to take one day at a time and enjoy each moment with family and friends.

2.4. What Things Will Worsen Dementia?

Heavy drinking, excessive amounts of mind-altering medications, such as sedatives like Valium or Xanax, and poor medical care will probably worsen the symptoms of dementia. People with dementia must do everything to keep their brain healthy and functioning for as long as possible to enjoy their family and friends.

2.5. What Legal Steps Should I Take If I Have Dementia?

Any person with possible dementia should visit an attorney with a trusted family member who is an expert on legal issues for older people. Dementia increases the chance that a person can become acutely confused during common illness, such as the flu. Persons with dementia can remain in hospitals longer than other individuals. The person with dementia should arrange for help with their personal and business affairs until their brain works better. The family or trusted individual should know where important papers and documents are located.

2.6. What Do I Say To Family Or Friends If I Have Alzheimer's Disease?

Tell your family that you are still you. Memory problems do not change your soul – they simply complicate your life. Tell your family and friends that Alzheimer's disease is a journey and no one knows where this life's travel will end. Assure your family and friends 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 diminish your spirit.

3. THE FAMILY GUIDE TO JUDGING ALZHEIMER'S DISEASE RESEARCH

3.1. Hope Through Research

Scientists are working hard to discover the causes of dementia. The common types include Alzheimer's, vascular, and alcoholic dementia, as well as diffuse Lewy body disease. Vascular dementia is caused by multiple small or big strokes and this brain damage is caused by heart disease or blood vessel problems. Excessive drinking for prolonged periods of time produces alcohol-induced dementia. The cause of diffuse Lewy body disease is unclear. There is no fool-proof test for Alzheimer's disease.

Alzheimer's disease may have several causes. An abnormal protein called amyloid is over-produced in the Alzheimer brain and researchers want to know how this amyloid protein is linked to brain damage. Drug companies are studying medications that stop the production of this toxic protein or increase its cleansing from the brain. A second different protein, called tau, also contributes to brain damage. A different group of scientists are working on ways to prevent this tau protein from accumulating within brain cells.

These massive teams of scientists are making rapid progress towards understanding the causes of Alzheimer's disease and developing ways to stop brain cell loss. Many new medications are being studied by scientists and soon there will be multiple ways to treat Alzheimer's disease. Alzheimer's research is a top priority for the federal government and the drug companies.

3.2. Understanding The Research Business

Research is a business and the researchers want to draw attention to their important work. Sometimes researchers will make announcements about research discoveries that become misrepresented in the press. Families and patients can assume a major breakthrough has occurred, when in fact, an important discovery was made. Breakthroughs usually require many important discoveries.

Major scientific advances are published in the most prestigious journals. Publications such as Science, Nature, The New England Journal of Medicine, and The Journal of American Medical Association, have the widest circulation and the greatest credibility. High quality research can always be published in peer reviewed publications. Peer review requires that the scientific work is examined by several other scientists who assess the scientific accuracy. Most importantly, the reviewers will decide whether the conclusions drawn by the scientists are supported by the data that is presented from the research. Family caregivers and patients

with dementia often struggle to determine whether the media hype is supported by the new science. The peer review process reduces the risk that media claims are over-stated.

Major scientific advances are generally repeated by other scientists to confirm the accuracy of the observation. Most clinicians wait for confirmatory studies to determine the accuracy of a single scientific report before they change their practice of medicine.

The pharmaceutical industry is performing a massive amount of research on new medications to manage dementia. The scientific process in the pharmaceutical industry expands the independent research conducted by the National Institute of Health; however, corporate management can control the release of “proprietary” information. Pharmaceutical research can sometimes be presented in a way to maximize the importance of the scientific discovery and minimize possible limitations of the information. The pharmaceutical industry is an important source of scientific advances in medicine. Families and patients should follow a few simple guidelines about media reports of “scientific breakthroughs.”

Guidelines To Follow:

1. Beware of reports published outside the peer review system.
2. The smaller the journal, the less important the discovery.
3. Major treatment breakthroughs require many important scientific discoveries.
4. Consumers should distinguish between a scientific discovery versus a research breakthrough.
5. Dementia is a very complex disease. Beware of any scientist who promises a magic bullet for any type of dementia.
6. Scientists are rapidly pushing back the frontiers of knowledge on Alzheimer’s disease.

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