Alzheimer's Mirror

your genetic reflection

> *"Congratulations for taking the first step to understanding your risk forAlzheimer's disease so you can make the best decisions for your* health, *your* family *and your* future.

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> “*Now that I know my risk,*
> *what can I do?*

your
health

your health

Now that I know my risk for Alzheimer's disease, what can I do?

- In partnership with your doctor, you can strive to make health and lifestyle changes that may lower your risk for Alzheimer's disease.
- You can pursue regular memory screening for early detection.
- You can volunteer for clinical trials.

health and lifestyle changes: a doctor's perspective

There is no *proven* way to prevent Alzheimer's disease. However, there is some evidence that certain dietary and lifestyle changes can lower the risk for dementia by helping to maintain a healthy brain. Below, one researcher offers an exciting new perspective on brain health across the lifespan.

Dr. Paul Nussbaum is a clinical neuropsychologist who specializes in aging across the lifespan and brain health. With a home base in Pittsburgh, Pennsylvania, Dr. Nussbaum maintains an Adjunct Associate Professorship in Neurological Surgery at the University of Pittsburgh School of Medicine. He lectures nationally and internationally on the human brain, brain disorders, brain-behavior relations, and promoting brain health. Dr. Nussbaum also serves as a consultant to independent research organizations throughout the United States.

Introduction to Brain Health

The single greatest system ever designed in the history of the universe is your brain. Your brain is responsible for your every thought, emotion, and behavior. Unfortunately we humans do not know much about our brains and it is time to change that.

Brain Basics:

1. Your brain weighs 2 to 4 pounds.
2. Your brain is comprised of 60% fat and is the fattiest system in your body.
3. Your brain consumes 25% of the blood from every heartbeat.
4. Your brain has two sides or hemispheres (left hemisphere and right hemisphere).
    - Left hemisphere helps you with language, detail, and analysis
    - Right hemisphere helps you with faces, spatial orientation, sounds.

5. Your brain has a cortex and subcortex.
    - Your cortex is conscious and helps you learn, remember, communicate, read, write, orient to space, process sensory information, and personality.
    - Your subcortex processes subconscious motor or procedural behaviors such as dressing, driving, and typing on your computer.
    - Your cortex and subcortex interact as a beautiful symphony.
6. Your hippocampus is the structure in your brain (sits in the middle of each temporal lobe just under each temple on your skull) that enables you to learn.

New Ideas about Your Brain:

The human brain (like the animal brain) can generate new brain cells. This new brain cell development (neurogenesis) occurs in the hippocampus. The human brain is now thought to have “neural plasticity” or be a system that is highly dynamic, constantly reorganizing, and malleable. It is shaped by environmental input.

Our brains need exposure to environments that are enriched, complex and novel. Environments that are passive and rote do not help the health of your brain. Exposure to enriched environments across your lifespan will lead to new brain cell development and increased cellular connections (“**Synaptic Density**”). Synaptic Density or **Brain Reserve** may help to delay the onset of neurodegenerative diseases such as Alzheimer’s and related dementias.

Your Brain Health

Brain health begins in the womb and needs to be promoted across your lifespan. Consider the following Brain Health Lifestyle to build up your brain reserve:

Five Domains of the Brain Health Lifestyle:

Socialization

- Do not isolate or segregate as you get older. People who isolate have a higher risk for dementia.
- Join groups and social organizations in your community.
- Maintain and build your friendship and family network.
- Be forgiving.
- Develop hobbies.
- Do not retire.

Physical Activity

- Walk between 7,000 and 12,000 steps daily. Walking several times a week reduces the risk of dementia.

- Buy yourself a pedometer to remind yourself to walk and to keep track of your daily steps.
- Dance as this is a behavior that reduces the risk of dementia.
- Gardening and knitting reduce the risk of dementia.
- Aerobic exercise will help the heart and thereby feed the brain with the necessary blood and oxygen. It also promotes cognitive functioning such as memory and is now believed to relate to positive structural changes in the brain.
- Use both sides of your body more often: become ambidextrous.

Mental Stimulation

- Learn a second language.
- Read and write (use your non-dominant hand) on a daily basis: the more complex the better.
- Learn sign language as it increases IQ and increased IQ reduces the risk of dementia.
- Play board games as board game playing reduces the risk of dementia.
- Travel reduces the risk of dementia because it involves a new and complex environment.
- Play a musical instrument.
- Listen to classical music as it helps to increase learning.
- Problem solve.

