ALZHEIMER'S, PART I

The Epidemic of the 21st Century

BY HEATHER O'NEILL

When Charles Barton's mother Peggy was worried that she had Lyme disease three years ago, he didn't think much of it. Barton took Peggy to see her physician, who assured her that she was perfectly healthy.

But weeks later, when Peggy demanded to see the doctor again, this time convinced that she had contracted another illness, Barton began to worry.

"It seemed like she wanted to go to the doctor every month or so to make sure that nothing was wrong with her," he said. "She thought she had Lyme disease, and then she was sure she had anthrax. The more we went to the doctor, the more he felt that she was declining and showing early signs of dementia."

Peggy's doctor believes she has Alzheimer's disease, a degenerative neurological condition whose hallmarks are memory loss, mood swings and paranoia. She was showing classic symptoms of the disease, but for Peggy, as with many patients, an Alzheimer's diagnosis was not simple to make. Alzheimer's patients often display extremely subtle symptoms or symptoms that resemble other illnesses like depression or anxiety disorders, making the illness difficult to diagnose.

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There is no blood test for Alzheimer's and no way to definitively diagnose the disease other than through an autopsy. So Peggy's doctor began a process of elimination: administering a battery of tests to rule out any other possible cause for her diminished capacity.

In the meantime, Barton says, his mother's condition worsened. Peggy's doctor became concerned enough about her safety to have her driver's license revoked. Peggy, who lived alone, left a pot boiling on the stove for so long that it melted. Normally calm, Peggy began throwing temper tantrums and became convinced that one of her children was stealing money from her. Another, she said, was trying to kill her.

Barton says his mother insisted on remaining in her Greenwich home, despite concerns on the part of her family and her doctor that to do so could be dangerous. The situation came to a head, he said, when his mother suffered a breakdown. She was hospitalized for several days then moved directly to a local assisted-living facility. Her children felt they had no choice.

Stories like Charles Barton's and Peggy's (names have been changed to protect the family's privacy) are devastating and, sadly, increasingly common. Today it is estimated that four million Americans are suffering from Alzheimer's disease. By the year 2050, experts expect that up to fourteen million will have been diagnosed.

With the number of diagnoses climbing, Alzheimer's disease has become what Dr. Stephen Jones, director of the Geriatric Health and Resource Center at Greenwich Hospital, refers to as the epidemic of the twenty-first century, particularly here in Greenwich.

Once a blip on the screen for doctors, the prevalence of the disease has increased dramatically in the last decade, due largely to the fact that people are living to be older and older. "The fastest growing segment of the population today are people eighty-five and older," says Jones. "The population is exploding. Back at the turn of the century, in the early 1900s, living to eighty-five was almost unheard of. The average life span was about forty-seven. Now the average life expectancy is eighty years old. So this is a relatively new disease, since most Alzheimer's develops after age sixty-five."

These statistics are particularly disturbing for the Greenwich medical community, Jones says. "The average age in the United States is 34.9 years. The average age in Connecticut is 35.4. That may not seem like a big difference, but it is. The really interesting thing is that Greenwich has the highest mean age of anywhere in Connecticut so, particularly in this community, Alzheimer's is very, very important to understand."

Of more than sixty known causes of dementia — characterized as a decline in intellectual and social abilities — Alzheimer's is the most common form, accounting for between fifty and seventy percent of what used to be simply called senility.

In laymen's terms, Alzheimer's is a disease that develops when there is a breakdown of communication between brain cells. Alzheimer's attacks the brain by destroying neurons, the brain's communicating mechanisms. Neurons work by generating electrical impulses relayed to and from your brain and other parts of your body.

Brain cells die each day and are not regenerated; as we age, the brain shrinks in size and weight. These changes can result in slight forgetfulness, but there should be no real loss of cognitive function in the normal aging process, according to Dr. Jones.

"Dementia is not a normal part of aging," he stresses. "People should be functioning well into old age without having any kind of loss in mental capacity. Things change when you get older. You get wrinkles on your face, you get gray hair, you get a little bit slower and your mind may get a little bit slower in terms of how long it takes you to process things, but the circuits should still be working."

Alzheimer's disease is named after Dr. Alois Alzheimer, a German doctor who first identified the disease in 1906. Dr. Alzheimer noticed abnormal clumps (called amyloid plaques) and tangled bundles of fibers (known as neurofibrillary tangles) in the brain tissue of a woman who had died

of an unusual mental illness. Today, these plaques and tangles in the brain are considered hallmarks of Alzheimer's disease, but they can only be found during autopsy.