Spirituality

- Pray on a daily basis as it enhances your immune system.
- Attend regularly a formal place of worship at it relates to better quality of life and longevity.
- Learn to meditate in order to slow down. Animals exposed to environments that are too stimulating demonstrate slowed brain development.
- Learn relaxation procedures with deep breathing and muscle relaxation.
- Slow down and do not be afraid to say “no”.

Nutrition

- Eat 80% of what you intend to eat at each meal. Reasonable caloric restriction can increase your longevity.
- Eat with utensils and you will eat less and also eat healthier foods.
- Increase your intake of Omega 3 fatty acids. This includes fatty fish such as salmon, sardines, and herring. Several ounces of salmon weekly reduce the risk of dementia. Walnuts and unsalted nuts are also good for you.

- Increase your intake of antioxidants. This includes Vitamins C and E. Colored fruits (grapes, apples, cantaloupe, and berries) and vegetables are good for you. The FDA recommends five servings of fruit and vegetables a day.
- Decrease your intake of processed foods and red meats. Lean meat such as chicken breast without skin is relatively okay.
- Green leafy vegetables are good for you.
- Eat one sit down meal with others a day. This activity provides many brain boosting effects at once (classical music, language, eating with utensils, slowing down, eating healthier foods).

Start your Brain Health Lifestyle Today!

-Paul David Nussbaum, Ph.D.

It is also important that you check with your doctor before making changes to your diet and/or exercise routine.

How do I talk to my doctor about my test results?

If you share your genetic test results with a doctor, you should be aware that they may become a part of your medical record. Sharing your test results is always your personal choice. Nevertheless, if you are at all concerned with your risk of Alzheimer's disease, it is very important that you find a way to discuss your concerns with a healthcare professional, since communicating your risk early will help you receive the best care possible. If you do not want your specific genetic test results in your medical record, you can consult your doctor about your Alzheimer's risk based on other factors, such as family history, general health, and lifestyle choices.

A physician's report is included for you to take to your doctor so that you can start making lifestyle changes to promote a healthy brain. *See* your resources *sections*

memory screening for early detection

Memory screening is designed to determine whether an individual is experiencing progressive memory problems—an early symptom of Alzheimer's disease. Memory screening is appropriate for those who are concerned about current Alzheimer's symptoms as well as those who are not symptomatic but want to establish a baseline score for future comparison.

10 Warning signs of Alzheimer's disease

1. ***Memory loss.*** Forgetting recently learned information is one of the most common early signs of dementia. A person begins to forget more often and is unable to recall the information later.
2. ***Difficulty performing familiar tasks.*** People with dementia often find it hard to plan or complete everyday tasks. Individuals may lose track of the steps involved in preparing a meal, placing a telephone call or playing a game.
3. ***Problems with language.*** People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand. They may be unable to find the toothbrush, for example, and instead ask for "that thing for my mouth."
4. ***Disorientation to time and place.*** People with Alzheimer's disease can become lost in their own neighborhood, forget where they are and how they got there, and not know how to get back home.
5. ***Poor or decreased judgment.*** Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or little clothing in the cold. They may show poor judgment, like giving away large sums of money to telemarketers.
6. ***Problems with abstract thinking.*** Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are for and how they should be used.
7. ***Misplacing things.*** A person with Alzheimer's disease may put things in unusual places: an iron in the freezer or a wristwatch in the sugar bowl.
8. ***Changes in mood or behavior.*** Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.
9. ***Changes in personality.*** The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.
10. ***Loss of initiative.*** A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

Source: Alzheimer's Association

What is memory screening and how is it done?

While memory screening tools vary, most involve a series of questions and tasks that help a health care professional identify signs of early memory loss. Often you will be asked to draw a picture or perform an activity that challenges your ability to remember and concentrate. These tests take anywhere from five to thirty minutes, and can usually be done in your doctor's office.

How do I talk to my doctor about screening?

Memory screening is best done under the care of a trusted health care professional. You may mention to your doctor that you are concerned about your risk for Alzheimer's disease, or you may choose to share with your doctor the results of your genetic test. If you choose to share your results, remember that they will become part of your permanent medical record.

Points to Consider:

- Memory screening alone cannot diagnose Alzheimer's disease.
- Memory loss can occur for a number of reasons other than Alzheimer's disease, including depression, alcohol use, or medication side effects.
- Memory screening tools are not perfect, and can fail to catch early memory loss. Likewise, they can falsely detect memory problems that are not actually present.
- While memory screening often provides reassurance, it can also create anxiety.

For additional information on memory loss and memory screenings:

- http://www.nationalmemoryscreening.org/MemoryScreenings/index.shtml
- http://www.alz.org

volunteering for clinical trials

You don't have to be diagnosed with Alzheimer's disease to be part of a clinical trial. A number of clinical trials are looking for healthy people of all ages. Many people who are concerned about their own risk for developing Alzheimer's disease want to personally help in the fight for the cure. This section will help you understand more about clinical trials, and how you can take part.

What is a clinical trial?

A clinical trial is a research study that uses human subjects to determine whether an experimental drug, therapy, medical device, lifestyle change, or test will help treat, prevent, or detect a particular disease.

Why should I volunteer?

In addition to breakthrough treatments for Alzheimer's disease, the results of clinical trials can lead to new treatments for heart disease, various types of cancers, stroke, and diabetes. Joining clinical trials can also benefit you personally in a number of important ways:

Clinical Trials: 10 Questions to Ask

The following questions might be helpful to you when discussing clinical trials with the trial researchers.

1. What is the purpose of the study?
2. Who is going to be in the study?
3. What kinds of tests and experimental treatments are involved?
4. Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?
5. How do the possible risks, side effects, and benefits in the study compare with my current treatment?
6. How might this trial affect my daily life?
7. How long will the trial last?
8. Will hospitalization be required?
9. Who will pay for the experimental treatment?
10. Will I be reimbursed for related expenses?

- Researchers check your physical condition frequently, allowing you to be continuously up-to-date on your personal health.
- You may be granted access to experimental treatments and/or prevention therapies for Alzheimer's disease before they are available to the general public.
- Your participation may help others gain access to better treatments for Alzheimer's disease in the future.

Are clinical trials safe?

Before you can enroll in a clinical trial, the research team conducting it is required by law to take you through what is called the **informed consent** process. This process is designed to inform you of all the details, potential risks, and benefits of the trial, as well as your rights and responsibilities as a participant. During this time you will have the chance to ask questions until you have all the information you need to decide whether or not a particular trial is right for you.

How do I find a clinical trial?

- Go to the U.S. National Institutes of Health's searchable website at http://clinicaltrials.gov.
- Keep in touch with the experts at Alzheimer's Mirror. As part of our ongoing support, Alzheimer's Mirror identifies clinical trials that are relevant to you. We'll keep you updated.

“What do my results mean,
for my family

your family

your family

what do my results mean for my family?

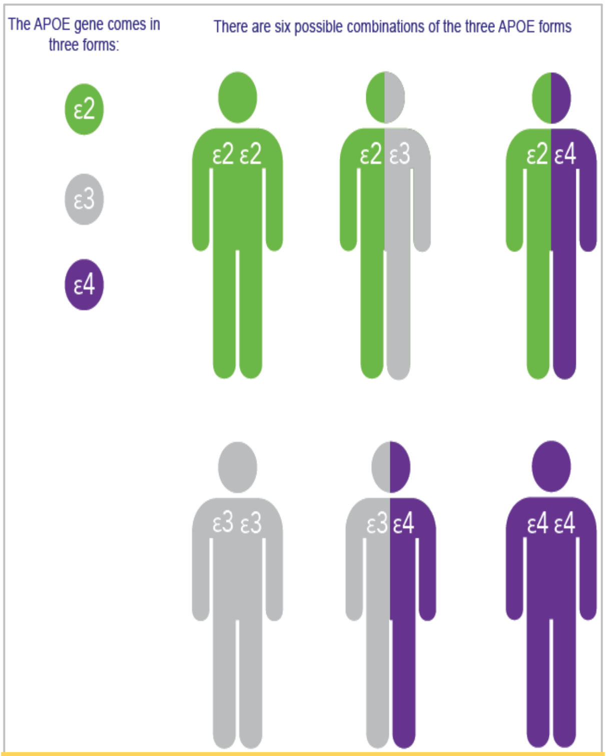
Because you have inherited your APOE genes from your parents, knowing your APOE status gives us limited information about the APOE status of other family members. Each of your full siblings shares half of your genes, and therefore has a 50% chance of sharing each of your APOE alleles. Each of your children also has a 50% chance of having inherited each of your APOE alleles.