Though memory loss is the most commonly known symptom of Alzheimer's disease, contrary to what most people believe, the first sign of Alzheimer's disease is not usually forgetfulness, according to Dr. Jones. "One of the first things you see in a person getting Alzheimer's is personality changes," he says. "People become more withdrawn. They may not be interacting as much as they used to. If they enjoyed gardening, maybe they have given that up. It is really one of the first clear signs of the disease and one that we look for when we have people coming in for assessments."

As for memory loss, it usually is so slight initially that it's virtually undetectable. The subtle onset of the disease is often shrugged off by the patient and can be largely overlooked by friends and family. However, once the disease begins, memory loss will progress to the point of disorientation.

Mild Alzheimer's, or early stage, is generally marked by the earliest signs and symptoms of the disease, like repetition in conversation — telling the same stories over and over again or asking the same question repeatedly. A person with early stage Alzheimer's disease might have trouble finding words for common items during conversation or may forget how to perform everyday tasks like following a recipe or balancing a checkbook.

"Alzheimer's also causes problems with visual/spatial impairment," says Dr. Jones. "In other words, people can't [process] what they are seeing, which is why they tend to get lost a lot."

People suffering from early Alzheimer's may still be working or maintaining a home, but a growing awareness of their own memory loss often leads patients to isolate themselves. "Some people are aware of the fact that there is something wrong but they don't know what," says Janet Giradat, regional office manager of the Southern Connecticut Alzheimer's Association. "Other people might think something is wrong but they are in complete denial and they won't get help and won't let the caregiver get help."

Moderate, or midstage, Alzheimer's disease, is the longest stage, lasting from two to nine years. It is marked by more obvious symptoms that often alert family members that something is very wrong. During stage two, patients may begin to exhibit behavior that makes it dangerous for them to live alone, such as wandering out of the house, forgetting to take medications, neglecting to turn off appliances or losing the ability to perform tasks that require fine motor skills like tying shoelaces.

Alzheimer's patients in this stage can also experience a disruption of their senses. Taste becomes dulled or distorted and some patients begin using inappropriate amounts of salt or spices on their food. Even the body's ability to register temperature is affected, making it difficult for patients to gauge the temperature of beverages, food and bath water.

It is often in stage two that patients begin to experience sleep disturbances, aggression or anxiety. "Sundowning" is a term used to describe an anxiety common in Alzheimer's patients, which manifests itself when the sun goes down.

According to Dr. Jones, most patients seek help during this stage of the disease, when dementia has firmly set in. "Most people start coming in to the hospital or the doctor's office when there is a really significant decline," Dr. Jones says. "They can't remember names, they're forgetting things, repeating themselves. It becomes almost a crisis situation. In fact, what a lot of research is showing is that if you look back at people's lives, you can probably see some of the telltale indications that people are starting to get early Alzheimer's or are predisposed to getting the disease."

There are several risk factors that the Alzheimer's medical community agrees on and others that are still under investigation. What is known is that the risk of developing Alzheimer's disease increases dramatically with age, doubling every five years after age sixty-five. Women seem to develop the disease at a higher rate than men, but experts concede that this can likely be attributed to the fact that women live longer.

About ten percent of the people who develop the disease have a family history of dementia. A history of stroke or head trauma, especially one in which the individual lost consciousness, can contribute to Alzheimer's later in life. And African-Americans tend to develop the disease more often than other races, though researchers don't yet know why.

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Like many experts, Dr. Jones also subscribes to evidence that an active mind can prevent or delay the onset of Alzheimer's disease. Everything from pursuing higher education to working on crossword puzzles has been shown to be effective. "Use it or lose it," he says.

Dr. Jones stresses that while there is no cure for Alzheimer's disease, early diagnosis is crucial. Medications exist which can slow a patient's decline into dementia and prolong quality

time with family and friends. The medications cannot reverse the ravages of the disease, only slow it. A person with end-stage Alzheimer's will not be helped by medication.

"The big thing for us is to educate people about getting evaluated before it is too late," Jones says. "You don't put a smoke alarm in your house after a fire."

Jones recommends that any person who suspects that she may be experiencing some of the early signs of Alzheimer's disease see her primary care physician immediately to ask for a referral to the geriatric center at the hospital. Its staff of geriatricians will perform a full evaluation and issue a written report, complete with test scores, to the patient's doctor who will determine, along with the patient and her family, a course of treatment and help the patient determine where and how she wishes to be cared for.