It is important to remember that APOE is only one risk factor for Alzheimer's disease. In addition to the other risk factors listed above, environmental and other health-related factors also influence the likelihood that any one person will develop Alzheimer's disease. While family members may share your APOE status, risk levels will vary from person to person due to individual differences in environment, lifestyle, and overall health.

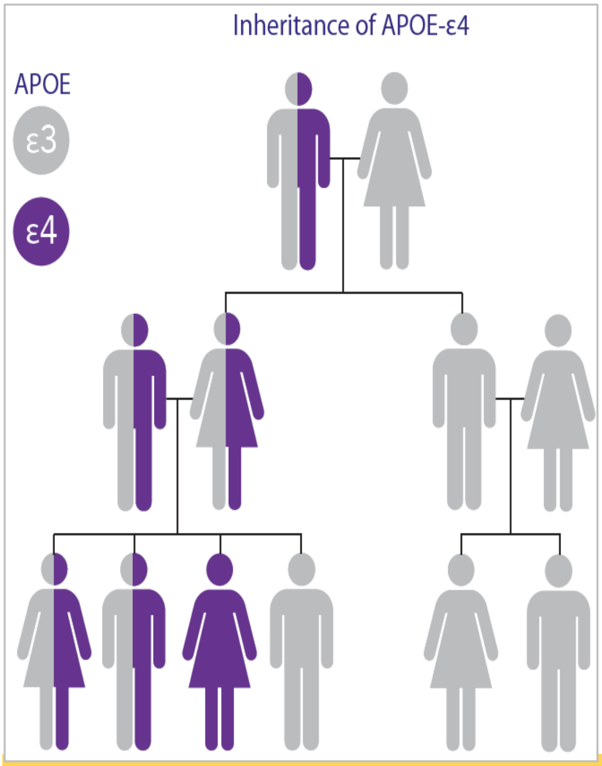
If you have a family history of Alzheimer's disease, your risk of developing the disease increases regardless of your APOE status. While APOE is the only known genetic risk factor for Alzheimer's disease, it is likely that other, yet undiscovered, genetic factors also exist.

How is APOE inherited in families?

APOE is one of our approximately 25,000 different genes. Genes, which are made up of DNA, are the basic physical and functional unit of heredity, the process by which characteristics such as height and eye color are transferred from parent to child. Every person is born with two copies of APOE, one inherited from each parent. Your particular combination of APOE alleles was determined by the allele combinations of your parents.



The APOE gene has three different forms, or alleles. Each allele of a given gene has a slightly different DNA makeup. Each individual possesses two copies of APOE, and thus one of six possible combinations of APOE alleles.



An individual with one copy of the ε4 allele has a 50%, or 1 in 2, chance of passing this allele on to each of his or her children. If a child inherits the ε4 allele, then he or she in turn has a 50% chance of passing it on. If a child does not inherit the ε4 allele, then he or she cannot pass it on to the next generation.

How do I talk to my family or friends about my test results?

Deciding whether, when, and with whom to share your genetic test results is an entirely personal decision. If you do decide to share your results with family members or other loved ones, it is important to keep in mind that:

- Everyone reacts differently to genetic information. Family members and friends may demonstrate a wide range of emotions, varying from anger and anxiety to gratitude and relief.
- Everyone has different ideas about health and disease.
- Everyone has the right ‘not to know.’
- Children will not understand the information in the same way as adults, and may not be able to share their feelings with you easily or clearly.

To begin a discussion, you may want to let family members know your motivations for getting tested. You may want to share how the results have made you feel about your risk, and by extension, the risk of your family members. If risk assessment has led you to want to make lifestyle changes for yourself and/or your family, this might also be the time to talk about these changes, and ask for your family's support.

alzheimer's disease: a caregiver's guide

Caregiving and Alzheimer's Disease

It is never easy when a family member or loved one is diagnosed with Alzheimer's disease. Likewise, caring for someone with Alzheimer's disease is not an easy process. If you have decided to become a caregiver, you will have to learn to understand and respond to your loved one's changing needs as the disease progresses. At the same time, you will have to recognize that needs are changing not only for your loved one, but for you and indeed, for your entire family. As a caregiver, it is vital that you seek out not only educational and training programs for Alzheimer's disease, but emotional support for yourself and your family. Research shows that caregivers greatly benefit from training as well as support groups, and that those who join these groups develop the resources to care for their loved one at home longer. If you are interested in joining a class or support group, please consult the sources provided at the end of this guide.

Caregiving in Every Stage

Because the symptoms of Alzheimer's disease change significantly over time, the disease is divided into three different stages: early, middle, and late. Though individuals with Alzheimer's disease all develop symptoms a little differently, and at different rates, it generally takes several years to progress through each of the stages. Accordingly, your role as caregiver will change as the symptoms of your loved one do. Below is an introduction for caregivers to the different stages of Alzheimer's disease: what to expect, and how to prepare.

Early-Stage Alzheimer's Disease

During this stage, most people with Alzheimer's disease will be able to care for themselves. For the most part, the symptoms that develop will be mild. Memory problems do not affect all types of memory equally, and in people with Alzheimer's disease, it is the short-term memory (used to recall recent events or learn new things) that begins to show impairment first. Typical symptoms of first-stage Alzheimer's disease include:

- Difficulty with short-term memory: recent conversations, dates, faces, names, new facts
- Shrinking vocabulary: decline in language fluency
- Tendency to become antisocial
- Tendency to lose things
- Difficulty performing household tasks
- Disorientation in familiar environments
- Questionable judgment: difficulty making decisions

At this stage, the person with Alzheimer's disease will not place extraordinary demands on the caregiver. As a result, you will be able to take the time you need to plan for the future. Making informed preparations during the early stage is the key to giving good care in the later stages. Right now, you as a caregiver have the opportunity to take the following proactive steps:

1. **Seek out a Support Network.** As you probably know already, having a loved one diagnosed with Alzheimer's disease is difficult for everyone in the family. Seeking out emotional support through counseling, support groups, and/or other family members is one of the most important first steps that you as a caregiver can take.
2. **Get Educated.** This is also the time to learn as much as you can about all the stages of Alzheimer's disease. You can read books or pamphlets, enroll in a class, research on the internet, talk to your doctor, or contact the Alzheimer's Association for free information about Alzheimer's disease, treatments, and caregiving options.
3. **Establish Legal Protection.** Many caregivers do not realize that when a person with Alzheimer's disease can no longer pay bills or make medical decisions, caregivers are legally powerless to do these things for her without prior court arrangements. It is important that you make these arrangements now, by getting two legal documents authorized: ***Power of Attorney for Finances***, and ***Power of Attorney for Healthcare***. These two documents will allow the caregiver(s) to access bank accounts and make medical and other important decisions for the person with Alzheimer's disease.
4. **Evaluate Finances and Explore Medical Options.** Living with Alzheimer's disease can be a very expensive process, as individuals diagnosed with this disease will need ongoing medical care. It is a good idea to use the time you have now to decide how to finance this process over the long term. Review your insurance coverage (health, disability, long-term care, etc.), making any necessary changes. At the same time, be mindful that you will eventually become involved with your loved one's medical care at every level. Make it a point to choose a doctor who

understands the role of the caregiver, and is willing to work with you, as well as your loved one, to help provide the best care possible within your financial means.

Middle-Stage Alzheimer's Disease

During this stage, the needs of the person with Alzheimer's disease will expand. Accordingly, the demands on the caregiver will increase. Memory problems, relegated to the short-term memory in the first stage, will now begin to affect long-term memories, to the point where the individual has pronounced difficulty with language, and may not recognize even close relatives. In general, symptoms of middle-stage Alzheimer's can include:

- Impaired motor skills: trouble handling objects
- Noticeable language deficiency: difficulty finding words, reading and writing.
- Difficulty with (and sometimes fear of) personal hygiene: bathing, dressing, toileting, etc.
- Difficulty recognizing faces, including caregivers and other family members
- Lack of awareness of symptoms
- Restlessness, irritability, and/or aggression, sometimes leading to violence even in previously peaceful individuals
- Hallucinations or delusions; paranoia
- Crying or outbursts
- Wandering from home
- Urinary incontinence

Ultimately, the individual with Alzheimer's disease will develop the need for constant supervision during this stage. This will, of course, place a lot of demands on you, the caregiver. In this stage, you can continue to take important steps to keep your loved one safe, while recognizing and respecting your own needs as a caregiver.