Alzheimer's disease leads to death, but the course of the disease is a slow one. Patients have been known to survive between eight and twenty years after the onset of symptoms. While the body may be healthy for years, the mind often is not, making it extremely important that major financial and care decisions be made early.

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While an elder-law attorney can help a family sort out financial matters and map out estate planning, only a family can make the personal decision regarding how to care for an individual with Alzheimer's disease. In-home care, adult day care and assisted-living facilities are all options, as is the more traditional nursing home.

But the vast majority of families choose to care for their loved one at home, at least during the early and moderate stages of the illness.

"What most people don't know is that seventy percent of people who have Alzheimer's are cared for in their homes by a family member, usually a spouse or an adult child," says Janet Giradat of the Alzheimer's Association. "It is a very personal decision because the demands on the caregiver are great."

Relationships change when a person develops the disease. For the caregiver, assuming an almost parental role for a spouse or parent can be challenging. Decision making, in almost all aspects of the patient's life, will have to be made by the caregiver and eventually, almost all daily tasks, from dressing to bathing to using the bathroom, will have to be supervised. As the disease progresses, the patient often ceases to recognize her caregiver at all, a facet of the disease that can be particularly difficult to deal with.

"It can be very emotionally draining to be with someone you were once very close to and have them not recognize you," Dr. Jones explains. "It is very hard to accept and it wears on people."

Carol Burns, director of the Greenwich Adult Day Care Center on Parsonage Road, emphasizes that from the very beginning of the process, caregivers need to take care of themselves just as diligently as they care for their ailing loved one. "It is just so critically important to do that. Caregivers often lose themselves in this disease," she says. "They get lost in caring for that person and do not take care of themselves. Ultimately, the person with the disease is so dependent on the caregiver that if something happens to that individual there is no alternative except for [the patient] to be institutionalized."

Carol says that a common mistake caregivers make is to put off getting a diagnosis, either because they are in denial about the individual's disease or to protect the privacy of their loved one. Too often, Burns says, families wait until there is a crisis or until the individual requires so much care that it simply cannot be provided at home before seeking assistance. An early diagnosis allows a family to plan ahead while the person is still able to participate.

Aside from financial planning and resolving a lot of legalities, Carol says families should determine with the patients how they ultimately want to be cared for and by whom. Who should make their medical decisions when they become incapacitated? Would they want to be resuscitated if something happened to them or would they rather not be kept alive artificially? Do they want to be buried or cremated? Decisions early on make it easier for the caregiver too, because she is not sitting there saying, "Well, what would he want?"

Adult day care is another option. Both Waveny Care Center in New Canaan and Greenwich Adult Day Care Center (part of the Nathaniel Witherell Skilled Nursing Facility) offer respite care for families. The programs are flexible and are designed to fit the needs of the caregiver. Some people stay all day while their caregiver works while others come only a few hours a week so their caregivers get a much needed break from responsibilities.

In the later stages of the disease, assisted-living or nursing home care is often needed, though for some the cost can be prohibitive. Both Waveny Care Center and Nathaniel Witherell offer assisted-living and nursing home facilities

home safety tips

- Keep a list of emergency numbers by all telephones.
- Have a first-aid kit, fire extinguisher and fresh batteries in all smoke alarms.
- If your loved one is confusing hot and cold, color code all faucets red and blue. Adjust your home's water heater to 120 degrees to avoid burns.
- Keep poisons and cleansers out of sight, particularly if your loved one is confused about what is edible.
- Keep medications out of sight.
- To prevent falls, eliminate throw rugs, keep stairs and hallways free of clutter, move electrical cords under rugs or tape to walls.
- Avoid rearranging furniture as this may disorient a person with Alzheimer's disease.
- Use appliances with automatic shut-off systems.
- If your loved one tends to wander out of the house, use alarms that will alert you if a door is opened or disguise the door to the outside using curtains. Place a dead bolt high up on the door to prevent wandering out at night. In case of emergency, never use these devices when the individual is home alone.
- Keep a spare key outside your home in case your loved one inadvertently locks you out.
- Limit stove use if necessary. Dismantle stove when not in use by throwing the circuit breaker, by removing knobs or by unplugging it.

ongoing alzheimer's research

AN ONGOING STUDY BY UNIVERSITY OF KENTUCKY SCIENTIST David Snowdon indicates that the way a person thinks and expresses themselves — even in young adulthood — could be a clue as to whether he is at risk for developing Alzheimer's later in life.