1. **Create a Safe Living Environment.** There are a number of ways to make your home safer and more comfortable for you and the person living with Alzheimer's disease. Consult your doctor about the possibility of purchasing or renting assistive devices and other medical products. Meanwhile, it is a good idea to enroll your loved one in the Alzheimer's Association's Safe Return program.
2. **Take Advantage of Your Support Network.** Now is the time to use the resources you have already set up for yourself. Reach out to get emotional help whenever you need it. This includes taking breaks from caregiving. It is essential to your own health, both physical and emotional, that you take turns with family

members, recruit volunteers, or hire part-time help to ease the burdens of caregiving from time to time.

3. **Explore Alternative Care.** If you come to feel that personally caring for your loved one over the long term is not possible or is not what you want, consider other options. Many residential care facilities are equipped to provide excellent care for individuals with Alzheimer's disease. Alternatively, you might want to hire an in-home nurse or other health professional.

Late-Stage Alzheimer's Disease

In the late stage, as individuals with Alzheimer's disease develop a need for constant, well-trained care, it is very common for caregivers to pursue outside help. During this stage, behavior becomes more or less automatic, with language being dramatically reduced to small phrases or single-word utterances before disappearing altogether. Feelings of exhaustion and indifference are also very common. The various symptoms to expect in the late stage of Alzheimer's disease include:

- Excessive sleep and weight loss
- Inability to maintain personal hygiene
- Drastic deterioration in language ability: eventually individual will not be able to speak
- No recognition of people, objects, environments
- Deterioration of muscle and mobility: eventually individual will not be able to walk, feed herself, etc. Ability to swallow may ultimately disappear.
- Muscle contractions or seizures
- Persistent incontinence

As this stage progresses, the person with Alzheimer's disease will gradually lose the ability to perform even the smallest tasks independently. For the majority of caregivers, it makes sense to reach out to skilled professionals for help. Hospice services, the choice of support by many families, can work to bring nurses and other medical professionals into the home to help during an individual's last stages of life. If hospice is not right for your family, you might want to consider placement in a skilled nursing facility.

With the proper planning, the experience of caring for a loved one with Alzheimer's disease can, despite its difficulties, be an experience that brings your family together.

> “*Does my risk increase*
> *as I get older?*

your
future

your future

planning for long-term care

This introduction is designed primarily as an information and planning resource for individuals who don't yet require long-term care. It also includes information about medical and financial services that can be helpful to all individuals.

What is long-term care?

Long-term care is a variety of services and supports to meet health or personal care needs over an extended period of time. The goal of long-term care is to help individuals who are not fully independent maximize their functionality.

Who needs long-term care?

Individuals who have a chronic illness or disability that causes them to need assistance with activities of daily living are generally the recipients of long-term care. Disabilities can include memory problems, confusion, or disorientation. This year, about 9 million Americans over the age of 65 will need long-term care services. By 2020, that number will increase to 12 million. While most people who need long-term care are age 65 or older, an individual of any age can require long-term care.

What is the cost of long-term care, and who pays for it?

Costs for long-term care services vary greatly depending on the type and amount of care an individual needs, the provider he or she uses, and where he or she lives. Many people mistakenly believe that Medicare will pay for any and all long-term care they need. On the contrary, Medicare will only pay for skilled services or recuperative care for short periods of time. Medicare will not pay for what comprises the majority of long-term care services, which consist of non-skilled assistance with activities of daily living. Those who require long-term care must therefore seek alternate sources of funding.

How do I plan for long-term care?

Planning for long-term care is a difficult task, which involves understanding and making decisions about products and services that are unfamiliar to many of us. These include medical, housing, and financial options as well as legal services. The following resources offer a valuable introduction to some of the considerations of long-term care:

National Clearinghouse for Long-Term Care Information

The National Clearinghouse for Long-Term Care Information was developed by the U.S. Department of Health and Human Services to provide information and resources to help you and your family plan for future long-term care needs. To learn more, please visit www.Longtermcare.gov

Own Your Future Long-Term Care Planning Kit

The **Own Your Future Long-Term Care Planning Kit** is a free resource from the U.S. Department if Health and Human Services. It describes what is and is not covered by public programs related to long-term care. It also offers valuable advice on planning ahead, addressing legal issues, assessing services, and considering private financing options.

References

Understanding and Planning for Long-TermCare: Adapted from The National Clearinghouse for Long-Term Care Information. www.Longtermcare.gov

Audio clips: Excerpts from *Own Your Future Long-Term Care Planning Kit* (Originals provided in the Planning Kit CD)

Legal Considerations for Planning for the Future: Adapted from *Legal & Financial Planning for People with Alzheimer's Disease: Tips from the National Institute on Aging.*

“ *Where can I find more information*

your resources

your resources

privacy and genetic testing

Can my genetic test results affect my insurance or employment?

People who avoid disclosing genetic test results on their medical record often do so to protect against a practice known as genetic discrimination. Genetic discrimination is generally defined as the denial of insurance or employment to an individual based on genetic information or test results. While the extensive recent press about genetic discrimination has led many people to believe it a pervasive practice, the reality is that cases of genetic discrimination by insurance companies and employers are rare. There are, in fact, a number of laws at both the state and federal level which provide protection against genetic discrimination.

- For laws in your state see: http://www.ncsl.org/programs/health/genetics/ndishlth.htm .
- For protection provided by the Health Insurance Portability and Accountability Act or HIPAA, see: http://www.hhs.gov/ocr/hipaa/.
- Specific legislation regarding genetic information is currently pending through a bill entitled the Genetic Information Nondiscrimination Act, or GINA. For more information, see: http://www.genome.gov under the Policy and Ethics tab.

How does Smart Genetics protect my information?

Your genetic information is stored on our secure site, and will only be accessible to your genetic counselor immediately prior to disclosing your results. After disclosure, only you and those individuals with whom you choose to share your username and password will have access to your information.

alzheimer's disease organizations

Alzheimer's Disease Education and Referral Center (ADEAR)
P.O. Box 8250
Silver Spring, MD 20907-8250
adear@nia.nih.gov
http://www.alzheimers.nia.nih.gov
Tel: 301-495-3311 800-438-4380
Fax: 301-495-3334

National Institute of Mental Health (NIMH)
National Institutes of Health, DHHS
6001 Executive Blvd. Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
nimhinfo@nih.gov
http://www.nimh.nih.gov
Tel: 301-443-4513/866-615-NIMH (-6464) 301-443-8431
(TTY)
Fax: 301-443-4279

Alzheimer's Association
225 North Michigan Avenue
17th Floor
Chicago, IL 60601-7633
info@alz.org
http://www.alz.org
Tel: 312-335-8700 TDD: 312-335-5886
Fax: 866.699.1246

Alzheimer's Foundation of America
322 Eighth Avenue
7th Floor
New York, NY 10001
info@alzfdn.org
http://www.alzfdn.org
Tel: 866-AFA-8484 (232-8484)
Fax: 646-638-1546

Family Caregiver Alliance
180 Montgomery Street
Suite 1100
San Francisco, CA 94104
info@caregiver.org
http://www.caregiver.org
Tel: 415-434-3388 800-445-8106
Fax: 415-434-3508

C-Mac Informational Services/Caregiver News
120 Clinton Lane
Cookeville, TN 38501-8946
caregiver_cmi@hotmail.com
http://www.caregivernews.org

National Family Caregivers Association
10400 Connecticut Avenue
Suite 500
Kensington, MD 20895-3944
info@thefamilycaregiver.org
http://www.thefamilycaregiver.org
Tel: 301-942-6430 800-896-3650
Fax: 301-942-2302

Well Spouse Association
63 West Main Street
Suite H
Freehold, NJ 07728
info@wellspouse.org
http://www.wellspouse.org
Tel: 800-838-0879 732-577-8899
Fax: 732-577-8644

National Respite Network and Resource Center
800 Eastowne Drive
Suite 105
Chapel Hill, NC 27514
http://www.archrespite.org
Tel: 919-490-5577 x222
Fax: 919-490-4905

genetics and genetic counseling organizations

The National Society of Genetic Counselors
http://www.nsgc.org

The National Human Genome Research Institute
http://www.genome.gov/

Ethical, Legal, and Social Implications
http://www.genome.gov/10001618

The Centers For Disease Control, National Office of Public Health Genomics
http://www.cdc.gov/genomics/default.htm

Genetics and Pubic Policy Center
http://www.dnapolicy.com/

financial planning

National Clearinghouse for Long-Term Care Information
The National Clearinghouse for Long-Term Care Information was developed by the U.S. Department of Health and Human Services to provide information and resources to help you and your family plan for future long-term care (LTC) needs. For more in depth information please visit www.Longtermcare.gov

Own Your Future Long-Term Care Planning Kit
The **Own Your Future Long-Term Care Planning Kit** is a free resource from the U.S. Department if Health and Human Services. It describes what is and what is not covered by public programs related to long-term care, as well as ways to plan ahead, address legal issues, assess services, and consider private financing options.