Snowdon has been studying 678 American members of the School Sisters of Notre Dame religious congregation who are 75 to 106 years of age to study the link between lifestyle and Alzheimer's disease. His research is aptly dubbed the Nun Study.

Chosen because their profession offers a degree of lifestyle conformity not found in the general population, the nuns agreed to undergo cognitive testing by Snowdon throughout the remainder of their lives. They also agreed to have their brains studied by him after their deaths, since autopsy is to date the only definitive means of delivering an Alzheimer's diagnosis.

Among other things, Snowdon's study has proven what doctors already suspected: that head trauma or a history of stroke were risk factors in developing Alzheimer's later in life. And his research also substantiated the idea that an active mind offered protection from the debilitating disease. In fact, his study found that those nuns who have a college degree fared better than those who had not pursued higher education.

The most surprising finding in the Nun Study, however, was that the way we express ourselves — even at a very young age – might be a clue as to whether we will develop Alzheimer's disease later in life. By examining essays that the nuns wrote upon entering the convent as young women, Snowdon found that those women who had been the most descriptive — who used what he called "high density ideas" — in their writing were less likely to be stricken with the disease than their less descriptive counterparts.

Other studies are looking at the possibility that diet could play a role in the prevention of Alzheimer's disease. In 1998 British researchers announced that Alzheimer's victims had low levels of the nutrient folate, or folic acid, in their systems. The results piqued the interest of many in the Alzheimer's community, especially since low levels of folate during pregnancy have been proved to play a role in some kinds of cognitive problems and mental retardation in infants.

Scientists are also looking into the possibility that vitamins C and E could be used in the prevention of Alzheimer's.

to allow patients to move seamlessly from one stage of the disease to the next, from assisted living to full-time nursing care.

Dr. Jones says that family members are often plagued by guilt at the idea of putting their spouse or parent into a facility. But he asks caregivers to remember that home care cannot work if the caregiver is overwhelmed.

For Charles Barton and his family, in-home care was not feasible. Peggy is now in a local assisted-living facility and is doing well, though she still longs to return home.

"She is starting to accept that there is something wrong with her, that she might have Alzheimer's," her son says. "But she still doesn't understand why she can't go back home. She doesn't remember the bad times she had there, only the good ones, so it seems unfair to her."

Barton says that he and his siblings feel blessed that they have the resources to keep their mother in a high-caliber facility for an extended period of time. "Physically she is in great shape and if she does live for another ten to fifteen years, we will be able to care for her," he says. "But as for her mental state, we have all seen it decline. We don't have much hope that it is going to get any better, but sometimes I think maybe that's not such a bad thing. Maybe soon she'll forget about going home and be able to accept her situation. Maybe soon she'll be a little bit more happy-go-lucky. That's what I hope for her." ◘

area resource guide

Greenwich Adult Day Care Center
70 Parsonage Road
Greenwich, CT 06830
203-622-0079

Greenwich Adult Day Care, part of the Nathaniel Witherell Skilled Nursing Facility, offers day care service to adults with physical handicaps and dementia. Program is designed to offer caregivers the peace of mind that their loved ones are in a safe, caring environment. Flexible hours and programs are available to help participants remain in their own homes and in the company of family and friends as long as possible.

Waveny Care Center and the Village at Waveny Care Center
3 Farm Road
New Canaan, CT 06840
203-966-8725

Waveny Care Center and the Village at Waveny Care Center combine to create a unique continuum of healthcare services designed to promote health and independence for adults with dementia. They offer a variety of care options, from adult day care to full-time nursing services, which allow individuals to move from one stage of dementia to the next without changing facilities.

Geriatric Health and Resource Center at Greenwich Hospital
5 Perryridge Road
Greenwich, CT 06830
203-863-4374

It provides a full range of testing and services to the geriatric community, and support groups for individuals suffering from dementia and their caregivers.

Alzheimer's Association
Southern Connecticut Chapter
607 Main Avenue
Norwalk, CT 06851
203-845-0010

The Alzheimer's Association, Southern Connecticut Chapter, is dedicated to providing support and assistance to afflicted patients and their families and to research for the prevention, treatment and cure of Alzheimer's disease and related disorders. It also conducts weekly support groups for people in the early stages of Alzheimer's and their families.